U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 1 – Question 1 – When Should I Be Concerned?

Conference Call 3

TUESDAY, NOVEMBER 8, 2016

12:30p.m.

PARTICIPANTS:

KAREN MOWRER, PH.D., HEALTH SCIENCE POLICY ANALYST, OFFICE OF AUTISM RESEARCH COORDINATION (OARC), NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH)

ALICE KAU, PH.D., HEALTH SCIENTIST ADMINISTRATOR, EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD), AND CO-CHAIR, WORKING GROUP 1

ANN WAGNER, PH.D., CHIEF, NEUROBEHAVIORAL MECHANISMS OF MENTAL DISORDERS BRANCH DIVISION OF DEVELOPMENTAL TRANSLATIONAL RESEARCH, NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH), AND CO-CHAIR, WORKING GROUP 1

SHANNON HAWORTH, M.A., SENIOR PROGRAM SPECIALIST, ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

NICOLE WILLIAMS, PH.D., PROGRAM MANAGER, CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS, U.S. DEPARTMENT OF DEFENSE (DOD)

DANIEL COURY, M.D., SECTION CHIEF, BEHAVIORAL SCIENCES, SECTION CHIEF, CHILD DEVELOPMENTAL

PARTICIPANTS: - Continued

CENTER, CHILDREN'S HOSPITAL BEHAVIORAL

SANDY MAGANA, PH.D., MSW, PROFESSOR, UNIVERSITY OF ILLINOIS AT CHICAGO

KAREN PIERCE, PH.D., ASSOCIATE PROFESSOR, DEPARTMENT OF NEUROSCIENCES, UCSD, CO-DIRECTOR, AUTISM CENTER, UCSD

DIANA L. ROBINS, PH.D., ASSOCIATE PROFESSOR PROGRAM AREA LEADER IN EARLY DETECTION & INTERVENTION, AJ DREXEL AUTISM INSTITUTE DREXEL UNIVERSITY

ANGELA SCARPA, PH.D., FOUNDER AND CO-DIRECTOR, VT AUTISM CLINIC (VTAC), DIRECTOR, VT CENTER FOR AUTISM RESEARCH (VTCAR), ASSOCIATE PROFESSOR, DEPARTMENT OF PSYCHOLOGY VIRGINIA TECH

AUDREY THURM, PH.D., STAFF SCIENTIST, PEDIATRICS AND DEVELOPMENTAL NEUROSCIENCE, NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH)

DEBRA WAGLER, M.A., MCOMM, PUBLIC HEALTH ANALYST, REGION VIII, MATERNAL AND CHILD HEALTH BUREAU, HEALTH RESOURCES AND SERVICES ADMINISTRATION

AMY M. WETHERBY, PH.D., DEPT. OF CLINICAL SCIENCES, COLLEGE OF MEDICINE, DISTINGUISHED RESEARCH PROFESSOR, L.L. SCHENDEL PROFESSOR OF COMMUNICATION SCIENCE & DISORDERS, FLORIDA STATE UNIVERSITY

PROCEEDINGS:

DR. KAREN MOWRER: Thank you. So welcome to our co-chairs, working group members and members of the public listening in to the call today. This is the third conference call of the ICC's Strategic Plan Update Working Group for question 1, when should I be concerned. I am Dr. Karen Mowrer. I'm a health science policy analyst in the Office of Autism Research Coordination.

The Director of our office, Dr. Susan Daniels, unfortunately has been battling the flu over the last several days and therefore doesn't have much of a voice to speak, but we felt it was really important to proceed with the work of the working group and all of your efforts. So I will be walking us through the agenda today which you should have received and Susan should be calling in.

I don't know if she's able to speak or on a speaking line but she'll be listening in to the call and following all of the discussion today and we'll be following up with all of the action items to follow. So as you should have been able to see on the agenda we sent, on today's call we'll be discussing a draft outline, the crafting of those strategic plan objectives that this working group will be charged with identifying, and also we'll be touching base on whether you all want to consider changes to the aspirational goal and chapter title for this question.

You should have already received the materials by e-mail in advance and for members of the public listening in, you can access all of the call materials on the ICC website. But first we'll go ahead and do a roll call so as I call your name, just if you could indicate whether you're on a speaking line or not. I guess you can't if you're not. Alice Kau?

DR. ALICE KAU: Here.

DR. MOWRER: Ann Wagner?

DR. ANN WAGNER: Here.

DR. MOWRER: Shannon Hayworth?

MS. SHANNON HAYWORTH: Here.

DR. MOWRER: Jennifer Johnson?

MS. JENNIFER JOHNSON: Here.

DR. MOWRER: Nicole Williams?

DR. NICOLE WILLIAMS: Here.

DR. MOWRER: Daniel Coury?

DR. DANIEL COURY: Here.

DR. MOWRER: Ami Klin? Catherine Lord? Sandy Magana? Karen Pierce?

DR. KAREN PIERCE: Here.

DR. MOWRER: Diana Robins?

DR. DIANA ROBINS: Here.

DR. MOWRER: Angela Scarpa? Audrey Thurm?

DR. AUDREY THURM: Here.

DR. MOWRER: Deborah Wagler?

DR. DEBORAH WAGLER: Present.

DR. MOWRER: Amy Wetherby?

DR. AMY WETHERBY: Here.

DR. MOWRER: And Lisa Wiggins?

(No response.)

DR. MOWRER: Okay, so we can go ahead and jump right in. I think we all felt like we had a very productive discussion on the last two conference calls with this working group and you'll see in the attachments we provided -- that included notes from the last two conference calls we did with you all -- for your reference as well as a draft outline which we'll all talk about next. The outline is just a rough version based on the previous discussions and it's certainly not set in stone. It's up for discussion at this time and modification. So if you can pull that up now and take a look, we can kind of briefly walk through it.

And remember that this Strategic Plan will cover not only autism research but also services and policy recommendations. So if you can look at the outline, you can see at the top we highlighted a few questions that we'll want to think about addressing for some of the major topics listed below that you identified in the previous two calls. So, what are the key research advances that have helped us make progress in the field?

What are the areas where research is ready to be moved into practice? Are there opportunities for practice to inform research? What are the most significant barriers? And most pressing, scientific questions, gaps, opportunities and needs. And then as you mentioned we also need to look at most pressing services needs today and any emerging needs.

And then some of the major sort of more overarching topics that were identified on the previous call have included those listed below in the bullet points - implementation of diagnostic and screening tools, disparities, workforce, the service system.

Some of the other topics mentioned addressing the USPST report. Again, starting to consider that policy piece of the strategic plan – that will need to be addressed. And some of the services implementation and policy issues - that can be addressed. And then below that we've just listed some of the topics that you all mentioned that are a little bit more specific that were topics you had identified as being important perhaps to call out in the report as areas that had contributed to progress overall in the field.

And then the final section deals with the aspirational goal but perhaps we can leave that for a later discussion in the call because we will be dedicating part of the agenda just to discussing the aspirational goal. So maybe at this time we can get thoughts on the topics that are listed in the outline, how they're roughly organized. If you have anything that you feel is left out, that's important to include, or ideas you've thought of since the previous calls about how you'd like to organize the report – we can discuss that now.

DR. WAGNER: So, Karen, can I just ask a clarification question?

DR. MOWRER: Sure.

DR. WAGNER: So (unintelligible) in the topical sections below discuss these bulleted things.

DR. MOWRER: Yes.

DR. WAGNER: Do you mean the things directly below there or the topic, the things under the topic?

DR. MOWRER: Right, yes, that's a little bit confusing, I acknowledge. We were referring to the more general topics directly below and I think the…

DR. WAGNER: The service needs – what are the – and starting with what are the service needs in the following bullets?

DR. MOWRER: Right. And I think the topics for overview were more just a list of key areas that had seen progress in the field.

DR. WAGNER: Okay. Do you envision the research and the services sort of pieces being sort of merged together or individual, separate sections?

DR. MOWRER: So I think we've talked about and other working groups have been talking about this as well, that it might make more sense to identify the major topics that are important to the working group and then since a lot of those topics include research services and policy issues, that you would discuss all of those under each topic rather than having a separate research for all topics as separate services…

DR. WAGNER: Yes.

DR. MOWRER: …since there's so much inter-relatedness.

DR. WAGNER: Okay.

DR. MOWRER: Does anyone else have comments on this? Do you feel like it reflects the discussion that was had in the previous calls?

DR. COURY: I feel like it does.

MS. JENNIFER JOHNSON: Hi, this is Jennifer Johnson. I was not able to be on the last call, so I apologize if some of this was discussed in the group. One of the things that I thought about when I was reviewing this document – it's great to see a lot of references to ensuring that work that's done in this area and thinking about how it's culturally appropriate and culturally responsive and competent – one of the things that I think is perhaps missing here is an ability to talk to people who come from different cultural backgrounds about disability and autism specifically because depending on what culture they come from, they may have a very different idea of disability and whether a person has a disability or not.

And so I think that affects one’s ability to be able to move forward with some families on identifying if a child has autism or not because again of culturally where they may be coming from and what they might understand about disability and autism in particular.

So that was just one thing that came to mind. So not only do we need to have culturally appropriate instruments but we need to think about having culturally competent ways of having conversations, and that might be related to the work force but I wasn’t sure if that’s what was the idea behind having a culturally competent work force.

I think the other thing that might be missing here is how do we support practitioners in having conversations with families about if they’ve had a screen done and there may be something going on that they need to refer a child for further screening. And then, let’s say that screening is positive and then the assessment is confirmed that the child has autism. In those different conversations, how do we support practitioners in having discussions with family members about that process?

And so, I’m not sure if that’s reflected here either but there is some research that has gone on around having those kinds of conversations with family members and supporting them but that might be helpful to include here as well.

DR. MOWRER: Okay. I think that can be called out more in this outline and keep that in mind as the drafting of the chapter proceeds.

DR. WAGLER: Hi, this is Deborah Wagler, HB, and I apologize, I may be asking a question everyone else is already aware of but I guess when I looked at this subcommittee originally, when should I be concerned, I was expecting it to be maybe a little bit more family-focused, so is it to be totally research-focused?

DR. MOWRER: This is Karen. No, I think, especially with this version of the Strategic Plan, we're going to be looking beyond the research to also include services and policies so that might include more focus on some of these family issues.

DR. WAGLER: And so I guess knowing that, this is a really good structure of all the areas, and you did capture our thoughts quite well, but as we go forward, if we can just keep in mind that big question, when should I be concerned, this really is addressing families' needs and that we do approach it with that in mind so we get the activities to be more family-centered…

DR. MOWRER: Yes.

DR. WAGLER: …and family involvement, thank you.

DR. MOWRER: And we'll be discussing - we'll be re-visiting the title of the chapter at the end of this discussion but all of the chapter titles are consumer-focused on sort of that community, so I think you're right, that that's important to keep in mind.

DR. PIERCE: Yes, hi, this is Karen Pierce. One thing that we had mentioned in the last call that I think is really important and I'm not positive that it necessarily goes in this question but it might, is we were considering potentially changing our aspirational goal to say we want as many children as possible to be identified as early as possible to get them into treatment as early as possible. But this interfaces with policy. For example, it’s great that in California now there’s a state law saying that insurance companies are mandated to pay for autism-specific treatment but only if the child has an actual clinical diagnosis. And so when we’re thinking about when should we be concerned, how is this early process going, I think it’s important to think about is it important or relevant or even accurate to try to give an 18-month-old a clinical diagnosis of autism?

What we do here in San Diego is – we’re fortunate – we can say that the child provisionally is showing signs of autism and that’s enough to trigger services through our state agency - ABA-related services up to ten hours a week so the children are getting taken care of - but I think there’s a lot of interstate differences and some of it is kind of bogged down by the language of having a diagnosis or not.

And as we try to push for younger and younger and getting more kids into treatment, I think that this interfaces with sort of public policy and laws and systems and the importance of actually having a diagnosis or not is unclear, particularly because we know that it’s not entirely stable during early development. So this may be something we might want to talk to in some way in our chapter.

DR. WETHERBY: So this is Amy Wetherby. I just want to add to what Karen is saying. I think, (Karen), you’re making some really good points. I do think that there is research now showing that a stable diagnosis can be made by 18 to 24 months in most children with an experienced diagnostician. So I think that we can at least lay out the research but whether that's actually accessible in communities is a whole other challenge.

But I think the other point you're making, Karen, too about the services – in Part C, the early intervention system under the IBEA, having the label of autism, the diagnosis of autism isn't automatic eligibility category, but then many Part C systems take the position that they don't diagnose - they determine eligibility. So we're in this huge catch 22 of who makes the diagnosis, and without it you may not get as many hours of treatment and you may not get autism-specific.

So I think all of those are important messages to weave and to use the current research to show how very critical this is to solve these. They're really disparities across states and service systems.

DR. PIERCE: Yes, just to kind of circle back. I think there are slight differences. We're trying to (unintelligible) to publish a large paper on diagnostic stability in very young kids tucked in the general public and it isn't as stable in 12 to 18 month olds. The stability obviously increases as you get to 30 and 36 month olds and it's pretty decent at 24 months but it's not 100 percent. And what are the consequences of having a false positive label in the minds of the parents? It gets a little bit murky.

I'm just questioning the fundamentals of the whole system. Wouldn't having somebody have a provisional diagnosis or showing signs, requiring treatment - essentially we're treating symptoms related to social attention and language that are foundational to autism but requiring this label because of the factors we mentioned, I'm just not 100 percent positive that that is what we should be necessarily pushing for. But you're right, it's a catch 22. It's too bad because people won't get their treatment paid for if they don't have it. So these 18-month-olds and 12-month-olds, they get to be a little stuck sometimes.

DR. WETHERBY: Yes, and the sadder news -- this is Amy again, -- is that in some states like Florida and some of my neighboring states, even if you have the diagnosis, it may not lead to very much intervention whereas in California, Massachusetts and other states, it will lead to a lot more hours and intervention.

DR. MOWRER: Okay, those are all great points. There's not anything else on the outline, we can maybe move on to the next item on the agenda.

DR. WAGNER: Just a comment about writing it up, it seems like, for each of those topics, it might be useful to start with the service needs because then that kind of leads into how research could conform. And that it might just be a way to set it up starting with what's important to families and what we know and don't know and what the gaps are and then could try to translate that into how research might help. And sometimes it might just be policy. It might not be a research need but a lot of times it might be that there's certain church gaps that could address those needs.

DR. KAU: I like that. So identify the needs and then address what needs to be done, right? It is policy from (unintelligible) perspective, so that would also combine the research and services into one coherent discussion.

DR. MOWRER: That's good, yes.

DR. WETHERBY: This is Amy. I think that's a great suggestion and it would help us then be able to highlight the gaps in research based on what we laid out with service – barriers and challenges and needs.

DR. ROBINS: This is Diana. I would just add that if you start with the services' needs, it also makes it a little easier to address. One of the questions at the top of the outline about are there areas where research is ready to be moved into practice? Because if there's a services' need but then there's clear evidence from the existing research rather than calling for more research, there can be a call for moving it from science to practice.

DR. WAGNER: Yes, good idea.

Dr. Kau: YES.

DR. WAGNER: Good point.

DR. MOWRER: Okay, great.

DR. WAGNER: So it sounds like people are happy with those – so we basically would have it divided up into topics – implementation disparity, workforce service system, USPS Task Force. And then it looks like the bullet is their new research evidence. That wouldn't be its own topic but would be woven into the ones above?

DR. KAU: Agree.

DR. COURY: I think so.

DR. WAGNER: And the last one too, I guess.

UNKNOWN FEMALE SPEAKER: Right.

DR. WAGNER: So the last two bullets would just be moved over to the other topics.

UNKNOWN FEMALE SPEAKER: Yes. Sounds good to me.

DR. WAGNER: Yes.

DR. WETHERBY: Okay.

UNKNOWN FEMALE SPEAKER: Same to me.

DR. MOWRER: So then maybe that sideways nicely into thinking about how that organization would fit into the Strategic Plan Objectives for this question. So, they'll remember that for the Strategic Plan, this working group is being asked to identify and craft three objectives and they should be fairly broad. It also most likely wants them to be relatively simple in a way and so we'd like your feedback on sort of the three main objective topics you'd like to highlight and we can also talk a little bit how you might want these to read or be worded.

And then remember that although we're going to have three broad objectives, that each objective can include underneath that a series of more specific examples of the types of projects that your thinking would be the kinds of responses to the objectives. And you'll also have a lot more room within the chapter, the narrative of the chapter, to go into more detail to flush out the objectives that you craft.

So you can see in the agenda there are three proposed draft objectives. These are based on the previous calls, discussions, and these are really just to get the discussions started, and they can definitely be reorganized or shuffled around and re-worded. So we can go over the three that we have here and you can give us maybe some feedback overall about how you like the way the topics are divided or if these are the areas you want to focus on and then maybe we can go through each one and get into a little bit more detail.

But the three that we have on the agenda are, one, strengthen the evidence base for the benefits of early detection of ASD, two, reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts, and three, improve and validate existing or develop new tools and methods for detecting ASD to facilitate early and targeted intervention. So people, thoughts on the objectives at this point?

DR. ROBINS: I have a comment about the first one. This is Diana. I think it might be helpful in some of the text that goes along with that objective. If we can talk a little bit about how different study designs can contribute to the evidence base. It feels like some of the scientific community has kind of made a determination that the only evidence worth considering is a randomized controlled trial, and obviously with a disorder like ASD, it’s really difficult to do long-term outcomes with very large samples treated intensively, detected in populations, you know.

Those are mostly outside the scope of what the average research study can fund or the average group can accomplish. So I think it would be really helpful to talk about how there are different types of research designs that contribute different aspects of the evidence that we consider as a whole.

DR. COURY: I think that’s a great point. I think that we need to do that so that we can provide some guidance into the kinds of studies that ought to be done.

DR. WAGNER: Yes, and then we could have some examples, I think, underneath the main topic.

DR. PIERCE: Yes, and we can read that in when we discuss the U.S. Task Force because they’re the ones that are trying to drive the research vote and saying that our old-fashioned RCT’s are required.

DR. WAGNER: Right.

DR. PIERCE: We can kind of weave it into that.

DR. WETHERBY: Yes, good point.

DR. ROBINS: And I think that was (Karen) who just said old-fashioned RCT's. I think that they certainly serve a purpose but they don't always complement the implementation science aspects of how one can bring things out of the lab and into the field. And since that's one of our goals is to bring research into service delivery, it seems especially valuable to talk about how efficacy and effectiveness and implementation like all contribute different aspects of understanding of how treatments work and how early detections works.

DR. WAGNER: Very good. Do people think that those three topics cover all of the things we discussed in prior calls as needs - that they can set everything into one of those three?

DR. COURY: They seem fairly broad and INCLUSIVE TO ME.

DR. WAGNER: They did to me too.

DR. PIERCE: Yes, I think if we're creative, there's certainly a lot of subheadings that can go under each of those and so I think at face value it seems feasible.

DR. WAGNER: Yes, and I think somebody already made this point -- but just to repeat it -- that it would be good to keep these in mind as we're crafting the upper sections so you want to kind of lead into these objectives with the overview that you're doing.

DR. MOWRER: And it sounds like there's a lot of consensus around these so far which is great but as you think about these more you can certainly wordsmith them more over e-mail. They don't have to be finalized today but we can also go into more detail - we have time if people have even suggestions about if they're happy with the terminology used in the wording or if there are pieces they want to think about suggesting modifications - that would be helpful too.

DR. THURM: This is Audrey. Just specifically with number three, I feel like improve, validate existing or develop new tools methods maybe in services or in systems - I just feel like that’s where a lot of the services would come into play so being a little bit more direct about that there.

DR. MOWRER: Okay.

DR. WAGNER: Yes.

DR. WETHERBY: And this is Amy. I just want to circle back to the comment earlier about the family center, the focus of the family and I’m hoping we can weave it in, not just to number two but also to numbers one and three. It just may be a theme to keep coming back across all three of these topics.

DR. PIERCE: Exactly, yes, and another speaker said we were going to kind of start out with the service needs, and I agree with Amy that that should be woven, I think, into each of the areas one, two and three. But I think there’s definitely opportunity and need for it in all of those three topics.

DR. WAGNER: (Unintelligible).

DR. MOWRER: So we had some members touch on some of the areas or examples we would want to highlight under the first. Do people want to discuss a little more, maybe some of the types of examples or other things we want to mention under two and three?

DR. WAGNER: It could be great to have some ideas about what could go under each of those. It would be great. Anybody have ideas?

(No response.)

DR. KAU: Or maybe someone could talk about what we have accomplished. These are not new challenges. Sort of have identified this for many years and probably research has (unintelligible) barriers.

DR. WAGNER: Do the accomplishments go under the topics, so the overview topics in addition to (unintelligible)?

((Crosstalk)

Dr. Mowrer: Yes, it can be up for discussion but I think under the objectives we would mainly focus on the needs and future suggestions.

DR. WAGNER: Okay, yes. So it's helpful to hear what people think we have accomplished because doesn't that kind of tell us where we left off? And have to go next, right.

DR. KAU: These really are new challenges and I wonder what we have done and what more we need to do and a focused session would be helpful.

DR. WETHERBY: This is Amy. I'm a little unclear about how much we're going to be spending time reviewing accomplishments versus identifying gaps and needs for the future both in service and research. But I'm just thinking, even what Alice was saying in number one, the evidence base for the benefits of early detection, so while this has been a problem all along and still is, I think even that we're having a discussion that you can make a stable diagnosis of autism at 18 to 24 months and we're thinking about going down to 12 months – that, to me, is the excitement of the research that has moved the needle. But then the service gap is still so big that the average age for diagnosis in the country is way behind that.

So I hope that that’s what will be coming out of this but I’m not sure, so I just wanted to check.

DR. KAU: Yes, that’s one perspective. That’s very helpful that we have improved our ability to diagnose earlier and earlier and yet the average age of diagnosis still lags behind. And then maybe even the interventions for say 12 months or 18 month infants are diagnosed – but what can we offer? Do we have everything, spaced intervention to provide to those for a diagnosis at an early age. Amy, yes, that’s one good way to point out. I still think that we fund a lot of research but yet the practice still lags behind what the science is saying, an overall arching manner in this area.

DR. WAGNER: I think it’s really important that the topics flow like that, (Amy), like what you said.

DR. WETHERBY: Yes, I like that very much.

DR. WAGNER: Because I think it is important to say what we do now and…

DR. WETHERBY: Yes.

DR. WAGNER: …what we have accomplished because it’s too easy to think we have to start all over…

DR. KAU: Right.

DR. WAGNER: …or reinvent the wheel.

DR. WETHERBY: Right, yes.

DR. WAGNER: But we don’t.

DR. KAU: Right.

DR. WAGNER: Are there any specifics that you want to be sure are listed under objective number two, reducing disparities – that one? Could that be some sort of beginning of the discussion we had earlier about being culturally confident. How would we translate that into a research question?

DR. ROBINS: This is Diana. I think one of the important things to call for is data demonstrating validity of screening and diagnostic tools in the context of different cultures. I think people sometimes think that you can pick something up and put it out in a new community and it should just work the same but there’s lots of evidence not just from the autism literature but from a much broader literature that one has to adapt things culturally to ensure that they work in the intended way. And so there certainly can be a call for probably screening diagnosis and treatment all to include validation and culturally diverse samples.

DR. WAGLER: This is Deborah. I learned whenever we speak of culturally appropriate we certainly need to involve the families and the persons who we’re trying to reach. We’re doing better in community health workers and lay person representation but families do say when they walk into a clinic, they want to see someone who looks like them. So any ways that we can make that happen – families and clinics or increase in diversity in the provider network – these are very long-ranging things and beyond our scope but somehow, some way to infuse in these lower sub-steps that families and persons who have autism are involved in even the research too. Thanks.

DR. PIERCE: Yes, just to kind of follow up with that, I think the call for actually implementing research and services programs in high poverty regions which are often shied away from because there are many more logistical challenges in implementing science, there would be a great goal to get representation up within the papers that are published, and in so doing I think we’d get a better understanding of more specific barriers to services uptakes.

But, you know, the CDC paper noted that the mean ages diagnosis for these groups and services, implementation is significantly greater for people who are from Latino and African-American backgrounds. So I think just doing the research in minority-rich and under-represented areas is important to do.

DR. WETHERBY: This is Amy. I think that’s a great point Karen. And it makes me think about our (ASEP) Network funded by NIMH. I’m just wondering. We have these grants underway. But we don’t – you know – have findings yet. But a large amount of investment is being made to do this. . So, I’m wondering where like current grants – the mention of it leads that there are efforts underway that hopefully – in the near future will provide information.

I don’t know if that would fit in anywhere. But it seems like – as we look at the progress of research – that the research that’s going ongoing is important to (we them).

DR. PIERCE: I think that’s good. I don’t see why we shouldn’t be able to mention it.

DR. WAGNER: I think you should. It does raise the question of – in my mind. I think you should. But we don’t have results yet. I guess – so how do we deal? Do we want to call for things that are already being addressed? You know what I’m saying. The research objectives - do we want to have objectives in there that seem to be calling for research that we already have ongoing to the (PEACE) network.

DR. KAU: Right. You know. Yes. I think you’re forcing the transition going from the achievement and then ongoing and then, but we don’t know.

DR. WAGNER: We don’t know.

DR. KAU: We don’t know the results. So, to the future it’s in that area – gray zone. But definitely needs to be mentioned. Because so maybe there will be a discussion about essentially do we know what being done – currently being done. And we can say maybe a different design or something rather than funding the same thing. But maybe call out what aspect of the needs that are not specifically covered in the ongoing research.

DR. WAGNER: Yes. It’s a little tricky because we’re doing that.

DR. KAU: Yes.

DR. WAGNER: Sounds like we’re (unintelligible) things.

Dr. KAU: Right.

DR. WAGNER: Because we know there’s research going on in it. But that’s – I can’t assume we have the results that we aren’t (unintelligible) to. Maybe it’s sort of emphasizing things. I mean the (PEACE) network is great. It’s going to help us a lot. But there’s always going to be more questions. Maybe sort of emphasizing.

DR. KAU: But we definitely mention that so that people won’t fund the same thing that are already being funded. So maybe identify that and by then – you know knowing – the research is ongoing.

DR. PIERCE: Yes. Thinking about what’s working and for what aspects maybe should be built on to – you know – extend further.

DR. KAU: Right.

DR. MOWRER: you know – would be important to highlight that maybe there’s a lot underway that’s making good progress. But that there’s still these needs and – you know – where it needs to be extended.

DR. PIERCE: Is it possible to modify a little bit the structure of the strategic plan updates? So each of the questions would have just a little paragraph at the end that says – you know – ongoing efforts. You know, these are the kinds of things that people are trying to do. Any – rather than kind of weaving it throughout the document. Maybe it would be something that is placed in a separate paragraph, possibly.

Because – I think – this is something that all the different questions would want to address. It is a little bit artificial to raise all these things. And we know some of it is actually going on. We don't know the results. But it seems relevant to mention it in some way either woven throughout or maybe as a separate section.

DR. MOWRER: Right. I think –

DR. KAU: and I don't know how much can be mentioned regarding ongoing research. Probably in a general process, right. We can't get into…

DR. PIERCE: Right. Can't get too detailed but…

((Crosstalk))

DR. MOWRER: There's only so much space you're going to have. But each question will have a section on the advances -- in the field that have occurred -- since the last plan. And – I think – that should include (research).

DR. PIERCE: Okay.

DR. MOWRER: You know maybe started but not…

DR. WAGNER: …major ongoing effort.

DR. PIERCE: Right.

DR. WAGNER: You know larger efforts. Yes, that makes sense.

DR. MOWRER: Any other thoughts on the objectives?

DR. KAU: So for the second objective we mentioned the research needs. How about policy? You know if we have culturally sensitive and validated screenings and diagnostic instruments and interventions. Does it mean that the children will get what – you know – we can reduce the disparity? So, because we are going to combine them together, right? Oh, this is just research.

DR. WAGNER: Okay.

DR. MOWRER: The three main objectives (stick to) research.

DR. KAU: This is just research.

DR. MOWRER: No. That objective – the three objectives can include research services and policies.

DR. KAU: Okay. So, this is that one area. So, we talk about research right now. I still think a lot of it is in the policy to reduce disparity so that we can do a lot of research and policy doesn't change.

UNKNOWN FEMALE SPEAKER: I don't know. I'm just thinking.

DR. KAU: Are there policies that hindering the progress in the disparity area?

DR. MAGANA: This is Sandy Magana and I would say definitely there are policies.

DR. KAU: Right. I'm waiting looking) for you.

DR. MAGANA: …to figure out how to speak. I was listening to everybody. Yes. So, one of the policies that really varies by state is – I mean once a child gets detected – well – first of all – there’s a long process to get a diagnosis, right.

DR. COURY: Right.

DR. MAGANA: And very (iterative) and difficult and challenging process with many barriers. And there are only certain – you know – places in a particular region that can do the (ADOS) and can do – you know – the diagnosis.

And so, that’s one barrier. But then – even with the diagnosis for example – in the state of Illinois the children on Medicaid cannot get (ABA) service. Because it’s not an authorized – you know – payment – reimbursement for BCBA’s. So, that just eliminates poor children from getting – and I was just in Texas. And they told me the same thing there. So, I’m sure that’s true of many states.

Those are policies that – and actually the federal government says Medicaid should be paying for these. But that doesn’t mean the states are doing it. One example.

DR. KAU: Right. Yes.

((Crosstalk))

DR. WAGNER: Yes. Very good.

DR. KAU: I’m sure there will be more as we think more about it.

DR. THURM: This is Audrey. I think the other one is what Karen and – I think – (Amy) were talking about that should you be required to have a diagnosis to get these services? But – I think more generally I think – a lot of the members here – I speak for myself for sure – just aren’t as familiar with what kinds of things. How direct we can be and what we can do in terms of the services. But – I do think – what's written on the outline about workforce and about service systems in both of those things – all of those can be used under - for Number Two.

DR. WAGNER: So, one of the things we talked about in the last meeting that may be implied in under that workforce bullets is the need for researchers who are trained in doing services research. I'm not sure under which of these objectives would go? But I don't think we want to lose that. I think that maybe under the second one actually. That's more services related.

DR. WETHERBY: But it seems like if we're going to cover services in all three. This is (Amy). That we could address that from the perspective of all three objectives.

DR. MOWRER: Any other thoughts on these?

DR. WAGNER: Audrey do you want to talk about your question -- you posed -- about boundary between in training, diagnosis and intervention. Do you feel like we're answering – we're addressing your question in our discussion today?

DR. THURM: I think – are you talking specifically about the aspirational goal?

DR. WAGNER: Well I was thinking more – you know we haven't gotten there yet. I was just thinking more in terms of objectives. Are you finding a reasonably good balance, I guess?

DR. THURM: Yes. I think the question – you know it – ultimately comes down to the aspirational goal. But just that can we be tying it – and for those not at the last (ICC meeting) – it was definitely talked about the fact that they were trying to figure out ways -- that each question would not be siloed on its own -- as they shouldn't be. But -- very specifically here -- I hope that all of us would agree that – you know – there’s no point in the question about when should I be concerned if it’s not going to be linked to doing something for it.

So, the question really is how closely can we link those things. No, our goals are not going to be – and for us to – you know – make sure we have effective treatments. But – at some level – it’s about when I should be concerned is when I can do something about it. And making sure that at every level, we’re tying those together.

DR. WAGNER: We could probably include something about the handoff. You know if it’s from diagnosis to intervention services.

DR. THURM: Right. So, I guess – you know – Number Three – that we just went through – is exclusive about it. But how much should Number One and Two…

DR. WAGNER: Yes.

DR. THURM: And -- I think -- that also tied into just being focused on what the family can do. Because…

DR. WAGNER: Right.

DR. WETHERBY: And this is Amy. I think Audrey that’s such an important point. I think we can directly relate it to screening and early detection. Because – particularly -- as primary care is the setting -- where you’re screening – they are not going to want to screen a lot that’s going to lead to treatment that they believe that’s effective. But also available. So – I think – it directly impacts screening in real world settings. And we don’t need to get into that. The level of evidence about the intervention but the availability of -- and the movement of -- knowledge on the effectiveness of early intervention – I think – is really important.

Because it supports the need to screen. And to screen earlier and earlier. I think we can weave it into all three.

MS. JOHNSON: This is Jennifer Johnson with (AIDD). I think another related item to three is not only how it relates to the follow on of services and intervention. But also, the continuity of that. You know there maybe things that the family is doing that's working that they want to retain in terms of what's working. Or there maybe things that need to be done differently. But the child that's likely somewhere -- either in the setting or not -- and how do we ensure that there's continuity as they start treatment based on – you know – what may be working for the family and what's not.

DR. WAGNER: So, on the topic of things that might be related to other questions, did we decide that all of these (dealt) stuff is going to go into a different question? Because I know we talked about that on our…

DR. MOWRER: Right, yes. So – I think – most of the adult relevant topics are going to go into Question Six.

DR. WAGNER: Okay.

DR. MOWRER: If there's – you know I think the chapter could touch on topics in Question Six if they want. But it wouldn't – you know, we can coordinate – we can help coordinate with the other working group as well to make sure they're not overly redundant. But you could certainly mention – you know – relevant to adult screening in this chapter. But it – you know – wouldn't be like a large focus.

DR. WAGNER: Right. Okay. I wonder if we want to sort of talk about areas for special populations that need in addition to different cultures that might need tools validated for them like adults.

DR. KAU: And girls.

DR. WAGNER: Girls. I don’t know. Intellectually disabled.

DR. KAU: Yes.

((Crosstalk))

DR. MOWRER: Okay. Unless other people have comments on the objectives – and again – we certainly keep thinking about this and keep working on them. But maybe we should – maybe now would be a good time to move on to the discussion of the aspirational goals since that’s already come up a little bit. But so, the goal in the previous strategic plan reads “children at risk for (AFD) will be identified through reliable methods before (AFD) behavioral characteristics fully manifest.”

And so – I think – the – one of the main comments -- from the previous call -- was the suggestion to maybe remove emphasis on file markers. And then – I know – Audrey you had some thoughts on the (bullets) as well. You might want to go into more. But we can certainly change this for the new version of the strategic plan.

DR. PIERCE: I don’t know if Audrey was going to say something. But, yes – I think – we had discussed revising it to say something about the aspirational goal is to get – you know – 95’% -- or a significant percentage of children with (ASE) -- into treatment prior to age three years or into maybe leave it more vague – into early treatment. I mean the goal is – you know – detect and get everybody into treatment.

DR. MOWRER: So, I saw – I think, in one of the email chains following the agenda and the discussion that was by email – (Susan) had proposed some different language that I can read as well which says "provide the earliest possible diagnosis for children and adults on the autism spectrum so they can be linked to appropriate intervention services and support for in as timely a manner as possible." So, that tries to get to that link between diagnosis and intervention services.

DR. WETHERBY: So this is Amy. I think that's an improvement. The only concern is we want to keep in mind that the Part C system doesn't require diagnosis for treatment. So, we – and often families aren't ready for diagnosis and they can get started in treatment. So, it's a bit of a catch 22 that we've been discussing. But I'm hoping we can word it in a way that'll move families faster toward diagnosis --but also towards treatment -- which may lead them to diagnosis. And there's also a long waiting list for diagnosis. And we don't want to hold up treatment. So…

DR. PIERCE: Exactly. Yes. I completely agree. But, again, I don't know that the end goal for us should be to just fast track a diagnosis. It really should be fast tracking detection of autism risk symptoms and signs. And then remediating those with intervention. And when the diagnosis happens, it happens. Because, yes, again, you might not be able to get it. It might not be appropriate in the 12 to 18-month-old. But you could really change the course of a 12 or 18-month old's life if you get them into this early treatment. So, we don't want that label to be a barrier to success. So, I agree that I don't know that we necessarily want the word diagnosis in the aspirational goal. Specifically, or maybe woven in a different way.

DR. WAGNER: How about something like this? "Provide the earliest possible detection of risk for ASD for children and adults so they can be linked to appropriate intervention services and support and diagnosis in as timely manner as possible or something like that.

DR. PIERCE: Yes. That sounds good.

DR. WETHERBY: That’s better. This is (Amy). I have a question just about risk. So – you know keeping in mind again Part C, children at risk may not qualify for services. So, we don’t want to make this sound like these are children that shouldn’t be qualifying. And when you say “at risk” – I think – it often brings in mind familial risk.

And – I think – the field has advanced to the point where we are able to detect signs, observable signs, certainly down to 18 months and even down to nine or 12 months. So – I think – there’s a way of maybe saying risk and/or early signs.

DR. PIERCE: There are quantifiable. I mean for Part C services in San Diego, you have to show a reduction in various domains and one of which is social behavior and social readiness. And so, we can kind of word the language about – you know – showing – you know – delays or signs in an autism related behaviors. Something like that. So, that it’s based on more of a quantitative index of social delays.

DR. ROBINS: This is Diana. On the flip side of the diagnosis treatment – you know -- question – you know – many, many kids who will qualify for early intervention services without a diagnosis will qualify for very low intensity. And they’re usually not geared toward things like the social communication or social deficit that we see in autism.

So, I would love it if we could come up with wording that would incorporate both diagnosis and treatment that could be in parallel and not sequential. But that they could both happen to inform one another. Because the reason -- why we give a diagnosis -- is that the label informs us about what to do next. And so, I'd take diagnosis out of it completely. But I wouldn't want to require kids to be on a long waiting list to get a diagnosis first before they start to trigger any services.

DR. WETHERBY: Sounds like we have agreement. Although – you know -- the exact wording might be slightly different. But, yes.

DR. WAGNER: Maybe play with the wording a little bit. Circulate some options.

DR. MOWRER: Yes. Let's all continue to think about the wording. But -- I think -- it sounds like everyone's circling around the same modifications and idea. So…

DR. ROBINS: This is (Diana). One more little tweak. When is says children and adults, it might be confusing for some people if we're thinking about very young children as early as possible and then also adults. Because there's a whole lot of between. So, it might just be worded as individuals so that you don't have to separately mention adults.

DR. WETHERBY: This is (Amy). I think you're raising a really good point (Diana). But then we talk about children, toddlers or infants as individuals sounds kind of weird, so we're going to have to struggle with that, yes.

DR. ROBINS: Well, that's true. And if it does end up being covered in a different question, I don't think it has to be in this one.

DR. WETHERBY: I wonder if there's a way of trying to focus it on young children. And then say "and in addition for those that are missed early."

Because really then you're talking about school age on up to adults.

DR. ROBINS: I like that.

DR. WETHERBY: We can refer to them separately but as importantly.

DR. KAU: I think the adult issue is more a new area that we know much less than we know in the younger children. So – I think – we probably need to decide the scope of our – how much we want to cover in terms of time. But then as an objective, it's – if the Question Six is going to cover adults, I would recommend that we make it very clear in the ending of Chapter One to say – you know – we limit our discussion to young children or to whatever – you know – we want, child, adolescents. Otherwise you have an aspirational goal covering the whole spectrum (unintelligible)…

DR. WAGNER: We need to find out from them if they're going to cover diagnosis and screening.

DR. MOWRER: Right. The topic of diagnosis in adults has come up in the other working groups. But – so we can definitely coordinate between the two working groups to make sure that this and the importance of it is covered. And decide if we want to sort of call out in Chapter One a reference to Chapter Six or how we want to balance that. But…

DR. WAGNER: Right.

DR. KAU: I think – in terms of services – probably definitely for adults will be covered by Chapter Six. But in terms of diagnosis and screening…

DR. MOWRER: Right. It's been touched on. But it hasn't been a huge emphasis of that working group. So – you know I think – it will be important to coordinate.

DR. KAU: Right.

DR. MOWRER: Okay. Well, then, maybe we should move on to checking in on talking about the title of the chapter which has come up a little bit which is currently “When Should I Be Concerned?” So, we can certainly revisit the title for this strategic plan and again – you know – all the questions are consumer focused in their perspective. So, we want to keep that in mind. But we can think about whether there are modifications that would better reflect the current state of the (needs) in the chapter.

DR. PIERCE: Yes. I think that when you read the current title, “When Should I Be Concerned,” it – you know -- brings to mind something about time, age. Should I be concerned at two months, six months, 12 months, nine months? And while we do touch on that – I think – the emphasis of this working group and this question is broader than that. It’s almost more like a how. You know, like how is ASD detected early in terms of mechanisms and services. Obviously, you’ll have screening. So – you know – I don’t know necessarily what the best title is. But I do feel like when is a very specific and narrow focus. And – I think – we’re much broader than that. I think we’re more of a how.

DR. WETHERBY: I like that (Karen). This is (Amy) and I wonder if we could even take it to one more step which is how can we improve our early detection. Because – I think – it is very much a moving target as we advance research.

DR. PIERCE: Yes. Good.

DR. ROBINS: If we’re going to go with something like “How Can We Improve Early Detection,” we might want to add in something about the early intervention piece too to always link the detection with what happens next.

DR. WETHERBY: Yes.

DR. ROBINS: Sorry. This is (Diana). I forgot to say.

DR. WETHERBY: Yes. We know your voice Diana. Well how about "How Can we Improve Early Detection" and something like "And Access to Early Intervention – or Care and Early Intervention?" So, that we don't go beyond our question.

DR. PIERCE: Right. Or "How Can We Improve Early Detection and Access to Treatment Services?"

DR. WETHERBY: Yes.

DR. WAGNER: I think that only – I think you're right, it should be broader. I guess – I think we're changing the perspective of the question that way. So, that we know when should I be concerned is like the parent saying that. Parent isn't going to ask how can I improve early detection. They're going to be – I'm trying to think how we would put it in a parent's words. Like "How Can I Find Out my child's has a problem. I don't know.

((Crosstalk))

DR. KAU: Right, right, definitely.

((Crosstalk))

DR. ROBINS: Well what about something more like "What Should I Look For?"

DR. WETHERBY: Yes.

UNKNOWN FEMALE SPEAKER: Or "What Should I Think About?"

DR. WAGNER: I guess we're trying to think about a question that a parent might ask.

DR. ROBINS: Yes.

DR. COURY: What should concern me? That kind of thing, yes.

DR. WETHERBY: I worry about the word “concern.” Is there a different way to frame to get at that? Partly because parents may not know to be concerned. And so, they’re not even thinking about it.

DR. COURY: I think why it’s titled “When Should I Be Concerned?”

DR. WETHERBY: Yes. I think we’re not liking that title.

DR. KAU: Are other groups thinking about changing the titles as well? Because you want to keep it parallel, right. I mean…

((Crosstalk))

DR. PIERCE: What about the simple one, “How is (ASE) Detected Early?” So, like a parent wants to know, well, how are doctors doing it? How should I be doing it? You know, maybe that’s broad enough.

DR. MOWRER: So, we’re definitely having other working groups making at least some slight modifications to the title. But they’re all keeping that perspective of the parents – like the family or the individual or the parent.

DR. WETHERBY: Okay. What about “How Early Can ASD Be Identified or Detected,” which still doesn’t link it to treatment.

((Crosstalk))

DR. PIERCE: Yes. But then it definitely orients your attention back to the age issue which, again, is important. But it’s more for me, it’s the mechanism. We’re doing – you know – a lot of screening, a lot of services. So, like how is ASD detected early and how are children – you know – facilitated to gain access to services or something like that. So, it's kind of a mouthful. But something about so a parent wants to know. Okay. How is my child or any kids getting detected early?

DR. SCARPA: Hi. This is (Angela). Can you hear me?

DR. MOWRER: Yes.

DR. SCARPA: How about something like "What Should I Do If I Suspect My Child Has (ASE)" or something like that?"

DR. ROBINS: I would actually shy away from that. Because a lot of parents may not know yet that they should be worried when a screening tool – that they complete at a check-up – orients both the primary caregiver and the physician that maybe there is something to be concerned about. So, if you wait for the parents to be concerned – especially if you wait for specific – it might actually shift the focus a little bit away.

DR. WETHERBY: Yes. I think that's an important point. What about – what did you say (Karen)? How…

DR. PIERCE: I said "How is (ASD) Detected Early." It's very…

DR. WETHERBY: "How is (ASE) Detected Early and Why is This So Important to the Family?"

DR. ROBINS: Or a different way of bringing in a little bit of timing could be going back to something broader like "What Should I Look For and When?" Because how is ASD detected – well, maybe anyone who would come and ask this question would already be thinking in more technical terminology. But I'm looking at the other questions – from the last strategic plan – and a lot of them are very –

they’re worded in lay language. Like what caused this to happen. Not what are the bio markers or what are the ideological trajectories or – you know – technical terms. So how is it detected sounds a little more technical than what do we do, when do we do it.

DR. WETHERBY: And – I think – the challenge is we want people thinking about the what and the how instead of just the when.

DR. WAGNER: Yes.

DR. WETHERBY: And how do we weave that into the question in lay language.

DR. ROBINS: Well I’m still thinking as a parent what should I do if I’m concerned is what I would want to know.

DR. WETHERBY: Yes. And – I think – that’s really important. This is (Amy). I think also for the parents to – that’s part of the population in families. The other part is the family’s that don’t yet know to be concerned. So, then none of this may be relevant to them. We want to make sure it’s relevant to all (unintelligible).

DR. ROBINS: How would I know?

DR. WETHERBY: Yes.

DR. PIERCE: Exactly. I do – I feel like it is a health thing. I like – I think it’s really important what should I do if I’m concerned. But that really again has a really specific focus that what we’re going to be talking about is access to services or access to getting detected which is part of it. But…

DR. WAGNER: What about “How Would I Know if I Should Be Concerned” or something like that?

((Crosstalk))

DR. PIERCE: Exactly. Because it has to be short. I’m wondering if we should all just sort of – you know – write out a few that we think are good based on our conversation and send it to (Karen) or (Amy) or whoever. And we can do a quick Survey Monkey or something. You know, just to kind of see if we get a consensus. And then we can tweak whatever one is the winner or something like that. Because it feels like we’re all slightly different perspectives on how it should be worded.

DR. WAGNER: Yes. I think that’s a good idea.

DR. WETHERBY: Yes.

((Crosstalk))

DR. MOWRER: Yes. I think there’s some common themes coming out. But getting the exact wording is always the challenge. But, yes, we can certainly keep – you know – going back and forth -- between you all -- and nail down something a little more specific. Okay. Great.

So just in terms of next steps – so you’re all informed. So (Susan) is going to be in touch with our co-chairs to -- finalize the outline and -- start talking about a plan for drafting the chapter. And they’ll be recruiting working group members to help out with the drafting of certain sections. So, if there’s a particular topic – in the outline – that you would definitely like to take the lead on drafting and especially if it’s in – you know – one of your areas of expertise, please let Susan or the co-chairs know so they can account for that in planning out the drafting of the chapter.

And the plan now is that once there is a draft put together, it will certainly be circulated throughout the entire working group. And everyone will be able to see it and provide suggestions and edits. And so, the hope is to have a draft ready for the next IACC meeting which is scheduled for January 13. And there will be a discussion with the full committee there of the draft.

If there is any other comments – at this time I think – that should be it. Anyone have any other questions or comments about anything we discussed today?

DR. WAGNER: January 13th you said?

DR. MOWRER: Yes. Okay. Well – I guess – we'll let you go a little early. And thank you all again for all of your efforts in terms of leading this effort. And thanks to everyone, all the members of the public who have listened in as well. Thanks, everybody.

DR. WAGNER: Thank you.

GROUP: Byes.

(Whereupon, the conference call was adjourned.)