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INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

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

Conference Call 2

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Proceedings:

DR. SUSAN DANIELS: Hello. Welcome to our public audience, and to working group members, to this conference call of the IACC Strategic Plan Update Working Group for Question 1, which is on the topic, “When Should I Be Concerned?” - About Screening and Diagnosis for Autism Spectrum Disorders?

We'd like to also welcome our chairs, co-chairs, Dr. Ann Wagner and Dr. Alice Kau, to the call. I'd like to go through and do some introductions. Last time I neglected to let everyone introduce themselves on the call. So as I read the names off on the list of people who are going to be on the call, please give maybe one or two sentences of introduction about yourself, so that everyone knows who's on the call.

So I know that Alice Kau will be joining us a little bit later, so I will wait on her. Ann Wagner?

DR. ANN WAGNER: Hi, this is Ann Wagner. I'm in NIMH in the Division of Translational Research, and a lot of the extramural funding for autism research goes out - is managed by a program in my branch.

DR. DANIELS: Alice Kau?

DR. ALICE KAU: Alice Kau from NICHD, and I manage the autism funding for NICHD.

DR. DANIELS: Thank you. Shannon Haworth?

MS. SHANNON HAWORTH: Hi, I'm Shannon Haworth. I'm the senior public health program manager at the Association of University Centers on Disabilities, and I work on workforce capacity-building projects.

DR. DANIELS: Thank you. Nicole Williams?

DR. NICOLE WILLIAMS: Hi, this is Nicole Williams. I'm the program manager for the Autism Research Program, which is within the Department of Defense, and we also support extramural funding.

DR. DANIELS: Thank you. Jennifer Johnson is not going to be joining us today. Daniel Coury?

DR. DANIEL COURY: I'm Daniel Coury. I'm a developmental behavioral pediatrician at the Ohio State University, and conduct research through the HRSA-funded Autism Intervention Research Network on Physical Health, and with the Autism Speaks Autism Treatment Network.

DR. DANIELS: Thank you. Ami Klin? Catherine Lord? Sandy Magana?

DR. SANDY MAGANA: Hi. I'm a researcher and faculty member at the Department of Disability and Human Development at the University of Illinois Chicago. I do a lot of research with Latino and under-represented families that have children with ASD.

DR. DANIELS: Thank you. Karen Pierce?

DR. KAREN PIERCE: I am a professor at the Department of Neurosciences at UCSD, and I look at early detection screening, eye tracking and brand imaging with toddlers with autism.

DR. DANIELS: Thank you. Diana Robins?

DR. DIANA ROBINS: Good afternoon. I'm an associate professor at Drexel University, and I also lead the research program in early detection and intervention here at the A.J. Drexel Autism Institute. A lot of my research focuses on screening and early detection of ASDs.

DR. DANIELS: Thank you. Angela Scarpa? Audrey Thurm?

DR. AUDREY THURM: Hi. I'm a psychologist and staff scientist at the intramural research program at the NIMH, and I'm involved in autism-related research as well as some research in toddlers at risk for autism.

DR. DANIELS: Thank you. Debra Wagler? Amy Wetherby? Lisa Wiggins? Okay, so there might be some other people that join us on the call. And if there's anyone who's about to join us on the call and you're on mute, please let us know you're on the call during the process of the call.

So I'd like to start with follow-up from Call 1. We have a transcript from the previous call up online on the IACC Web site, so anyone from the working group who wasn't able to make that first call, you're welcome to check the transcript. We will be sending out some notes from that. I haven't been able to do that as yet, but we'll be trying to put that together for you before you start your writing tasks, so you have some information from the first call.

So the first item on our agenda for today - well actually maybe just to back up, on the structure of the IACC Strategic Plan that we discussed last time we had a call, today's task is going to be discussing information that will contribute to the overview of progress in the field section of the Strategic Plan document that you're going to be working on.

So this section will include an update on research, including advances in science, and gaps, opportunities and needs in research, as well as services and policy issues that relate to Question 1. So all of the different discussion topics today will relate to that, and we will use it to help put together an outline for the group to use in your writing task after the call.

So to start off today, we're going to talk first about the public comments that were received through a request for information that was put out by my office, the Office of Autism Research Coordination at NIHM. So over the summer, our office put out this request for public comment for the IACC, so that the IACC could receive public input about the different topics that span the Strategic Plan.

So we've collected this information, and it's available on our Web site. If you go to the Care cell on the home page of our Web site, you can get to it from there. Or if you go down to the bottom of the Meetings page, you can also access the Public Comments area, and you'll see the request for public comments and the place where we inserted all of the comments that we received.

So I wanted to give you all an opportunity to talk about what we've heard through public comment. Our office also provided a list of themes from the public comment for each of the question areas, and so this working group has a list of the themes that our team found among the comments. And just to - and this document is available to the public as well, if you go to our Web site.

The topics that we identified in the public comments were sub-groups. Early signs and symptoms, family support after diagnosis, sex and gender disparities, screening and diagnostic tools, biomarkers, adult and adolescent diagnosis, genetic screening, cultural, racial and regional disparities, greater and lesser early screening or diagnosis.

That was just some people arguing that we should be doing more early screening and other arguing that we should be doing less. Faster diagnosis, linking diagnosis to services, parent education, parent concerns - talking about the need for practitioners to recognize parent concerns, universal screening, practitioner training, and some comments that just acknowledged that the current priorities in the Strategic Plan, they felt, were appropriate.

And in Question 5, there were also some comments on early intervention services and the need for access to those services. So those were some of the topics broadly that were shared through public comment. Does anyone have any observations or comments about what you've observed in the public comments? Or do you have any thoughts about those?

DR. PIERCE: Yeah, this is Karen Pierce. One thing I noticed is that there were two areas that seemed to have a disproportionately large number of people commenting. People really were interested in biomarkers and the use of biomarkers for screening and diagnosis. And then the other area was multi-faceted disparities of diagnosis against racial and cultural and socioeconomic and regional lines.

So just from the perspective of what really got people's interest, those two seem to be the highest. And the lowest, one of the lowest, was need more access to genetic screening, which got eight responses, in comparison to disparity, inequalities question got 58. So…

DR. DANIELS: Thanks.

DR. PIERCE: Sure.

DR. DANIELS: I'm sorry. I didn't mean to cut you off. Is there more that you wanted to say about that?

DR. PIERCE: No. I mean, you know, certainly the first thing I did was look at frequency and see what people are excited about. And then, you know, we could certainly have long discussions about what people said. But I was initially just -

you know, wanted to think about what the public was really interested in. So for now that was my comment.

DR. DANIELS: Great. Anyone else have any reflections on the public comment, or the issues that were raised?

DR. WAGNER: I guess I just - I think these are all good issues and things that we have, I think, at least tried to address in prior ones. But it's really good to hear what things people are still concerned about, and what things still need to be done.

So the sub-group one is interesting, because I'm curious about what people think about that, as the intent to find sub-groups and then tailor services or intervention to those groups - or I don't know if their actual comments went into any more detail. I didn't look. But…

DR. MAGANA: This is Sandy, and I just have a question. How are we incorporating these comments into the work that we're doing? I'm not exactly clear on that. How should we take…

DR. DANIELS: So this information was here to provide you with some background on what issues are of importance to the public, so that you could just weave some of this into your writing to acknowledge what issues are out there.

It's not something very direct that you would take something from a specific comment and necessarily put it into the Strategic Plan. But all of this is there to inform you about what priorities the public who wrote to us feels are important. So…

DR. PIERCE: Hi, this is Karen again. I just wanted to follow up on the previous speaker's comment about recognition of sub-groups. I do believe that that's actually a really extremely important area, particularly now with the new DSM criteria.

And we have - you know, some individuals with autism are really verbally fluent and go to college and, you know, really, you know, have a straight path in terms of what they want to do in life, and they really are doing a great job in achieving that. And then at the same time you still have people with autism who are completely non-verbal, and have a lot of, you know, challenges. And so I think a lot of researchers are trying to disentangle this heterogeneity and understand the sub-groups, thinking that there might be ideological differences with these sub-groups. Certainly there might be treatments that are better matched with these sub-groups.

And we've been doing some eye tracking research to address this. That seems to be promising. So I just wanted to chime in and say that I think this is really important. We shouldn't just necessarily be diagnosing, but we might want to, you know, in this particular question, think about things like prognosis and sub-grouping as a high priority.

DR. COURY: This is Dan Coury. I want to echo what Karen is saying. When I see these comments from the public with the interest in biomarkers, the message I'm hearing is that it would be wonderful if we could identify these children before we have to wait for delays in development that are the current criteria for making the diagnoses.

And along with this idea of biomarkers that might be able to be used earlier in the screening and diagnostic process, the hope that this would also help us with separating folks into different sub-groups which then, as Karen points out, may lead to different prognoses and different treatment regimens.

DR. DANIELS: Thank you. Other comments?

DR. KAU: So in terms of biomarkers, it's definitely something that is very important and we have been working on now from NIH's perspective. But to be able to use the biomarker for diagnosis and screening is - to me, it's that, you know, we need to establish the research first, seeing if it's viable. And so application of biomarkers in diagnosis and screening, it's the next step, I think. Yeah.

But it's good to know. I'm very happy to see all the public comments. And, you know, it's all very thoughtful and all within the areas that we think are important. Very helpful.

DR. PIERCE: Are we going to be discussing papers relevant to these particular questions now, simultaneously with the public comment? Or is that going to be later in the call?

DR. DANIELS: I was going to do that separately in the call. I mean if you wanted to bring it up here that would be okay. But I was going to just focus on the public comments, and then move on to talking about science advances.

DR. PIERCE: Okay, sounds good.

DR. DANIELS: Thanks. One of the areas - this is Susan - that is a little bit new, I think, for the Strategic Plan, is talking about sex and gender disparities in diagnosis. I don't think there was a big emphasis on that in previous strategic plans. But because more information is coming out about that, apparently the public is really interested in seeing that area progress.

DR. KAU: Then again, identifying the unique characteristics of females with autism is an ongoing area of focus and from NIH's funding. But to be able to, you know, apply it to the actual screening and diagnosis I think, you know, it's sort of the next step. But I could be wrong. I might be missing some information. So I was just thinking that, you know, like biomarkers will link to Question 2, you know, right? Of the research, and the gender disparity thoughts are linked to research, you know, on the underlying biology.

DR. DANIELS: Right.

DR. WAGNER: The way I could see Question 1 being relevant for the gender disparities would be if one wanted to look at the psychometrics of screening instruments that we have, and see if they're equally sensitive or specific for girls versus boys.

((Crosstalk))

DR. KAU: Yeah, yeah, I mean yes, that's right. We do have very good tools. I mean, you know, they are being used as a gold standard. So we can use that to see if there are they are sensitive enough. But, yes. And then once we know more about biomarkers and females underlying mechanism, or unique features when they want to modify, that definitely works with the simultaneous, you know, going on.

DR. ROBINS: This is Diana Robins. I wanted to just make an observation that it seems to me that we could divide the themes into a category of more basic and translational science, and a category of more applied science. And that might be helpful going forward in thinking about shaping the next version, because both are really important, and they can work in an integrated fashion if we're thoughtful about it a priori.

But other times, I think, there can be kind of a disconnect between what's happening out in the field. So thinking about linking the science to the services as well, what's happening in the applied research, and linking it to services now, and also what's happening in the more basic or translational science, and how in the future that could impact the applied and services side of things, I think might be a helpful way of sort of framing some of these themes.

DR. DANIELS: Thanks. You can keep that in mind for the draft that you'll be working on. Any other comments on public comment?

MS. HAWORTH: This is Shannon. I had a comment around genetic screening. The comment is around the increased access to genetic screening. A lot of that has to do with insurance and what they will and will not pay for. So I was wondering are we going to tap into that? Have any recommendations around that? Or is there someone from CMS or Medicaid on the work group that could help address that aspect?

DR. DANIELS: There isn't anyone from CMS on this work group, but we can get some opinions from them if we need them. And you can definitely discuss those types of issues in the services and policies section of your write-up.

MS. HAWORTH: Thank you.

DR. KAU: And also discussions about the readiness, you know, of the field to conduct genetic screening. So there might be different opinions on that until we have the platform to do it now.

DR. DANIELS: Anything else on this?

DR. MAGANA: I just have another comment - this is Sandy - regarding the cultural, racial, regional disparities. I didn't see that - maybe I missed it. I didn't see that in the Strategic Plan priority list explicitly that way, and I think we really need to be explicit about that in terms of finding whether there is actually research on - I mean what research is out there, and what research is needed on specifically, you know, racial, ethnic disparities, rural disparities, and other kinds of socioeconomic disparity.

DR. DANIELS: You're talking about the list of topics that we handed out for the call?

MS. MAGANA: No, I was referring to the Strategic - you know, I was looking at the last Strategic Plan. So maybe I…

DR. DANIELS: There were some references to disparities in some of the objectives…

((Crosstalk))

DR. MAGANA: …not very explicit.

DR. DANIELS: Yeah, I think it was thrown in to various objectives, and throughout the plan in different places. But certainly that's been an important theme, and you can further develop that in this update of the Strategic Plan.

DR. MAGANA: Okay, good.

DR. DANIELS: Great. Well thank you for your comments on these. Unless there's anything else that people have to add, I'm going to move ahead to the discussion of research progress. So I've given you a few framing questions just to help you think about these things, and hopefully you've had some time ahead to think about the most important advances, gaps and opportunities that you see in the field.

And we'd really like to hear from every working group member, if possible, about what you feel are the most notable areas of recent progress - let's start with that - and how the fields have changed in the last few years, and what new opportunities have emerged, and how that can inform what we're going to do. So the floor's open to anyone who'd like to start.

DR. PIERCE: Okay, well I guess I'll just follow up a little bit more - hi, this is Karen Pierce - on the discussion about biomarkers that may assist in screening, and/or may be useful for prognosis.

It's easiest for me to, you know, speak about our own research. We recently published a really large eye tracking study of 444 subjects, where we were not only looking to see if there is specificity for autism and what the positive predictive value was in this pretty large sample - it's probably the largest sample of eye tracking in the eye tracking field to date.

And using kind of this one-minute test we call the Geometric Preference Test, we found that specificity for autism was 98%, and positive predictive value was 86%.

But interestingly, sensitivity was only 21%, and that is because, as we mentioned earlier, there's definitely a wide range of, you know, kind of behavioral phenotype in autism, and only a small sub-group. You know, so 1 out of 5 kids with autism shows this unusual pattern of visual fixation.

And interestingly, in this paper we also noted that this happens to be associated with worse symptoms - so higher ADOS scores, lower IQ scores, worse adaptive scores. And so we're kind of looking into this further, you know, both as a utility as a diagnostic biomarker, but maybe even more importantly as a prognostic biomarker.

And so I think that - I'm very proud of the paper and excited about it, and I think it's a nice little baby step towards discovering biomarkers that speak to the question of sub-groups particularly.

DR. DANIELS: Great. Thank you. More comments?

DR. AMY WETHERBY: This is Amy Wetherby. First I just want to see if you're able to hear me. I joined a little bit late.

DR. DANIELS: Thanks. Welcome, Amy.

DR. WETHERBY: Excellent, thanks. So I just wanted to make a quick comment here that I think that we've made tremendous advances in, number one, early diagnosis. So I think there's been exciting research clearly documenting we're able, with the tools we have, to make a diagnosis in that range of 18 to 24 months or 18 to 30 months.

It also illustrates the gap that, I think, some of these themes touch on - the gap of but it's not happening out in the community. So I think that's important.

And I also think in terms of screening, we've made really good advances in understanding the strengths and limitations of existing screening tools in different populations, children who are referred for suspected symptoms versus primary care. So I think we've made really nice advances in those two areas.

DR. DANIELS: Thank you.

DR. KAU: Amy? This is Alice. Are you differentiating how what we know in terms of research, and what the community is actually applying the research findings?

DR. WETHERBY: Right. Thanks for the question for clarification. Right, so I think the research - yeah, the point I was trying to make is that I think we have the research base, but there's a very big gap between the research and community practice. And I think there's even evidence in the research that that gap is larger for minority families, for rural families, and low-income families.

So yeah, there's a huge gap in terms of available, but at least the science, I think, is now solid on early detection and, again, strengths and limitations of early screening.

DR. KAU: Thank you.

DR. WETHERBY: Did that clarify, Alice?

DR. KAU: Yes, thank you, yes.

DR. MAGANA: And this is Sandy. Along those lines, I think that there's room for research on sort of the translational piece of actually getting - you know, getting these screening methods and referrals and diagnostic methods, you know, used in communities, and particularly adapted for minority and under-represented communities.

There's very little progress on that, you know, and I'm thinking, too, in terms of getting into early interventions that have evidence base behind them. I can find very few articles where there's actually intervention studies that have included minorities, or have looked intentionally at that. So that's an area that really needs a lot of research.

DR. COURY: This is Dan. One of the other areas that we've made progress in is the recognition of some of the medical co-occurring conditions, notably GI problems. Epilepsy is another one. And we're becoming a little more focused on being able to identify some of the sub-groups we were commenting on earlier.

There still is a lot that needs to be done in terms of finding any genetic underpinnings that would help better describe that. But we are starting to recognize the fact that these do occur fairly frequently, and that managing these better is part of the overall management of the patient's autism disorder.

DR. DANIELS: Thank you. Other comments about notable areas of progress?

DR. ROBINS: This is Diana again. I think this actually builds off of something we talked about in the last call, about now that we have more validity data on certain things around screening and early diagnosis, it's a big step forward, but it actually opens the door to this whole implementation side of things, that addresses the gaps between what research has demonstrated and what's actually happening in practice.

And so I think even as we kind of look to the biggest achievements and the biggest gains, it actually lets us ask new questions that probably weren't even on the table in the last Strategic Plan or two.

DR. DANIELS: You have some examples of that?

DR. ROBINS: Well thinking a little bit about parent report screenings, since that's my area that I'm most familiar with, we know that if you look at our M-CHAT paper from 2014, using a standardized protocol where every child got screened at a check-up, and every positive screen got offered a diagnostic evaluation, the median age of diagnosis was just after the second birthday.

But we know that that's not happening out in the field. And so what we're sort of left with is asking questions now about what are the barriers to implementation.

And I hear a lot of them anecdotally when I talk to physicians in CME workshops, or doctors I'm trying to enroll in various studies, where they say that it's too hard or it takes too long, or they have too many other things to do in a check-up to be administering screening questionnaires that are specific to one particular disorder, and not just broad for a whole lot of disorders all in one.

And so I think that the fact that we now have better validity data on tools like the M-CHAT lets us know look to what are the barriers to getting this out there to every family, and letting every family who's screened positive get an immediate referral for early intervention, and for diagnosis.

DR. PIERCE: Yeah, and I just want to comment - this is Karen - that those kind of studies are really important. And the new CDC paper just came out, whatever, a few months ago, 2016 citation, and still it's only around between 20 to 40% of children are getting a diagnosis under age 36 months.

Now the caveat to all the CDC studies is that they did a cross-section at 2012, but the children were 8 at that time. So that means they were born in 2004. So we're pretty far behind in seeing how, quote/unquote, the “real world” implements what we're doing because of this huge lag. But certainly the new report that came out suggests we still have some ways to go. And I think it's an important paper as well, this new CDC study.

DR. DANIELS: Thank you.

DR. KAU: Karen, do you have the data on screening?

DR. PIERCE: So I have the answering - so we certainly…

((Crosstalk))

DR. PIERCE: Are you kind of - in terms of implementation, you know, one thing that we're doing here is, you know, we have pretty good data in terms of, you know, what pediatricians are doing or not doing, in the absence of any support.

But then we do provide follow-up support in terms of providing the evaluations. And so I think what Diana and I are both talking about, and we talked about in the last call, is sort of this implementation in the community without any, you know, researchers calling up to kind of get a family in for an evaluation with a child who may have screened positive, but wasn't seen.

And so I don't know that those kinds of data are fully there yet. I know that with our peds network, with Amy and some other folks, there are people who are trying to do kind of a purely hands-off model, and investigate sustainability. But the data aren't fully in yet on that. And we are starting to move in that direction as well with our center, but we don't have, you know, ironclad data yet on that. But that's where everybody's moving, and I think that's the right direction to move in.

DR. DANIELS: So in terms of - this is Susan. In terms of the evidence base for early screening and diagnosis, on the last call we talked a little bit about the USPSTF report, and how does that fit into what we think is progress, and where some needs remain.

((Crosstalk))

DR. WAGNER: I guess my question for the group is - so I know, Amy and Karen that your peds network has been talking about this to some extent. So do you have thoughts about the gap areas that that report highlighted, that you would want to get into for the Strategic Plan?

DR. WETHERBY: And this is Amy, just to get this started. I mean I think that clearly the conclusions drawn in that report are based on a requirement for very, very strong evidence. And so if there's agreement that you need that level of evidence, then it's going to be very important to prioritize that level of evidence.

I'm not sure that we agree. And so I'm just sort of wondering how everyone feels, or how that plays into priorities. Do you understand my question?

DR. WAGNER: Yeah, I do understand your question. So what you're saying is the level of evidence would require - that they are saying what needs would require significant resources to do, if it was even feasible, I would ask. But yeah, so how this weighs out with what is feasible to do, and also whether or not everybody agrees that that's - I think that's an open question. Do people agree that that level of evidence is needed.

DR. PIERCE: Exactly. I mean I think as you pointed out, it's very resource intensive. And so, yeah, it is a fundamental question, as Amy, you know, suggests. I'm on the fence. You know, on the one hand I think that the RCTs that they're talking about, kind of showing that doing all this early identification and screening does lead to a better outcome. I think that's, you know, fundamentally a reasonable thing to say.

But on the other hand, I think that there is some evidence to suggest that it does already. And it feels like life is short, you know? Our resources could potentially be better spent trying to optimize treatments, and starting treatments as early as possible, and seeing which treatments best match whatever profile a child has.

And if we spend a lot of time and energy kind of on this one question, which is debatable, you know, are we, you know, losing ground and spending precious time that we might, you know, better put somewhere else? So, you know, I think about it a lot. I don't know that I am 100% on one side or the other just yet.

DR. ROBINS: And this is Diana. I can chime in on this, too. I had a really good meeting with some folks who are ethicists, who approach questions about when research is ethical to conduct and when it's not, because I was trying to think of how to design an RCT where we wouldn't withhold what we think really works. And the ethicists basically really helped me understand the idea that when the American Academy of Pediatrics says one thing, and the US Preventive Services Task Force says the opposite, that there isn't a definitive knowledge in the field. There is still uncertainty. And what an RCT can do is pretty much bring the data that will answer that question of which side has the evidence.

So I think that some parts of what the task force identified as research gaps are possible to address. They are large, expensive, labor-intensive studies, but some of them feel like even if you threw all the money and personnel and effort, you know, in the world at it, you wouldn't really be able to tackle it - like they're suggestion of intensive follow-up of large samples of screened-negative children.

And I just can't think of a single circumstance where that kind of study would take priority over lots of other really good research proposals that are competing for the same resources. So I think that it is important to address the task force, because they certainly have influence on preventive care in the US. But I don't think that all of their suggestions of what gaps need to be filled are necessarily equal in feasibility or importance.

DR. WAGNER: Yeah, that's a really good point, and I think it's the (unintelligible) into this. It's not just the money that it would take, but it's also the time that it would take, so do we, you know…

DR. ROBINS: Exactly, yeah.

DR. WAGNER: So I guess the question here, Susan - so just in terms of this, and thinking about the process, so the work that we're doing right now is discussing the gap, and sort of the research progress in gaps that eventually we're going to get to writing some…

DR. DANIELS: Objective…That will be the next call.

DR. WAGNER: So that would be where we would have to really grapple with this, like what - how…

DR. DANIELS: Exactly.

DR. WAGNER: …specific do we want these things to get into…

DR. DANIELS: Yeah, so any work that you're doing now is kind of ground work, because on the next call we really want to narrow down the three objectives for this…

DR. WAGNER: Okay.

DR. DANIELS: …chapter. So…

DR. WAGNER: Okay.

DR. DANIELS: If you can even distill out from this conversation that you've just been having, what are some of the areas you might want to focus into an objective…

DR. WAGNER: Yeah.

DR. DANIELS: …that might help you later.

DR. WAGNER: Okay, thank you.

DR. DANIELS: One of the other questions on my list for you is, what significant barriers are there to progress in the field? And I think you've talked about some of them. But are there others that you'd like to highlight that are important barriers? And especially maybe barriers that funders might be able to address, or that the field needs to address in terms of, you know, thinking about both the topic and finding creative solutions?

DR. PIERCE: I certainly think one of the barriers relates to funding itself. So, you know, if we were to step back and not move forward with a lot of screening studies that have scientists and researchers sort of holding the hands of community from trying to move towards more community-based, certainly an issue for these Part C providers through state agencies like regional centers, is there's a high volume and they contract out these people who are dong sort of these readiness evaluations to see if these children are eligible for services.

And the individuals aren't necessarily trained, and they don't look at an autism-specific level. They have, you know, varying degrees of what they do. And so I think that's kind of a barrier, because even though a child might get identified as having a delay, they'll get maybe one or two hours of speech, and they're not recognized as actually having ASD until they're in preschool, when somebody actually gives them a full diagnostic evaluation.

So I think that maybe needs to be entered into the conversation, that kids, you know, maybe are getting services early at some level, but most often they're not autism-specific, which is why there are several papers - I can get the references - showing the high rates of autism that are found in preschools and Kindergartens.

They were receiving services, but they just were never identified because of this, you know, initial step through the state agencies. And they just don't have the money, really, to do an in-depth evaluation and/or the expertise.

DR. WAGNER: So you think it's both funding and expertise?

((Crosstalk))

DR. DANIELS: So partially a workforce issue, too.

DR. PIERCE: …workforce expertise and how that gets paid for.

DR. WETHERBY: So this is Amy Wetherby. Just to add on to that, I agree with what you're saying, Karen. I think it's this sort of balances portfolio of funding priorities, and how much money goes into community-based services. And I think we really need the research. We need to try to get more equal funding in that direction so that we can better understand.

There's so many aspects to why this research-to-practice gap exists, and then much that we don't know. How do we effectively train doctors to, you know, implement the screening? How do we effectively train parents? How do we - so there's a lot that we don't know.

There's also, at the level of service implementation, there's such a huge disparity from state to state. And so just having more research focused on understanding, even the states that pay more, the children maybe aren't necessarily identified earlier or more improved by the time they get to Kindergarten or beyond.

So I think just more community-based services research, putting more funding there, will help to have a bigger portfolio of research questions.

DR. WAGNER: Amy, I think that's a really good point. And I guess my question is about workforce of research services researchers, because my impression is that we could use training and workforce development of researchers to go in that direction.

DR. WETHERBY: Yes, that's a great point, absolutely. Even those of us that are doing it could benefit from more collaboration and then more training, and more understanding of advances.

DR. WAGNER: Yes.

DR. DANIELS: So along the same theme of research to practice and the gap there, what are some other barriers that you see, or ways that that could be improved?

DR. WAGNER: So I think people have mentioned -- both in public comments and maybe even in the last strategic plan -- sort of what are the gaps between screening and diagnostics for older people, for adults or older folks. And I guess I would ask the group if people still see that as an area that is in need of development. And if so, what would be the barriers that you see there?

(Pause.)

DR. WAGNER: Maybe people don't feel that this is their area?

((Crosstalk))

DR. KAU: …wondering who would be the lead person in our work group. But that definitely belongs to Question 1, right?

((Crosstalk))

DR. DANIELS: We've been putting - for adults, putting the research in Question 6. But there's nobody with really that type of expertise on the Question 6 working group. So if this working group had comments, we could pass them along.

DR. WAGNER: Okay.

DR. WETHERBY: I'll just say that I think it's a question about whether the screening and diagnosis in adults is more of a problem than the entire lack of services for adults altogether.

MS. HAWORTH: This is Shannon. I would agree. From personal experience, no adult's going to get a diagnosis. It's because of something happened in employment, or there was a lack of - you know, there was something that led them to that. So I think the services and support would be more of, I guess, an important question.

DR. KAU: Okay. So yeah, if these older adults are not diagnosed, then they're definitely not going to, you know, receive services. How about the tools? The tools to diagnose older adults?

MS. HAWORTH: This is Shannon. Wouldn't a diagnosis ADOS still be used for adults? I don't know if there are any other tools that are being used primarily for adult diagnosis.

DR. WAGNER: Yeah, I think that would be the gold standard one, I guess. I don't know of screening instruments particularly, or how one would even implement screening.

DR. KAU: Right.

MS. HAWORTH: Would the SCQ be appropriate? Or - Social Communication Questionnaire?

DR. ROBINS: This is Diana. I think one of the interesting challenges in diagnosing adults is the question of how one balances self-report versus report of an informant. Because when you're talking about a child, a parent is an obvious informant. And there's often other likely informants like teachers, who see the person on a daily basis and can really comment on their strengths and weaknesses, what's a challenge for them and what's not.

But when you're talking about an adult, I think the question of potential informants and how one might weigh the evidence provided by an informant versus by the individual really has shifted from when you're talking about a child.

The other thing I would just suggest that maybe become part of the conversation is if somebody already has made it to adulthood without a diagnosis, the odds are that they have some really notable strengths, and that those strengths have carried them through those kinds of moments when otherwise they might have been detected.

And so a tool that would be helpful for a screening in an adult would have to be sort of calibrated to the higher end of the - functioning end of the spectrum, because many of these adults who don't have a prior diagnosis have a lot of parts of their lives in which they are functioning at a reasonable capacity.

So I think that some of the screening tools we might think about, some of these questionnaires that parents might fill out, may not be the best for an initial diagnosis, or an initial screen to make a referral for diagnosis.

MS. HAWORTH: This is Shannon. I was just going to say when you were mentioning informers like for adults, most likely it would be like spouses or peers or - my husband got an adult diagnosis of autism, so that's just an interest of mine. But yeah, I agree. It's definitely different in types of questions you would ask.

DR. ROBINS: And I think there are people, adults with autism, that have never been diagnosed with autism, that have severe, like, intellectual disabilities or other disabilities that would not put them on the high end of the spectrum. So we have to think about those, but maybe the current - like the SCQ and other measures would work for those folks. But then what would be the benefit to them? Because the service system is generally set up for developmental disabilities as adults, not autism-specific. So it may or may not benefit them at that point.

MS. HAWORTH: I think the benefit - this is Shannon. I think it's more of just knowing - they probably have some co-morbid mental health issues as well. I think what I've seen is that just knowing, you know, having an answer - yeah, it's not so much of services you can get, except mental health.

DR. PIERCE: Yeah, hi. This is Karen. I think that the individuals who have more challenges, I think there could potentially be some benefit in giving them a diagnosis. But I think it's an interesting question for the individuals who have gone through life, as Diana pointed out, and have done really well, and they're not being recognized until they're having problems in their 30s or 40s.

And this kind of intersects a little bit with the neurodiversity movement where individuals with autism who are like that argue that, you know, they are just essentially on one end of the continuum of typical, and that, you know, they should not actually receive a diagnosis - particularly, you know, individuals of that character.

So it's an interesting question. Because if it's not really impeding your ability to hold down a job or, you know, engage in the world, then I think it's a little bit more of an open question about whether or not diagnosis makes sense entirely. And I don't know where to draw the line, and what level of impairment, you know, should be that.

But I do know that, you know, since I give a lot of lectures all over the world, I've definitely been getting more and more, with increasing frequency, comments about this idea of neurodiversity. And we should move the - what we consider being in that diagnostic envelope, we should reconsider, you know, how we define that and who's included in that.

MS. HAWORTH: Yeah, and people in that movement - there are people in that movement who do embrace their diagnosis, right? And so they're not just all saying that we don't think there should be a diagnosis. Many of them are saying, this is our identity. This is part of who we are, and we want to embrace that.

DR. KAU: Right. And in addition, I think this sub-group of individuals actually is asking for different kinds of services, you know, for them. So, you know, the issues have - the names are different, and the strengths and the weakness and views are different.

DR. PIERCE: Yeah, that's true. That's a really important point.

DR. DANIELS: Great discussion on this area. This is Susan. We'll be sure to pass that along to Question 6. I'm sure it will inform their discussion. I did hand out a list of topics for Question 1 that is just a start of some of the types of things that have been discussed in previous Strategic Plans.

Just going back to that, thinking about some other areas you might want to comment on, how do you all feel about the level of outreach to, and education for, parents and providers in terms of recognizing early signs of autism? Where have we come? Where are we now? And are there still areas that need to be addressed more?

DR. PIERCE: I'd like to just jump in on Amy's behalf. A few times she has shown at conferences, and I've looked a little bit myself. She's really been developing amazing sort of dissemination and information videos and pamphlets and things like that for parents. And so I would say that Amy can chime in and give more details.

But I think we made a lot of progress in that area thanks to what she and her team have been doing - really impressive stuff like 16 Gestures by 16 Months. And it's really clear and compelling, and I really think that's been a huge value for the field.

MS. HAWORTH: And this is Shannon.

DR. WETHERBY: This is Amy. Thank you. I just want to say thank you. Go ahead, Shannon.

MS. HAWORTH: Oh, no, I was just going to mention along with that, I think the CDC Learn the Signs, Act Early program - that's something that we support here at AUCD. I mean there are - you know, that the - there's a state - you know, state ambassador for almost every state. And they're really working with families. Although it does not mention autism - you know, there's still some stigma around that - I think it is raising the awareness about developmental milestones.

DR. WETHERBY: And this is Amy. I just want to add to that. So I think those materials are great. The concern I have of them is the accuracy of the milestones and the benchmark of the milestones, so that I think they selected them to be very low milestones, closer to two standard deviations below the mean, or the second percentile.

So I think part of the challenge is helping the public understand what milestones children should have versus, you know, if the milestones are missing or so low. It doesn't mean your child's just falling if they meet those milestones. Do you see what I'm saying? So I think it would be really nice to have more research on backing the accuracy and validity of these materials.

DR. DANIELS: Are you talking about Learn the Signs, Act Early or Birth to Five? Or…

DR. WETHERBY: Both.

DR. DANIELS: …any particular one?

DR. WETHERBY: And part of it is it's sort of the state of the field. And then federal agencies, it's my understanding, are maybe required to use these or tend to use them. They're freely available. So it's just do we have the research to back them? And I guess my opinion is the research doesn't necessarily back them. Or what are we trying to accomplish with them?

DR. KAU: When you have CDC officials on Question 1…

DR. DANIELS: We do. I don't think that they're…

DR. KAU: Maybe we can engage…

DR. DANIELS: Yes, it's - and our ACS representative was on detail, but is back. So maybe she can also weigh in a little bit.

DR. KAU: Right.

DR. WETHERBY: That'd be great. And just where does this fit into research priorities, and what research hasn't funded or could be funded?

DR. DANIELS: Sandy, do you have any comments about outreach and education with respect to health disparities and underserved groups?

DR. MAGANA: Well one of the things I was thinking is that, you know, we definitely need more work on outreach and education in terms of, you know, looking at strategies that work. I think there's some evidence that navigation is a good strategy - use of community health workers are good strategies to reach minority populations.

One of the issues, though, that I think was raised before is that, what happens when people get, you know, screened? There's long waiting lists on the diagnosis. And there's no treatment.

Like it varies so much by state. I think Amy made this point. So like in Illinois where I am right now, children cannot get ABA if they're on Medicaid, because it doesn't pay for it. So, you know, you screen them. You get them a diagnosis. Now all they can get is OT and speech, but not necessarily with providers that, you know, use evidence-based behavioral strategies.

So I think there needs to be more research on that transition, like what happens after you get a diagnosis, you know? What are ways that children can get services right away, maybe when they're screened - get right into service programs.

You know, I see a lot of evidence that particularly Latino children miss that birth to 3 period, because they get diagnosed at 4. And so, you know, they miss that period. So now what do they do? When they get diagnosed, what programs and interventions can they get?

And I think there needs to be more focus on policy research related to that, so understanding how these different systems work with each other. So who's doing the screening? Who's doing the diagnosis? Who's doing the treatment? You know, who's funding these different programs?

And how do we coordinate those efforts on a state-by-state basis? But also maybe some comparisons across states to see what are promising models in terms of service delivery.

DR. DANIELS: Sandy, with regard to disparities, what do you feel are the biggest barriers to underserved groups getting early diagnoses? It might help you in terms of thinking about objectives.

DR. MAGANA: Yeah. Well definitely - I mean I'm just thinking where I am locally, right? I mean there isn't enough screening for one thing. But big barrier? Long waiting lists. In the state of Illinois, we have no budget. So, you know, anybody who - our Illinois autism program was decimated because of that. So and they paid for a lot of screenings throughout the state.

So again, it varies by state, but I'm sure probably in most places, there are long waiting lists for the diagnostic clinics that have people that know how to diagnose autism, right?

Even when I was in Wisconsin, they had a developmental clinic there that had a long waiting list. And they tried to shorten it for the young children, which was great, but there were many barriers that I saw Latino families had getting to that clinic, like not only language barriers - so there's a lack of, you know, Spanish-speaking or other language providers, or interpreter services that they would use - lack of competence in psychologists in doing any kind of assessments.

I mean, you know, I've seen psychologists who turned people away because they didn't feel they could deal with a Spanish-speaking family, you know, I mean which is - you know, that's another issue.

But so there’s a lot of barriers that families run into - making them pull up their own records. You know, I've seen clinics do that. They make them bring their own health records before they'll have an assessment. And, you know, that's a big hurdle and barrier.

So I think there are a lot of systemic barriers. You know, I don't like to - you know, I think there is some research on cultural issues within families, and but I think for the most part if families are educated, that they're going to bring their children. But if there's these barriers, it makes it harder for them to do it.

And that's another area, is parent education. You know, once they do get a screen and once they get a diagnosis, what happens? What is the education that they get in terms of getting to treatment right away?

DR. KAU: So it sounded like, Sandy, a long waiting list is obviously a result of not having adequate funding and budgets, but also having culturally competent providers available, right?

DR. MAGANA: Yeah.

DR. KAU: Is also a workforce issue.

DR. MAGANA: Yeah, exactly. Workforce issues, yeah.

DR. KAU: Yeah, so and I know we all - you know, we all want to focus on services research, and it's just so variable from community to community. And we can give you that research for many, many years. But something like the question, the scenario, you just described, we do have a long waiting list. And obviously money's one thing but, you know you need to have people who can do the work. Because even if you have money now, you don't have culturally competent providers to manage children, right?

DR. MAGANA: Right, exactly, yeah. And we do need more research on understanding diagnostic tools for different cultural backgrounds. And I did a study funded by NIH on the validity of the ADIR with Spanish-speaking families, and had mixed results in terms of the sensitivity and specificity. It was fairly - it was lower than the general population.

Not that it wouldn't be a usable tool, but they're different. We need to understand what's useful about it and what's not useful about it in different tools. So that's another area of research that needs more work. I don't think the ADOSs have been looked at in that way, and other diagnostic instruments.

MS. HAWORTH: This is Shannon. And along with barriers, I know one of the barriers for minority children getting diagnosed with autism is that they often get diagnosed with a behavior disorder first. That's what, you know, parents notice most. And usually if they don't - if they get a diagnosis in school, you know, it's because of behavior. So I think that's - in my reading of research, I've done some research on that, that's one of the barriers.

DR. WAGNER: That's a good point.

MS. HAWORTH: They're getting the diagnosis later.

DR. WAGNER: Good point.

DR. KAU: And why is that? Because of the provider, as a whole, diagnosed other disorders, are not trained in autism? Or is it because there's no follow-up?

MS. HAWORTH: A lot of it is clinician bias, to be honest, yes.

DR. KAU: All right, well that is important.

DR. PIERCE: And also, as I mentioned earlier, I think a lot of kids from both - you know, from multiple racial and ethnic backgrounds, and it might be disproportionate let's say, for certain groups than others, but again I think a part of the barrier happens when - most feeds do have Part C funding and they're supposed to be doing these eligibility evaluations if a pediatrician or somebody has a concern about a kid.

And they do them but they're not autism specific and so a child might be looked at and say, oh yes, you're fine behind and you'll get an hour of OT, or speech, or something and they go through their merry way in life.

And then again, it's not until preschool, or kindergarten, or even beyond that they're finally recognized as having ASD. So maybe part of the barrier is a sort of false sense of security. Okay, my child had this eligibility evaluation and that's that. And people are not able to seek out these more autism specific evaluations or those long (unintelligible) whatever.

So part of it is the way the system is structured now doesn't allow for kids to really be getting these autism specific evaluations quickly because, you know, there's not a lot of money, there's not a lot of expertise so they do it the way they do it and they have people with varying levels of expertise doing these eligibility evaluations.

DR. MAGANA: And back to Shannon's point, I think that's a really important point because I think that there is some evidence that minority kids gets misdiagnosed so they get diagnosed with something else first and then autism later.

So it might be ADHD. It might be something around the behavioral issues and so there might be some implicit bias there in terms of, well, we think because this child is African American they're going to have a behavioral disorder or something like that.

And you know, I think that we need more research on that type of bias and we also need - we do need more research on disparities with large datasets. There is the pathways dataset that I've looked at. We just recently published something from that, but the problem with that dataset is that most of the families, the African American Latino families are actually much more high income than the general population so it's not representative and they didn't do it in Spanish.

So really, you're not going to find the kinds of disparities that exist out there with a dataset like that.

DR. ROBINS: This is Diana. I think some of the disparities that are out there in the field are really hard to capture with data - existing data - at all. I'm thinking about conversations I've had recently with pediatricians and also with parents about how many times you have to call to get that Part C eligibility appointment.

So it's not a perfect world where you make one phone call and then it gets scheduled and they show up and they have their 45 days or however many days it is to give you the plan of what services a child is eligible for and when they're going to happen.

I've heard some pretty alarming stories about the disparities in who gets a call back or who's persistent enough to call more than once and not assume that, well, maybe they shouldn't be pressing for it if they're not getting the appointment. Maybe somebody else needs it instead or I'm not even sure what all of the potential barriers are. But it seems that they're quite disparate by income and probably by race and ethnicity as well.

DR. WETHERBY: And this is Amy. I just want to echo these comments. I think that the Part C system, the federal data from the U.S. Department of Ed shows that it's now missing close to 80% of the children who will be eligible for Special Ed when they get to school age. The preschool services are still missing half but when you get down to infants and toddlers under three, it's 80%.

So even if - so it's really understanding why the families aren't getting to that system. So Diana raised - one of the issues is scheduling that evaluation. But some of them - many don't act on the screening results. Many don't get screened. There's many, many complicated reasons why families are getting missed and so I do think there's a lot of data out there from the U.S. Department of Ed Part C implementation that supports that health disparity and, again, across state disparity. Now, the ASCP's network funded by NIMH is, in our current grant, so we are really taking a look at some strategies to reach out.

So for example, if a family's on Medicaid they may not see the same doctor when they keep coming - if they keep returning for well visits and so they may not have a connection with their doctor. So there may be other agencies that are better suited to do the screening or in collaboration with the doctor. As an example, our study is really focusing on that.

DR. DANIELS: Anyone else want to chime in on this topic? We've had some really good discussion.

DR. KAU: So I want to add a point in the context of the evaluators for the first evaluators deciding eligibility on the child. This is the first time they're coming with a bias and so they diagnose whatever they think, you know, is obvious at first and then they either don't - not catching the ASD symptoms or they think it's not important. I don't know. There's the bias.

But in the whole system level, I often - I know we focus on autism but that's how they work, right, because children come to disability, could have intellectual disability, could have physical illnesses, and they also could have autism.

And there's a whole spectrum of issues that need to be taken into account and prioritized. So I don't know if the - since services research need to look at the bigger picture so that to help to activate a whole system so you make sense, like where should be autism screening be done, at a frontline level, at a second tier.

There has been a lot of discussions and I know we're limited to autism, but I wonder if that's realistic and if that will limit our ability to make a system work.

DR. THURM: Alice, this is Audrey. I think that's a great idea and I just want to underscore the points related to this about stigma and education of the providers, those two things combined. Because I think those are reasons why people are focusing on other disorders as well instead of ASD. So looking at the bigger picture and why other things are focused on more than ASD in these initial screens.

DR. PIERCE: Hi, this is Karen. I just want to follow-up. I think Alice's point is really an excellent one, which is why I really love using Amy Weatherby's CSCS because it's a broadband screen and you can detect kids with various delays.

And also we're investigating sort of the fluid nature of the early phenotype and how things move, what the diagnostic stability is, how kids that looked originally just like they had a language delay really ended up being ASD when they got older and a general population cohort, which doesn't really exist currently at such a large size. We've got around 800 kids in this particular study.

And I do think we may need to rethink it a little bit, the way that Alice described, without necessarily being autism centric per se, because during the time we're talking about, 12 to 36 months, you know, the water is a little bit murky and I think it requires a little bit more thought about those blurred lines.

DR. WETHERBY: And this is Amy. I just want to add on, I think the pediatricians become overwhelmed to think about screening for autism when they also need to address all developmental disability. So I think the broadband screen for whether it's communication delay or other developmental delays is more palatable as a first step. But again, we've got to validate that twostep process.

And I think the work that Karen's done, the work we've done with the infantile checklist and then going to an autism screen from there at least support that direction.

DR. DANIELS: Great. More comments on this? So another topic that was on our list of topics was implications of changes in diagnostic criteria and I don't know if anyone wants to comment on what we've learned since we've changed the diagnostic criteria a couple of years ago, what the impact has been and how that might inform research going forward.

DR. MAGANA: This is Sandy. We have a paper under review looking at the change in diagnosis using the ADIR for Spanish speaking parents of kids with autism. And what we found there is that actually there's better sensitivity with the DSM-5 than there is with the DSM 4 and slightly lower specificity but I mean, there might be a number of reasons for that. There are more sort of items under restrictive repetitive behaviors that -

because some of those items we found are difficult for Spanish speaking parents to kind of grasp. They're a little more complex that try to convey and for a parent to have no experience with any of that to understand.

So that's one issue there and also the separation. I think having - in our first paper around this, we found that the language questions were not very discriminate between a DD group and an ASD group with Spanish speaking parents and it partly is because parents don't always know what the language of their child is, if they speak English or are bilingual and the parents only speak Spanish.

So the new DSM-5 kind of eliminates that issue by putting language and social communication together. So that is very preliminary results with a small sample.

DR. WETHERBY: And this is Amy. First and full disclosure, I was on the DSM-5 workgroup. I think that what you're saying is very consistent with the research that the workgroup reviewed to make the decision to remove the language from the diagnostic criteria. So I think - and I think the research coming out on toddlers is supporting the applicability of the DSM-5. I'm not sure that the actual book has all the references in it but there were supporting documents. So there was a lot of literature review that went on with the workgroup. Just want to make sure everyone knows that.

DR. DANIELS: Anything else that you want to note with regard to DSM-5? I know that it was kind of a big topic a couple of years ago and we'll definitely want to have something in the draft that talks about where we've come since then.

DR. WAGNER: Yes, I think it would be important to be able to summarize any data that has come out.

DR. DANIELS: So we've been having a really good discussion. I have tried to go through most of the different topics that were on our list but are there any other pressing topics that we haven't discussed on the call so far that you wanted to bring up that you want to make sure are a part of our update?

(No response.)

DR. DANIELS: And including any recent policy changes or programs - innovative programs that are good examples of things that we might want to replicate?

DR. WETHERBY: This is Amy. I guess I just have a general comment in looking at the topics that you listed in the email. You have a section on research and a section on services and policy. I'm hoping that we can somehow integrate not - they're almost like pitted against each other or where are we going to put money.

I hope that - it seems like with each research topic, there should be a services and policy not only implication but also thinking about where's the gap in what we know. So that somehow integrate these a bit better I think would be really nice in this chapter.

DR. DANIELS: So it's more of a matter of how, this is Susan, how the structure will be for all of the different chapters. And I think in this one, as we've been talking about it, I think the services and research issues are very intimately intertwined and so you've been discussing all of them together. I think in some of the other chapters, like Chapter 2, it won't make as much sense probably to integrate that same way, but we can figure out a way to do that.

The reason they're separated now is the last strategic plan that we did or the original way the strategic plan was done, it was a research plan.

So Congress had set it out as a plan to cover research priorities and now Congress has expanded that to say that we need to better cover services and supports issues.

And so that's why we added that on to make it look intention that we are not just putting in services as an afterthought, but we're really going to think about it. But in terms of how you work it into the draft, as long as it's reasonably easy to read and consistent with what we're doing across the whole plan, you will be able to integrate some of those.

And I think it has completely made sense how we're discussing it here but many of these issues are closely intertwined. But I just wanted to make sure we're not missing any important services or policy issues that you might have wanted to discuss. Is there anything else that anyone here wants to bring up?

DR. MAGANA: I would like to add - when we're talking about services and policies, are you talking about research on services and policies or development of service and policies, or both?

DR. DANIELS: I'm talking about issues in services delivery, implementation, but you've been discussing some of that. Are there major policy changes that have happened externally that have affected the field and that - or ones that need to happen, policy changes that would help to move things forward or help make it easier for people to access the services they need, et cetera, in the area of screening and diagnosis.

((Crosstalk))

DR. KAU: You mean both

DR. MAGANA: Yes, both

DR. WAGNER: …try to separate them out, I think, at least (unintelligible) for this (unintelligible).

DR. MAGANA: I was thinking an additional thing related to a recent policy is that the Affordable Care Act does call for autism treatment and there was some federal policy that came out that said that Medicaid services should pay for autism treatment, but it doesn't actually happen state by state.

And so it would be interesting to do a policy study, you know, looking at which states are doing it, which states are not doing it, you know, why - what are the barriers to them doing it and so on. And are all insurance programs covering it, are they not? How is the Affordable Care Act influencing, you know, access to autism treatment and diagnosis?

DR. DANIELS: Okay. Yes, the autism treatment part, of course, would be a part of question four on interventions but if it has to do with diagnosis and screening, we could talk about it here. And so we have some people that are a part of question five and question six that have more expertise on all the latest policy updates with regard to implementation of the ACA. So we can ask them for a little bit of help with that.

Anything else that you want to talk about with regard to implementation services, policy changes, areas where we feel that there's research evidence that should be informing policy or that needs research evidence that should be translated that, you know, isn't being - we've discussed this already on the call in a number of areas but just checking to see if there was anything else that comes to mind.

All right. Well, the last agenda item that I have on the call is to discuss the aspirational goal for question one. And so when the ICC first created the strategic plan, they created an aspirational goal for each of the question areas.

And so the question one aspirational goal is in your agenda, it's written as children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest. And so that was the long-term overreaching goal for the chapter, for this question area.

Does the working group still feel like this aspirational goal is appropriate? Is it still up to date? Is there anything that you think should be changed about it or would you like a different aspirational goal if you feel it's not current?

DR. ROBINS: This is Diana. I've always struggled a little bit with this aspirational goal because what we have is a disorder that's behaviorally defined and if the only way to ascertain the accuracy and the validity of identification is through verifying diagnosis, how can you actually do that before the behavioral characteristics are fully manifest?

Because it's very hard to tell when you're looking at a very young child who's showing some features that seem autism like but they don't have full blown clinically significant symptoms at this point in time.

It's hard to tell if that child is emerging as a child with autism, so the symptoms are growing and developing, or if the child has some weaknesses that will be mitigated by other factors and will - the child will catch up to peers over time and these sort of mild weaknesses will actually dissipate rather than intensify.

And so if we had definitive diagnostic markers that were not behavioral, I think that this aspirational goal would be achievable. But in the current state of the field, I'm not sure - maybe aspirational means it doesn't have to be achievable right now but I'm not sure how far down the road this could ever be achievable given our current state of what we know about non-behavioral markers or measurable traits.

DR. DANIELS: Those are great comments. Just as background, I do think that the committee was thinking in terms of non-behavioral biomarkers when they wrote this and I think back in 2009, they were hoping that maybe in the next several years we would come up with some really useful biomarkers that could be used to provide a very early diagnosis or confirmation of diagnosis.

DR. PIERCE: Yes, I agree. I'm sure that's exactly what the spirit of this was that we want to move towards kind of moving out of this purely clinical, sometimes subjective goal of diagnosing autism based on behavior alone into biological. And if you look at the genetics research, I think at this point they're up to around - you can find genetic mutations or some genetic issue in about 20% of cases with ASD. Sometimes it's not always specific to ASD.

Also, as I said, we have a little bit of progress in I-tracking, and we have an incredibly long way to go but I think there's been a little bit of movement there.

So for what it's worth. And we may want to reconsider, you know, what this aspirational goal is but I definitely am sure that's what they had in mind, that it was all about biomarkers.

DR. ROBINS: But I guess my question is, has there been enough movement since 2009 for us to continue to make this our aspirational goal or does the fact that so many people thought we were on the brink of discovering more about genes and more about early brain development than what we've actually managed to identify and replicate across different scientific groups that maybe it is a good time for us to reconsider modifying this aspirational goal in some way.

DR. DANIELS: So that's the opportunity that's before you to definitely think about whether this should be modified or overhauled in some way to reflect the current state of the science and where you think that science may lead in the future.

DR. COURY: How far in the future, Susan, for this aspirational goal?

DR. DANIELS: Well, I think for all of the chapters, it probably is a little bit utopian about a perfect world where every person is going to be served with every service that they need perfectly personalized, funding is not an issue, you know, a lot of those kinds of things. So it's aspirational.

DR. COURY: Okay.

DR. PIERCE: And are we limited to one aspirational goal? I mean certainly, I would love to see an aspirational goal where, you know, no child falls through the crack, that you don't hear these stories of kids not really being detected until they're, you know, kindergarten when you may have missed that moment of opportunity for treatment to be implemented at a time where it could potentially have had the best impact, which is the first few years of life.

And so another goal for me would be that we really improve screening detection so much that you don't have such large groups of kids being detected at late ages.

Again, that CDC paper suggests only a third of kids, at least with that cross sectional sample, which is definitely a little out of date, only about a third of kids are getting detected and presumably treated before 36 months. And 70% are not.

So for me, an aspirational goal is let's really try to move the needle considerably on that score and more and more kids are getting detected young and treated young because at least at this point, we believe that gives them the best chance for the best outcome in life.

DR. WETHERBY: I agree.

DR. ROBINS: I do too, Karen.

DR. DANIELS: That makes sense and it's also - it's an umbrella that doesn't exclude biomarkers from being a part of that.

DR. KAU: Well, this would be one of the recent objectives (unintelligible).

DR. DANIELS: It could be a research objective or it could be your aspirational goal for the entire area as well. So you might want - maybe you want to think about it. I know it's kind of - maybe it's a little too much to think about it on one call but we could always do that as a part of the next call, too. You'll have three opportunities for objectives but if you want to make the aspirational goal something overall about improving early detection and the link to treatments, appropriate treatments and whatever.

DR. KAU: In my mind, since it's potentially achievable goal, like we can see it happen…

((Crosstalk))

DR. WAGNER: If quantifiable to change the percentage (unintelligible).

DR. DANIELS: All right, so I think that that's something maybe as food for thought and you can think about before the next call. We've, again, made pretty good time on this call so I think that we're about ready to wrap up unless anyone has any last minute comments to add. We really appreciate all the thoughtful comments.

On the next call, we're going to be talking about the objectives. And so as you prepare for that call, which I don't have in front of me what the schedule is for that call yet, we're going to try to focus down to three broad objectives that can characterize where you want to see this field go. And so in the meantime, as you think of these things, if you want to jot some of them down, if you want to send them to me, I will be sending you some follow-up emails and you can certainly respond by giving some ideas about objectives that you think might be ones that the group would want to consider, we can collect that information and share it. Or you can just do it spontaneously on the phone on the next call.

We might not be able to do all of the perfect wordsmithing but if we get the concepts down, we can always work on the wordsmithing afterwards. And in the meantime, the other thing that we are going to be doing is our office will try to take information that was shared on this call and provide you with a draft outline. We will share it with the chairs, have them look at it, and then the chairs can discuss with the working group how we'll want to go about the writing and editing of the document that you're preparing.

So we'll try to give it some parallel structure with the other chapters but want to make sure that all the issues you think are most important are included.

DR. PIERCE: Hey, Susan, I have a question. Given the timeline, I think you had said you wanted a new draft assembled by, like, January 1 or the first week in January or thereabouts - is that correct?

DR. DANIELS: Something like that, yes.

DR. PIERCE: Yes, I just want to put a plug in and say, I'm completely slammed through Thanksgiving. I don't know if there's any opportunity to consider really a lot of intensive writing and thinking going back and forth, maybe for the first few weeks in December and then the first week in January. I can totally contribute before then but I just want to note that I have just a lot of commitments between now and Thanksgiving and it's really important to get this done and get it done right, but I just thought I'd casually mention that, that I'm going to be really available right after Thanksgiving and a little bit more challenged prior to that time.

DR. DANIELS: Thanks. We'll try to work around it and, you know, do the best that we can. We have seven different groups and I'm sure everybody has all kinds of different schedule issues but we don't have a hard deadline for having this done but we want to try be efficient and not drag it out longer than it needs to go. So we'll do our best to make sure that everybody can contribute.

So if there are no other comments, I'd like to thank everyone for joining us for this call and we will be in touch about the next call and the posting information about that on our website and sending it out via email so the members of the public can join us as well.

Thanks very much.

GROUP: Thank you and bye.

(Whereupon, the conference call was adjourned.)