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INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 7 - Question 7 - What other
Infrastructure and Surveillance Needs Must Be Met?

Conference Call 1

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12:30p.m.

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PROCEEDINGS:

DR. SUSAN DANIELS: Thank you. Thank you to our public audience and to the members of this working group, the IACC Strategic Plan Update Working Group for question seven for all being here and thank you to Ms. Alison Singer who's a member of the IACC and the chair of this working group.

So we welcome you all to listen in. We have all the materials for the meeting up on our website at, on the IACC website if you go to the tab for meetings and it's under Working Groups so you can access all of the materials.

So we are going to be starting our work to help update the IACC strategic plan which was developed initially in 2009 and has gone through subsequent updates and this year is due for a more significant update. And so you will all be a part of helping provide updated information about what's happening in science and policy around this area, what other infrastructure and surveillance needs must be met which covers the areas of scientific infrastructure for supporting autism research, surveillance activities, workforce issues, or service, or research workforce issues, outreach, and collaboration.

So this is a cross cutting chapter that was put into the strategic plan by the committee because they wanted to ensure that some of these cross cutting areas were captured that impact all of the other research areas and as well as many different policy areas for autism. I've provided a number of materials for the working group to consider. Today our task is to look at what has happened in the past and how that can inform the strategic plan going forward.

We're going to be considering 2013 data that my office, the office of autism research, office of autism coordination collected from a number of funders. So that's what we're going to be doing on

this call but first I'd like to go forward with going through the roll call so that everybody knows who's on the call. I'm going to read your name and if each person could just give a one or two sentence summary of who you are and what work you do on autism that would be really helpful. So we'll start with our chair, Alison Singer.

MS. ALISON SINGER: Hi everyone. I'm Alison Singer. I'm the cofounder and president of the autism science foundation and a member of the IACC.

DR. DANIELS: Thank you. Daisy Christensen.

DR. DAISY CHRISTENSEN: Hi, I'm team lead for surveillance in the developmental disabilities branch at CDC where we're responsible for autism surveillance activities through, primarily through the Adam Network and I'm the alternate member for CDC for the IACC.

DR. DANIELS: Thank you. I don't believe Samantha Crane is on the phone. Are you there? No she won't be joining us today and David Mandell had a conflict and wasn't able to join. Robert Ring?

DR. ROBERT RING: Hi folks, Rob Ring here. I'm a neuroscientist by training and have been involved in autism research across a variety of different roles both dating back to (unintelligible) advisor recently was a chief science officer at Autism Speaks and now work as a independent consultant in the area.

DR. DANIELS: Thank you. Adriana DiMartino is not going to be able to join us today. Maureen Durkin?

DR. MAUREEN DURKIN: Hello, my name is Maureen Durkin. I'm a Waisman Center investigator and professor of Population Health Sciences and

Epidemiologist at the University of Wisconsin School of Medicine and Public Health.

DR. DANIELS: Thank you. Is Michelle Freund with us from NIMH? Okay she's not on the call yet. Dan Hall from NIMH? Robin Harwood? Not on the call. Paul Lipkin?

DR. PAUL LIPKIN: I am Paul Lipkin. I'm Developmental Pediatrician, longstanding faculty at Kennedy Krieger Institute and Johns Hopkins and I'm currently the Director of the Interactive Autism Network here at Kennedy Krieger.

DR. DANIELS: Thank you. Gretchen Navidi?

MS. GRETCHEN NAVIDI: Hi, I'm Gretchen Navidi. I work at NIMH with NDAR, the National Database for Autism Research which has actually grown into what we now call the NIMH Data Archive and I'm also a parent of a child with autism.

DR. DANIELS: Thank you. Jessica Rast?

MS. JESSICA RAST: Hi I'm Jessica. I work at the AJ Drexel Autism Institute. I work in the National Autism Data Center here mostly with large national datasets creating national level indicators about autism, outcomes for adults and young adults.

DR. DANIELS: Thank you. Cathy Rice?

DR. CATHY RICE: Hi, I'm developmental psychological at the faculty of Emory University, the Director of the Emory Autism Center, was formally the principal investigator of the Autism and Developmental disabilities monitoring that work at CDC and a past CDC alternate for the IACC committee.

DR. DANIELS: Thank you. Michael Rosanoff?

MR. MICHAEL ROSANOFF: Hi everyone. Michael Rosanoff. I'm an Epidemiologist and Director of Public Health Research at Autism Speaks. I manage our organizations research portfolio and epidemiology focused on prevalence and risk sectors.

DR. DANIELS: Thank you. Andy Shih?

DR. ANDY SHIH: Hi everybody. Andy Shih, Vice President of Autism Speaks. Oversees our public health and (unintelligible) development portfolio.

DR. DANIELS: Great. Well thanks for all those introductions. We really appreciate everyone's time to be on the call today. So as I started to say earlier, today we're going to be talking about the strategic plan structure and about the 2013 portfolio analysis that my team here in the Office of Autism Research Coordination has done.

And by the way, I'm Susan Daniels, Director of the Office of the Autism Research Coordination and my office manages the IACC, the Interagency Autism Coordinating Committee.

So we will start with the first document that I shared with the group to talk about the overview of our strategic plan structure.

So many of you may be familiar with the IACC strategic plan that started in 2009 and 2011, IACC members added a number of different objectives to the strategic plan and the plan overall is framed around seven consumer based questions that the IACC felt described what the community wanted to know about Autism and hope to learn through research.

So the first question is "When should I be concerned?" which is about screening and diagnosis. Question two is "How can I understand what is happening?" which is about the underline biology of ASD. Question three is "What caused

this to happen and can be it prevented?" which is about risk factors both genetic and environmental risk factors.

Question four, "Which treatments and interventions will help?" which is about a variety of different types of interventions for ASD. Question five, "Where can I turn for services?" which is about services in the service system.

Question six, "What does the future hold particularly for adults?" which is the chapter that was added in the second year of the strategic plan to cover lifespan issues and have a focus on adolescence and adults.

Question seven which is the topic of our conversation today is "What other infrastructure and surveillance needs must be met?" which I mentioned covers research infrastructure, surveillance, the research workforce collaboration, and outreach.

I've provided a brief outline of the plan for developing the update to the strategic plan. So this will follow roughly the outline of the current strategic plan but it will have a lot of new and updated information in it.

So the document will start with an introduction and we will also have a description of the question and the aspirational goal so each of the seven chapters has an aspirational goal that was developed by the IACC to describe the long term goal of the research described in each chapter.

So the aspirational goal for question seven is "develop and support infrastructure and surveillance system that advanced the speed, efficacy, and dissemination of ASD research." And today we'll be talking about various facets of this chapter and what it may contain, what it has now and what it might encompass in the future and

at the end of the next call we will talk about the aspirational goal again and whether you think it might need any revisions based on your full discussion.

And the opportunity that if you feel that the cross cutting issues have changed in the last few years and you want to be more inclusive of other topics that you may want to adjust the aspirational goal but that is the current aspirational goal. So for each of the seven question areas, we're going to have a write up of overview of progress in the field and this is something that the working group is going to be developing in writing.

So on the next call we will talk about updates in research so that will include science advances that have been made in the last couple of years, practice to research, gaps, opportunities, and needs in the research field as well as services and policy issues related to all of the issues that are encompassed within question seven including any new programs and policies, new research evidence that can inform policies or services needs, gaps, and needed policy changes.

And so one of the differences in the strategic plan update that we're going to be doing this here from previous years is in the latest legislation that authorized the IACC, the Autism Cares Act of 2014, congress revised some of their language to ask the IACC to in more depth include issues related to services and support throughout the strategic plan.

And so the IACC is going to be attempting to do that and so we're, it will no longer be just a strategic plan for research but it will be a strategic plan for autism spectrum disorder so we will cover services and policy issues as well so be thinking about those. We also will talk about progress towards the question's aspirational goal which will be the end of the next phone call and

another new requirement in the law is that the congress wanted the IACC to consider what types of recommendations it could make to ensure that there's not duplication of effort within the efforts of all the different federal agencies.

And also the private organizations which are doing very significant work in the autism field so things that can be done to try to enhance coordination and prevent duplication. So I'll be asking you something about that today. Next we will have a section that will include all the new strategic plan objectives. So the current strategic plan has 78 objectives across the seven different question areas.

And these are going to be replaced with new objectives since the last time the objectives were revised with 2011 and so in discussions with the committee over the past several months, the committee agreed that it was time to refresh the strategic plan with new objectives.

The committee also agreed that we want the strategic plan to have fewer objectives in order to really focus the intention on particular areas and make it easier for congress and the public to understand so we, the group decided that the working groups should be shooting for about three broad objectives per question area.

So for this working group, one of our tasks on the third phone call will be to talk about three possible broad objectives that could capture some of the most pressing needs in this area. So I've given you some examples of broad objectives for question one. They can be more long term and broad scope including both research and services concepts and under each of these objectives, we could have several examples of the types of projects that might be responsive to that objective.

Next, the strategic plan also is required by Congress to include budgetary requirements and in the past the budgetary requirements has been specified for each of the objectives but the law is open in terms of the, open ended in terms of how those budgetary objectives should be created and what they're attached to.

And so once the objectives are created and the draft start going back to the committee, the committee can decide how they want to do the budgetary requirements and whether they would want to create budgetary goals for each of the specific objectives or for whole question areas or for the whole plan or any or all of the above.

So we will discuss with the committee but this working group is certainly welcome to recommend or suggest ideas for that and I'm sure the committee will be interested in hearing those ideas and then the written plan will have a summary or a conclusion. Does anyone have any questions about the structure?

(No response.)

Your writing task will mostly be in the overview of progress in the field question and our team here in the Office of Autism Research Coordination will help capture your discussion on the objectives and help you with crafting the language of those three objectives that will capture what you all see as major priorities to recommend to the committee.

So if there are no questions about that, I'd like to move on to the next group of documents that I've provided for you. So I've provided a set of data analysis slides that were prepared by the staff in the Office of Autism Research Coordination that portray what is the, what has happened with research funding in 2013.

So our office selected data from across several different private funders and federal funders of autism research and was able to analyze the data and provide these summaries of what has happened with federal and private funding over time and in 2013.

So starting with the first figure in the packet, we provided a figure that portrays the distribution of research funding across federal and private organizations for autism research and similar to past years among the different funders that we collect from about three quarters of the funding is from federal sources and about one quarter is from private sources. Keeping in mind that there are some private sources that we are currently not collecting from including some family foundations and possibly some industry groups. So any questions about that?

(No response.)

So the next figure, number two, shows the percentage of 2013 funding by the agency organization that provided it. And so you'll see in that figure that about half of the research funding that was included in our analysis was from the NIH and there were also significant portfolios of research funded by Simons Foundation, Autism Speaks, CDC, Department of Education and several other funders and so you can see the proportions across all of those funders. And in the tables to the right you can see exact amounts that we collected for 2013.

In the following figure, we've tried to show the distribution of funding across all the different question areas in the strategic plan keeping in mind that this isn't all planned centrally by one organization, this is all multiple organizations that are all individually funding research based on their own missions and priorities and funding structure and this is the compilation of what's being funded. And so you can

see that for question seven, it represents about 15% of the funds and about 9% of the project.

In the next figure, we show the alignment of the projects with the IACC strategic plans objectives and this is something that we did to try to give the committee a sense of from the research portfolio that we collect how many of the projects are directly related to the strategic plan objectives set by the committee.

And as background, with the development of the objectives, those objectives were created by the committee to target areas of research that they felt were promising opportunities that might be emerging new or in need of attention. And so their objectives don't capture the entire portfolio, things that were already ongoing and established were not necessarily represented in the individual objectives.

So when we look at the alignment figure here, we see that about 75% of the projects in the portfolio did have some relationship to the objectives that were identified by the IACC and about 25% were not directly related to the objectives representing either established areas or new. And emerging areas that might not have been described by the IACC when it developed those initial objectives in 2009 through 2011.

DR. LIPKIN: Susan, what kind of things would belong to that basket? Any examples?

DR. DANIELS: Yes and for question seven, actually when you look at the project list, you can go into the seven other or the core projects and you can see a list of those particular projects so you jump to the project listing packet, if you look on pages 12 and 13 you can see a listing at least for this question of what kinds of projects fell into that area for question seven.

DR. LIPKIN: Okay thanks.

DR. DANIELS: And so you can see that there is work about electronic medical records, telehealth, some different core facilities that may have fallen into this category because they had a lot of different topics that they were covering and they didn't fit neatly into any of the particular objects.

So those are examples for question seven. We also have all that information for the rest of the strategic plan but it didn't provide it to this working group however if you're interested in any of that, let me know and we're happy to share it and it's also online with the meeting materials for each of the working groups. So does that answer your question?

DR. LIPKIN: Yes it does. Thanks.

Dr. DANIELS: Okay. Sure. On the next figure, the funding alignment with IACC strategic plans, strategic plan objectives by question, if you look at question seven, you can see that approximately maybe a quarter or not quite a third of the projects were in the core other designation.

So they were either foundational elements, established research, or emerging research and the rest of the projects were specific to the question objectives.

Now when you're looking across the entire strategic plans, you notice that in question two biology, a lot of their projects are in the core other section partially because there were a lot of very established areas of research of basic research that were already being funded that were not specifically targeted by the IACC as well as many emerging areas.

I'm going to skip the next slide because it's kind of repeated in the following packet. In the

packet that I have, I don't have the next figure but, sorry, I was thinking of another working group in a different figure that I sent to them. So ignore that, let's move on to the last figure in this packet which is the question seven percentage of 2013 funding by subcategory.

So the Office of Autism Research Coordination developed a number of research subcategories to help describe the entire portfolio partially because as we just looked at the distribution according the objectives that there are areas that fall into this core other category and it's not clear exactly what's in them.

And so this subcategory categorization scheme will show the entire portfolio and give you a sense of what types of research are included and you can see that the subcategories for question seven that we've created our biobanks data, tool, research infrastructure, research recruitment and clinical care, research workforce development, and surveillance and prevalence studies.

So those are the major areas that are represented in the portfolio. Moving to the next packet which is the multiyear funding table, we provided some information about the progress made across the strategic plans over the years 2008 through 2013. And the most important column in this table is to look at the total and so in that column, if you note the color coding, the highlighting, the green color coding means that the content of the objective as well as the recommended budget that the IACC created were both met or that objective over the years measured.

The yellow highlighting indicates that either part of the content or part of the recommended budget or both were met but not fully during the years that we were looking at and if it's in red it means that there were zero projects in any given year and at the end if there were no projects that captured that or addressed that

objective, they were in red. And so you can see tons of varieties for question seven, there are some that are in green, some that are in yellow, and some that are in red and I've given you a list also the final packet was the listing of projects in each area.

So does anyone have any observations or questions about each of these objectives and what was accomplished or what's included in the portfolio and areas that you feel that might still be gaps or comments about the objectives themselves and how they have changed overtime or how, what the status of research was in 2009 when these were first created. And how that compares to where we are now and whether these questions are still as relevant today so I'll open up the floor to anyone to discuss.

(Pause.)

DR. RING: Susan this is Rob. I have a quick question maybe I'm just not understanding the asterisk but at the bottom of the first page the development of web based tool that provides population assessments on ASD prevalence is checked as completed without having any projects or spend against that and you can just tell this understands against why that's...

DR. DANIELS: Yes and so with this project, it was met through, for this objectives, the objective was met through a project that was not an autism specific project and so it's not a part of the portfolio that we counted but the goal of that objective has been met through another project and so that's why the funding is not there because we didn't count it as a autism project.

It was a broader project from CDC, their environmental tracking tool and Daisy you might have comments about that.

DR. CHRISTENSEN: Yes that was, that was a project that was initiated at CDC and the current status of that I'd really have to check on. That has not necessarily been an ongoing project.

DR. DANIELS: So at the time that we received data for 2013 where in 2012 we were notified that that project had been initiated and it met our objectives so that's why we considered it completed.

DR. CHRISTENSEN: Right. Right.

MS. SAMANTHA CRANE: Hi everyone. This is Sam Crane from ASA. I'm a little confused because I just dialed in and it sounds like this meeting has been going on for a while but I thought one o'clock on the calendar? Did this meeting start earlier?

DR. DANIELS: Oh, so the time was moved back of last week so an e-mail was sent out and we updated it on the IACC website. It was in order to accommodate another working group that is having a call at three so we wanted to put a little bit of space in between in case our call ran over a little bit.

MS. CRANE: I am so sorry. I don't know why I didn't see the second e-mail.

DR. DANIELS: It's okay. That's fine. We just went over the various documents that I sent out and we're really starting discussion now so you're just in time for that.

MS. CRANE: I'm sorry. I don't think I ever got this e-mail because I'm actually seeing the most recent e-mail being, the group seven working call? Okay I see it. Sorry about that.

DR. DANIELS: No problem. So you're welcome to join into the conversation. So we're just talking about the multiyear funding table and the various

objectives and what our office tracked over the years in terms of what projects or what objectives were completed or not completed.

When you look at the columns that are designated by the various years, the color coding was really there to give the committee an idea of what was happening on a year by year basis because at first we really only had a few years' worth of data and it wasn't enough to really look at a trend very well. So we thought that was helpful but now that we have many of years of data really the total is the most important but if you were curious about the color coding under the specific years, we based that on an annualized budget.

So we took the budget and divided it by however many years the committee thought that that objective was supposed to last and gave it an analyzed total to get a sense of whether the objective was moving forward. But at this point, we have enough years of data that several of the objectives have been completed, some of them are partially completed and there are others that were not completed. And I do have information from the last strategic plan update in 2013, the working group that helped with that update provided some detailed commentary about their thoughts, about various objectives including the ones that were not completed.

But I wanted to see if you all had any other questions about it or any other observations that we should note for this strategic plan update.

MS. CRANE: Have we already discussed you know, whether or not we should look at trends, rethink some of the objectives?

DR. DANIELS: So we have discussed that that will be the topic of the third phone call is when we are going to create new objectives so on this phone call we're just talking about what happened in 2013 in terms of the latest on the research

portfolio and what it showed. On the next call, we're going to talk about major updates that have happened in the last couple of years that should inform the plan going forward and on the third call, we're going to create objectives.

MS. CRANE: Right. Thank you, Susan. Sorry about that.

DR. DANIELS: No problem.

MS. NAVIDI: Susan, this is Gretchen.

DR. DANIELS: Yes.

MS. NAVIDI: So I'm looking at objective number, letter H related to NDAR and it's a slightly different objective in the way that it's written because it's got a metric of 90% (unintelligible). And yet I see that when we add up the total we get green there indicating that the objective has been met and I would argue that is actually not the case when we're looking at the 90%. It could be that there are projects associated with working toward that objective but I wouldn't say that we're anywhere near 90% on that. So does that make sense?

DR. DANIELS: It does. So that was what we had the last time that we looked at this so the notes that I have on progress from the last strategic plan update are the objectives to create mechanisms to support the contribution of data from newly initiated projects that NDAR has been met. And NDAR has lined with several other existing data sources such as the ATP Agree in IAN. In 2012, 81% of NIH funded extramural studies were contributing data to NDAR and all NIH grants have terms requiring linking of data to NDAR.

And in terms of remaining and needs, it says that infrastructure will need continued development to enable greater availability of standardized data and analytical tools for cloud

computing. IAN data collection could be expanded to include locations of residence to enable geographic data collections on environmental exposures. So I don't know if that's still up to date. We certainly will want to update the information.

MS. NAVIDI: Right.

DR. DANIELS: And it's possible that there are new projects now that may not be linked and that might contribute to what you feel is less than 90%. So we'll certainly want to circle back to you and (Dan) to get the most updated information and try to ensure that we incorporate it into the update.

MS. NAVIDI: Okay that sounds good.

DR. DANIELS: Thank you. Anything else that people have in terms of comments?

DR. DURKIN: Hey Susan, this is Maureen. Just looking at the next one, 7I, it was the objective was to supplement ADAM site to use hypothesis driven research and I just don't know it's supposedly been achieved but I don't, is there some sort of documentation of that?

DR. DANIELS: Is this Maureen?

DR. DURKIN: Yes.

DR. DANIELS: Yes so we have the listing of the projects that were responsive for 2013 in the packet so if you go to the page where 7I is listed, you can see the specific projects that were listed.

DR. DURKIN: Okay.

DR. DANIELS: And these are of course CDC projects.

DR. DURKIN: This is in a separate document, right?

DR. DANIELS: Yes it's in the one that's the long project listing that...

DR. DURKIN: Oh yes, okay.

DR. DANIELS: Those are the projects that were considered to be responsive so there's a good number of them.

DR. DURKIN: I see. Thank you.

DR. DANIELS: Yes, 13 projects that we counted for this objective and one of them was yours.

DR. DURKIN: Okay. Thank you.

DR. DANIELS: Sure. Any other questions or comments? Any thoughts about...

DR. DURKIN: Well the only thing that was said is supplementary funding. I don't know if that's really true. But maybe it was and I just didn't know about it but I don't know that there was supplementing, supplementary funds given to, for the hypothesis testing work.

DR. DANIELS: So I do know that this was the place in the strategic plan where Adam Sites were included because it was the best fit objective but in terms of supplements, Daisy do you have any comments on that?

DR. CHRISTENSEN: Yes I would agree with Maureen, I don't think that there were supplementary funding that was given for that. I think that was probably included in the you know, in sort of the typical requirements for analysis to be conducted during the you know, sort of during the course of regular surveillance activities.

DR. DANIELS: So I have listed in the progress that, section that was listed for the last strategic plan update the research goals and the objective have been achieved. Initially supplements were needed to support these analyses.

But now the Adam Sites have been well established and are conducting some analysis using funds from Adam Grants themselves well outside supplements are supporting additional, other additional analysis so that was the documentation that we had from the last time. So on this update, if we need to update that information, you know, we can do that when we're working on the written document.

DR. DURKIN: Okay.

DR. RICE: Yes. This is Cathy Rice. If I can, recall at the time I think that the supplement was aspirational in terms of trying to accelerate and make more use so maybe it's, when we talk in the future about achieved versus the next levels of what do we need to do better and more of and what are some of the foundational opportunities that we can build on to advance the science in that way? So I think it was somewhat met but I think the intent was to even do more utilizing that data.

DR. DANIELS: Thanks. That's something that we can try to incorporate into our update and that's true across the strategic plan in many areas where some projects, major projects were established and now people see a lot of opportunities for building on those projects.

DR. RICE: Right. And it's such a challenge I think when of course when trying to measure progress and depending on who the audience is, people want to say yes, achieved as in we can move on and do something completely new and it's not as interesting or exciting to build on and go deeper.

But I think one of the things that I noticed in the progress since the 2013 and 2011 when it was written and 2013 when we're looking at the progress is really that there has been a great deal of progress in the basic infrastructure, in the ability to have coordinated data system to have biobanks, to have the registries across projects and to have that consistency.

And so, so much has been, has been achieved in many of the foundational aspects but there's still a great deal more to achieve particularly if we think about the next iteration of the plan including services and policy. And even in sort of the infrastructure for putting services and policy research into practice, those are some of the most striking goals that have not been achieved like having the promising practices or the quick replication of promising research.

So I think that will be a big challenge for us to think about really how to one, build on the research infrastructure related to services and policy but actually how deep and how are we going to look at that for this next iteration in the plan to make sure that we are including that translation to practice.

DR. DURKIN: This is Maureen. I agree completely that there's been a lot of progress but I'm just finding this relate not very satisfying you know, for us to look at this chart and the green and the yellow and the red and then look at the evidence for it, it doesn't, there's a disconnect.

So I mean, to me for example, going back to that 7I, I would want to know what were the five analysis, not five hypothesis proven studies, not just a, just a list of the P.I.s and the funding to establish the infrastructure which that was important but it has nothing important to do with 7I.

So if we're going to be really using these findings to evaluate, to be convinced that the objectives are met, I feel like we need better evidence.

MS. SINGER: So I have a question, this is Alison, I, are the green and the yellow measuring whether the financial, whether the budget was reached or are they making an subjective determination as to whether the goal was met?

DR. DANIELS: They are measuring both to some extent. So the, certainly whether the IACC recommended budget was met and in general whether say if the objective was initiate three projects on women and girls with autism and if there were indeed three projects that were funded and that met the IACC recommended budget, it would be green. Now whether those projects went on to achieve great things or produce important data, that's not considered when just doing this color coding. This is just one layer of the analysis.

So this is what our office was able to do in terms of providing some quantitative background but on the next call we'll be talking more qualitatively about what's happened in the field.

And so that's what I think Maureen is getting at and we hope that the strategic plan update as it has in past years will contain elements of both of those because we recognize that we can't do everything just measuring numbers of grants awarded. It really is also about what kind of progress has been made in the field so on the next call we'll be calling on the experts on this group to really share what they think have been a major breakthroughs that have been made or the major foundations that have been built in this area and what we...

MS. SINGER: I also...

DR. DANIELS: ...must do going forward.

MS. SINGER: I also just want to add to that as a funder and the, participants from Autism Speaks may want to comment on this as well but when we are signing objectives to our funding when we submit our data to the IACC for the purpose of creating this report, it's not always so easy to put them in a category. So for, where it talks about the hypothesis driven objectives with regard to Adam, we also put anything related to Adam whether it's hypothesis driven or not because there's not always another place to go so we sort of use best fit, so it may not be exact.

Another example would be on the replication study, if there's a replication study, we may code that to the actual content area rather than as a replication study. The same as post-doctoral fellowship, that could be coded either to training in chapter seven or to the content area. So this is not really an exact science.

DR. DANIELS: Thanks Alison for that additional explanation. It is true that it is not an exact science. We have tried to create a system that is somewhat consistent to try to look at all of this information that we are for example, coding each project to only one area even though it may contain elements of other areas in order that we aren't double counting or triple counting the funding in different places.

It gives the committee a better idea of the total funds so that's why we try to do this as a multilayer process so we're looking at the projects awarded as one step in this process but certainly the part which will give you more opportunity to provide opinions and thoughts from the field will be the section where we're talking about progress made and getting your ideas about that.

MS. NAVIDI: Susan this is Gretchen. So for that step then, do you need us to you know,

volunteer or assign ourselves in a way to the areas that are most applicable to our area of expertise and sort of figure out if you know, this color coding scheme is really an accurate representation of the current state of affairs?

DR. DANIELS: So the color coding is not a representation of the entire current state of affairs so what I was saying is that there are multiple layers to understanding what's going on in you know research and research is really only one portion. We also in strategic plan update want to talk about services and policy which is a huge area that's also very important and this analysis here doesn't even cover that at all.

So we will be doing this in multiple ways. One is to look at the research portfolio and this is the best system that we've been able to come up for looking at the portfolio and getting some sense of whether research is moving in the direction of some of the goals of the strategic plan that was created by the committee. It is quite complicated. There are 78 objectives and this is one reason that the committee is now going to try to simplify down to 21 objectives and make them broader so that we don't have this problem of trying to fit projects into very specific little buckets where they might not be a perfect fit.

But we also will have to come up with a new way to decide how we're going to describe progress and it may be more qualitative and maybe the next time around we'll have to talk with the committee what they want to do about that. So the goal here isn't really to reevaluate whether you like the way that this has been analyzed over the years. At this point we are really just presenting the data to you to get your feedback on what you think is happening in the field and just to give you a sense of where we think we've made progress based on what's been awarded if that makes sense.

DR. DURKIN: Okay. Yes that actually is very helpful and now that we've had this discussion, I think that that really makes a lot more sense in supporting this notion of going down to 30. So my next question actually has to do with that promising practices papers. Have we checked with anyone you know, like some of the folks here like, like Denise Pintello just to see if that's really true that there haven't been any papers to come out, that have come out?

MR. ROSANOFF: Can I just, can I jump in Susan before you respond, this is Michael Rosanoff from Autism Speaks and this really speaks to what we've been discussing over the last few minutes and that although this is a looking back exercise, we are, we are noting some not misclassification but maybe incomplete classification of how the projects have been identified in terms of their areas of focus.

So Autism Speaks has made investment in 7M as well as 7A which you know, our folks have zero total funding amounts indicated here but I do want to, you've answered the question Susan in that thinking and looking forward, we wanted to provide additional information and comment to whether or not objectives have been completed and where investments still needs to be made.

But I would like to go you know, on record here noting that there have been some investments made in this area by Autism Speaks in particular, maybe others on the call and so that the, although this is a looking back exercise, this may not be as a comprehensive of you as we might get out of, get out of this process as we discuss it.

DR. DANIELS: So Michael, this is...

Alison Singer: ...a little institutional memory that, this is really where over specify (unintelligible) was a particular document that the Department of Medicaid was producing. There was one member of the IACC who wanted it

specifically in the plan to say promising practices so that funding could go to that project. So then Medicaid stopped producing promising practices documents so that's why there's nothing there. It's not really saying that none of the organizations or universities or government agencies have produced white papers or documents outlining that content. It's just this particular title.

So that's another reason why I think the committee voted to be more abroad in the objectives so that it wouldn't look like no intellectual work has gone into policy making of the last four years.

DR. DANIELS: Thank you, Alison. I was going to say pretty much the same thing that this particular objective was developed through CMS and based on a very specific project they were hoping to fund and then it didn't really get funded. And so I think that they did two initial papers and after that in the years that we were recording, there were no more papers funded and that's why it didn't have any funding.

However with Autism Speaks, I know Autism Speaks does very detailed and lengthy coding for our project and so if there were projects that Autism Speaks didn't include and didn't indicate went with this objective and you want to revise your data and send it to us, we're more than happy to take revised data to update this before we publish the 2013.

But in the data call that you returned to us, there was no indication that there were research projects that supported this particular objective so you know, we're happy to talk offline about that and get that fixed if there are some projects that you would like to suggest to include there. But this was at the time referring to those CMS promising practices papers. Anything else?

DR. RING: Hey Susan...Rob Ring here and this is slightly off of where we just were and it kind of takes us back to an earlier part of the conversation and you know, it's obvious as I look at this and maybe more for the discussion moving forward but how will or has it been discussed previously how you might account for this.

How will activities that may be going on in the four profit sector be accounted for in terms of the contribution to the larger research ecosystem that all these traditional players in the nonprofit and/or academic space are considered? Is that out of scope or is that you know, how will that be addressed?

DR. DANIELS: So that's a great question, Rob. It's something that's certainly not out of scope. It's not something that we've been able to tackle as yet however if you as a member of the IACC are able to help us make some inroads with PhRMA or any other times of companies that are doing research and they're willing to be very open about their data with us in order to share it, that's great.

I know that with a lot of commercial entities they would have some issues with being open with their data and giving us all this information like all the nonprofits do...

DR. RING: Right.

DR. DANIELS: ...and the federal funders but if there are any that are willing to work with us that way we would love to engage with them. So offline I'd be happy to talk with you and if you have some suggestions of people to reach out to that would be terrific for future analyses.

DR. RING: Yes I would agree. Those are all probably fairly obvious points that you know, I think with the increasing movement towards more and more precompetitive collaborations between

industry and academic institution, government institutions, you see a lot more transparency in terms of how in kind contributions are valued.

And so that's what thing that's difficult to see in here is how in kind contributions are valued monetarily and the accounting on things like that but good things for us to talk about in the future.

DR. DANIELS: Certainly and for anybody here on this call who is a funder, if you do have areas where there are in kind contributions, you can indicated that just with the \$0 designation on the project. So I think that we've had a really good discussion of the data that we presented to you. I wanted to leave a couple of minutes at least to talk about duplication of effort because this is one of the things in the law that we need to include in the strategic plan.

The committee will be coming up with a statement on recommendations to avoid duplication of effort and I wanted to know if as you looked through the portfolio, if you had any concerns about duplication of effort or saw any areas where you think actions could be implemented to prevent duplication or increase coordination. Not general coordination, just talking between agencies, that type of coordination but to prevent duplication of effort so any comments on that?

DR. LIPKIN: This is Paul Lipkin. I would say that a duplication of effort in and of itself is not necessarily a bad thing as long as there's some sort of coordination of effort at the same time. So I guess really, but you know, what you're saying and what I think is important here is that duplicated efforts not result in excessive redundancy without any, without anything additional being provided through that duplication.

So but I think you know, I think we all are mindful of the fact that we shouldn't waste money here and so any duplication needs to be considered as to its value or not.

DR. DANIELS: Thank you. Anything else on that?

MS. NAVIDI: Susan, this is Gretchen. So I think NDAR is really the answer to that whole duplication of effort question and it also needs this 90% objective at the same time. If we were to have a colleague of all of the projects going on regardless of the funding source, it would be very easy to see where the duplication exists and as Paul mentioned and I think probably everybody on the call is of the same opinion that duplication does serve a purpose and this really folds nicely into the NIHS new effort for (unintelligible) and reproducibility.

So I think that really looking at as we narrow down some of the objectives within this question, looking at NDAR as a way to catalogue all of these projects and see more overlap may or not may not exist is really a good effort to consider.

DR. LIPKIN: So you obviously feel that NDAR is essential to do that?

MS. NAVIDI: Yes absolutely, absolutely.

MS. SINGER: This is Alison and again, I just want to bring a little institutional memory here. The duplication of effort clause in the new law is a direct reference to the government accounting office report that came out a few years ago that referred specifically to duplication of effort in autism funding because multiple agencies within the federal government were funding autism research.

So we, the IX center letter of response to the GAO where we made many of the points that you, that were just brought up on this call that

replication is part of the scientific process and that different agencies were tackling different parts of the, of the autism picture. But that's what the laws referring to with regard to duplication of that.

DR. DANIELS: It is. Thank you, Alison.

DR. LIPKIN: Yes and I appreciate that, Alison, it is Paul again. And so I think that behooves us as we look at duplication to really just take into consideration which duplication is a value and which is not. Yes.

MS. SINGER: So maybe it would be valuable Susan if you want to send out the GAO report and then the IX response...

DR. DANIELS: Sure.

MS. SINGER: ...that were all on the same page when we're talking about duplication of effort.

DR. DANIELS: Sure I can do that. That's not a problem. So finally I know that we're almost at our time here. Are there any areas of emerging research that you don't see represented among the various objectives here that you want to take note here for the next discussion?

And of course we'll have two hours to discuss things on the next call but is there anything really striking that you think we'll want to take note of?

DR. DURKIN: This is Maureen, I don't, maybe I just don't see it but I don't see much on disparities in access to autism services and diagnosis and maybe related to the screening that this one could get into the call next week or next time but the whole thing that came up in the past year about was it the public health committee that didn't approve of screening, early screening?

DR. LIPKIN: Yes.

DR. DANIELS: Yes we do have a whole group question one on diagnosis and screening that is going to be discussing those issues so we, I know that they will be talking about disparities but if there's an aspect of disparities that you think fits in this cross cutting objective, we can certainly consider it.

DR. LIPKIN: This is Paul. It's a long complex list and I just had a chance to skim and not go into detail but you know, we are now funded, we at the interactive (unintelligible) funded through PCORI as essentially as the autism node for their national network. So PCORI and a big issue that this broad group is tackling is finding ways to promote and reinforce the importance in the value of patient-centered or participant-centered empowered research and that sort of thinking, I would like to see sort of imbued in the, in the work of the IACC over time.

So research is not just something that comes from, that's directly from researchers and from community advocates but from the community at large and so that does, when it comes to our question, I mean, there is infrastructure that needs to support that. It gets down to other things that we talked about so in terms of integration of data networks but there's a whole set of data network opportunities that the PCORI networks bring to the autism world that I think one needs to consider.

DR. DANIELS: Thank you. PCORI is a new funder that we are including in our analysis now so that's, their work will hopefully be represented here.

DR. LIPKIN: Thank you.

DR. SHIH: This is Andy Shih. I'd like to suggest that we consider implementation science as part of an extension of the dissemination.

DR. DANIELS: Thanks, I think that question five is going to do a lot with that, with David Mandell as one of the co-chairs there but certainly if there's aspects that fit better in this area, we can, we can consider including it here too.

DR. SHIH: Great. Thank you.

DR. DANIELS: Of course, without duplicating. Anyone else? Any comments? So well on the next call, we're going to be talking about recent progress that has been made and so I'd like members of the working group to take into consideration major breakthroughs and foundational elements have been put into place within the last few years that can inform the strategic plan going forward.

I'll be sending you an agenda, a list of discussion questions and materials for that call so your next call is on October 6 at 10:30 AM and we look forward to talking to you again. Any questions before we adjourn?

(No response.)

DR. DANIELS: And thanks again to Alison for chairing this group.

Well thank you all for your contributions and we look forward to talking to you again soon.

(GROUP): Thank you.

DR. DANIELS: Thank you everyone.

(Whereupon, the conference call was adjourned.)