

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 1

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1:00p.m.

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PROCEEDINGS:

DR. SUSAN DANIELS: Thank you, so this is Susan Daniels from the Office of Autism Research Coordination at The National Institute of Mental Health. And I'd like to welcome everyone to this conference call of the IACC strategic plan update working group for Question 1, when should I be concerned, which is a part of the IACC strategic plan. We have a number of working group members who should be speaking on this call.

We also have a public audience who have dialed in. For members of the public, if you're interested in looking at the materials for this call please go to our website, and look for the conference, the first conference call of working group one, and you'll see the materials there for you. I'd like to take role to see who's on our call, also to welcome our co-chairs Doctor. Alice Kau from The National Institute of Child Health and Human Development and Doctor Ann Wagner from the National Institute of mental health. So, Alice, are you here?

DR. ALICE KAU: Yes. I'm here.

DR. DANIELS: Thank you. Ann

DR. ANN WAGNER: I'm here.

DR. DANIELS: Ann Wagner.

DR. WAGNER: Hi, I'm here.

DR. DANIELS: Thank you. And we have Shannon Haworth who is a member of the IACC. Are you here?

MS. SHANNON HAWORTH: Yes. I'm here.

DR. DANIELS: Thanks. Jennifer Johnson, who's an alternate on the IACC.

MS. JENNIFER JOHNSON: I'm here.

DR. DANIELS: Thank you. Nicole Williams.

MS. NICOLE WILLIAMS: Yes, I'm here.

DR. DANIELS: Thanks. Also a member of IACC. And then we have our external working group members. Dan Curry. May be joining us later. Ami Klin? Catherine Lord?

DR. ANGELA SCARPA: Hi. This is Angela Scarpa.

DR. DANIELS: Hi, Angela.

DR. SCARPA: Hi. Are we...

DR. DANIELS: Sorry.

DR. SCARPA: Are we in the group?

DR. DANIELS: Sorry. Is this Audrey? Sorry. Who's speaking?

DR. ANGELA SCARPA: Oh, this is Angela. I'm just not sure if we're in the group or not.

DR. DANIELS: Yes. You are in the group. You're on the call. I'm just taking role. So, I was checking to see who all is on the call. Sandy Magana. Karen Pierce.

DR. KAREN PIERCE: Here. Hi.

DR. DANIELS: Hi. Thank you. Diana Robins.

DR. DIANA ROBBINS: I'm here.

DR. DANIELS: Thanks and we already got Angela Scarpa. Audrey Thurm.

DR. AUDREY THURM: Here.

DR. DANIELS: Thanks. Debra Wagler.

MS. DEBRA WAGLER: Present.

DR. DANIELS: Thank you. Amy Wetherby? And Lisa Wiggins?

DR. LISA WIGGINS: I'm here.

DR. DANIELS: Thanks. So, there are a few members that might not have dialed in yet. Hopefully, if they're in the process of dialing in and can hear us right now, we'll speak up when they get on the call, so that we know that they're there or we'll make comments. I would like to ask everyone as we talk through call, when you're making a comment if you could identify yourself just because it's a little difficult being on the phone to know who's talking.

So, I'd like to open the call by starting to talk about the strategic plan updates and give you a little bit of background about what the task is for this working group. So, the IACC in...the Interagency Autism Coordinating Committee, which is a federal advisory body that provides advice to the Secretary of Health and Human Services and federal agencies on issues related autism, has been tasked by Congress with developing and annually updating a strategic plan for autism spectrum disorder.

And so, in 2009, the IACC developed its first strategic plan with the help of outside experts like many of you who are on the call today. And that plan was updated in 2010 and '11. And each year new objectives were added to the plan to provide some targeted areas that the IACC felt were important to prioritize and try to achieve some growth in.

And so, the strategic plan has continued since then, and each year the committee has provided an update on the progress that's been happening in

each of those areas. And under the new Autism CARES Act of 2014 the Congress decided that they would like to see the strategic plan expanded a little bit to cover more in the area of services and supports.

So, one of our goals will be in this new update of the strategic plan to include more information about services and supports. In addition, the law requires that the new strategic plan talk a little bit about how to - recommendations from the committee to avoid duplication of effort to be as efficient as possible. We're going to be doing this update. And it's really - the committee has had a couple of meetings - well, met in November, January, and April, and July and discussed the need for the (inaudible noise) objectives themselves.

And so one of the tasks of this working group will be to help formulate new objectives for Question One, which is focused on "When should I be concerned?" around the topic of screening and diagnosis. And so, this working group will be helping refocus the strategic plan in that area. So, we'll be looking to you to help us write a chapter of the new strategic plan that will be on screening and diagnosis and to develop objective.

And so, I've laid out in the first document that was in your materials for the call. I've listed the seven IACC strategic plan consumer-based questions that provide the framework for the plan. But Question 1 is about screening and diagnosis; "When should I be concerned?" Question 2, "How can I understand what is happening?", which is about the underlying biology of ASD. Question Three, "What caused this to happen and can it be prevented?" which is about genetic environmental risk factors.

Question 4, "Which treatments and interventions will help?", which is about interventions. Question 5, "Where I can turn for

services?" That's about services and supports. Question 6 "What does the future hold particularly for adults?" which is about lifespan related issues.

And Question 7, "What other infrastructure and surveillance needs must be met?", which encompasses research infrastructure, surveillance, the research workforce, collaboration and outreach. And so those are the seven focus areas of the strategic plan, and we have working groups assigned to each of these questions. And so, as I said this working group will be focusing on screening and diagnosis.

We've also provided an outline of the strategic plan and what components will be in the written document itself. So, it'll have an introduction, a description of the question, and the aspirational goal for the question. And currently, the aspirational goal for this question reads, "Children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest". And so that was the aspirational goal that the committee originally wanted to be reaching for as they planned and developed the strategic plan.

We also will have a section that describes progress toward current strategic plan objectives. And currently there are 78 objectives in the entire plan. And so, the call today will be focusing on trying to get this working group's take on what the progress has been toward meeting the current strategic plan objectives which then as we move forward we will develop new objectives that will replace those old objectives.

So, for the each of the seven questions, the middle portion of the strategic plan update will contain an overview of progress in the field. So, we'll be updating the community on research, providing what some of the latest scientific advances and breakthroughs have been in the last

few years, information that's from practice to research and also gaps, opportunities, and needs in the research arena.

We also will be including information about services and policies; so, any new programs and policies that may have been developed in recent years and how that's impacted the field, new research evidence that can inform policy, and services needs and gaps and needed policy changes. And so we'll be discussing all of that on the next call.

We also will have a brief discussion about the progress that's been made toward the aspirational goal and whether after all of that discussion you feel that the aspirational goal needs to be adjusted in any way. Today, I will be asking you about recommendations to ensure non-duplication of effort because we will look at the portfolio and you'll have information about what's been funded to date. Then have an opportunity to tell me a little bit about any thoughts you have about ways to avoid duplication of effort.

On the third call that we'll be having, we're going to talk about new strategic plan objectives to replace the current objectives. And the committee in its previous meetings agreed that they wanted to keep the total number of objectives much smaller than 78.

And so the final conclusion was that we will be shooting to develop about three broad objectives for each of the questions. So, this group will be working on three broad objectives. That will be accompanied by several examples of more specific types of research that would be responsive - research and services programs and projects that would be responsive to that particular objective. And our team just provided some possible types of broad objectives. We used Question One as an example just because it was the first one on the list. But you will be able to

come up with what you think are the top three priority areas that you want to include in those objectives.

And the committee will also work on budgetary requirements for each question or objective... The law requires that some budgetary requirements be included in the plan. And so, we will leave it to the full committee to decide how that will be implemented. And if they want to call on people from the working groups to help, we will let you know. And then there will be a written summary and conclusion. So, the task that we have is to have these discussions by phone, and then your group will be working on a written draft that particularly focuses on progress in the field. And so Ann and Alice will be helping lead the writing of that draft, which will be begun after the call is over and probably as a part of the second call. So, does anyone have any questions about that overview?

(No response.)

DR. DANIELS: All right. Has anyone else also joined the call since I took role? Is there anyone new on the call besides those who already said they're here? All right. So, then let's move forward to the next item.

In order to, on this call, do kind of a review of what has taken place so far where we are with respect to the current strategic plan objectives, our office-- the Office of Autism Research Coordination has collected data from across several private and government funders of autism research and helped categorize this information according to the current strategic plan.

And we provided some data to you to help you understand what's in the research portfolio now. So, in your first packet, the data analysis packet - I'll just try to quickly walk through these slides. And you can see what's in here. So, the

first figure that we have shows federal versus private autism research funding to give you an idea of the proportion of funding that is being provided by federal sources and private sources based on the organizations that we're collecting from.

So, the private sections may not include certain family foundations that are also doing important work in this area, but all of the - there are several other large foundations that are included there. And then the federal proportion, which has stayed about the same for the last several years. So, it's been about three quarters federal and about a quarter private.

On the second page of this packet, we provided information about the specific funders and the proportion of the funding that's provided by each agency and organization just for your information so you can have an understanding of how that funding is distributed. And then we have the listing in the table on the right that gives us specifics.

So, you can see that NIH funds about half of the research portfolio and then some private organizations like Simons Foundation, Autism Speaks, also fund some larger portions as well as CDC and Department of Education. And then there are a number of other federal agencies and private organizations that are funding various aspects of the portfolio.

On the third page, you can see the distribution of funding across the different strategic planned question areas. And keep in mind that each agency or organization is funding projects based on their own mission, what types of applications they receive. So, it's not like this is one pot funding and someone's distributing it among the areas from some central place.

Each organization is contributing and this is how it adds up when you put it all together. So, you can see that Question One was close to 9% of the funding and close to 9% of the project count as well.

On the next page we wanted to give you an idea of how well the funded projects align with the strategic plan objectives. This is because the strategic plan objectives were created by the committee to target areas of the portfolio that needed more attention or maybe new and emerging areas. But it didn't cover all of the existing areas. So, you'll find when you look at the portfolio that's currently funded about 75%, about 3 quarters, were related to the objectives that are in the strategic plan and about a quarter were not related to - specifically related to those objectives but include projects that might be more related to established areas of funding and other core foundational research areas.

The following page shows the alignment of some of this funding according to the different strategic plan question areas. So, with Question 1 you can see that most of the funding that is assigned to Question One is related to the objectives. And a very small proportion is related to areas that were not prioritized by the IACC strategic plan. The area that has the most projects that are not related to the IACC strategic plan are in basic biology. And that is largely due to many areas that were already well established when the strategic plan came into being.

DR. WAGNER: Also, when I looked at the ones for Q1 that were not related, some of them looked like they might have been things that sort of came up prior - I mean after the known objectives like the DSM 5. So, some of that might be just...

DR. DANIELS: Newly emerging.

DR. WAGNER: ...newly emerging things.

DR. DANIELS: Absolutely. That's correct. And so, some of those things depending on how the new objectives are created may be captured in the strategic plan objectives on the next round whereas other things might fall out.

DR. WAGNER: right.

DR. DANIELS: Good observation. So, on the next page, we gave a breakdown of what's been going on with the funding in Question One in 2013. However, if you look at the multi-year funding table, that will give you this information plus all of the prior years and the totals to give you a picture of how funding has changed over time.

So, if - let's go to the multi-year funding table just so you can see that. In the final column under the totals we have a - kind of a stoplight indicator - green, red, and yellow. So, the green indicates that the strategic plan objective has been met in terms of the content of the objective and in any recommended budget that was provided by the committee for that objective.

If the total is in yellow, that means that there might be aspects of the content of the objective, or that the recommended budget was only partially met. And then if it's in red that means that it didn't have any projects. And there's one objective within Question One that had no projects all the way across. And on the last evaluation that the IACC did of the strategic plan, they looked carefully at that. And they're reading from the last strategic plan update.

This is a summary that was provided that the planning group, which was similar to the working group that you all are on felt that the wording of this objective is confusing. Based on transcripts from when this objective originated, it appears that the committee wanted to better understand if

early diagnosis led to early intervention and if so if that led to better outcomes.

Some of the questions that could be asked are whether or not early diagnosis leads to early intervention and whether or not early diagnosis is always associated with better outcomes when compared to late diagnosis. But the committee as they discussed this concluded that the objective was almost obsolete when it started. So, it was something that was still a little bit of a question at the time the strategic plan was first formulated. But I think that the evidence quickly accumulated that made this objective not as applicable.

So, there is nothing that is categorized to this objective. But all of the other objectives were either completed or in progress. Does anyone have questions about the status of any of the objectives?

DR. ROBINS: Susan, I have a question. This is Diana Robins. Can you clarify what you just said? You were saying that the one that's red... The wording on the table didn't quite match up to what you just said out loud about whether early diagnosis leads to early intervention and whether early diagnosis leads to better outcomes. But were you saying that you think that, that objective is no longer relevant?

DR. DANIELS: That's what the committee concluded the last time that we did a strategic plan update. So, what I was reading from was the report from the strategic plan update in 2013.

That was sort of the working group's assessment of what happened with this objective, because they did look into it. They looked at the project - or there wasn't a project listed, but they looked at the wording of the objective and felt that it was both unclear and possibly not as

relevant as time went on from the time the objective was created.

DR. ROBINS: Okay. And will we have the opportunity to revisit that in this group?

DR. DANIELS: So, if you have a different opinion, you're welcome to say so. In terms of having to revise the objective, you don't need to revise the objective because we're going to be writing new ones. So...

DR. ROBINS: Okay. I guess my concern is that the US Preventive Services Task Force conclusion was opposite that, that we don't have enough evidence to fulfill this objective yet. And so perhaps that should be revisited.

DR. DANIELS: So, then that's something that you probably should consider in the - on some of the future calls.

DR. WAGNER: Yes. So, I was thinking that, that objective doesn't sort of directly address the USPSTF report but that we should have objectives on there that would address the gaps. So, other than worrying about the wording of this one, we can just make sure we put appropriate objectives in if that makes sense.

DR. KAU: Right. Yes. I agree.

DR. PIERCE: Yes. Hi. Yes. This is Karen Pierce. I completely agree. I think that's one of the most important objections we have. And I don't - in my reading of the literature, I don't think that no matter how it's worded that we have data to leverage to relay that gets at this adequately.

And as Diana said, that, that was, you know, really the motivation for the task force, lack of recommendation of screening. So, I think it's very important. And I'm really looking forward to the opportunity to revise it, rewrite it, whatever we

need to do to reconsider this in a new version moving forward.

DR. DANIELS: Yes. So, you'll have an opportunity to write a whole new objective to capture some of that. And at the time, the IACC does its last revision here, they didn't have the USPFTF report as a source. So, they weren't really considering that. Any other comments about the progression?

When you look at the columns, the red, yellow, and green are based on an annualized version of the recommended budget. So, if - when you divided that budget across several years it - if we - if there was more funding allocated or equal or more to that annualized budget, it was in green.

If it was less it was in yellow. And if there was no funding allocated at all it was in red. And that was - those kinds of - those color indicators were really more useful when we were looking at one year at a time.

And especially in the first couple of years we only had one or two years of data and so the total didn't seem as meaningful. But now that we have many years of data, the total column is probably the most meaningful.

MS. HAWORTH: Hi, Susan, this is Shannon Haworth.

DR. DANIELS: Mm-hm. Sure.

MS. HAWORTH: I had question about objective 1SF. It said that it was fulfilled in 2011 and I was wondering were there any discussions about continuing that objective going forward -- the workshop.

DR. DANIELS: There was some discussions in 2013 about possibly continuing that idea or thought. And so, they thought it was an important

area and thought it should be revisited in the future if a new strategic plan with new objectives was created. So, that was mentioned with this working group.

We will be trying to focus on the three top areas to prioritize in the objectives. So, the group will have to decide what are those top priorities. But it doesn't mean that the committee can't recommend several different things informally throughout the text as well. So, even if you only have specific objectives that you're naming that we're going to be tracking, the committee can also say that these are some areas that also should be highlighted or, you know, kept in mind. So, there certainly would be an opportunity to include those too. But...

MS. HAWORTH: Thank you.

DR. DANIELS: ...yes, so committee previously did think that there was more work to be done in that area. Any other questions or comments on this?

DR. PIERCE: Yes. Hi. This is Karen Pierce. I just have a general comment. So, one of the objectives that we have today is to sort of examine the degree to which objectives set by the committee in 2011 have been accomplished through the funded projects list that you are sharing with us. I was wondering, has there ever been any consideration of also including number of publications generated by each product for example as an index of movement towards achieving objectives.

DR. DANIELS: So, actually, our office did try to do a publications analysis back in 2010. And the limitation on that we found was that many investigators didn't cite their grants in the papers. And so when they went to look, at that time in 2010, only about the third of the papers had a citation that we could link to. So, it was really hard to link publications to projects.

DR. PIERCE: Yes. But I was thinking, what do you think about the idea of when investigators are doing their annual progress report and we also have to list the papers that are generated that you - we could use that? And now that everything is really nicely online you could even go to the level of, okay, we have this publication and here are the eight or whatever number of IACC objectives. And they could just click which area it falls under to actually make your lives a lot easier.

I think the annual progress report might be an opportunity to get a little bit of better data. Because it seems like just understanding the number of projects that it's funded is only part of the - is part of answering the question. Really, I think we want to see the impact, the dissemination of the findings. You know, I think those might be even stronger metrics than just grants are funded. Sometimes grants are funded and it doesn't really generate a lot.

DR. DANIELS: Right. And so, in the second call where we're going to be talking about progress is kind of the way that we get at that. And we usually have groups of experts talk to us more qualitatively about what's happened. And so it may not be as thorough as going through every single objective and every single publication. But having the working group highlight for us really important breakthroughs, important progress that's been made and so, we've done it by that mechanism rather than through a quantitative analysis.

DR. KAU: And, Karen, it may not be as easy as you think to implement that stuff. Yes. And many of the research are not funded by NIH, so we can't really require them to do anything. And some of important findings may not be funded by anyone we know of. So...

DR. WAGNER: (Unintelligible) up-to-date would be PubMed. I mean that, you know, we try to get everybody to get their things registered at PubMed.

DR. DANIELS: Right. And our office is interested in potentially doing another publication analysis in the future. I've heard that the citation rate has gotten better. So, I've heard from people working on other disorder and disease categories that they've had better success with that in recent years.

And so, if we were to go back sometime in the future it might be easier to link those things and be able to get some meaningful data. But for us since only a third how to link, it was really hard to make much out of those.

DR. WAGNER: (Unintelligible) just a little bit. This is Ann. I was thinking a little bit about strategies (unintelligible) and analyzing how far we've come or progress that's been made. And it seems like it's not number of publications and that a lot of publications...

I mean it's kind of like the big picture. Like do we have new instruments, you know, since 2011 that are valid; sort of more at that level that we need for this than, you know, if somebody doing a research project on the M-CHAT has 8 or 10 publications. We don't need to know what's in each of those publications. We just need to know what's the status of the M-CHAT.

DR. KAU: Right. I agree. Yes.

DR. DANIELS: So - and hopefully that's something that we can move toward on the second call when we talk about progress and really trying to assess what are the major areas where research has moved forward and what areas it hasn't moved forward. And what public areas within to progress.

So, I appreciate that comment. Anybody else have comments on this?

DR. WAGNER: I have a comment about the budget stuff, which is not something that you grapple with on this call. But I just wanted to raise it for you...get you aware that I'm sort of thinking about it.

But I just - it's always been tricky to estimate budgets. But if we're going to now be developing broad objectives, it's going to be even harder. I mean like it's - we're going to have to really think creatively for the IACC about how one would assign numbers to these broad objectives when kinds of (unintelligible) that goes into (unintelligible) that we (unintelligible).

DR. DANIELS: Yes. And that will be a challenge. And it's something we'll bring up with the full IACC. The law really says that they need to have budget estimates in the strategic plan. But it doesn't really say whether those budget estimates have to be linked to objectives, whether they have to be linked to questions, whether they have to be linked to any specific part.

And, you know, one could envision budget estimates could be based on maybe the current budgets - it's not really a budget for a question, but the current amount that's spent on an area and a percentage increase or something like that.

It doesn't necessarily have to be the way we've done in the past. But I think the committees going to need to think creatively. I agree that as the objectives broaden, I think in many ways for tracking that's going to be much better. But it will be difficult in terms of being quantitative about budget figures. And so, the committee might have to think about what they want to attach to the - a budget to.

DR. WAGNER: Yeah...

DR. DANIELS: So, it could be like this, or it could be something really different. But as we go along, if people have suggestions about that, please send them our way because maybe we'll want to make a list of possibilities for the committee to consider.

DR. WAGNER: Okay.

DR. DANIELS: The last figure in the packet is percentage of funding by subcategory. And so, our team went through the whole portfolio and tried to assign some broad subcategories to the data, so that you could get a sense of what's in the portfolio overall; because some of the objectives are very narrow and specific, and there are other things that might not be specific to objectives.

This tries to capture the breadth of what's in the portfolio and using very easy terminology to describe what's there. So, I don't know if you have any comments about (unintelligible) and the proportions of research. Is this what you expect - surprising? All right. So, I have a few questions to ask you about the specific projects that were assigned to each of these areas. So, with each of the objectives, I've given you a project list so that you could see what kinds of projects were funded in 2013 related to these areas.

And I wanted to get a sense from you about you know, several ways to assess this. Did anyone have any comments about the number of projects of any particular objective, whether, you know, you felt that they were adequate, or there were particular areas where there's still - there's a project that needs to be - or an area that needs more attention.

MS. HAWORTH: Hi, this is Shannon Haworth.

DR. DANIELS: Hi.

MS. HAWORTH: Under 1SC, there were only 5 projects around on health disparities for early screening and diagnostics. Is that something that we can discuss, or does the committee feel that there's a need for more funded projects under that area?

DR. DANIELS: So, in terms of the objective itself, the objective said that they were looking for three projects. So, in terms of meeting the objective, the objective, the content has been met in terms of the number of projects. But in terms of needs for health disparities, that's a wide open field for anyone to discuss.

DR. WAGNER: So, this is Ann. I admit, I think we haven't made enough progress on the disparities question for diagnosis. At least my - that's my understanding is they're still lagging. So, it seems like, you know, and when we're evaluating where we are it would be good to know specifics about where we are and let's see what other gap - research gap areas that might help with that.

I also did wonder if this shows... Sometimes things kind of morph into services and morph into risk factors on the other end. So, I think we might want to just look and see what's in the other services portfolio list as well and see where that apply.

DR. KAU: But I think maybe going forward we need to differentiate is it a lack of measurement to identify children at risk in a diverse population or is it...

DR. WAGNER: Access.

DR. KAU: ...It's actually access onto intervention, which are very different. And those are important.

DR. DANIELS: And in the strategic plan update because the strategic plan now is being expanded

to look at services more, this group will have an opportunity to make comments on access issues as well.

DR. KAU: right.

DR. DANIELS: So, definitely keep that in mind that - and any objectives you come up with can incorporate elements of both services and research.

DR. WAGNER: And will part of the next call or future call be about things that may have happened since 2013?

DR. DANIELS: Yes.

DR. WAGNER: So, we do have like a (unintelligible) services that is relevant, so we should figure out where that - what that contributes to. So, that's part of the intent, right?

DR. DANIELS: Yes. And so - and if you have, you know, after this call if you have specific projects you know of that have happened since 2013 -- now, our office hasn't had a chance to assess those data. We have the '14 and '15 data in our hands. But we haven't been able to analyze them yet.

If you want to point out areas where you think more work has been done, we can add that to the notes for your strategic plan update, and put in some information about that even if it might not be specific numbers we're adding on.

DR. WIGGINS: So, Susan, this is Lisa Wiggins. I have a question for you. For large multi-site projects where there are numerous objectives, how are they taken into account for the strategic plan objectives and funding?

DR. DANIELS: So, if your question is about how we - how the funder and OARC together decide the coding for a multi-site project, so we can only assign one code per project because we're trying not to double count any funding. So, we ask the funder to try to go for the best fit. And so the area that's of greatest emphasis, which can sometimes be hard if they're really different areas and they're close to equally important.

DR. WIGGINS: Um-hmm.

But we try to note that as well if there is something like that, that applies. Say, if it's been categorized to one objective but it really strongly applies to some other objective, in our portfolio analysis we try to note that where we're aware of those things to, you know, account for that. So, if you are aware of some of those issues, you can let us know. And when we collect the data for the portfolio analysis, that can be included in the notes, which often it is by various funders.

DR. WIGGINS: Okay.

DR. DANIELS: But unless each subproject is a - counted as a separate project which there are some grants ...

DR. WAGNER: For ACE centers would each project get its own code? Do you know? Anybody know? (Unintelligible).

DR. KAU: I thought each project is counted separately with (unintelligible)

DR. WAGNER: Yes. For contenders where there are separate projects then those get coded separately.

DR. DANIELS: They each have a separate grant number.

DR. KAU: (Unintelligible) program project, yes. But if you have like R01 with different aims that touches multiple objectives then you only can count it once.

DR. WIGGINS: Okay.

DR. DANIELS: It just depends on how the project was assigned, so...

DR. PIERCE: Susan, is there a specific timeline associated with when you hope the new supervised strategic plan will be achieved?

DR. DANIELS: Yes. So, we're hoping that the working group will finish its work by December and that we can have a discussion with the IACC in January about the draft strategic plan, and, you know, hoping that it might be a pretty complete draft and they might be able to approve it in January. But nevertheless, hoping that the working group will be done with most of its work by December and that we will publish it sometime in the following year as soon as we can get it together. It usually takes several weeks to be able to get something published once we've finalized all the text.

DR. PIERCE: Okay. Thank you.

DR. DANIELS: Sure. Are there any other comments about progress that's been made toward any of the objectives, things that you're aware of that might not have been taken into account...

(No response.)

DR. DANIELS: areas that have significantly changed since the objectives were written?

(No response.)

DR. WAGNER: I just - I mean I just think there's been a lot of activity so it would be

really important to have the expert, you know, the people who are experts in the different areas be able to sort of summarize where we are, you know, (unintelligible).

DR. DANIELS: Um-hmm.

DR. WAGNER: I was wondering about the genetics one and whether we have anybody who's done...

DR. DANIELS: Which one is that?

DR. WAGNER: It is objective one (ESE).

DR. DANIELS: Conduct at least one study to determine the positive predicted value and clinical utility e.g. prediction of co-occurring conditions family planning of chromosomal microarray genetic testing for detecting genetic diagnoses for ASD in a clinical setting.

DR. KAU: Do we have the expertise?

DR. WAGNER: Do we have anybody - does anybody on the call feel like they have expertise in that area?

DR. DANIELS: And if not we can always ask for additional help. Yes. We can. And there may be some people on questions two and three that might have some expertise in this area as well.

((Crosstalk))

DR. DANIELS: So, we can pass the draft to them. Something that would be helpful, is for us to as a working group develop an outline of particular areas that you want to be able to provide some content on, areas that you think are the most important where progress has been made, and areas that not enough progress has been made.

So, you can keep those areas in mind. And on the next call we'll try to get those into some

kind of a written format, so you can start fleshing it out.

DR. WAGNER: Okay.

DR. DANIELS: Did the working group as they looked through this list of projects feel that there were any areas that you had - that provided any concerns about duplication of effort? And that's an area that the new law requires us to look at, and so we wanted to get the working groups help in determining if there are areas where there would be concerns and if you had suggestions or recommendations for how duplication of effort can be avoided. So, any thoughts on that?

DR. PIERCE: Yes. Hi. This is Karen. My thought is I think that's a really important goal. I'm just - I'm not sure that just based on the title alone it would be really enough information to make the determination about true duplication of effort. So, I think if that's, you know, really an essential goal then it might just require a little bit more than looking at the titles. We'd have to kind of, you know, read at least the abstracts and probably more.

DR. DANIELS: Right. And so the abstracts are there under the links for the title. Like you click on the links that (unintelligible) it would be time consuming.

DR. PIERCE: Yes.

DR. DANIELS: But, so just looking through the portfolio if you felt like there were things that looked kind of, you know, like they were concerning in any way about duplication, or if in general you have thoughts about how duplication of effort can be avoided in the field -- if there are things that can be done by funders to help avoid duplications.

DR. PIERCE: Yes. That's probably something we would have to do a little bit offline because it will take I think a little bit more time to consider that than just here on the call I think.

DR. DANIELS: Okay. That's fine. And so anyone who has any thoughts about that you can feel free to email separately about it if you've had a chance to look more carefully through it.

And this will be something that we'll cover more on the next call, but did you note any emerging areas of research that were not represented very strongly in the portfolio that should be considered in the next strategic plan?

DR. PIERCE: Yes. I mean I think that a previous speaker -- this is Karen Pierce again -- commented that there is sort of this graying boundary between services, research and treatment research. And this questionnaire is - so this might be something that's already sort of more emphasized than these other areas. But I don't know that any one of the objectives really clearly articulates research that's focused - that's highly translational and focuses on community research.

So, we have screening tools and we have markers -- biomarkers that have been discovered -- but what has, you know, necessarily been the translation of those?

I don't know that any of these objectives really specifies that in a clear way. Like something is translated, and then research supporters were moved during the final years of funding. And sustainability is required. Like something, you know, at that level of really looking at translations of findings into practice, because I know even with screening research, there's a lot of sort of research assistant intervention and making some of that happen.

So, I think research that really aims to fully translate without any support in the end of the grant is really important. But I'm not sure. That might be a little more representative of the services. I'm not sure. But it certainly I think is an emerging trend that's important.

DR. WAGLER: And this Deb Wagler. I'm CHB. I had the same reaction looking more for the translational research and some better ways to bridge. An earlier speaker had talked about, you know, at one end it's services or the other end it's risk factors.

There's so much about social instruments of health. We have a little bit about cultural and health disparity, but I think the social instruments of health and certainly that community practice and really, you know, where families live, that is definitely missing.

DR. DANIELS: Yes. And from knowing a little bit about the rest of the portfolio that type of work is really mostly pulled into Question One. I don't think that it's too highly represented in some of the other areas. We're happy to share the listing of projects for some of the other areas that will be relevant in the follow-up. I'll send that out to those of you that might be interested in looking at that.

Question Five may have some projects that are really broad that cover services and that might have something about face screening services or diagnostic services, but not... If it was really specific for that it was in Question One.

DR. ROBINS: This is Diana. Kind of along the same lines, you might want to think about terminology like implementation and dissemination -- to capture some of what I think Karen was saying -- and ways of going beyond just one study that measures whether you can diagnose or whether you can screen but what can happen in the

community when there aren't the researchers standing by to do a lot of it for them.

DR. DANIELS: Great. Thank you. Sounds like these are some themes that might be more strongly highlighted in the next strategic plan. And thinking back to 2009, maybe those weren't the priorities that were coming to mind for the committee at the time. But...

DR. KAU: In 2009 we still working on improving measures and developing measures. So, yes, this is good. It's exciting to be able to move into implementation research. It's a very good sign.

DR. WAGNER: Yes. I agree. I think it's a sign that there has been progress.

DR. DANIELS: So, we sound like... We'll be putting these into some notes for the working group and hopefully some of these types of themes can be fleshed out a little bit in the next call and in your drafts. Any other thoughts? I guess we're coming to the close of our time, so does anyone else have thoughts to share about any of this?

DR. KAU: I have a general comment. It's not related to anything specific we've already discussed so far. Just can we make sure that the members of working group 1 can be present on the call because we missed quite many of them and they are on a committee for, you know, their expertise. And so I worry about not having all - everybody, a majority of them present or available.

DR. DANIELS: Right. So, our team works with all of the working group members and we did doodle polls to see what days people were available. And so, I mean we thought that this was a day that most of the working group people were going to be available.

But I hope that - are there any other people who might have joined the call since I took role earlier?

(No response.)

DR. DANIELS: And hopefully nobody is having any phone problems. But there may have been people that had a conflict. We tried to pick the dates that had the majority of the members able to join. But certainly people will be able to contribute in writing although it's not the same as being present on a discussion with the team.

DR. THURM: This is Audrey. And I know, I was on the other call for the other working group and someone asked us too. It's like how is this going to get done. So, just relating to people being present, will we have notes from this call, and then also get a little more pointed with some of the things we can do move towards the next call to make sure that we've done our homework?

DR. DANIELS: Yes. So, we'll be sending out some notes. We'll send out the transcript as well for the call. And I will be sending out an agenda for the following call. And so, I'll be working with the chairs on the agenda for the next call. So, we'll be sending you that information. And then, probably after the next call will be when you start working on the draft and the actual writing.

DR. THURM: Thanks.

DR. KAU: I mean, and then we can strategize ways to engage the ones - the members who missed a call, be more specific as to what - how they can contribute even though they missed the call.

DR. DANIELS: Yes. So, we definitely can assign them areas that you want them to help write and ask if they can fill in certain parts of the update. And, you know, the challenge with that is

that we will have seven different working groups each putting together a draft.

We want to capture the information, then we'll probably have to do some editing to get everything more uniform, similar tone, and length and so forth. But we can just start with getting the expertise in to fill in the information.

So, yes, we'll be sending you more guidance. So, any other final comments?

(No response.)

DR. DANIELS: So, we will be sending you information about the next call in the coming probably week or so. I think that the members have... With this call I don't know if this one is scheduled...

OARC STAFF MEMBER: Twenty-seventh.

DR. DANIELS: September 27. So this one is already scheduled for September 27. So, we have a little bit of planning time. In the meantime, if anyone has thoughts after the call you want to let us know something that you didn't have a chance to say on the call, please send it forward by email and we'll try to incorporate it into some of the notes we're keeping.

So, well, thank you so much for being a part of this call, for the thoughtful discussion, and we look forward to talking to you again.

DR. WAGNER: So, this is Ann. Thank you everybody for your time.

DR. KAU: Yes. Thank you. Thank you. This is Alice.

DR. PIERCE: Thank you so much.

MS. HAWORTH: Thank you.

(Whereupon, the conference call was adjourned.)