

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR  
BASIC AND TRANSLATIONAL RESEARCH

STRATEGIC PLAN QUESTION 7 PLANNING GROUP  
CONFERENCE CALL

FRIDAY, SEPTEMBER 27, 2013

The Strategic Plan Question 7 Planning Group convened via conference call at 2:00 p.m., Susan Daniels, *Executive Secretary*, IACC presiding.

PARTICIPANTS:

SUSAN DANIELS, Ph.D., *Executive Secretary*, IACC,  
Office of Autism Research Coordination (OARC),  
(NIMH)

THOMAS INSEL, M.D., *Chair*, IACC, National  
Institute of Mental Health (NIMH)

DONNA KIMBARK, Ph.D., U.S. Department of Defense

CATHERINE RICE, Ph.D., U.S. Centers for Disease  
Control and Prevention (CDC)  
(representing Coleen Boyle, Ph.D.)

ALISON SINGER, M.B.A., Autism Science Foundation  
(ASF)

TABLE OF CONTENTS

Roll Call and Opening Remarks.....	3
Discussion of Question 7 IACC Portfolio Analysis Documents and Strategic Plan Progress.....	7
Planning Group Discussion of Strategic Plan Update Process.....	15
Wrap-up and Next Steps.....	73
Adjournment.....	77

PROCEEDINGS:

Operator: Welcome and thank you for standing by. All participants will be in a listen-only mode throughout the duration of today's conference. Today's call is being recorded. If you have any objections, you may disconnect at this time.

Now I will turn the meeting over to Dr. Susan Daniels.

Dr. Susan Daniels: Thank you. Welcome to our listening audience and to the IACC members who are joining us for this conference call of the Question 7 Planning Group that will be involved in the 2013 IACC Strategic Plan update.

We're going to start with a roll call just to see who's here on the phone with us today.

Dr. Tom Insel, are you here?

Dr. Thomas Insel: Yes.

Dr. Daniels: Thank you.

Donna Kimbark?

Dr. Donna Kimbark: Here. I'm here.

Dr. Daniels: Thank you.

Cathy Rice will be joining us around 2:30 p.m.

Alison Singer, are you here?

Ms. Alison Singer: I'm here.

Dr. Daniels: Thank you.

So then we have three of the four members of this Planning Group, the IACC members that will be a part of this Planning Group here on this call.

On today's call, we're going to be doing the first part of the Strategic Plan updating process that was shaped by the Question 1 Planning Group using pilot information to try to put together a plan for how we would do this. I shared a guidance document with all of the IACC members who are a part of the planning groups and laid out the plan for how we're going to do the Strategic Plan update.

On this first conference call, we're going to have each planning group meet and go through the portfolio analysis data for the past 5 years that OARC has collected on behalf of the Committee to get a sense of the status of the objectives in relation to what has been funded. And so we've provided a number of documents.

For those who are listening on the phone, you can access this by going to the IACC Web-site and going to the Meetings and Events page, and if you find this particular meeting of the Question 7 Planning Group at 2:00 p.m. on September 27th, you can click on the link for materials. And you'll

find all the materials there, and the agenda should also be there.

So we will be going through the documents that OARC has prepared and, you know, laying out some of the -- a little bit of the background and history and then letting you go through these documents and make some determinations about where you feel the objectives have come over the past 5 years and what you think is the status of this entire question area.

And the deliverable at the end of this, it's not going to happen right at the end of this call, but after the call is over and you all have gotten a feel for how you think the objectives are doing, we're going to have somebody volunteer from this group to put together a short summary -- it can be anywhere from one to five pages -- to talk about how you feel all of the objectives are doing in terms of funding support.

So that's sort of the outline of what's going to happen here. In the next meeting of the planning groups, we will be having external participants join the planning groups, and we will be going through the Strategic Plan but really looking more at qualitative aspects of progress in

the different fields to understand what are the results and outcomes and what barriers might be in place that are preventing progress. And then from there, what does the Committee want to do next? What do they feel are the key priorities and recommendations they might want to make?

So that gives you a sense of that structure. The next part of this will also be a Strategic Plan update workshop that will take place on October 29, 2013, and it will be an all-day workshop with a videocast. There will be a time for public comments during that workshop, and we will have discussion of all seven questions, including all of the invited external participants as well as the members of the IACC. And that will be taking place at the end of the month.

So we have a lot of work to do between now and October 29th. We have after this call another 12 meetings that will be happening as we lead up to October 29th.

So with that, I don't know if anyone has questions at this point about the overview of the process? Do you feel that that is reasonably clear?

Ms. Singer: Before we start, I just want to

thank you, Susan, and the whole team at OARC for collecting and assembling this tremendous amount of data. It's very well organized and extremely useful. So thank you.

Dr. Daniels: Thanks so much, Alison. So we will -- I will walk you through the information that we've provided about Question 7 and then let you begin discussion. So the first document we have for you is the 5-year Strategic Plan Status Chart, or the cumulative funding chart. And this chart shows each of the 5 years that we've collected data for all of these areas from the various Federal agencies and private organizations.

And then the final column in this document shows the total of all the funding that we have been able to track through our mechanisms over the past 5 years from the various funders who have participated. We have a red, yellow, and green indicator system to give you a sense of whether the funding is looking like it's meeting the recommended budgets that the IACC provided for each of the objectives.

In the 2008 through 2012 columns, this is estimated based on an annualized estimate of the

recommended budget. So in some cases, if a recommended budget was only over 2 years and you see 4 years of funding that are green, you definitely may have gone over what was actually recommended.

And just as a reminder that the Committee, when they put together these recommendations -- these particular objectives -- they were targeting gap areas and identifying what would be the minimum amount of projects or funding required to stimulate these areas that were seen as being areas that needed further attention beyond the standard parts of the portfolio that were already being funded by the agencies and organizations.

So on this first chart, this will give you a sense of where the funding is, and we realize that funding is only one piece of the picture and that you will need to have more information about what's actually happened in the field. And that will be a part of your next call. So we want to kind of focus more on the status of the portfolio. What's the content of the portfolio? Is it meeting the objectives that the Committee intended to try to fill these gap areas?

And is the funding adequate? Is the number of



projects adequate? Are the size and scope of those projects meeting the needs, or are there areas that still need further attention? So that's the first document.

The second document that we have is a distribution of funding across all the Strategic Plans, and these are pie charts that you're all pretty familiar with, I think, from previous portfolio analyses, and we provided that to you just to give you a sense of where Question 7 falls in the overall distribution of funding for the 5 years.

The next document and I don't know how quickly you're following this. I don't want to lose you as we're going through, but I know some of you have been through this already before in the past day or so. We have subcategory pie charts for Question 7, and this one in the title of the document, it will say "Subcategories."

And what OARC has done, in response to an IACC comment in 2009 that it was a little bit hard to understand what was in the "Other" category for some of the questions, OARC has tagged each of the projects in the entire portfolio with sort of some general scientific or research terms to give you a

sense of what is the content of each of these questions. And so, we have the data for 2010, '11, and '12.

Although I think on 2012, there might be an error in the title of it. It might say 2011, but it really is 2012, as I'm looking at the documents here. So that will give you a sense of what the content is. The subcategories for Question 7 are biobanks, data tools, research infrastructure, research recruitment and clinical care, research workforce development, and surveillance and prevalence studies, to try to break that down for you all.

The next set of documents is full project listings for Question 7 for 2011 and 2012. And if you need the full project listings for 2008 through 2010, those actually can be accessed from the cumulative funding table by clicking on the links for the projects. If you click on those links, they will take you into the Web tool and show you a list of projects. But because '11 and '12 are not live yet in the Web tool, we gave you a static list of the projects so you could at least see the project titles for everything that's in the portfolio.

And then we provided, finally, a summary sheet that has some key facts that might be important or helpful to you. And at the bottom of that, we looked particularly at the "Other" category and pulled out some of the key types of projects that are in the "Other" category because that seemed like something the Committee was really interested in knowing.

So that's kind of a rundown of what you have in front of you, and our task is going to be to go through the questions that are in our agenda, which are to find out what kind of progress has been made toward achieving the Strategic Plan goals in terms of funding of Strategic Plan objective areas over the past 5 years? Which objectives have been partially or fully accomplished based on the information available from these particular funding documents? Which objectives received little or no funding and why?

And that might include also identifying barriers. And then, four, what are the conclusions that you can make, just based on this particular set of data?

So then, with that, you know, I welcome you all to start looking through these different

objectives and discussing how you feel the objectives have been doing over the past 5 years.

Dr. Kimbark: Susan, can I ask a question? This is Donna.

Dr. Daniels: Sure.

Dr. Kimbark: Susan?

Dr. Daniels: Yes?

Dr. Kimbark: Can I ask a question? This is Donna.

Dr. Daniels: Yes.

Dr. Kimbark: I'm just wondering as far as our outside experts are concerned, when will we know who's going to be on the -- involved?

Dr. Daniels: We're going to be sending out that information as soon as we have verified who all is going to be involved in those panels. So I'll be following up with an email. But I've been working with the subcommittee chairs on finalizing that based on the nominations that were received from the IACC members, as well as a list of people that were invited last year but, unfortunately, couldn't participate because of the hurricane.

Dr. Kimbark: Mm-hmm.

Dr. Daniels: So we will -- we will be going down that list. There are some people that do have

schedule conflicts, and in those cases, we will have to move to the next person on the list as the subcommittee chairs guide.

So we'll be trying to get you that information fairly soon, and hopefully, they will be able to join us on the second call, where we'll be talking more about the general status of the field and research progress in each of these areas.

Dr. Kimbark: Okay. Thank you.

Dr. Daniels: Sure. So would you like to start with objective 7.I?

[Pause]

Or sorry, I might be on the wrong page here. I'm sorry -- 7.A. I was confused why -- I was on the second page. Sorry -- objective 7.A - "conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education, and social services by 2009."

Ms. Singer: I mean evaluation of this one appears to be pretty straightforward.

[Laughter]

There's no spending. There are no projects. I guess the question for this one is really for

the next session, which is why is that? Is it not an area of need? Is there some major obstacle that's preventing the study -- the project -- from being completed? Does no one want to fund it? You know, why is there no funding?

Dr. Daniels: Right. Or is it a case where the portfolio analysis might have not captured the activity because it was funded in some other mechanism that's not reflected in the portfolio analysis?

Dr. Insel: Yeah, this is Tom. I think that's a good point, Susan. That we had that happen on one of the other areas yesterday.

In this one, for those who are on the phone, do you know of anything like this that might have been done that wouldn't have been picked up by our portfolio analysis? Sounds like the answer is no?

Dr. Kimbark: I don't recall anything.

Dr. Insel: Okay, so useful to go through. So this would be one also to work with the external advisers about and to get some sense about whether they still feel that there's a great need for it or whether -- how other people might see this.

But it looks like this one's pretty easy to evaluate in terms of what the investment is.

Dr. Daniels: Excellent. Well, it sounds like you all agree on that one. So we can move to the state of the States, which is objective 7.B. With this one, CMS has been funding a project for state of the States or has been leading that project.

Dr. Insel: Do we know -- I guess this is getting ahead of us a little bit, Susan, because it will be for the next call -- but do we have anything from them that is a deliverable at this point, an early version of that or something that people can begin to use?

Dr. Daniels: We do have the -- we had CMS come and present that nine-state study --

Dr. Insel: Right.

Dr. Daniels: -- of a year and a half ago or so, and the state of the States. I've been discussing with CMS when they're going to be ready to present it, but they want to wait until their publication is ready, and their publication right at the moment is not ready for release yet. So they are working on it, and I have been actively discussing with them when they will be able to present to the IACC about their findings.

Dr. Insel: Yeah. So I think it's a good one to keep in yellow because the funding disappeared, it

looks like, in 2012. So it was last funded in 2011, and in terms of our fiscal year, we're starting 2014 next week. So I guess the question is what happened, and where are we 3 years after the last funding?

Ms. Singer: Or it could be the case that in the past call -- in the previous call -- we talked about if there's a zero, but there's still a project, that that means that it was a multiyear project that was funded in advance. So it does say one project.

Dr. Insel: Could be.

Dr. Daniels: Yes, so that would be -- you're right, Alison, because there is a project listed, that would be one where the funding was already allocated and the project is ongoing, but no new increments.

Dr. Insel: Okay. So I'm comfortable having that in yellow, with flagging it as a place where we need to get some information about -- again, and the way that I think about this today, we're asking what's been the investment, and in our next call, we'll ask for what's been the return. So we'll need to find out more about the return on our next call.



Dr. Daniels: I'm wondering on this particular one, John O'Brien is not on Question 7, but we might want to ask him to join the next call just to comment on this?

Dr. Insel: Or even if we could just get some input from him before the next call by email?

Dr. Daniels: Sure.

Dr. Insel: Can you take care of that, Susan, to find out what the status of this is?

Dr. Daniels: Yeah, we could -- I could get information. Sure.

Dr. Insel: And you could say that came up in looking at the portfolio. That would be helpful, and I really do think since this has been in the discussion on the IACC agenda for at least 5 years, maybe longer -- it preceded Question 7 -- one wonders what's the delay in getting this done.

I think we heard this several years ago as something that the community really wanted. So I think it will be good to get an update and find the details.

Dr. Daniels: Great. Well, we'll be happy to provide that. So the next objective is objective number 7.C. What is your feel on that one?

Ms. Singer: I mean, this one looks good for me

-- funding and the number of projects -- I mean, this one looks good. I think this is really one that we have to evaluate whether what we have is useful and valuable. It looks like we have something.

Dr. Insel: You know, this one's a little bit misleading as well. It may -- you could look at this and say, my goodness, this is so much redundancy. Do we really need -- we've spent 10 times more than recommended, and there are at least 6 projects that were being supported in 2012.

But when you look at the actual projects in the list, they're doing very different things. I think they are, anyway. I mean, IAN is certainly very different from the Group Health Cooperative Autism Registry.

Ms. Singer: Yeah. True.

[Pause]

Dr. Kimbark: I have to agree. I think one of the things that we have to be really careful about is deciding that something might be duplicative just because it's in the same topic area.

[Pause]

Dr. Insel: Well, I think, at the very least,

we can say this is a bona fide green. I don't think there'd be any question that there have been attempts to create these registries and to the extent possible track involvement of people in ASD research.

Dr. Daniels: So it sounds like then you feel this one is on track with what the Committee's intent was?

Ms. Singer: I think on -- I mean, for this call, since we're just looking at funding, I would say yes. I think the real question for this one is, is it what we needed? Is it more than what we needed? Is it useful? Do people use it?

Dr. Insel: Yeah, exactly. I think that's where I would go with this as well. I think the question now is, having built it, did they come? What's come out of it? And we may recommend that enough has been done here and this is not one to continue. Or maybe we need to.

But I think we need to really get a sense from others what the value of this has been.

Dr. Daniels: Great. Well, hopefully, we can get some input from some external participants on the next call to help fill in some of that gap of knowledge.

Good. Well, if you don't have any further comments for that one, we can move to 7.D on biobanks.

Dr. Kimbark: Susan, this is Donna. Can you just tell me once again what this color is? I mean, not on the red, yellow, and green.

Dr. Daniels: Right.

Dr. Kimbark: What the colors in the -- in the words mean?

Dr. Daniels: So the colors in the words indicate words that were added as the Strategic Plan changed over time. So you can see that with this objective, when it first started, it was a lot different than how it's ended up because the blue and the red show additions over the years.

Dr. Kimbark: Thank you.

[Pause]

Dr. Insel: Susan, on this one - oh, okay, I take it back. I understand now.

Ms. Singer: So I mean, I look at this one, and I say many of these were projects that were underway before the Strategic Plan. I think in terms of bio-banking and brain-banking, there's been a lot of forward motion in 2013 that we can point to. But --

Dr. Insel: Yeah, I think this is a generous yellow.

Ms. Singer: Yeah.

Dr. Insel: This is an area of enormous need, and you know, I think this is one of those places, unlike much of the Strategic Plan, you can say how many cells, how many brains --

Ms. Singer: Right.

Dr. Insel: -- what's actually there in the bank. And I think the reality is there may be fewer brains now than there were in 2009.

Ms. Singer: There are absolutely fewer, but we were talking about that on the Question 2 call that this is an area where we have -- we have negative growth. We have regression. We have fewer brains now than we did in 2009.

Dr. Insel: So that funds were invested. The number here is \$24 million, which is a little surprising. The recommended funding was \$82 million. So that's certainly well below what was recommended.

But I think what's really of concern is that there is no product, I mean, on the really critical issue here of creating a national neurobiobank. That has not happened at the scale

that anybody would have wanted in 2009.

So I guess, I mean, the question for me is, I suppose it should be yellow because something has been done, but I would want to make sure that our final assessment on Question 7 has some strong language about the need for much greater activity here. And as Alison says, a lot of that's happened in FY '13, which is not part of the -- of this assessment.

So the big national neurobiobanks from NIH were just announced in the past month, and there's similar effort from Simons and Autism Speaks. And so, there's a lot going on. But it's still really late in the game here. I mean, this is a place where there's enormous need.

Dr. Daniels: Well, great. That is exactly what we want the Planning Group to do because the indicators are only indicators, and we need more of this knowledge to try to understand fully what's going on in each of these objective areas.

Ms. Singer: And I think if you look at the projects, you know the funding for AGRE, that's not really getting at a lot of the specifics in this objective. I don't think they're collecting fibroblast. I don't think that they're doing --

they're accompanying -- that AGRE is doing anything with imaging.

So you know, I remember when we wrote this really to try to take advantage of new technologies and new advances and rapid throughput, and now we were able to -- we understood the genome, and that was going to revolutionize. So a lot of the projects in here preceded that, and I feel like some of them were put in this category simply because there's no other place to put the funding for AGRE. But it doesn't really get at what we intended when we wrote this objective.

Dr. Insel: So I have one other comment about this. And I think I'm on the same page as Alison here. But on -- from a separate perspective, there's been a very large investment, which I think is going to be transformative, that was made in 2010 and 2011 and I think still in 2012, which doesn't show up here, which was the BrainSpan Atlas, which fulfills part of what is asked for here, the third bullet, which is providing sort of a lifespan, Web-based digital brain atlas with high-resolution images and quantitative anatomical data, but it even includes molecular anatomical

data.

And that's already becoming a heavily used resource for the autism community. There's a paper that will be out in the next couple of weeks in *Cell* that uses that essentially to understand a lot of the current genetic findings.

So I wonder, even though it doesn't say autism, it was really set up through the Allen Brain Institute as a national resource for people who work on brain development. Should that be included as well?

Dr. Daniels: Yeah. So Tom, actually -- so I have some great news that I haven't shared with the Committee yet, but as of yesterday, we've received OMB clearance now to be able to collect data from more than nine external funders. So if the Committee wants us to collect data from the Allen Brain Institute, we will be able to do that in the future.

Dr. Insel: Except, so on this one, NIMH paid for it to the tune of I think it was about somewhere between \$20 million and \$30 million with Recovery Act dollars. And it's -- there's never been anything like it. It's really going to be, I think, an extraordinarily helpful picture of what



the human brain looks like through fetal and postnatal development.

And what's already stunning from that is that it doesn't look anything like the adult brain. I mean, not even like the same organ. So it's getting a huge amount of attention right now. Even though it's not published, it's available on the Web, and people are using it. And it's already showing up in some very high-profile papers.

So it does seem to me that it's relevant to this question. It doesn't include autism data. Well, it doesn't include autism tissue, but it will be the control samples for autism tissue. So it provides some of what is requested in the third bullet on 7.D.

Dr. Daniels: Right. I'm thinking, actually, the reason it probably wasn't captured is it's probably not in the RCDC category for autism for NIH. It's probably some general category for neuroscience or something because it covers a number of different areas.

Dr. Insel: Yeah, it's really a study of human brain development. But it seems to me in studying a neurodevelopmental disorder, the first digital atlas that captures the molecular development of

the brain would be important to know about or important to include.

Dr. Daniels: So we can -- we can try to get the funding figures for that, but I think we can't -- because it's not in the autism category for NIH, we can't probably put it in the official numbers here, but it's something we can note --

Dr. Insel: Okay.

Dr. Daniels: -- and provide for you.

Dr. Insel: Okay. And maybe it could go into the text when this is --

Dr. Daniels: Right.

Dr. Insel: -- in the form of a progress report. I think it is important for people to know what's not in these figures for one reason or another.

Dr. Daniels: Exactly. So we can do that in a text note.

Dr. Catherine Rice: Hi, everybody. This is Cathy Rice from CDC. I just wanted to let you know that I joined a little bit ago.

Dr. Daniels: Thanks, Cathy. Welcome.

Dr. Rice: Thank you.

[Pause]

Dr. Daniels: Does anyone else have comments on

7.D?

Dr. Kimbark: I have a comment. This is Donna. I just wonder if 7.D as an objective has grown too large and whether or not it needs to be teased into separate objectives or not. Maybe we're casting our net too wide there?

I mean, to go from something as simple as protocol and stem cells all the way up to brain tissue, I mean, I think that maybe there's a possibility that just because we're just lumping everything into brain tissue, bio-tissue, that that might be the wrong way to go about it, especially we're talking about bio-tissues. We're talking about RNA, expression profiling, MRIs. I mean, it's just the whole gamut, and maybe we need to subcategorize them?

[Pause]

Dr. Insel: Donna, this is Tom. I'm not sure I quite follow your suggestion. This particular bullet is really just about the infrastructure for that range of studies, and they all depend on having tissue.

Dr. Kimbark: Right. Right, and I mean, maybe we're not getting -- we're not explaining it as well to the outside community because, I mean,

what I see, I mean, I just had a meeting yesterday, and this kind of reminds me of that meeting, is that they were -- they formulated more or less a hub with spokes, essentially, to get all of the tissue and the information that they wanted on the disease they were looking at.

And I can see that this is very -- this can be very similar to that. But what I'm seeing is that a lot of the mishmash of asking for information, but nothing interconnected, if you can understand what I'm saying? And do we want it interconnected, or don't we want it interconnected?

I think we do, and I think that that's something that's not coming -- that's not coming out in this objective.

Dr. Insel: It may be the objective is not optimal, but we don't want to rewrite the Plan at this point. This is really just to figure out whether we've invested according to what is in the Plan for an objective.

Dr. Kimbark: Right. Right, I'm just bringing that up, food for thought.

Dr. Insel: Okay. And then I think in reference to, Alison, I think it was your comment about iPS cells and AGRE, we can go back and check. I

thought that AGRE might actually be collecting fibroblast, but I can't recall.

I know that the Rutgers repository has been doing that, and I think some of the -- they've been storing them. I think they're coming from the AGRE collection system, but that would be something we could find out before the next call.

I think it would also be useful, if we can do this as part of our accounting, is to actually provide in the report that we do, that three-page or four-page, whatever it is, that short progress report, a real concrete accounting of what's there. It's still not entirely clear how many fibroblasts been banked and how many brains have been banked and what tissue exists for anybody who's getting into this field. I think it would be useful to have a better accounting of that.

This is one of the few places in the Plan where you can actually get down to concrete numbers.

Ms. Singer: And I thought they were collecting fibroblast at Yale as well, and I didn't see that study in here.

Dr. Insel: Yeah, we should do a little more homework, I think, on this to figure it out.

Because I think that a lot of the projects that are in the genomics arena are now collecting cells. At this point, just banking the cells, but often that's going along with collecting the DNA.

Dr. Daniels: So it's possible if there's a project like that that you're not seeing here, it might be coded to some other part of the Strategic Plan.

Dr. Insel: Yeah, I wonder if maybe, Susan, maybe David Panchision at NIMH, he would know immediately what the collection of fibroblast is for autism and related disorders and who's doing it and how it's funded. So --

Dr. Daniels: Okay.

Dr. Insel: -- maybe we can -- I can't remember whether -- I guess he won't be in on the next -- on this call or the next call, but it would be good to get that information from him.

Dr. Daniels: Okay.

Dr. Insel: And I think what we ought to plan to do is really for the final report on this, come down to the final numbers and the best sense that we have of what actually exists currently for investigators as a national resource.

[Pause]

Dr. Daniels: Okay. Do we have any further comments on 7.D? If not, can we move to 7.E about the Web-based toolbox?

Ms. Singer: So 7.E, I think, is a little misleading here because where it says two projects, it's actually one project counted twice. If you click on them, it just says one is at Drexel and one says Drexel School of Public Health. But it's the same project.

And it's the same project across all of the years. It's basically the report of Craig Newschaffer's conference on communicating research results, which I get that it was put in here because it was about communicating and responsibly disseminating research findings, but it has really nothing to do with the development of a Web-based toolbox, which I think is what was primary about this particular objective. It was not so much that we should talk about the essence of communicating research, but that we should develop infrastructure.

Dr. Daniels: Alison, when you're seeing it listed twice, does the second one say "supplement" at the end?

Ms. Singer: No.

Dr. Daniels: Because it probably was, for whatever reason. That's just an administrative aspect. It probably was provided in two separate awards. I just wanted to clarify that I don't think that's an error in the data. I think that's what the data actually show.

Ms. Singer: Okay. You're right. One was \$305,000 from Autism Speaks, and one is \$25,000 from the NIH.

Dr. Daniels: Oh, okay. Alright, just wanted to clarify that for those who might be listening to the call.

Ms. Singer: But it's still really one project, and it's a project that I think doesn't speak to the objective of building infrastructure.

[Pause]

Dr. Daniels: So I think in that workshop, they did have a discussion of responsibly disseminating findings to the community, which is probably why it got coded here.

Ms. Singer: Yeah, absolutely. I mean, I was there, and it was a very robust discussion. It was a great conference. The paper is great. But it doesn't really -- this section is about -- Chapter 7 is about building infrastructure.



Dr. Daniels: Right.

Ms. Singer: And this objective is about developing a Web-based tool, and that topic did not really talk about building a Web-based tool. So you know, to me, there's been zero here, and it should be red.

Dr. Daniels: And so, that's why it's important for you all to be doing this analysis to try to understand in finer detail.

Ms. Singer: The other side of that coin is do we still need a Web-based tool? Are scientists getting along without it? Have other infrastructure needs come along, like other Web sites and other platforms like the, you know, SFARI Web site does a great job, honestly, at disseminating research.

So, but I think that's a conversation for the next -- the next call.

Dr. Daniels: Any other comments on this one?

Dr. Insel: I'm not sure -- Alison, I'm not sure I would make it red. I get the point that we don't have a Web-based toolbox. But it does feel like something has been done on this, short of that, in terms of the responsible dissemination of findings.

And I'd also wonder if the SFARI effort could be included here as well. I gather, Susan, they didn't cite that when they reported their portfolio?

Dr. Daniels: I'm guessing that -- I mean, SFARI gave us a lot of data, but it probably got coded to something else.

Dr. Insel: Yeah.

Dr. Daniels: There is a lot of overlap between these objectives, and so sometimes when people are making that judgment call, they end up in one objective or the other because we don't do double counting.

Dr. Insel: Got it. Well, so could -- would you be comfortable with turning this to a yellow with comments that would flag for us the need to comment on it, I think? And I think, along with what Alison was saying, the really important question is, is this worth even doing at this point, or this was a 2009 objective, apparently. So maybe in 2014, it's no longer something that's a high priority.

Ms. Singer: And I think we could add that the goal of helping researchers disseminate findings has been -- we've definitely moved forward with

that. I mean, we have a person who works with the researchers to write blog posts and disseminate findings, and SFARI spent a lot of money on its Web-site.

They're not site based. So I mean, we did it for that data or that amount of spending, but we definitely do that. It's just I think we should say that we've accomplished the goal of this objective, but not necessarily by building the Web-based toolbox, through other means.

Dr. Daniels: Mm-hmm.

Dr. Rice: And I wonder -- this is Cathy -- if mentioning some of the other efforts that it is Web based and it's more being able to access the data in a way that's digestible. Like there is the [childhealthdata.org](http://childhealthdata.org) Web-site that HRSA supports that pulls data together on child and adolescent health and includes information from national surveys on autism.

That is a format to disseminate that in a much more digestible way as another example of progress in this area, not necessarily guidance for the researchers, but for those that are using National Health Survey data certainly provides a nice outlet.

Ms. Singer: And I think when you look over the 5 years, there is a lot more research available on the Web for the community, for people with ASD, their families, and health practitioners. It's not in a Web-based toolbox, but we've moved forward with it.

Dr. Insel: Why don't we go on -- I'm not sure this is worth spending a lot more time on. Let's flag it as something that we want to talk about in the final summary.

Dr. Daniels: Good. So then we can move to 7.F. That one --

Ms. Singer: 7.F and 7.G, I think from the standpoint of evaluating the funding is pretty clear. So I think that these moved forward to, do we still need these objectives, or what is the reason why there has been no funding towards these objectives?

[Pause]

Dr. Daniels: For 7.F, in terms of creating funding mechanisms, it would be rare for a grant to be able to create a funding mechanism. So I would think that the portfolio analysis is never likely to capture this because funding mechanisms are created other ways than through an actual

grant award.

Ms. Singer: I think the idea here when we talked about it was that there would be a specific RFA for replication. So the question was, has there been that RFA, or has there not?

Dr. Insel: So this is a very important issue at the NIH. It's the source of intense discussion right now. There are some replication RFAs that have been launched in a couple of areas. I think there's one for ALS and a couple of others. There has not been one for autism.

There is always this tension about how much money do you want to spend on replication studies when there's still not -- it's not clear that we have a big hit in any initial findings and so, one could argue that this is just premature. We're not ready to create something like a replication RFA.

I'd point out that at least the reason this got started is that something like two-thirds of the studies that people have tried to replicate in industry that are coming out of academic labs related to preclinical studies of cancer could not be replicated. And it was that finding and a couple of similar findings that have led to this intense discussion and trying to figure out a

mechanism by which replication studies could be done, either through an RFA or through a contract or potentially through a small business that would do this but has not been done for autism.

So I'm not sure there's much to talk about here, except to say it's a red, right? Susan, you want to move us on here, and we can -- because I got a couple of red.

[Pause]

Dr. Daniels: Yes. So are you done with both of these, 7.F and 7.G, or would you like to discuss 7.G?

Dr. Insel: I think the only issue is if somebody knows of something that's either being done or has been done; absent that, I don't think there's anything to discuss.

Dr. Daniels: Cathy, I know that 7.G kind of came up through some of CDC's recommendations. Is CDC doing anything related to developing this Web-based tool at this time?

Dr. Rice: Well, there are two things. The Environmental Public Health Tracking Network -- that's mainly how we've been doing that. They provide a Web-based search tool for a range of prevalence issues, and we've added our autism data

to that.

Dr. Daniels: Okay.

Dr. Rice: So that, I think, in some ways is finished, unless we're talking about something --

Dr. Daniels: No. That was, I think, the impetus for this. But if you're doing it through that kind of mechanism, that's something also that would not be captured in the portfolio analysis. So we might need to have some text for whatever document we're preparing to explain that.

Dr. Rice: Okay.

Dr. Daniels: Great. So then that one, you know, in terms of the Committee's evaluation could be turned kind of green, I guess, even though we -- we aren't assigning specific funding. It sounds like that that's been done. It's just been done in a different way through a different portfolio other than an autism-specific portfolio.

Dr. Rice: Yeah. We also need a link for that --

Dr. Daniels: Great. Excellent, alright, 7.H? How are you all feeling about this -- "Creating mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects to the NDAR database and

linking NDAR with other existing data resources by 2012."

Ms. Singer: So I think the initial projects here were to merge existing databases like AGRE and other databases into IAN, and those required funding. And I think now -- I know our grants -- the contract requires them to contribute data to NDAR using the funding. So there's not supplemental funding for that. It's now part of the overall grant.

So I think it's happening. I'm just not sure it's being captured here.

[Pause]

Dr. Daniels: Tom, do you have any specific comments about NDAR and how they're doing on this?

Dr. Insel: I think we need to get the data from them. I don't know whether it's 90 percent or 60 percent. We should just find out --

Dr. Daniels: Okay.

Dr. Insel: -- and make sure we have that for the next call.

Dr. Daniels: Okay.

Dr. Insel: But in terms of the investments, they've been made. I would support the idea that this is one that's probably largely been done. The



recommendation was \$6.8 million and looks like over \$9.5 million has been spent. And there are several projects that have done pretty much what was requested here.

Dr. Daniels: Good. Well, we can get some information from NDAR to try to fill in the --

Dr. Insel: Yeah. Again, I think we want to get a number. So if it's not 90 percent, you know, what's the gap, and how has it changed since 2008 or '09, whatever it is? So it'd be good to have some of the numbers.

Dr. Daniels: Okay.

Dr. Insel: All we can do today really, and I think all we want to accomplish on this call, is to look at the dollars.

Dr. Daniels: Right.

Dr. Insel: That is a very -- you know, that's necessary, but it's not sufficient to know what's really been done.

Dr. Daniels: Right. Great, now we're going to move to 7.I. Now we're on the second page of the cumulative funding table - "supplementing the existing ADDM Network sites to use population-based surveillance data." So that is Cathy's territory.

[Pause]

Dr. Rice: Yeah, and others may have more, more -- you know, more comments on this. What this doesn't reflect are the specific analyses that are being done within each of these grants. So this certainly covers the umbrella that is supporting some of those analyses, but there are -- there is a range of papers and analyses and projects that would be more in this hypothesis-driven field.

Dr. Daniels: So you mean that there should be -- there are more projects than what's reflected here that are actually doing this?

Dr. Rice: Well, they're part of these projects. So they are just analyses that are ongoing, using the ADDM data. So, but they're not, it's, you know, just like with any grant, we don't list every single analysis or paper that people are working on. You know, we list the overall umbrella mechanism.

But there are at least five analyses going on, and many more than that, actually, that would -- that would fit here. So I think it's really up to the Group if this is still a priority. I think it's a nice -- you know, ADDM Network, as it continues to have more data over here, there are

more opportunities for one replication earlier.

We're seeing if earlier findings can be replicated or new analyses as well, with an eye toward linking to other data whenever possible.

Dr. Insel: Cathy, this is Tom. Just not -- I mean, it seems to me that the conspicuous issue on this one is that the original recommendation was for \$650,000 over 2 years, and it looks like \$23 million has been spent over 4. So when it comes to describing this in the text, in the report that will go with this, how best to -- to explain that?

Dr. Rice: Yeah, I think that's a good distinction. Because I think when this was originally written, the point was to supplement the sites above and beyond to do even more analyses than they are able to do with their base funding, which is what's listed here.

Dr. Insel: Ah, so what we're seeing isn't the supplement? It's the actual base funding.

Dr. Rice: Yeah, that's the actual base funding.

Dr. Insel: Ah, okay. Was there -- were there supplements provided to those sites?

Dr. Rice: The only one that is a supplement is the Medical University of South Carolina that

Autism Speaks has provided the supplemental funding to do two studies, a screening study and another study comparing *DSM-IV* and *DSM-5* criteria.

Dr. Insel: So I guess I would wonder whether it's appropriate to list all of the funding if -- because what you've done -- what we've done here is to list the whole network rather than just the supplement for this purpose.

Dr. Daniels: Right, but it --

Dr. Insel: To me, it ought to be focused on what was in the plan originally under Question 7.

Dr. Daniels: Well, the issue may be that if CDC doesn't break that out in separate awards, because the methodology that we use in this process doesn't include any proration for the most part.

The only exception we've ever made to that was the LEND Program because of that problem that was pointed out by the Committee that if you included the entire LEND, it really threw off the numbers. And so, we did allow proration there, but in general, the methodology for this report doesn't prorate anything. We just include the entire project if it's relevant.

Dr. Insel: So Susan, has the ADDM Network been

listed anywhere else?

Dr. Daniels: No. So this would be where it is.

Dr. Insel: So this is the only accounting of it?

Dr. Daniels: Right.

Dr. Insel: Ooh, okay.

Dr. Rice: Unless it goes -- it could go under L.

Dr. Insel: Yeah.

Dr. Rice: Yeah, but then that is actually -- so L is done in a way that is much more along the lines of what you're saying, Tom, is the funding here is above and beyond the base, and that is for specific studies to expand to younger ages. And so, yeah, that is the challenge of where to put it otherwise.

Dr. Daniels: Yeah, this is one of those -- those issues with the overall way the objectives are designed and so forth. As we worked with CDC on determining where these things fall, that was really the best fit in the Plan, but the Plan really only covers gaps. It doesn't cover the mainstream areas as well. So -- because that all ends up falling into "Other."

Dr. Insel: I see.

Dr. Daniels: So that's why the main ADDM ended up in one of these objectives.

Dr. Insel: Then the other thing --

Ms. Singer: That's why I think we have to change the name from "Other," because "Other" implies, in my mind, less important or ancillary. And it's -- that's not what this is. It's not that in Chapter 2, and it's not that here.

Dr. Daniels: Right. And if the Committee can help us come up with another name, we'll be happy to change it.

Ms. Singer: I will think about that.

Dr. Daniels: Yeah, give it some thought and bring it up at a future meeting. We still have time for the 2011 and 2012 report. It hasn't been published yet, so we can change the name if the Committee recommends something.

Dr. Insel: And that might be helpful. And then under -- but just to go back to 7.I, where we're stuck here, is there a way to define how much is being spent on the South Carolina supplement? So even if it's just for our internal use, would that be helpful to know?

Because that does sound like it addresses specifically what's requested in this objective.

Dr. Rice: Yeah, and that's the \$275,000. But I'm looking here. I'm seeing --

Dr. Insel: Oh, yeah. I see it under Autism Speaks. This is the Lydia King, Medical University of South Carolina. Okay, so it's in here.

Dr. Rice: Yeah, and so the base funding for MUSC is the first one listed.

Dr. Insel: Got it. Okay. Ah, alright, so Susan, your guidance here: What's the right thing to do? You --

Dr. Daniels: It sounds like, from what Cathy has said that CDC has basically achieved what the Committee initially intended. Now the Committee has to decide do you need to continue doing this, or are you fine with what's already been funded, and where do you want it to go next? But it does sound like the initial goals have been achieved.

Dr. Insel: Well, so you -- just so we're on the same page: A goal of having a population-based surveillance project was achieved through South Carolina. Is that -- is that the idea?

Dr. Daniels: And that Cathy mentioned there are other hypothesis-driven analyses that might not be easily broken out from these base projects.

Dr. Insel: I see. Okay.

Dr. Daniels: But you said, there were more than five --

Dr. Rice: And I think this was written at a time when the ADDM sites were, you know, just having the data and the basic prevalence was really all they could do with the funding. And since that time, as they've really gotten going, they, as part of their base funding, have been doing a variety of analyses and trying to look at trends.

And so the initial idea was that they didn't really have the resources to do a lot of additional analyses early on, but that that's really become more standard as we've gone on. So it probably needs some sort of tweaking for the future to really reflect where do we want to emphasize the future use of these data, not only maintaining so the trends can be looked at, but what is there -- are there additional supplements that are needed to look deeper?

So for instance, with the South Carolina site, what's different about that project is that it's actually funding them additional to collect screening data within their catchment area so they can compare whom are they identifying by records



and who might they be missing in the community by doing an actual screening study in a subset.

So, but that's only occurring in part of the South Carolina site, and that's only one ADDM site. So in the future, doing supplemental screening as a way of looking at completeness trends over time, being able to really see what we're getting in terms of the records base versus the population, you know, that's a methodology that could be expanded.

So I think it goes back to the -- you know, in the -- in our comments, since we're not really changing the objectives at this point, but saying that, you know, we may need to think more targeted about what are the crucial questions that we really have about surveillance now. It's not just about having those data and doing some basic analyses of trends over time in terms of certain subgroups, but it's about further evaluation to make sure that, you know, we are being as complete as possible.

And I think some of that may be reflected later on in the -- is it the L objective? -- yeah, that looks at different ages, you know, expanding to adults. You know, those are still objectives

that have not been met, and you know is that the direction? And so, maybe this particular one is not needed, and more focus on the L objective may be more appropriate.

Dr. Insel: Susan, I have a question for you. Is there a way -- I'm just very concerned about the optics of this because it looks like we're spending something like, what is that, 50 times more than requested -- or than recommended. Is there a way to put an asterisk here to just explain the discrepancy so that other people aren't as confused as I was in looking at this?

Dr. Daniels: Absolutely. We can -- we can put that in a text note. At this point, since the data are collected and we've already locked the data for the first 3 years, I wouldn't recommend suddenly changing to a proration.

Dr. Insel: No. I'm not suggesting we change it. I just think in this table --

Dr. Daniels: Yeah.

Dr. Insel: -- I think anybody who sifts through these numbers is going to say "what?"

Dr. Daniels: Right.

Dr. Insel: And it's simply the way that we've been reporting it. So if you could -- if there's a

way -- you just put in the same line, you know, NB. This is -- these numbers reflect the entire ADDM Network, which includes a supplement to MUSC for \$225,000 to do exactly what's recommended. Something like that.

Dr. Daniels: Yeah.

Dr. Insel: Then it would -- you know, I think it would leave people a little more certain about what this means.

Dr. Daniels: Right. That's definitely something that we can do.

Dr. Insel: Okay. Why don't we go on, because we're going to run out of time here.

Dr. Rice: Just one point about that, that the budget under 7.L actually is much more reflective of the full network so we have the opposite problem there, where it looks like we're --

Dr. Insel: Exactly. I know. It's just too bad that, you know, we're caught between the two objectives that don't really match with what you want -- the way you want to report this. I don't know how we'll fix that, but maybe we could do something similar there.

Why don't we go to 7.J? So we'll get there soon enough.

Dr. Daniels: Yes. So let's move on to 7.J. How do you all feel about this one?

[Pause]

For those who are on the phone: "Develop the personnel and technical infrastructure to assist States, territories, and other countries that request assistance describing and investigating potential changes to the prevalence of ASD and other developmental disabilities by 2013."

So I think CDC was pretty instrumental in helping develop this objective. So Cathy, you might have a feel for this?

Dr. Rice: Yeah, I think overall -- besides the projects listed -- we're in a very similar state as far as CDC providing technical assistance and that we do as requested, but we don't have a strike team, if you want to say, that can -- that can go out and really dive deep for a long time.

But there are projects that we don't have -- there's not funding reflected for -- but that we are constantly consulting and talking with people that ask us for this information.

So I'm not sure what else to list here except for the potential role of the Autism Speaks Global Public Health Initiative and that there are

multiple projects along these lines that they are funding that don't seem to be reflected here -- studies of prevalence in Taiwan, Thailand, India, a variety of places -- so I'm not sure why that may not have been listed here.

Dr. Daniels: I'll look into that. I don't know if that was in what Autism Speaks submitted to us. It might be, and it might have been coded elsewhere, but we'll check.

Dr. Rice: Okay.

Dr. Insel: And Cathy, I'd be curious. How -- given the way this is worded -- how many requests have you received along these lines?

Dr. Rice: So I can think of -- I personally have shifted. So I don't answer the phone for various particular requests in the last year. But we certainly get a handful a year.

Dr. Insel: So it's a continuing need?

Dr. Rice: Yeah. It is definitely a continuing need. And I think -- and within the United States. I mean, I'm thinking internationally there, but even within the United States, you know, we get regular inquiries about how would I determine prevalence in my State or my area? And we try to provide information and help them think through

what they're trying to do and technical assistance, but it doesn't really come with any funding.

So it is -- it is definitely still a need.

Dr. Insel: And in terms of the investment that we've made, to you, that looks about right from the way it's described here in terms of the number of projects and the number of dollars?

Dr. Rice: Yeah, I think the main would be what else Autism Speaks would contribute. But I think that in terms of having a -- you know, the intent of the -- of the objective was really to have a more supportive infrastructure in place versus sort of ad hoc give what we can give. So I don't think this has been achieved. I think there's been progress, but not achieved.

Dr. Insel: Okay.

Dr. Daniels: Good, so then how about 7.K: "Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary training, and recruit early-career scientists into the ASD field by 2013."

Dr. Kimbark: As I recall from the -- from the discussions last year? One of the things that we were especially worried about for this one was

that, after the upsurge of funding with the Recovery Act that this would actually decrease in the future.

So I'm not sure we want to just abandon this, even though it's in the green, because in the future, we might see a really large downtick in this because of lack of funding.

[Pause]

Dr. Insel: I have a question about the specific grants that are mentioned here. So the objective had to do with the research workforce and research training and early-career scientists, but -- and not knowing a lot of the details about it beyond the title -- some of these are recruiting and preparing highly qualified special educators, preparation of leaders across the lifespan for autism.

Let's see, leadership training in high-need students with severe disabilities and autism. Are we convinced that these are actually training scientists, or are they training service providers?

Ms. Singer: I think that's a good point. On the other side of the coin, though, when we do predocs and postdocs, and I'm not sure how Autism

Speaks does this, we have been coding them to their subject area. So you know, if they're doing a tissue study, we would put it in Section 2, Chapter 2.

But you could argue that pre- and postdoc fellowships are really designed to promote workforce enhancement.

Dr. Daniels: Right.

Ms. Singer: So that might be an underreporting.

Dr. Daniels: Yes, that's absolutely true, Alison. That's -- in many cases, some of the training opportunities have been put in their scientific category rather than in this, where this tends to capture more directly named training programs. Or in some cases, conferences where they're going to have a special emphasis on recruiting new people into the field or helping train young scientists.

Dr. Insel: So I think that would be worth also noting here that this isn't inclusive because in sorting what you're describing like through your fellowship program, Alison, is exactly what is being recommended here, right? It's early - early-career scientists in the ASD field.



And it's -- that's what you've been doing. And I'm not saying we should make a change in this, but again, I think someone should note that -- that there are other programs that have -- that are not showing up in this listing because they've been listed under the topic area.

Ms. Singer: But we should be able to actually get a number. I mean, I think we can give our number, and Autism Speaks knows its Weatherstone [Predoctoral Fellowship Program] number. So we could say this much could go in this category but is allocated elsewhere in the Plan.

Dr. Insel: Yeah, we just can't double-count.

Ms. Singer: No, not to double-count. Right.

Dr. Insel: But I mean it could be shown as parenthetically. But I'm still -- still back to the first question about whether we're confident that all of these grants that are listed, all these projects, are really focused on scientists or whether some of them are for providers.

Dr. Daniels: So this is the only training objective in the Strategic Plan, and so it may be that any kind of a training emphasis -- well, I shouldn't say that, because in Question 5, there is something about provider training.

But the agencies and organizations that submitted as they read through these objectives felt that these projects sit here. So we would need to -- you would need to look at the abstracts to see what you thought about that. But that's what the agencies determined as they looked at it.

[Pause]

Something like leaders across the lifespan for autism -- that could include scientists as well as what do call them?

Dr. Insel: Providers.

Dr. Daniels: Providers.

Dr. Insel: Yeah, it could. I just -- it's not -- the ones from the Department of Education -- it's not evident to me that they're -- what they're suggesting here matches at all what the spirit of the objective was. So Susan, how best to deal with this? I mean, are you suggesting we should just drill into the abstracts and figure out whose system --

Dr. Daniels: I think you can, Tom. I think that you can look into that further. I don't know that I would -- I know that 2011 and 2012 aren't locked, but I wouldn't necessarily recommend recoding or asking those agencies to consider

recoding.

But you might want to just take note of what the span is here or what's included in these.

Dr. Insel: Yeah. I have to say that it makes me really uncomfortable, just from the titles, to include it here. And maybe if we don't want to recode it or redo it, then the other way would be if we can capture actually how much is going into provider training and just, again, specify that somewhere in the table so that we're not misleading anybody.

Still, you know, I think there's no question that this would end up in the green zone because there was the recommended budget of \$5 million, and you can take out all the Department of Education programs, and you're still in excess, I think, of \$20 million. So it doesn't change the way we -- we rank this.

But I think we need it -- I need to feel a little bit better about the rigor of what's in here because so many of these don't look like they have anything to do with science.

Dr. Daniels: We can take a more careful look at that and go through the abstracts and --

Dr. Insel: Okay.

Dr. Daniels: -- give you some more information. But we'll have our --

Dr. Insel: Okay. That would be good. I think at the end of the day, you're still going to be well beyond what was recommended by the IACC. So it doesn't really affect the outcome, and that way I just want to make sure the numbers that we're putting out here are ones that we can feel confident in.

Dr. Daniels: Okay. Well, we'll have a look at that more carefully.

Dr. Insel: I think we should go on to 7.L. So 7.L is the next ADDM one, right? That's the -- so Cathy, this is back in your -- in your turf.

Dr. Rice: Yeah, and I think this one looks like -- the projects listed look like what is meant there. The projects, though, are more about -- they're all about expanding to younger ages than older ages. And the MUSC project, so I guess that's a question of the one we were talking about before, actually reflects this direct screening piece.

So it could reasonably be put here, though whether it goes there doesn't matter either way. So I think that there has been some achievement

here, but the adult piece is still unachieved.

[Pause]

Dr. Insel: So you'll be able to help us with that when it comes time to put the text together to explain the part that hasn't been done?

Dr. Rice: Sure.

Dr. Insel: Okay.

Dr. Daniels: Good. So 7.M, the promising practices papers. I think this one is really clear, that we didn't find that there's any evidence that more promising practices papers have been published since the development of the objectives.

And this objective was sort of developed by CMS, and CMS is the agency that publishes these papers. So it -- it appears that they did publish an early group of these papers, and that was -- I think, the idea behind this objective was maybe continuing that process. But it looks like that hasn't really continued.

Dr. Insel: What are those? Are they -- these are -- when they call them "promising practices papers," are they published in a journal, or are they published on their own Web-site or --

Dr. Daniels: I think they're published on

CMS's Web site. I don't know if they're published in a peer-reviewed journal, but I do know they're on the CMS Web-site. And what they did is they -- I think they looked at promising practices taken from the States, like examples of best practices -

Dr. Insel: Oh, okay.

Dr. Daniels: -- and wrote them up, basically, to be examples to other States of how to best provide services for individuals with autism and developmental disabilities.

Dr. Insel: So is that something they actually fund? Do they put out money for those, or do they do them internally? I ask because it's possible that they've done it, but it wouldn't show up as any dollars.

Dr. Daniels: They -- I think they may have used internal-type funding. But having seen this objective, I would have thought they might have let us know if they were doing --

Dr. Insel: Maybe if you're going to call John about that other question, we can put this on the list as well. So, so with the state of the States, we can find out if they've done anything about that.

Dr. Daniels: Okay. Sure. We can ask him.

Dr. Insel: I mean, the ideal thing, right, would be if we didn't have to spend any money, but we could fulfill the objective completely because people had just done it.

Dr. Daniels: Right.

Dr. Insel: That would be the most efficient use of funds that we could have.

[Laughter]

Dr. Insel: So it would be helpful to know.

Dr. Daniels: Right. And the other thing I'm wondering is with those promising practices papers, that was a while ago, and now they have some of these bigger projects, like the state of the States that are going on, and I think they may be pulling out some best practices. So maybe they don't feel the need for these papers anymore. I don't know. I'll ask John. He can explain.

Dr. Insel: Okay.

Ms. Singer: We can also ask Ellen Blackwell. I always think of this as the Ellen Blackwell objective. She is very involved in writing these promising practices. So maybe she has more information for us.

Dr. Daniels: Sure. We can be in touch with

her. [Pause]

So 7.N?

[Pause]

This is the objective about "enhancing networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological, medical, and treatment history data that would provide a platform for conducting comparative effectiveness research in clinical trials of novel autism treatments by 2012."

Dr. Insel: So this is the ATN?

Dr. Daniels: Yeah, the ATN.

Ms. Singer: This is the ATN objective.

[Pause]

Dr. Insel: And this is another example where the recommended budget was \$1.8 million, and the spend has been \$19 million.

[Pause]

I don't know. Is there any question whether this should be marked as green or not, or I'm not sure what we were thinking 4 years ago when we said this was the 1-year objective. But that's the way it was spelled out.



[Pause]

Maybe we should just go on, unless there is any question?

Dr. Daniels: So, so then you all feel that that one is pretty much completed at this point?

Ms. Singer: I think this is more a question for the value call next time where we talk about have people actually gained value through the ATN --

Dr. Daniels: Okay, great.

Ms. Singer: -- have researchers found value in the ATN? You know, who has it been good for?

Dr. Daniels: Great. That's good. So we can do that on the future call. So, 7.0: "Create an information resource for ASD researchers, the PhenX Project, to share information to facilitate data sharing and standardization of methods across projects by 2013." What do you all feel is the state of this?

[Pause]

Dr. Kimbark: I think I'd like to hear a little bit more about the value here, like we talked about for some other ones, and I'd also like to hear what the experts have to say and that whether or not this is -- what we have is worthwhile or

not.

Dr. Insel: Yeah, I agree. I'd like to know from -- like from the NDAR people -- whether they have actually fashioned common data elements, which is kind of what this is about.

And again, that's maybe not so much a money question as -- as whether the work has gotten done, whether there's still a need for that or whether the field has come together even without making a big investment. I don't have a sense here about whether what's being asked for has been done or not.

So, and the only -- the only -- the only investment that shows up here is the ATN registry from HRSA, and I don't think that, as far as I know, I don't think HRSA has developed, for instance, a common data element infrastructure or a data integration plan. So --

Dr. Rice: Yeah, this definitely seems more NDAR associated.

Dr. Insel: Yeah. So maybe when we have the next call, we can get a little more information about this.

Dr. Daniels: Okay. Hopefully, we can -- we'll have some participants from the external community

who can help us with that, or we could get some more information.

So the last regular objective is the 7.P:  
"Provide resources to centers and facilities that develop promising vertebrate and invertebrate model systems and make these models more easily available or expand the utility of current model systems and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013." What do you think is happening here?

Dr. Insel: I think it's all been done, but not through -- it has nothing to do with autism. At least for public funding, model animals, when they're created, go into the -- go into the JAX sharing system, and for invertebrates, the flies are almost universally shared. So I'm not sure this is really -- maybe this seemed like it was a greater need 3 years ago.

I'm not convinced that there's anything unique to autism here or that there is a specific need that needs to be funded for autism separate from what's done in every other area of medicine.

[Pause]

The one project that's described in 2010, I

don't have that here, but --

Dr. Daniels: It would be available through the link.

Dr. Insel: Yeah, I have to bring that up. I'm just looking at a printed-out copy. But I would really wonder whether this is still a need, and again, that might be a question to put to our experts. I'd be curious whether there are -- there's a particular transgenic mouse that nobody feels they can get their hands on.

Because we used to hear that a lot, 6, 7 years ago, but it's -- everybody who's funded with public dollars these days, I believe, is required to share.

Dr. Daniels: So I brought up that project. The project is an NIH-funded project to James Pickel, and it looks like it's an intramural project.

Dr. Insel: Yeah, he runs the transgenic core in the intramural program.

Dr. Daniels: Yeah. So that's it -- transgenic animal models for neuroscience research.

Dr. Insel: Right. But --

Dr. Daniels: That's the project.

Dr. Insel: -- again, I don't -- I think that was involved -- he was making mice for Jackie

Crawley.

Dr. Daniels: Oh, okay.

Dr. Insel: So that's how that was relevant. She left in 2012, so it makes sense that that would come off the budget. But I just really wonder if there's a need -- a continuing need for this particular objective. It would be good to ask our experts. Hopefully, we'll have somebody who's using model systems, and we can find out.

Dr. Daniels: Good. So then the last item we have is "7.Other," and I don't know if you have any thoughts about that? That would be the grab bag of all the other things that were not in gap areas that were just kind of in the mainstream of funding for resources and surveillance-type activities.

Dr. Insel: Yeah. You know, here, Susan, I think I'm with Alison. "Other" makes it sound like it's kind of unimportant or it's the leftovers, but there's a lot of really key stuff here.

Dr. Daniels: Yeah. I really think that this would be a great idea if the Committee comes up with another way for us to describe that, and we'll be happy to add that in.

Ms. Singer: I'll try to come up with another

word for "Other."

[Laughter]

Dr. Insel: Maybe "nonspecific"? Ah, that's kind of dismissive. I don't know.

Ms. Singer: Or "ongoing" or, you know, something that captures --

Dr. Insel: Yeah.

Ms. Singer: Where we could actually put the ADDM spend that's not the supplement. I mean, that's really where it should go.

Dr. Insel: Right.

Ms. Singer: The objectives are focused on gaps. They weren't focused on the total overall spend. So let me -- let me think about that.

Dr. Daniels: Okay. Good. So you see here that there are a lot of administrative and other cores that are research resources in this list.

Dr. Insel: Maybe that's the way to describe it, as "research resources"?

Dr. Daniels: Yeah, we could do that. We could -- maybe we could have a different name for every particular question because I'm sure that it might be hard to come up with an umbrella term that if you did want to come up with one for this, research resources might capture a lot of it.

Dr. Insel: It's the single biggest -- in terms of dollars -- it's the single biggest objective and in terms of projects. So it would make sense, I think, to make it sound like something other than the leftovers.

Ms. Singer: What about, I mean, the ACE review is core? What about "research core," "core spending," or something like that?

Dr. Daniels: Sure, whatever -- I guess you all can come up with some things, and maybe we can --

Ms. Singer: Yeah.

Dr. Daniels: I wonder if maybe on the 29th, when we get everyone together in the same room, we could come up with an idea for a name.

Ms. Singer: Okay.

Dr. Daniels: Yeah, we could call it something like "core funding" or something like that. So then you've successfully gotten through all of your objectives and gotten a, you know, temperature on each of these. So the next action item is to decide who might be able to help draft a one- to five-page summary of what your feel was for the health and status of each of these objectives.

We will have some minutes that we can share

with you, but they will be more of a capturing some of the comments that were made, and this document will be more just sharing the Committee's viewpoint on the status of this question and objective -- and the list of objectives.

Dr. Insel: Sue, you were looking for volunteers?

Dr. Daniels: Yes, so I'm looking for volunteers.

Ms. Singer: I will do it.

Dr. Daniels: Thanks. I know Tom volunteered to do Question 4. So he already has that on his plate.

Dr. Insel: I can send you my Question 4 when I get it done, Alison, if you want to use that as a model?

Ms. Singer: That would be great. Yes, thank you.

Dr. Insel: It's going to be really short. So it will be --

Ms. Singer: Perfect. I love it.

Dr. Insel: -- less than one page. Maybe less than half a page.

[Laughter]

Ms. Singer: Excellent. I'm right behind you.



Dr. Insel: Okay.

Dr. Daniels: That's great. So then we can get that together. We'll share the minutes with you as soon as possible.

And if you can put together a summary of what your findings are here, and we've heard a number of items that you wanted some more information on, and so we'll have someone from our Office try to get some of that information together. And if I get it together and can share it by email, we'll just send it to you by email so you have that information as you develop your draft.

We're going to be working with the subcommittee chairs on getting your experts and external participants together, and then we're going to be setting up the next call for some time in mid-October. So you'll be hearing from me about setting up that call and, hopefully, getting more information about the October 29th workshop.

Dr. Kimbark: Susan?

Dr. Daniels: Yes?

Dr. Kimbark: This is Donna. This is probably a good time for me to chime in and tell the group that I probably won't be participating as much because my family is undergoing -- right now,

we're suffering a major medical crisis in that we will -- I'll probably have to deal with surgeries and follow-up treatments, and I'm not sure how much I'll be able to participate at this point.

So I apologize, but there's really nothing I can do. I have to shift gears a little bit and follow-up in that regard. I apologize.

Dr. Daniels: Well --

Dr. Insel: Donna, this is Tom. No apology necessary. I'm so sorry to hear that, and keep us posted.

Dr. Kimbark: Thank you.

Dr. Daniels: Yes, and I'm sure we have enough hands here to probably get done what we need to do, and plus, we're going to bring in some external folks who can at least weigh in, although probably the IACC members will do the bulk of the actual writing and so forth. But I think we have enough people. We should be able to carry that all through.

So unless there are any other questions, I think that we're finished with our work here. Does anyone have any comments or last thoughts?

Dr. Rice: Just thank you, Susan, to you and your team for always doing such an amazing job

pulling this all together. Thank you.

Dr. Daniels: Thank you.

Dr. Insel: Susan, you think you might want to do this for a few other disease areas because this is really spectacular.

[Laughter]

Dr. Daniels: Autism is keeping us pretty busy. So I don't know if we have time to take on more diseases at this point, but we'll let you know.

Dr. Insel: I can tell you there's nothing comparable to this for anything else that I know of at NIH. It's a really, really comprehensive accounting of funding.

Ms. Singer: It really is. It would be great, Susan, if you guys could put this together into a booklet and just send it to Congress. It's remarkable. It's an amazing amount of work. It's really well presented, very interesting.

Dr. Insel: It is.

Dr. Daniels: So that booklet will come into being, hopefully, by the end of the calendar year, called the Portfolio Analysis Report, and we will be -- we don't have an official mandate to send it to Congress, but we do try to make Congress aware of it.

And so we will try to make sure that they and the rest of the public have access, also have the database, the Web tool to access the data directly.

Ms. Singer: It really speaks to the hearings that were held last year where I think it was the Government Oversight Committee members were saying has anything been done? Is anyone in the Government doing anything about autism research?

And here you've got it all laid out in a very user-friendly manner. So it would be very useful, I think, to have it.

Dr. Insel: Yeah. You know the other thing I thought -- I found this fascinating to go through, and I've been now going through several of the questions. What's really striking is the growth in private funding as well and the way in which this right now, compared to a decade ago, is very much a public-private effort. And I think people should see that, and that's actually not so true in many other areas that we deal with at NIMH.

This tells a really interesting story, and I mean it when I say I don't think that there's anything quite comparable for Alzheimer's or for Parkinson's or for most of the other areas that

we're concerned with. So thank you -- great job.

Dr. Daniels: Thank you. So, well, we appreciate all of the efforts of all the participating funders who make this possible and are willing to share their data openly and work with us in this very tedious process that takes us almost a year to put together each year's analysis, and we appreciate all the input from the Committee that makes the analysis better each year.

So thanks so much for joining us and for -- for the hard work you've done on this call, and we'll be in touch with further information in the coming weeks. Thanks, everyone.

Dr. Insel: Thank you. Bye. Have a good weekend.

Dr. Daniels: You, too.

(Whereupon, the conference call of the Strategic Plan Question 7 Planning Group was adjourned.)