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INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR
SERVICES RESEARCH AND POLICY

QUESTIONS 5 AND 6 PLANNING GROUP

CONFERENCE CALL

MONDAY, SEPTEMBER 30, 2013

The Strategic Plan Questions 5 and 6 Planning Group convened via conference call at 10:30 a.m., Susan Daniels, *Executive Secretary*, IACC presiding.

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PROCEEDINGS:

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

I would now like to introduce Dr. Daniels.

Dr. Susan Daniels: Good morning. Welcome to all our listening audience and to members of the IACC who are joining us for this conference call of the IACC Strategic Plan update's Questions 5 and 6 Planning Group, which is a group that is going to focus on Sections 5 and 6 in the IACC Strategic Plan that cover services and lifespan issues.

I'd like to get started on today's call with a roll call. We apologize for starting a little bit late. We were waiting to see if more people would join, but hopefully, others that join the call will speak up and let us know that they're on the call when they -- when they join us.

Dr. Sally Burton-Hoyle: This is Sally Burton-Hoyle. I'm on.

Dr. Daniels: Oh, hi. Thanks.

Dr. Burton-Hoyle: Sorry, sorry.

Dr. Daniels: All right. So let's get started with the roll call.

Idil Abdull? Idil?

Ms. Idil Abdull: Here.

Dr. Daniels: Thank you.

Jim Ball?

[No response]

Dr. Daniels: He may be joining us a little bit late.

Sally Burton-Hoyle?

Dr. Burton-Hoyle: Here.

Dr. Daniels: Thank you.

Jan Crandy?

Ms. Jan Crandy: Here.

Dr. Daniels: Thanks.

Denise Dougherty?

[No response]

Dr. Daniels: May be joining us in a few minutes.

Laura Kavanagh?

Ms. Laura Kavanagh: Here.

Dr. Daniels: David Mandell?

[No response]

Dr. Daniels: May be joining us in a few minutes. John O'Brien let us know that due to extenuating circumstances, he can't be -- he can't join us this morning.

Scott Robertson?

Mr. Scott Robertson: Here.

Dr. Daniels: Thank you.

Cathy Rice?

Dr. Catherine Rice: Here.

Dr. Daniels: Thanks, Cathy.

Alison Singer had a previous engagement and won't be able to be with us, and Linda Smith is involved in Government meetings this morning that will not enable her to attend today.

Larry Wexler?

Dr. Larry Wexler: Here.

Dr. Daniels: Okay. So we -- we have most of the individuals who are supposed to be on this call.

So I'm going to be the facilitator for today's call, and I'll be walking you through all of the

information we've provided. For our listening audience, you can access all of the documents if you go to the IACC Web site and go to the Meetings and Events page and look up this particular meeting. There is a materials link, and you should be able to get the materials there, as well as the agenda. So you can follow along with the discussion today.

We will be providing updates over the next few days. As many of you know, there is a potential that there could be a lapse in appropriations that would prevent Government work from continuing through this week. And just so people are aware, and especially for our listening audience on the phone, we will be providing updates to our IACC Web-site to let you know if we're not going to be holding certain calls, et cetera.

So we will provide emails about that as best we can. And in the case that the Government is not running in the next few days, the OARC will be closed, and we will not be responding to any emails, so just wanted people to be aware.

And we will provide updates about the upcoming

October 9th meeting. If the Government is open for business next week on Tuesday, we will hold the meeting as planned, but there is a possibility that the meeting could change to phone-only format if we are forced to do that by the circumstances of the appropriations situation. So we'll try to keep you up to date as much as we can.

So to get started on today's materials, I want to give you a little bit of background about the Strategic Plan, as we have some new members to the IACC who might not be quite as familiar with all of this. Just to kind of recap how the Strategic Plan came about, the Strategic Plan was developed by the Committee as a document to describe priorities and areas that the Government agencies and partners in the private sector could focus on to help advance the field of autism research.

And when the Committee constructed this document, they have introductory sections to each question area, but the Plan is divided into seven question areas that correspond to important consumer questions about different fields of research, and then each question area has

objectives, which are basically goals for further research that would address gap areas. These are areas that the Committee felt were high-priority and unmet needs, and so they identified several different gap areas and designated them as objectives for each question area.

There also was ongoing activity in all of the Federal agencies and private organizations before the Strategic Plan came about, and there has been activity ongoing ever since. And so projects that are not categorized in those gap areas in the objectives are put in this “Other” category that we labeled "Other" for the past 5 years, for lack of a better word.

Although in the last couple of days, we've had calls with some of the other planning groups, and someone came up with the idea of perhaps naming it something better than “Other” because “Other” sounds like those projects might be extraneous or superfluous. So we're going to be working with the Committee to see if we can come up with a better title -- maybe something along the lines of "core activities" to indicate that those are also

important activities, but they weren't identified as gaps by the IACC.

So we've prepared a number of documents. As you know, the IACC and the OARC each year do a portfolio analysis, gathering data from all the Federal agencies and private funders who are part of this analysis. And in the past, we've always been limited to collecting data from only nine or fewer private funders, although within the last few days, we've received OMB clearance to be able to in the future collect from more than nine private funders if the IACC decides that there are other funders we would like to hear from.

So we've collected all of this data. It's actually at the individual grant and project level, and we've collected very detailed information about each of these projects and worked with the agencies or organizations to try to categorize them according to the Strategic Plan objectives. And then we've analyzed the information and issued a number of Portfolio Analysis Reports.

And the OARC plans to put out another

Portfolio Analysis Report in the coming months, and what you have in front of you are excerpts from what will be the upcoming analysis, although I would caution you that the 2011 and 2012 data is still preliminary, and there could be some changes, although we doubt that there would be dramatic changes to the data at this point. Most of the data are pretty much in, but we may have some small changes that shouldn't materially affect what you're going to be looking at in your Strategic Plan update exercise.

So the goal of today's call is we're going to go through, first, all of these reference documents. I'm going to give you some orientation and explain them to you, and then we're going to walk through each of the objectives for each of the two questions because this Planning Group is covering two questions that are highly interrelated on services and lifespan issues.

And we're going to try to get a feel from those who are on the call as to -- based on this budget and funding information -- if you feel -- and project information -- if you feel that from

the standpoint of Government funding or Government and private funding whether these objectives have been largely completed. Are they only partially fulfilled, or are some of them really not addressed adequately? And to find out what are the gaps in those objectives based on the portfolio that you see in front of you, and what might be some of the barriers that are preventing forward movement on these if there is that problem.

So let me take you through the different charts that we provided. The first is the 5-year Strategic Plan Status Chart for Questions 5 and 6. Or let's start with Question 5, and then we'll just repeat for Question 6. I won't give you the orientation on Question 6.

But if you look at the Question 5 Status Chart, which is also called the cumulative funding chart, we've provided a first page that gives you some of the details of how to read this. But I'll -- I'll walk you through this verbally.

If you look at this chart, you'll see that the chart is divided into six columns for 2008 through 2012 and that there's a total column for total

funding. In 2008 you can consider that funding to be sort of the baseline because in 2008, there wasn't a Strategic Plan in place.

But we did take the 2009 Strategic Plan objectives and look at the 2008 funding to get a sense of the baseline of where we were before the Strategic Plan started. And then, after that, have been using the Strategic Plan as a template to try to fit in all the projects that are being done of what we're collecting and to get a sense of how the portfolio looks.

We've got red, yellow, and green coding associated with each of these areas, and the green indicates that in the 2008 through 2102 columns, if it's green, that means that if we annualized the budget, the recommended budget that the IACC provided, that the recommended budget was met in that year, although it's only an estimate because we did annualize it. And in some cases, only 3 years of funding were called for, and so if you see 5 years of green, then you've, you know, spent more.

We also want to remind you that the IACC, when

devising these objectives, identified the minimum number of projects and an estimate of the funding that might be required in order to do these projects. But there really was no feeling that the Committee didn't feel that, for example, if you look at the first objective, support two studies that assess how variations in and access to services affect family functioning in diverse populations, including underserved populations, by 2012.

The Committee's intention wasn't to say that two studies would be adequate to meet the need overall but that two studies were the minimum that would need to be done to start working on this area, if that, hopefully, makes sense to you?

So in the last column, we also provided red, yellow, and green coding to give you a sense of whether in terms of the recommended budget, was the recommended budget spent? And there isn't a requirement that we have to spend that much to be able to achieve these because, in some cases, maybe there are cost savings and you can achieve the objective without spending all of the

recommended budget. But it gives you a sense of whether investment has been going into that area.

And also just to remind you that the Strategic Plan is a guidance document and an advisory document to the Federal agencies. It's not a situation where the Federal agencies received this document and then went out directly to fulfill these objectives. This exercise of doing the portfolio analysis is really bringing in all the projects that are being funded by agencies and organizations and fitting them to the Strategic Plan to give a sense of whether these priorities are being addressed.

But in many cases, projects are coming in as investigator-initiated projects. There are only certain cases where agencies may have gone out with a specific solicitation to target one of these objectives particularly.

So I think that that gives you some background. And then if you see at the bottom, we have the “Other” category -- or we could maybe call it “core activities” for today until the IACC comes up with a better name for it -- that

indicates other activities that are outside of these gap areas.

So does that make sense to everyone? Does anyone have any questions about this table?

Ms. Crandy: I do have one question, Susan -- this is Jan -- in how it relates. For instance, on the third one, it says evaluate five models. I look over and I see there's a total of 20 projects, but they might have been looking at, say, 4 models.

Dr. Daniels: Right.

Ms. Crandy: How does that -- how are -- without looking up every single one under the Web portal, and I did try to do that to see if we touched on five different models, and I could not tell if we did.

Dr. Daniels: Right. And so, that's part of the Committee's role in this. When we -- when our Office -- worked with the agencies and organizations to code things, we would categorize things to these objectives if they met part of it, and you can tell some of these objectives are multifaceted and have many different components.

So if it was at all relevant, it went in the category. But we didn't do a further analysis to try to determine whether all the specifics of each objective were met.

And so that's part of the Committee's task to get a sense of that.

Ms. Crandy: Gotcha.

Dr. Daniels: And we don't think that you would have to necessarily read every single project. But we're hoping that you might be able to eyeball some of the information at least from the projects that have been provided.

So on this table we have active links for 2008 through 2010 that will take you to a project list for those particular objectives. And then in 2011 and 2012, because the data are not yet uploaded into the Web tool, we provided you with static tables. And so, those are the project tables that we gave you. I think they're called "full project listings" for Questions 5 and 6, and those -- if you page through those, you can see actual lists of all the projects.

So that will help you, and even by the project

title, you'll get a sense of what is in those. In the Web tool, we actually have links out to the specific abstracts or the project descriptions for each and more detailed information. But these lists should give you a pretty good sense of what's in the portfolio.

Any other questions that anyone has about this table?

[No response]

Dr. Daniels: Okay. Let me -- I'm going to first walk you through all the documents, and then we'll start talking about the objectives.

So I also provided you with pie charts showing the distribution of funding across the IACC Strategic Plan, and you'll probably be fairly familiar with this pie chart because we use it in the portfolio analysis documents that you've seen over the past few years. And so that is something that you probably all will recognize.

And the purpose here is for you just to get a sense of, with Questions 5 and 6, where they fit in with the rest of the Strategic Plan in terms of the proportion of funding that may be going into

these areas and to see -- to see any changes.

Although because there have been new funders that have been added over the years and various other -- other changes -- you need to consider it, you know, that there -- that changes might not be statistically significant between, if you see a change from 1 percent to 2 percent, that might not be super meaningful.

But you also should be looking at the absolute dollars to get a sense of any particular changes. If you look over the past 5 years, you'll see that the lifespan area has stayed relatively the same, and the services area has also stayed relatively similar.

So the other documents you have in front of you are the subcategory pie charts, and these are pie charts that show the entire portfolio broken up into sort of subtopic areas. And the reason that you have this is, in 2009, the IACC, when they saw the first Portfolio Analysis Report -- or actually, maybe this was 2010, the second Portfolio Analysis Report -- they asked us to -- or they asked us what was the content of the

"Other" category because they felt like they didn't have a sense of what was really in there without going through every project.

And in response, the OARC created a subcategory coding scheme to try to break this down and look at the projects in a different way. Because these objectives are very targeted, and there might be some more general categories that would be helpful for the Committee to understand.

And so we broke this down into a number of different subgroups or subcategories here.

On the first page, I think one of them might not be correctly labeled. But on the second page, we have "services utilization and access, community inclusion programs, efficacious and cost-effective service delivery, family well-being and safety, and development or evaluation of practitioner training programs."

So these are some of the -- this is sort of a breakdown that gives you a sense of what's in the portfolio in a different way, and we thought it might be helpful to the Committee.

You also have the full project listings that I

mentioned, and then the last piece is you have a summary sheet for each question that gives you at a glance the total funding for Question 5 across the years, the percent of total ASD funding that that represents and the number of Question 5 objectives. And so you can see it's grown from four to nine for Question 5.

And then we gave a very quick rundown of the status of the objectives based on just the funding aspect and gave you a little bit of a sense of what's in the "Other" category. And in Question 5, we have "training for therapists, education, and other service providers, Autism Now funding, and service access and evaluation."

So what we're going to do now is we need to walk through each of the objectives in Question 5, and I want to hear from you all about what your thoughts are about based on the goal of having projects be funded to cover some of these areas; do you feel that that has happened in the past 5 years? Have projects been funded? Has the work started, and is it moving in the direction the Committee wanted for each of these areas?

So the first one is objective 5.S.A: "Support two studies that assess how variations in and access to services affect family functioning in diverse populations, including underserved populations, by 2012." Does anyone have any thoughts about how we're doing on this objective based on the information you have in front of you?

[Pause]

Ms. Abdull: Hi, Dr. Daniels. This is Idil. Sorry, I put you in mute, and I don't know when the phone is off mute or on mute. But hopefully, can you hear me?

Dr. Daniels: Yes.

Ms. Abdull: Oh, good. So on the diverse and underserved populations, I think, first, just to say two studies, and I know you said that's -- and first, before I start, thank you so much for explaining and thank you for the colors. It's wonderful.

And those of us that are not in the Federal Government or are not researchers or scientists, it's very easy to understand. It's just simple lingo. So I really appreciate you and your staff

at OARC for putting it, as I would say, explain to me like a 6-year-old in Denzel's film, if you remember the *Philadelphia* film.

And so, I guess my comment would be for two -- just two studies, even though it could have been more, I think that -- that doesn't even touch the surface, right, for not just the diverse, but then underserved. Because underserved doesn't -- is not necessarily racially and ethnically underserved.

It can be rural areas. It can be, you know, children even in the urban. It could be older kids who are underserved because everybody wants to get the younger children, but then what happens when a child is not diagnosed at a younger age?

And then when I look at the studies that were done even on the training professionals, there isn't really anything that says we want to -- we want to -- get diverse therapists or train diverse practitioners or seek diverse practitioners. And I just -- and I know Dr. Insel always says we don't want to change anything at the ninth inning, but personally, I don't think we have even touched the surface on -- on that objective at all.

Dr. Daniels: So, so what would be helpful, really -- if you take the 2012 portfolio analysis project list, you can see the six projects that were funded in 2012 to get a sense of are these projects addressing the question, what are the gaps, what's not being addressed by these projects?

Or certainly in terms of the funding that was recommended, the recommended funding was $1 million, and there was $5.2 million spent. What -- what's missing here?

Ms. Abdull: So for example, it says that there is a $20,000 funding for identifying disparities in access to treatment for young children with autism. Like, so I would have -- I don't think that's enough.

So disparities for African Americans, disparities for Hispanics, disparities for minorities, for rural? Which, you know, it just seems like the question -- the objective is so broad and that if I was a researcher, I wouldn't even know where to start.

And I feel as though the objective could have

said for racially and ethnically diverse population, for underserved rural populations. And then if you look at the other projects for getting family navigators -- so it would have been -- I would have liked it if it said underserved and minority communities, helping and training those parents to navigate the system and teaching those families so that they could help themselves and other parents.

Even on the one that says the effects of State -- on page 2, still on 5.S.A, it says the effects of State and Federal insurance. Obviously, that there is a gap, right? So there are 35-plus States with private insurance, less than like a dozen for State and even the States pay a lot less than the private for early intervention.

So it would better if we -- if it was -- if there was like a breakdown, if you will, of those that are low-income families, those are the ones that are underserved, versus mainstream upper, middle-income families, and how are they accessing services?

Who is telling them? Is it the doctor's

office? Are there enough trained professionals that reflect the faces of autism's diverse populations? And are we training enough professionals, enough speech, enough OT, enough ABA, enough, you know, developmental behavioral pediatricians that can talk to these diverse communities in a way they understand, and so they can get the services.

So I would say all of those are just -- I can have more gaps, but I think that's a good start. Does that make sense?

Dr. Daniels: So the goal here really is not to say how you would have reworded the objective to cover more things. It's really what we're trying to do is say this objective, as devised by the Committee years ago, in 5 years, have we gotten anywhere close to achieving that objective? Not -- not achieving the overall maybe -- many of these have huge goals, like develop biomarkers for autism. That's a huge goal.

But in terms of supporting two studies to get started on this, have we gotten there? Have we -- based on this list -- are these studies related to

this question enough? Do you feel that some of the areas have been covered?

One of the things that the Committee might recommend is that you could, for example, say that, based on the objective as written, that this particular objective has been met in the sense of the funding, but there's much more work to do and that, in the future, you might recommend further funding for this objective or expanding the objective. But, but based on the way it is, have you --

Ms. Abdull: Yeah. Right. Right. So --

[Inaudible comment]

Ms. Crandy: Susan, this is Jan Crandy. I do -- when we look at the money, we have spent the money that we said we would spend toward this goal. I do not think we've answered the question or solved the problem.

Because I did go through this in-depth, looking at every study, and we have done a lot of studies on different questions and different groups, but we definitely -- it's so huge we are not even touching it, like she's saying. We

definitely need to continue to address it and figure out how we're going to solve the problem, not just study it.

Dr. Daniels: Right. And so --

Dr. Rice: I think that -- this is Cathy -- if I can add for clarification? One challenge I always have when we talk about Questions 5 and 6 is that the capacity issues become very clear in that and really making sure that the number of service providers and that information is disseminated and is in the hands of people that need it. And that there are huge gaps there, but that in this Plan, we're talking about the research aspect of it, and is there a good model that could be disseminated and that capacity should be built around?

And I think that I just want to clarify that -- that we should really be focusing on the research questions and the models and then maybe in our summary statements talk about the importance of the capacity piece to actually make sure that if there is a good model identified, if there are essential services and supports that we

know are effective and have had good research behind them, that a crucial step that we haven't really addressed is how do we build that capacity?

And we've struggled in this Committee about do we have a separate services plan or not? But I think where we are right now, and I guess I'm asking for clarification, is that we're focusing on the research-based models of service provision. Is that --

Dr. Daniels: Yes, that's correct, Cathy. The other thing I might want to clarify is, on today's call, we're really talking about have projects been funded meeting the exact letter of what was described in the objective. The objective, of course, has kind of a larger overall goal in terms of results and outcomes. But that's not the topic of today's discussion.

On the next call, we'll be bringing in our external participants to help us talk about where the field is in terms of these objectives. But today we're not really talking about has that field moved forward? Have we gotten the results? Have we gotten the outcomes?

We're really talking about were projects funded? And were an adequate number of them funded, according to what was written here?

Mr. Robertson: Susan, this is Scott Robertson. I -- you know, according to that goal for today's call, it would seem to me that the first objective, you know, has been funded. I don't necessarily know that it doesn't necessarily mean that we don't want to be funding it in the -- in the future.

Dr. Daniels: Right.

Mr. Robertson: We do. But I think -- I think you can clearly tell that, you know, we've spent $5 million on multiple projects aligned to this objective when we -- when they originally envisioned spending $1 million. So I think that, you know, that seems, you know -- you know, pretty good progress to me as far as funding.

Dr. Daniels: Right. And so, that's really what we're looking for here. We're not talking about whether we need to continue doing this.

And actually, on the next call, we might get into that more with our external participants

about, even with some of the objectives that have been met, is there still a need? Is there a greater need? Are there areas that weren't addressed? And if there are, you know, in the future opportunities to expand the Strategic Plan or change it, would the Committee want to continue in this direction or expand the direction or change it a little bit?

But, yes, what we're looking for here is based on how it was written over the past few years. Did we achieve at least the initial part of what the Committee wanted us to do? I mean, not us, of course, figuratively speaking. It's the agencies and the organizations who fund research.

So it sounds like --

Ms. Abdull: Hi, this is --

Dr. Daniels: Do others have comments?

Ms. Abdull: This is Idil. I just -- I understand what, you know, Cathy and Scott are saying in terms of funding, yes, and in terms of are we saying there was this -- you know, was this met in terms of funding? Yes, we've spent $1 million. Clearly, more has been done.

But if you -- if you read the objective and it says "family functioning in diverse populations, including underserved populations," and then you read the projects that are being done, I don't think in that sense it has been met. In terms of the funding, yes, but in terms of funds in it and using the same terms of looking into diverse populations and underserved populations and not just looking at it, but hopefully coming up with solutions, as Jan has said, I personally don't think that has been met.

Dr. Burton-Hoyle: I don't think -- this is Sally. I don't think it's probably adequate for the need. However, that was included. That, you know, racial, diverse, underserved was included in the sample of the family navigator study. That was, you know -- again, it's limited as to early childhood, but they did -- that was supposed to be included in the sample.

Dr. Daniels: Laura Kavanagh, do you have any comments, since some of these are HRSA projects?

Ms. Kavanagh: Yeah, I can speak to -- this is Laura Kavanagh. I can speak to the HRSA

investment.

So family navigator model does include diverse populations in the sample, as does the parent-to-parent model of support and services. Mary Beth Bruder is the principal investigator there. Access, quality, and financial implications of the transition -- I have to look at that more carefully. I know the first two do absolutely.

Dr. Daniels: Okay.

Ms. Kavanagh: I'm wondering if, as a group, we could agree to say something like we feel that the IACC has achieved initial objectives outlined in the Strategic Plan, but we see a need for much greater investments as the needs are so great here. Something like that?

That gives us a segue into what the expert panel will be reviewing as well.

Dr. Daniels: Yes; that would be completely appropriate.

Dr. Burton-Hoyle: That's, you know, I think that's a good idea.

Ms. Crandy: I agree.

Dr. Daniels: So can we --

Mr. Robertson: I think also one thing to keep in mind -- this is Scott Robertson -- is that, you know, some of the conceptions of some of these things -- we have to be reminded that, for instance, like "underserved" included not only just diverse, ethnicity, race, et cetera, but included low income. And so, for instance, we have a study, you know, a project there on low income, you know, that's targeted right, you know, back to that.

And if you thought of, for instance, underserved as only being projects around ethnicity/race, you'd say, well, that doesn't seem to fit. But then when you realize that the question is talking about underserved populations, which definitely include socioeconomic background, then you -- so you have to -- you have to consider also that these projects and the way they were funded are under a very broad objective that has to address, you know, some really, really major problem areas as far as the -- as far as the underserved. So also keep that in mind with the funding.

Dr. Daniels: So based on what I'm hearing here, does the Group feel that they could say that the initial targets of this objective have been met, but there would be further work that needs to be done in the area?

Dr. Burton-Hoyle: I think so.

Ms. Crandy: I would be supportive of that.

Ms. Abdull: Yeah, me, too.

Mr. Robertson: I'm supportive of that.

Dr. Daniels: Okay. So I --

Dr. Wexler: I am -- I am also. This is Larry Wexler.

Dr. Daniels: All right. So that's basically what we need to do then for all of these -- these questions -- and that's -- you know, I know it's hard on the first one to get through it. But I think that you've done a good job of discussing some of the issues and kind of getting a feel for this one.

And we're going to try to go through the rest of them. We are 45 minutes into the call, so we want to try to keep things moving ahead as much as we can. We will try to cover both Questions 5 and

6 on this call, but if we're not able to cover them all, then we will have to schedule another call.

So the next objective is "Conduct one study to examine how self-directed, community-based services and supports impact children, youth, and adults with ASD across the spectrum by 2014." And you can see here that in 2009 and '10, there were six projects each devoted to this objective and in 2011 and '12, one project, and now zero projects. So you might want to dig into that a little bit further to see what was going on. Go ahead.

Ms. Crandy: It did look at more than one study on self-directed, community-based. So we have met that piece of the question.

Dr. Daniels: Okay. And I see that in 2011 -- so the dollars can be a little bit tricky because if you see a project that says zero dollars, that usually means that the dollars were invested earlier in the project because some agencies and organizations put their money in on the first year, and then they just continue spending that money throughout the years, but they don't put new

increments in.

And the way we count it, if the project was still running but didn't receive any new dollars, it gets zero funding. So the funding there, there obviously was an active project in 2011, but it didn't receive funds that year.

Mr. Robertson: What I don't understand on this one is why -- and I know some of this is because we make +the advisory recommendations and then DHHS decides what to do, you know, NIH decides what to do with the funding. Why this -- I mean, this was kind of underfunded to begin with, and then kind of, you know, tailored completely off into the zero-dollar range in the last couple years.

And what's the -- if there's -- I guess we don't really have any explanation background on -- on what happened when funding decreased substantially, huh?

Ms. Crandy: This is Jan Crandy. I want to -- also, even looking at the studies, I don't think that it really, to me, what we were looking for there is looking at community-based services that

are -- are we just looking at treating and support? Because when you look at the actual studies, most of them are around recreation.

Dr. Burton-Hoyle: Yes.

Ms. Crandy: So I don't think that it answers the question for us. You know, although there are multiple studies, it definitely -- I think we need more money. We need to be looking at true self-directed, community-based services, the magnitude of what those services should look like, not just one area.

Dr. Burton-Hoyle: And this is Sally, and I agree fully. I was looking in this objective for employment. I was looking for housing, you know, for people to have self-determined lives, and it looks just like recreation to me.

Ms. Crandy: Yeah, I definitely think we're not there on this one.

Mr. Robertson: Yeah, I'm going to -- I'm going to concur on that one, that -- that I think we're substantially not there on this one in terms of what it should look like as far as – besides, I'd agree that self-directed should be things on

employment and housing and being able to, you know, live your life in the community, and a high quality of life should be a part of that with self-direction. And we're not there really much at all on this one.

Dr. Daniels: Yes, in terms of unemployment and housing, I'm not actually sure with the portfolio analysis how much of that we would be likely to capture because -- I don't know if Laura can speak to this at all, but since we're only collecting -- we're not collecting data from Labor or HUD or anything like that. So I don't know how much HRSA and NIH and CDC and so forth would be funding in unemployment and housing.

Ms. Crandy: But Susan, even self-directed could be self-directed treatment. I mean, there's community-based people that are -- groups that are doing self-directed of treatment, picking their own providers, what kind of treatment they're getting. We should be looking at that.

Dr. Daniels: Right. That's certainly something that the funders we have now -- I don't know, Laura, if you have any comments on that?

Ms. Kavanagh: Yes.

Dr. Daniels: I just was thinking to myself in terms of, if you're really looking for unemployment and housing, we -- we might fall short just because of the fact that we're possibly not collecting from places that might be doing that kind of work.

Ms. Kavanagh: This is Laura. We are supporting research around transition services, broadly defined, which includes employment, housing, recreation, and many other areas.

Dr. Daniels: Okay.

Ms. Kavanagh: So this might be an example where because of the coding structure, you sort of pick one as a primary focus. So we might want to examine the investments under transition more carefully, too.

Dr. Daniels: Okay.

Mr. Robertson: The only question I have on that, though -- this is Scott -- is whether -- while those areas might be under transition, is there a self-directed notion about them when they're when -- they're listed under transition?

Because this particularly gets at self-direction, and just because those other things are happening in terms of funding doesn't necessarily mean that they're happening with -- that they're funded in a self-directed manner, as this objective is requesting.

Ms. Kavanagh: You are absolutely right. You are absolutely right.

Dr. Daniels: So good. It sounds like, if I'm hearing the Group correctly then, it sounds like, you know, some projects have started, but the objective is not anywhere near where it's supposed to be going in terms of what the Committee had intended at this point in time.
So you would definitely be recommending much more work in this area. Is that correct?

Ms. Crandy: Yes.

Dr. Burton-Hoyle: Yes.

Mr. Robertson: Yes.

Ms. Abdull: Hi. I would agree with that. I just have a question, Susan.

Dr. Daniels: Sure.

Ms. Abdull: In terms of you said we were not

collecting data from HUD and Labor, is it because we're restricted or -- or is there a way, given that for youth and adults with autism, that is the two most important areas, employment and housing. And when we talk about especially next question -- what does the future hold for adults -- I think really we need to have something from those two agencies.

Dr. Daniels: Well, so in 2009, when we first -- we did our first data call, or actually, it was for 2008 data that we called for the data in 2009, we did approach HUD, and HUD said they had nothing. But you know, it's been a few years now, and it's possible maybe the offices that we reached out to weren't the right offices, et cetera, and so that's something that maybe should be re-explored.

It's also possible that -- and of course, these projects needed to be somewhat related to research. I don't really know how much research HUD funds. But we could try again, and if maybe some people on the Committee maybe have contacts within HUD or know the -- I know that there's a

disability section in HUD -- maybe that would be the correct group to reach out to, to ask if they have activities, although they might not be funded --

Dr. Burton-Hoyle: This is Sally. And you know, it doesn't -- I wouldn't think it would be HUD because, you know, a self-directed life in the community is going to be mental health, Medicaid dollars being spent for that. So I mean, it's -- you know -- it's a small percentage of people whose maybe families are purchasing a home, and they're the landlord, and then Medicaid money, SSI and such is used for that.

So I don't think it'd be HUD. I think it would be more mental-health-related funds.

Dr. Daniels: And ACL works on self-direction, but they don't really fund research. So you know, ACL is a part of our data collection, and they didn't report anything here.

But I think what Laura mentioned might be worthwhile to look through the portfolio and see if there is anything else that might have been coded elsewhere that would be relevant. But I

think, regardless, it appears that certainly adequate work has not occurred in this area yet, and it sounds like you've all reached consensus on that.

Ms. Kavanagh: Yes.

Dr. Daniels: So if it's okay, let's move on to the next one: "Implement and evaluate five models of policy and practice-level coordination among State and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and their families, which may include access to augmentative and alternative communication technology, with at least one project aimed at the needs of transitioning youth and at least one study to evaluate a model of policy and practice-level coordination among State and local mental health agencies serving people with ASD by 2015."

And that one is quite a mouthful. It is a conglomeration of an awful lot of different ideas,

and so -- but you have a project list here. In 2010 there were 15 active projects, and over 2011 and '12, we identified 3 and 2 active projects in this area. And it looks like in terms of the recommended funding versus the amount that actually was expended in this area, that the amount spent was not as much as what was recommended.

So what's the Group's feel on this?

Ms. Crandy: I do think there are some good studies that have been done in this area. But I don't think we've reached it yet, and I don't know if we've touched on every point that we've included in this. So I would think we'd need to do more work on it.

Mr. Robertson: Yes. Partly -- this is Scott -- partly because the funding has -- has, you know, tailored off on this -- on this, you know, that it's -- the funding drops, you know, pretty substantially from where we were funding, you know, 15 projects at -- we are still on the third objective, right?

Fifteen projects at $4 million and then, you

know, tailoring off to just, you know, $600,000 each year, which is a substantial difference on funding and not really fitting. Like when we were at the $4 million, you were closer to, you know, covering what the goal is on the $25 million over 5 years, and we're not -- you know, we're not really doing that anymore with the $600,000 only.

Ms. Kavanagh: This is Laura. A substantial number, 13 of the 15 projects in 2010, were from HRSA State demonstration grant programs which were included that year but were not included in subsequent years. So that explains part of the variation in the funding over years.

They're not really research projects, but they are examining innovative models of care within States. So I do feel like that variation sort of deserves an asterisk maybe for that year as to why it spiked so high in 2010.

Dr. Daniels: Right.

Ms. Crandy: I think, too, and the other study is the nine-State study?

Ms. Kavanagh: Right. We funded the Donna Noyes also. That is a research study -- and one is a

research study, and one is the State ASD demonstration. You are correct.

Dr. Daniels: So in this particular objective, this was something that has been an issue that we've discussed in the IACC. When you read the words of the objective, it is a little bit unclear as to how this objective exactly relates to research because implementing and evaluating five models of policy and practice-level coordination doesn't sound like a typical research project. It sounds more like, you know, a policy demonstration, which I guess can be considered experimental in some senses. If you're doing a demonstration, it is an experiment. So it could be -- if you want to look at research in a broad sense -- it could be considered research in that way.

But given that there has been a change in terms of what HRSA is reporting is for this. But Laura, do you feel that the work that HRSA is doing on those programs is relevant to this objective?

Ms. Kavanagh: I do think it's relevant to this

objective. I think our criteria for what makes for a research project have evolved, but that we definitely are examining the issues outlined in this objective. We still have a very long way to go, though. So I would say needs -- needs additional resources.

Ms. Abdull: This is Idil. So Laura, for I know you have the planning State autism grants, which is different than the State implementation. And then for this year, you funded -- you funded a little less than previous years, right?

Ms. Kavanagh: Correct. Mm-hmm.

Ms. Abdull: Okay. And so, if you read the objective of this question, I would say it's more even those things that -- programs that HRSA does relates to this because each -- whatever State wins this grant, they have to come up with a better practice level of coordinating between the local agencies and throughout the State.

Ms. Kavanagh: Exactly.

Ms. Abdull: But I don't -- and so, they're not listed here, and as Susan said, they're not research, per se. But I feel like as though it

relates to this question exactly the way at least the first sentence is written.

Ms. Kavanagh: Right. I agree with you, Idil. In 2010, they are listed. So the State demonstration grant programs are listed, and I do think they address this objective.

Ms. Abdull: Right, in 2012. Sorry, 2012.

Ms. Kavanagh: Yeah, 2012, I'm trying to -- sorry, I've got multiple things open here now.

Ms. Abdull: I know. It's a lot.

Ms. Crandy: So do -- every year you're adding more States to this?

Ms. Kavanagh: Yes. So we continue to fund the base State demonstration grants for 3 years to implement a State autism plan that coordinates services, and then we also fund planning grants that are for a shorter period of time to get themselves running more. But, yes, we fund new States each year.

Ms. Crandy: How many new States each year?

Ms. Kavanagh: This coming year, for fiscal year '13, I think we have four States -- hold on just a minute.

Ms. Crandy: So how many total States have received these grants?

Ms. Kavanagh: Sixteen.

Ms. Crandy: Sixteen. So we definitely need to keep working on it then, right?

Ms. Kavanagh: Yes.

Ms. Abdull: Oh, God, yeah. We're not even half the States. And -- and sometimes even the States that had it or their applications are good, like I think Minnesota's app was good this year, but they didn't get it because HRSA ran out of money. So I'm hoping that we can recommend more because this is really the meat of the bone, if you will.

If we can get the States to coordinate within their local public health, within the providers, within, you know, the system -- the providers and the caretakers -- then that will eliminate not just even disparity, but it will eliminate and make sure the children get early access, early intervention because everybody knows what everybody's role is, if you will.

And so, if there is -- if there was one objective that I am just wholeheartedly hoping

gets more funding and more States are funded would be this one.

Dr. Daniels: So --

Ms. Crandy: Do we also know about the augmentative communication, how many of those States addressed that?

Ms. Kavanagh: This is Laura. I don't -- I am not aware of any of those 16 States that have that particular priority for the whole State. They might have it in a smaller area.

Ms. Crandy: Okay.

Ms. Kavanagh: But I would say that's not the primary focus of one of our State demonstration grants, for example.

Ms. Crandy: Okay.

Ms. Abdull: Hi. This is Idil. So could I ask you, Laura, then, remember you guys have those family-to-family grants? And the agencies that usually fund them do the alternative communication. I mean, it's not a lot of money, that sometimes they just get $100,000 or less. But some of those things, they -- for example, in Minnesota, we have an organization that's a lot of

augmentative devices and teaching, you know, families how to use it or you can rent it if you think it's good for your kid --

Ms. Kavanagh: Right.

Ms. Abdull: -- and test it out. So while it's not the State planning or the State implementation grant, I think HRSA does fund with family-to-family, and then you also fund the health department's child and maternal health departments.

Ms. Kavanagh: Correct.

Ms. Abdull: Which then their job is to help parents about various communication devices and various things that a child might need, based on their -- where they are on the autism spectrum.

Ms. Kavanagh: So correct.

Ms. Abdull: I don't think they're listed here, but yeah.

Ms. Kavanagh: Right. There are multiple strategies that would be supported through HRSA, including the MCH block grant to States where, in some States, yes, families could have access to alternative communication technology through those

funds, as well as even our training grants. Some have access -- have also funds as well.

But again, I don't feel like we have a research grant that's focused on this particular topical area. So yes, I think we're investing in a lot of different areas, family-to-family, State demonstration, the block grant program. There are multiple investments that are not all reflected in this -- the response to this objective.

Dr. Daniels: And this has been one of the challenges, I think, in doing the portfolio analysis. Because we did have this discussion last summer about, you know, what to be including, and some of these objectives that, again, are quite murky because they don't describe classic research.

And so, if you're limiting the projects collected to strictly research, then you'll be missing a lot of things that actually are funded.

And so I don't know if we need to revisit what the strategy is for -- for having an accurate reflection of what's being done. But Laura, what would you envision would be the kinds of projects

that could be funded that would be really meeting this?

Ms. Kavanagh: Well, I'm wondering if for objectives like this -- this takes us off task for our immediate task for today -- but I wonder if we might do a more qualitative response to some of these in the future to talk about really what's going on around alternative communication. We're certainly not the only ones making investments here, and the mental health agency collaboration, a lot is being done there that I don't think is reflected in this Plan either.

But that seemed to me a different purpose than the Strategic Plan analysis. I don't know how the Group feels about that. I don't think we're capturing everything that is being done in this area. But I don't know that it's the purpose of this particular process to collect that. I wonder if there's another strategy that we could use to collect that information.

Dr. Daniels: So with -- I guess the issue is that this objective lies within the Strategic Plan, and so how -- how can we best assess what's

going on in relation to the objective, regardless of whether we're calling it research or not calling it research? How do we adequately capture what this --

Ms. Abdull: I think, Susan, if we could -- if we could capture what not just even HRSA, but other agencies are doing in terms of what the objective is. So not, it doesn't necessarily have to be is it research, per se, but even if it's policy and implementation and State coordination.

If we can list those and ask agencies like HRSA and even, you know, maybe CMS I know is trying to do a little bit and others, and list those. I think that would give us a better sense of is this objective being met?

Ms. Crandy: I think, too, it is relevant to include these State initiatives because that shows that we are looking at what policy and practice-level coordination is happening among States. So it's definitely relevant to include them.

Ms. Kavanagh: Right. I think it's relevant to -- this is Laura. I think it's relevant to include them, but I'm wondering, like, do any of these

projects -- none of these projects are from CMS, right?

Ms. Crandy: I thought that nine-State study was, no?

Dr. Daniels: The nine-State study is from CMS.

Ms. Kavanagh: Okay. Good. Okay, so we have one that's CMS. Okay.

Dr. Daniels: Right, and that's -- yes. So we do have a CMS project, the nine-State study.

Ms. Kavanagh: Right.

Dr. Daniels: So maybe I can work with Laura offline to think about how that might be better reflected, especially in the 2011 and 2012 analysis.

Ms. Crandy: I think that nine-State study tells us a lot about what's going on in those nine States, and we need to go further and look at all the States, right, with that view.

Dr. Daniels: Right. And there is a state-of-the-States project. And actually, that's something that we should mention. It's categorized in Question 7, and so that one is supposed to be looking at all 50 States, and that is funded.

So you might want to take that one into consideration as well. And John O'Brien isn't on the phone right now, but they're actively working on that, and they will be trying to present at the IACC in the future when they have their data fully completed.

Ms. Abdull: And with that -- Dr. Daniels, are they looking at -- and I don't remember what John told me. I remember asking him. But are they looking at both public and private insurance of the state of the States, or are they looking at just what CMS funds, which would be the public part?

Dr. Daniels: I'm sorry. I don't have that information. You would have to ask someone from CMS for the detail about that study. But that is a study that we have in the portfolio analysis that is coded elsewhere because there is a specific state-of-the-States objective in Question 7. So that's something else -- sorry, what?

Ms. Crandy: Could we include that here, too? Could we include that under this one, too, though?

Dr. Daniels: We can't count it in terms of the

dollars because -- we can put, you know, an asterisk and say that the state of the States is categorized elsewhere, but we're not double-counting any of the dollars. And because --

Ms. Crandy: Okay.

Dr. Daniels: -- the specific objective for state of the States is elsewhere, we counted it there. We tried to count things in the place of best fit. But I think that's a really important contributor here. So, and that --

Ms. Kavanagh: And even the -- sorry, even the nine-State study it says on the description that it goes through 2011, too. So we might be able to reflect that in more than one year here also.

Ms. Crandy: It seemed like there was a 14-State study, too, on CMS that was updated later, or no? Anybody recall that?

Dr. Daniels: I don't recall that one. So in 2011, the nine-State study was -- is on the list.

Ms. Kavanagh: Is on the list. Okay.

Dr. Daniels: It's zero dollars because the dollars were put in up front.

Ms. Kavanagh: In the front, gotcha.

Dr. Daniels: Earlier year. So, so I think that based on what I'm hearing here is that work has started in this area. There is work ongoing, but more work is needed.

Ms. Kavanagh: Yeah. Yes, because there's so much –

[Multiple speakers]

Ms. Abdull: I would agree. Can I also say that -- this is Idil. Can I just say that Dr. Mandell -- David Mandell -- is, I think, on the phone. He was having a hard time with the -- he was like on the mute side rather than on the speaking side.
Dr. Daniels: Oh, okay. Great. Thank you for letting me know.

Dr. David Mandell: Hi, guys. Sorry about that. I had a little work emergency, and I -- and I apologize also because I'll have to -- I'll have to get off the phone a little before 12:00 p.m. to continue to deal with this. But I did want to call in for the time I did have.

Dr. Daniels: Okay. Great. Well, thanks for being on the call.

So we've gotten through three objectives.

Let's move on to the next one: "Support two studies to examine health, safety, and mortality issues for people with ASD by 2012." And you can see that we have a total of 5 projects between 2010 and 2012, and $4.5 million was recommended over 3 years, and we're definitely significantly below that.

So, so what do you feel is going on here?

[Background noise]

Ms. Crandy: That is just – dollar-wise we're not there. We're very under.

Dr. Daniels: So we have in 2012, we've got a wandering study. The Paul Law, Kennedy Krieger study that you all are pretty familiar with, I think, that addresses safety issues.

And it looks like we have one, an Autism Speaks study in 2011: -- "victimization, pragmatic language, and social and emotional competence in adolescents with ASD."

Ms. Crandy: Wasn't there also some mortality studies? That doesn't seem like those are reflected here.

[Inaudible comment]

Dr. Daniels: There is that Utah study. So in another objective, there is -- that we covered the other day, I think it is in Question 7 maybe, because it might have been somehow put in surveillance. I mean, not inappropriately, it just, I think, is a surveillance-type study. There is a Utah study that has published a few papers that I think does look at mortality over a long period of time since 1980.

So that one is one that, you know, we could probably note has been funded. I don't have at my fingertips exactly how much money was spent on that study. But that one probably would be something that could apply here as well.

Dr. Burton-Hoyle: This is Sally. I was specifically looking for that. So yeah, can it be included in this area? Because otherwise, I don't think we even deal with that. I mean, it could be wandering, but --

Dr. Daniels: Yeah, so that, we would have to just make a footnote of it because it is categorized for the other area, and we aren't double-counting funding. So --

Ms. Crandy: There could be some in the comorbidity because of it affecting mortality when they can't explain that there's something wrong with them; they can't communicate.

Dr. Daniels: I'm not -- I'm not actually aware of any study like that, but I don't know.

Ms. Crandy: No? Okay.

[Several speakers]

Mr. Robertson: So what was also intended by the -- by the health aspect of this -- of this objective? Was that supposed to look at health disparities or what?

Ms. Abdull: The overall health maybe? And that was my question. I guess I see obviously we're not there with the funding, but for safety and mortality, even if there is one or two studies for health, I'm just wondering what the Committee intended to look at? Was it the overall health of people with ASD or -- and if so, I don't think then we've done that part of that objective.

Dr. Burton-Hoyle: Because that one study -- this is Sally -- is on bullying. So it's victimization, but you know, I was missing any of

those other factors when I looked.

Dr. Daniels: So it's sounding like, you know, there have been a few studies, but they're not really covering the waterfront of what the Committee may have been intending here.

Dr. Burton-Hoyle: I think that.

Ms. Abdull: Right.

Mr. Robertson: Yes, I concur.

Dr. Daniels: Okay. So, so then I think we can assume the Committee would give that one a yellow, and we can move on. "Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013."

This is 5.L.A.

And it looks like a number of different funders here. We have HRSA. We have Department of Ed. We have NIH, DOD, AHRQ.

Ms. Crandy: This one actually looks good.

Dr. Mandell: Yeah.

Dr. Burton-Hoyle: That is a very broad objective.

[Coughing]

Ms. Abdull: I would -- this is Idil. I would say this -- this probably has the most research that I've seen here so far in the objectives we went through. But again, I just emphasize when we say the words "diverse" that I see there's the one there for the Latino, but then, you know, there is more diverse. And even training and educating, they should be exclusively looking for diverse professionals and recruiting and training them.

So I would say, in the way it's written, which is too broad, one can say, okay, it's been met.

But then if you look at it and you look deeper into the question, and you say implementation and evidence-based interventions, we're still kind of not there because nobody -- no one can tell us which evidence is actually -- which therapy has the best evidence and it's going to work, or which method has bulletproof evidence that's going to work for children and adults across the lifespan or across the ASD spectrum.

And then if -- if we were to go into the diverse communities, they are still obviously behind. So there are not enough practitioners.

There are not enough providers. There are not enough -- we don't know how to do this.
So the objectives are written so broadly that it can -- one can look at it and say, well, there's a Latino one, we've met that. But there is so much more.

Dr. Daniels: Yeah, there's one about Spanish version of an online dissemination tool.

Ms. Abdull: So that's what --

Dr. Daniels: There are a few different things, but –

[Pause]

Ms. Abdull: So there's like nothing for African Americans, nothing for --

Ms. Crandy: Have you tested four methods, though?

Dr. Daniels: Have you what?

Ms. Crandy: Have we tested four methods?

Dr. Daniels: Looking through the list, what's your sense of that? Are there at least four methods that have been covered by the projects?

[Pause]

Ms. Crandy: I kind of think so, but what do

the others think?

Mr. Robertson: Well, it's -- how do we define testing in here? That's partly the only question I have as far as fitting with this is, well, we may have four things. What do we define as testing? That's the problem.

Dr. Rice: Yeah. This is Cathy. I think that's vague, and I think the intent was, is that there really wasn't -- when this was first written -- wasn't much of anything that we could point to in terms of the dissemination, implementation, sustainability. So I think what was meant was just a project-met area. And the challenge then speaks to, you know, there are four different ways that have been looked at to reach different communities.

But the capacity, the access to these methods and the capacity to actually follow up on the services is still not there. So that becomes the other important issue to note for the future.

Ms. Abdull: Mm-hmm, I agree.

Ms. Kavanagh: I agree.

Dr. Rice: But I think in terms of this

research objective, it should be green.

Dr. Daniels: So, actually, and folks, please look at this. I realize there's an error here -- that this should have been green because we've got $26 million in funding and $7 million that was recommended. So it should be green.

So in terms of absolute funding, you've -- you know, $7 million versus $26 million, and you do -- it does look like you're looking at at least four methods. But it sounds like maybe the Group is saying that perhaps the letter of this objective might have been met, but further work is still needed in this area?

Dr. Burton-Hoyle: Yes. This is Sally. I think so because many of the studies alluded to trying different sorts of things, but it's really not clear exactly what --

Dr. Daniels: And I think when you have the --

Ms. Crandy: We've met the money --

Dr. Daniels: Sorry. Go ahead.

Ms. Crandy: -- we've met the money, and we have looked at four methods. So we could say we need further work on it, but we have met this

objective.

Dr. Daniels: Okay. And you might get a better feel for what's going on in the field once we get the external participants involved on the next call and workshop.

So, so let's move on to the next one: "Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with ASD across the spectrum and of all ages living in community settings by 2015."

You have a recommended budget of $16 million and a spend of $603,000. So that is partial --

Ms. Crandy: I don't know believe we've met this.

Dr. Daniels: -- and very few projects. So what do you all think is going on here?

Mr. Robertson: Is this another case of accounting like before, where that's one of the reasons why the -- why the funding changed so dramatically? Where it's 3 out of the 5 years like there's nothing there, and then, you know, you get a little funding in 1 year and then 2 more years, and then, you know, is it accounting purpose for

this one or not -- or not like before with the HRSA funding?

Dr. Daniels: Hold on for a minute. Let me see if I can find out a little bit more about the project.

[Pause]

Ms. Kavanagh: It looks like all of the projects in --

Dr. Daniels: They're Autism Speaks, right?

Ms. Kavanagh: -- 2009 are Autism Speaks, yeah.

Dr. Daniels: So then they were probably short-term funding. So then it doesn't look like -- unless you know there are Federal funds that might have gone into another category here that also were covering this area. Laura, do you have any thoughts in terms of HRSA's work and if this is covered at all in maybe other projects that got categorized elsewhere?

Ms. Kavanagh: I think that this is so broadly worded that people probably fixed -- assigned more specific objectives to it.

Dr. Daniels: Mm-hmm.

Ms. Kavanagh: So I think that's more the issue

with this objective.

Dr. Daniels: Do others concur with that or have other thoughts?

Dr. Mandell: This is David. I think that the efficacy and cost-effectiveness, it's the "and" that's killing you. So there's -- I think that there's much more efficacy or broadly effectiveness research going on. But my read even of the things that are being submitted in this area is there's really not a lot in the cost-effectiveness domain that's even being submitted for funding.

Ms. Kavanagh: Good point.

Dr. Daniels: Good.

Ms. Crandy: And I don't think we addressed all ages.

Ms. Kavanagh: Correct.

Dr. Daniels: So it looks like this objective, you know, apart from maybe any other funding that might be elsewhere, has not been overly successful. So you -- would the Group want to make a comment about possibly the wording of this objective possibly needing more clarification in

the future?

Ms. Crandy: I think that we could change the wording, but I think that it's important that we find cost-effectiveness.

Dr. Mandell: And fund it.

Ms. Crandy: It's easy to look at it.

Dr. Daniels: Or that you just -- it's not -- I guess David had brought up the point that maybe the way it's worded makes it a little bit difficult to categorize things here. But I guess if you want to stick with kind of how this -- not that we're changing the wording of the Strategic Plan right now -- but if you wanted to just go with what we have here that, plain and simple, more work is needed.

Dr. Mandell: Well, could I make another suggestion? This is David again.

Dr. Daniels: Sure.

Dr. Mandell: Is that certainly more work is needed, and so -- and I apologize for missing the first part of the call. Is that the -- is that the sort of the wording that's available to us?

Because there is a sort of easy, specific

suggestion we could make about the cost-effectiveness component, which is that there be supplements to existing efficacy and effectiveness grants specifically to study cost-effectiveness.

Dr. Daniels: Mm-hmm.

Dr. Mandell: So that could easily build on currently funded research.

Dr. Daniels: Yeah, and that would be a strategy point that probably could be brought up on one of the future calls in terms of --

Dr. Mandell: Okay.

Dr. Daniels: -- how do we address the problem with meeting this objective? And that would be a strategy that could be brought up.

Dr. Mandell: Okay.

Dr. Daniels: So take note of that because maybe we can bring it up in the future. So it sounds like this one is far below expectations. So does that accurately capture what you all think?

Ms. Abdull: I would say so. This is Idil.

Ms. Kavanagh: Yes.

Mr. Robertson: Yeah, I concur, yes.

Dr. Daniels: Okay. Good. The next one then:

"Evaluate new and existing pre-service and in-service training to increase skill levels in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers to benefit the spectrum of people with ASD and to promote interdisciplinary practice by 2015."

Ms. Crandy: I think a lot -- I think this is an area that has been really addressed. Do I think that we've met the need? No. But I think that we really have done a lot of research in this area.

Dr. Daniels: Laura, do you have any comments on this area, since it's an area that HRSA is a large funder in?

Ms. Kavanagh: So the bulk of our funding around ASD is in interdisciplinary pre-service and in-service training. So I think that's completely reflected in the year 2010, and then in subsequent years, we reported just more particular research aspects that were included in the training program.

I think we've made significant investments here. We still have a long way to go to make sure

that becomes the standard of practice in every training -- every training arena -- but I think we've made significant progress.

Ms. Abdull: Would that be, Laura, the LEND? Would LEND be part of that?

Ms. Kavanagh: Yes, LEND and developmental behavior pediatrics training programs we support. So there are 43 LEND programs across the country, and there are 10, only 10 developmental behavioral peds (pediatrics).

Ms. Crandy: And I think the educational area, too, has significant -- Department of Ed has done lots of grants in this area, too. Yes.

Dr. Daniels: Larry, do you have any comments?

Dr. Wexler: In terms of -- in terms of what? I mean, this is -- this is about studying sort of personnel prep. We don't really study it. We do it. You know, I mean, we actually fund training.

So --

Dr. Daniels: Mm-hmm.

Dr. Wexler: -- I don't know if IES is doing anything around it. I don't tend to think so, not a whole lot. I mean, a lot of the -- a lot of the

listings there from OSEP, most of the Department of Ed are personnel training grants. They're not research on personnel training.

Ms. Kavanagh: The same is true for HRSA.

Dr. Daniels: Right. And so, we -- in the guidance that we provided in the past year with the discussion with the Committee last year, we added some additional guidance asking only for projects that involve more innovative types of training and evaluation of the training -- so really trying to develop or improve training versus just delivering standard training, for it to be narrowed down to that. And then this is the list that we got back.

So it sounds like, you know, Department of Ed had a number of things, and what I'm assuming is that each of those projects involved an evaluation component to evaluate the effectiveness of those training programs.

Dr. Wexler: We do an evaluation overall of our training programs. But, yeah, there's an evaluator for each of those projects, but what we're really looking at right now is we've embedded language in

the priorities which is asking the grantee, so the university training program, to pursue how well the trainees do in actual schools and programs.

What their -- are they rated by their principals, for instance, as effective or highly effective?

But that's down the line, and we're going to have to -- yeah, I mean, frankly, we -- we're collecting those data. We're not sure what we're going to do with them yet, and the whole -- whole evaluation of special education providers is very challenging. So, but that's the direction we're going.

Dr. Daniels: Okay. So --

Ms. Abdull: I have a -- sorry. I have a question for Larry and Department of Ed. There is one training paraprofessionals in 2012, the same question -- paraprofessionals to provide appropriate social opportunities for children with ASD.

And I just wonder -- I always see a lot of training and professional development for ASD special Ed teachers, but not -- and I wonder what

Department of Ed's take is, not a lot for paraprofessionals, which, if you think about it, that person is the person who is with the child the most and they're not really trained on not even ABA or other developmental therapies or even positive behavior supports.

I just wonder if there is a way -- I don't think we've met that part of the objective. We've done a lot for training the teachers and the other professionals, but the paras, who are mostly with the children, I think we're lacking there. And even this one, it's only $20,000.

Dr. Wexler: I think you're totally right. However, we have a shrinking budget, due to sequestration as well as simply not getting congressional approval for increases in our personnel preparation budget. It has gone from $91 million to, I believe, $86 million currently. And we have to serve all ages and all disabilities.

So I mean, I think you're right. There could be more done with paraprofessionals, but we have to kind of triage what we can make investments in.

I would say that the main training grant

program that we do, it is -- it is open to programs who want to train paraprofessionals. We get very few applications from that community.

Part of it just -- I'll expand just briefly -- Part of that's because a lot of the paraprofessional training programs, I think the vast majority, are not necessarily disability focused. They not only don't focus on disability in general; they don't focus on a particular disability. There are very few of those programs that do.

The vast majority of “para” programs are preschool programs, and they may touch on autism, but they're also touching on intellectual disabilities and emotional disturbance and the whole spectrum of disabilities. So that's our -- that's our challenge -- and I recognize, I don't disagree that we could do more. We would love to be able to.

Ms. Abdull: Thank you very much.

Dr. Daniels: If we want to summarize this area, I think what I may be hearing, the recommendation was for $8 million over 5 years,

and we've got $46 million estimated as potentially having been expended in this area. So in terms of the funding goals, those are met, and in terms of projects, you have a number of projects.

However, there is a need to potentially sustain this area, and even if the initial goals were met, that you would want to continue work in this area. Is that -- is that reflective of what this group thinks?

Ms. Crandy: And I think a justification, too, for it is we know we don't have the workforce out there to serve the population.

Dr. Daniels: Okay. So there are remaining significant workforce needs.

Ms. Crandy: Mm-hmm.

Dr. Daniels: And possibly more of an emphasis on paraprofessionals is one thing that came up.

Ms. Abdull: Mm-hmm. I agree.

Dr. Burton-Hoyle: I agree.

Dr. Daniels: Okay. So that's --

Mr. Robertson: I agree.

Dr. Daniels: All right. So we will note that and move on.

"Evaluate at least two strategies or programs to increase the health and safety of people with ASD that simultaneously consider principles of self-determination and personal autonomy by 2015." And we have a handful of projects from 2010 through 2012 just because the objective didn't exist until 2010 and a recommended budget of $2 million over 2 years and $631,000 that was spent.

So what's your sense of this one?

Ms. Abdull: So we haven't -- this is Idil -- so we haven't met -- the budget was small, to start with, I think -- and we haven't met it. And then also if I can comment on -- I think we need more for reducing obesity. And I say this because children and people with autism either over eat or under eat, the way from what I've seen. It's never, like, moderation.

And so when they overeat, then there is the risk of obesity, and that's another second medical condition. And a lot of these waivers or anything from CMS -- they are 1915(c) or 1915(i) or any of those home and community waivers -- they don't really support for children or people with autism

who are obese to get active.

They don't pay for those services because they say that's -- at least for children. And it's not like you can take children to -- with autism, especially if they have nonverbal, other sensory issues to a regular playground or have them join a regular soccer team.

So I think in this area, we need to do more, and maybe if we had research -- maybe if CMS had research that says, look, these children are -- you know, can be more obese because they're overeating, because they're having difficulty with food or with feeding, maybe they'll be prone to pay for it or cover those services.

Right now, I am not seeing any CMS waiver that covers helping children with obesity. And with this, you know, get healthy, all this stuff that President Obama's wife does, it doesn't really help people with disabilities because nobody covers it.

Dr. Daniels: Right. So --

Ms. Kavanagh: Idil, this is Laura --

Ms. Crandy: I think, too, Idil, on that is --

orders within our population, too, because some of the self-stimulatory behavior.

Ms. Kavanagh: This is Laura. It doesn't address the issue of services being available. But in 2013 HRSA did fund a Healthy Weight Research Network. So it will be addressing some of the research issues that you're raising --

Ms. Abdull: Oh, good. Good. Thank you.

Ms. Kavanagh: -- but it's not addressing -- it's not -- it's not to where you're -- the issues you're raising in terms of services and CMS.

Dr. Daniels: Right. And similarly, in 2011 and '12 there was a grant that was funded by NIH for reducing obesity risk in children with developmental disabilities. It's a small grant, about $29,000, almost $30,000. But that is addressing part of that. And there is also one about the effects of a bicycle training intervention on health, physical activity, sleep, and so forth that may touch on that a little bit.

But certainly here --

Ms. Abdull: That one has -- Susan, that one has zero. Does that mean it's been funded in 2012?

It's been funded before, and so it's just not added here?

Dr. Daniels: Yes. That would mean that it's something that received its initial funding earlier, and it's an ongoing project that didn't receive a new increment that year.

Ms. Abdull: Right. Right, right, so I guess my point is, once these -- once we know the results of these studies, hopefully, then CMS is driven or those that pay for autism services are driven by research. And so then, if research says these children have, you know, the risk of obesity because of this or that and the other, then they will be more prone likely to pay for it.

So I just hope that we can do more than $29,999, you know, in those studies throughout the country, and then even more, I'm noticing in obviously communities of color and socioeconomics.

Because if you've got the funding, you can maybe get -- hire your child to do -- one person just or help them run around. But if you're low income, if you're a minority, it's even worse.

So if we can concentrate more on, is the risk

higher -- the risk of obesity -- is it higher on those of low-income and racial and ethnic minorities, I think then we can decrease the secondary medical conditions that these children and people can get because of that risk of obesity.

Dr. Rice: Yeah, I think -- along those lines, I think looking at health effects of quality of nutrients and diet is important, too, whether not just over or underweight, but also the quality and what are the long-term implications of the restricted food diets and the types of things that are consumed, in addition to potentially reduced access to physical activity and community events as well that help with physical activity.

Ms. Abdull: Thank you, Cathy. That's -- that's perfect. Because my own child has for I think 4 years ate chicken and rice and salad from one particular Whole Foods store for like 4 years.

So, obviously, he wasn't getting the nutrients, and you could do supplements. But nutrition and feeding is just a huge problem for this community.

Dr. Daniels: And that may have some overlap with one of the comorbidities-related objectives because with some of those GI studies, they do touch on diet. So we might need to check there to see if there might be some overlap.

Also you'll note 5.S.D and 5.L.D have some overlap as well because safety is in both. And in this group, there was a grant in 2012 for teaching stranger safety skills to children, and there was one in 2011 on teaching children with autism to seek help when lost. But there was also a wandering study that was counted as 5.S.D.

So there is a little bit of coverage that might cross more than one objective. But overall, it sounds like work has started in this area, but significantly less funding than what the Committee might have thought. So would you all think that this is partially -- the work has started, but much more needs to be done?

Mr. Robertson: Yes.

Dr. Burton-Hoyle: This is Sally. I'd concur with that. It's such a broad thing, and there are so many aspects of life that have to be

considered. You know, having seen the bicycle study, because that's where I live, in Ann Arbor, it's an awesome -- it's kids with absolutely significant behavioral issues that are learning to ride bikes.

I mean, but there's so many pieces to it that I think touch on a number of other different things. So asterisking or however you can do it, but it's covered in other ways, too.

Dr. Daniels: Okay. Well, I think then that one -- we're good on that one. So let's move on to the last one in this question, which is "Support three studies of dental health issues for people with ASD. This should include one study on the cost-benefit of providing comprehensive dental services, including routine and non-routine emergency medical and dental or surgical dental services, denture coverage, and sedation dentistry to adults with ASD compared to emergency or no treatment. One study focusing on provision of accessible, person-centered, equitable, safe, effective, efficient dental services to people with ASD, and one evaluating pre-service and in-

service training programs to increase skill levels in oral health professionals to benefit people with ASD and promote interdisciplinary practice." And another one that has a number of things combined.

And in terms of the funding, $900,000 was recommended, and we have $948,000 that we've been able to capture through the portfolio analysis and a few projects here. In 2011 and '12 there is a CARD project and two NIH projects -- one on establishing compliance with dental procedures in children with ASD, sensory-adapted dental environments to enhance oral care for children with autism, and developmental disabilities dentistry online. So, so what do you all feel about this one?

Mr. Robertson: So I think -- this is Scott. I think that the funding is aligned. I just don't know whether it's completely meeting the goal in that it's kind of limited to children, not necessarily looking at what dental care looks like as far as going into adults.

But other than that, the funding is, you know,

on target, I think.

Ms. Crandy: Have we answered all the questions?

[Pause]

For each of the studies?

Ms. Abdull: Do we have --this is Idil. I don't see the service training. So like, that would be training because that's a huge -- another problem. These children and dentists just don't mix. And I feel as though a lot of times there are not enough trained dentists to deal with people with autism or even that place is -- you know, if you have sensory issues, the dentist can make anybody scared.

Dr. Daniels: I don't have the abstracts in front of me to look to see if there was training involved in any of these.

Ms. Kavanagh: This is Laura. We do include dentists as part of the interdisciplinary teams, as part of our LEND programs. But it's probably the toughest discipline to get people, both faculty and trainees, on those teams. It's very uneven.

Ms. Abdull: Yeah, I've actually never seen, at least in the LEND in Minnesota, I don't think I've seen a LEND trainee that was going to be a dentist.

Mr. Robertson: Is the -- is the difficult part of it also why -- why it's not necessarily covering across the lifespan?

Ms. Kavanagh: I think it's probably linked. I think that's a good point. I think if they're not comfortable providing services to children and young adults, they might not be comfortable providing services to adults as well.

[Inaudible comment]

Dr. Burton-Hoyle: In treating autistic persons, people have been bitten. When dentists get bitten, then they seek training.

[Laughter]

So I don't know -- maybe more dentists need to get bitten because that's been the emphasis on many of the trainings I've got.

Ms. Kavanagh: We have pockets of great -- University of Washington has wonderful connections with both community dentists as well as dental

residents and others, but there are just – there are pockets of excellence, but they're certainly not national.

Ms. Abdull: This is Idil. I wonder if the problem here is more awareness. I've noticed that the dentist just seems to think I need to know teeth, not so much about anything else that's going on with the patient. And they do good if you have diabetes or if you have colds or if you have other medical conditions, but I don't know if they do good with any disability, not just even autism.

And I think maybe just, kind of like, "learn the signs, act early," if we can also do some campaign. And I know it's not this objective, but I think maybe the problem is awareness, educating and making dentists -- the dental professionals -- more aware that, yes, you do need to be trained and you do need to understand how to serve this population.

Dr. Daniels: So then --

Dr. Rice: Maybe that's a suggestion for a future rewrite in terms of really needed to focus on the public awareness and accessibility of

models out there and tools that could help make dental visits doable and successful, that they're crucial.

I mean, I think then a question would be, do we want to think about that for the broader many health issues that go along for people with autism where they may have those ignored and seen as part of their autism or not as essential, but we really don't have a good focus on what the long-term outcomes are of that ignoring of those health issues, as well as the challenge that, you know, people are people and have health issues and need to be attended to proactively.

So you know, maybe that's just a note for future thoughts in terms of the next iteration of the Strategic Plan to really think about the whole health issues in context and how can we do a better job of increasing awareness, understanding accessibility of tools and supports that help keep people with autism proactively healthy.

Ms. Kavanagh: Healthy. That's a good point, Cathy. This is Laura. I'm struck with this one about how specific this objective is compared to

all of the other objectives. Does anyone remember the history?

Dr. Daniels: Yes, I do. So this is Susan. With our group, I think Ellen Blackwell kind of led the charge on this, and I think that she had particularly had some experience in this area. And she has an adult son with autism, and dentistry was one area that she was very concerned about.

And so, in working with the Committee, they decided to make this dental area a priority. And I know from NIH in particular, they have seen this objective, and I think that it was influential in some of the work that they've ended up supporting.

Ms. Kavanagh: Terrific.

Dr. Daniels: So I think that what I'm hearing here is that while the funding is on track, that there is a gap in terms of the lifespan issue and that adults are not particularly addressed in the currently funded projects and that you may be missing a training component for professionals in this area that is needed.

And so, would that be a good summary of where things lie with this one?

Mr. Robertson: Yeah, I concur with that.

Ms. Crandy: I concur, yes.

Dr. Rice: Yes, Susan, I would just add that instead of being so narrow, we need a more comprehensive health focus and what are the components of good health beyond dental, making sure that that's also included, but --

Dr. Daniels: Okay. Good. So we have that. And then the last part here is just as the core activities funding, maybe instead of calling it "Other," was at $36 million, and you have a listing of those projects, and I gave a little summary --

Ms. Crandy: Susan?

Dr. Daniels: Yes?

Ms. Crandy: Because looking at some of those projects, they can't fit under some of our other bullets points for sure? Because there seemed like some of them could fit under, like there were a couple that looked like they could go under "health."

Dr. Burton-Hoyle: And also "family navigation" or whichever -- that sort of objective.

Dr. Daniels: Family navigation -- From the work we did with these funders, they didn't feel that these particular projects fit well within the objectives, and remember, the objectives are covering gap areas. And so, we don't expect that the entire portfolio of projects is going to fit in just the gaps; what we expect that there, hopefully, is a foundation of other projects going on besides the gap area projects.

If there are particular ones you want us to look at, we could look at them, but we would have to contact the funders.

Ms. Abdull: So this is -- this is Idil, Dr. Daniels. So training, training personnel in minority institutions to serve -- that would fit with the first objective we had that I had questions on -- we need more -- more, you know, communities of color. I thought that if that was in there, I probably wouldn't be so pissed.

Ms. Crandy: Yeah, I thought there were a lot of training ones that could be moved into different areas for sure.

Dr. Daniels: So last summer --

Ms. Crandy: Collaboration with adolescent autism teacher training -- that could make the training meeting more of the ACE band. School psychologists, GNSA students -- there are quite a few that I thought could move.

Dr. Daniels: And that was really part of the discussion we had with the Committee last summer in July. We originally -- if you look in the training, 5.L.C, that one in 2010 had 83 projects, and then at that point in time, everything related to training was going into that objective. But then the Committee was concerned last summer when they saw what was in that objective, and they said that they really wanted this objective to focus on projects that are doing evaluation and not just to include all training.

And so anything that's training that doesn't really involve as much of an evaluation component went into “Other.” So that was a change we made based on the Committee's recommendation last summer.

So if the Committee changes their minds and wants to do it differently now, we would -- I

mean, we certainly want to hear your feedback about that, and if we do need to make a change, we would want to discuss that with the Committee.

Does this Group have that sense of -- I mean, this is the difficulty. It's not black and white. It is -- there are gray areas, and the risk of moving things out of the objectives because they don't fit absolutely every piece of it is that you might miss a lot of things that are already funded and think that there's nothing going on, and that was the approach we were taking with that earlier.

But then I think the Committee had the opposite concern last summer that, instead, maybe too much is being counted and that isn't relevant. So what's your feel?

Ms. Crandy: Susan could -- sorry. Then could we take these categories for "Other" and break them up into, say, that it's for training or for that -- just so that we get a sense that this is occurring, but it's not about the evaluation process. Because I think, for sure, it would be nice to see that we are touching those diverse populations at least through training or if we

could break those up a little bit more.

Dr. Daniels: So we actually have done the subcategory coding for the -- all of the projects, including the other projects, and we have that information. We haven't presented it in a specific graph to you. But we -- for example, all the training-related "Other" projects we can pull up through our data. And eventually, when it's on the Web tool, you'll be able to do it in the Web tool.

But if you want to have that listing, we could -- we could give you a listing of all the training-related projects in that -- in the "Other" category. In terms of the diversity-related things, we don't have a subcategory for that. So that would have to -- that could only be done by actually reading through all the projects and determining whether they had a diversity component to them.

Ms. Abdull: I have a -- can I ask a question, Dr. Daniels?

Dr. Daniels: Sure.

Ms. Abdull: On the diversity and disparity issues, did we decide at the August meeting there

was going to be like a planning group or sub-planning group for that, along -- in addition to the comorbidities or -- I thought we did that?

Dr. Daniels: We are having -- we have the Services Subcommittee, and they are going to be doing a project related to disparities, but there's not a disparities planning group.

Ms. Abdull: Okay. So the people who then signed up for it, which included me, then those -- because I saw when you said to decide which group do you want to be on, I saw the comorbidities and I didn't see the disparity, and I thought we wanted first the disparity and then people said, well, let's do the comorbidity different or separate --

Dr. Daniels: So the comorbidities --

Ms. Abdull: -- or did I misunderstand?

Dr. Daniels: The Committee voted to create a planning group for that under the BTR Subcommittee, the Basic and Translational Research Subcommittee, but that group has not met as yet.

Ms. Abdull: Okay. And the disparity one hasn't met either, or that's all of us or --

Dr. Daniels: There is no specific disparities planning group. There is a Services Subcommittee -- Services, Research, and Policy Subcommittee that will be discussing disparities, but we have not scheduled another meeting of the Subcommittee as yet.

Ms. Abdull: Okay. That's -- yeah, thank you. That's the one I wanted to know.

Dr. Daniels: Sure. Yeah. So we'll let you know.

Ms. Abdull: Too many meetings. I feel for you. It just feels like if I'm confused in my little two meetings, I don't -- I can't even imagine how you feel.

Dr. Daniels: Yeah, this fall we have a lot of -- we have six different planning groups running concurrently and running multiple meetings, plus we have a workshop and a full Committee meeting. So that's keeping us all pretty busy, I think.

Dr. Wexler: Susan? Susan, this is -- this is Larry from Education. I just wanted to put a note of caution. We are not permitted to solicit training for particular minorities or ethnic

groups. So we cannot -- we cannot post something that says we would like to train African American teachers of children with autism or Hispanic teachers of children with -- you know, teachers of children with autism.

That's kind of a Supreme Court thing that happened a number of years ago.

Dr. Daniels: Mm-hmm.

Dr. Wexler: I mean, what we -- when we say minority institutions, now, frankly, there's an implication, or there are two things going on there. We are supporting minority institutions, which is OSEP has a long, long history with that because it's in our legislation for IDEA.

There is also an assumption that when you're supporting minority institutions, you may be getting a lot of minority trainees. That isn't necessarily true because, you know, Johns Hopkins is a minority institution under Federal law. So is University of Maryland. So is, you know, Berkeley, I mean, for a variety of reasons.

What we do is we state -- there is specific verbiage around recruitment of minority candidates

for the program, but it's not exclusively targeted as such. So we would not have -- we would not be funding a cohort of trainees of a particular ethnicity, and if that was the requirement to be trained, that wouldn't be consistent with Federal law right now.

Dr. Daniels: Thanks for sharing that. So is there any other item that we need to discuss for Question 5? We have half an hour left on the call in terms of the official time that we were supposed to be on the call. So if there isn't any further discussion for Question 5, I'd like to move into Question 6. But --

Dr. Wexler: Hey, Susan?

Dr. Daniels: Sure.

Dr. Wexler: Before you go into 6, can I quickly give a little bit of good news to the -- to the people on the Committee and the public?

Dr. Daniels: Sure. Sure. Please do.

Dr. Wexler: We just -- you may or may not be aware of it, but we just funded a program called PROMISE, which is Promoting the Readiness of Minors in Supplemental Security Income.

Essentially, we're looking at randomized controlled trials of a minimum of 2,000 subjects, and these are children who are -- have disabilities and are on SSI, and it's looking at improving their outcomes, improving the outcomes for their families, and ultimately, we want to look at do these children come off of SSI?

We made these awards to California, to New York, to Wisconsin, to Arkansas, to Maryland, and a consortia that consists of Utah, South Dakota, North Dakota, Montana, Colorado, and Arizona. This is -- this was a $210-million effort on our part.

And what -- I only bring it up in that it will be focused on -- on, you know, kids with significant disabilities and not significant disabilities.

And folks in those States, as they just got these grants, who want to kind of get a seat at the table might consider contacting their States because children with autism and really young adults with autism is what we're talking about, can benefit dramatically from this program.

So they're just -- they're one of many

populations, but it is there. So I'm sorry. That was just a commercial for the Department of Education.

Dr. Daniels: Great. Well, thank you for sharing that information. And actually, at the upcoming meeting, maybe we can have you elaborate a little bit more on the program?

Dr. Wexler: My pleasure.

Dr. Daniels: Great. So let's move on to Question 6, as we have a small amount of time, but I think the Committee, the Group has now gotten the feel for how we're going through this, and hopefully, we can get through these efficiently.

So the first objective we have in Question 6 is 6.S.A: "Launch at least two studies to assess and characterize variation in the quality of life for adults on the ASD spectrum as it relates to characteristics of the service delivery system, that is, safety, integrated employment, postsecondary educational opportunities, community inclusion, self-determination, relationships, and access to health services and community-based services, and determine best practices by 2012."

And just to point out that, as you look at the wording of the objectives in the cumulative funding table, the blue and red type in the font indicates that those were wording changes in various iterations of the Strategic Plan. So you can see that this objective had significant changes in its wording over time.

So $5 million was recommended over 3 years, and about $1.8 million, $1.9 million was funded so far.

Ms. Abdull: So, clearly, we haven't met the budget one. That would be --

Dr. Daniels: Right.

Mr. Robertson: You know, one -- one positive on this one, though, and I don't know whether it's the result of accounting changes, is that the funding at least has been -- has been shifting in the upward direction, though, and the number of projects has been going up as well. So that's a -- that's a positive.

Ms. Abdull: This is Idil. I wonder if the other reason might be this one, the projects have the least funding. I mean, they have like, you

know, $24,000, $20,000, as opposed to the others that we've done in Chapter 5, which had -- some of those research had hundreds of thousands.

So I wonder why we're spending, are people just -- those researchers -- just asking for less, or are the agencies on the ground just offering less money to do the studies?

Ms. Crandy: This is Jan. And I think, too, even if we look at the pie charts overall for adults, it's like 1 percent or less than 1 percent over all of our time of -- years of funding.

Ms. Abdull: Right.

Ms. Crandy: You just are not funding this area appropriately at all.

Dr. Daniels: Well, this is kind of an emerging area, too. And initially, when the Strategic Plan first started, we didn't have a Question 6. We -- that kind of evolved -- well, we didn't have a focus on adults, and that has evolved over time.

So I think that awareness in the community is also rising. So I think that this is evolving and emerging. So we wouldn't necessarily expect this area to be as mature as some other areas that

maybe have been recognized for a long time.

And to answer Idil's question, the amount of funding may vary from funder to funder in terms of the size of grants they offer. So you know, typical NIH grants might be a lot larger than what some of the other funders might have for their particular subject area, and that just is, you know, a matter of how that organization or agency does its funding.

So, so what do you think in terms of the projects we have here? We haven't met the budget, but what's the scope of these projects, and how well does that align with what the Committee intended?

Dr. Burton-Hoyle: I think they're great. They're great projects, and again, under what it asks for, yes, I think it does meet their needs.

Why there's not more of an emphasis, unfortunately, is because of the overemphasis on early intervention because people think, well, we don't -- we're not going to need anything if we get them cured quickly.

But it is meeting what it says, but again, not

enough.

Ms. Crandy: I think, too, there needs to be some evaluation of if they did not get treatment, what is the lifelong cost and what different treatments did they get? How does that affect the cost of taking care of someone the rest of their life, too?

Dr. Daniels: Mm-hmmm.

Ms. Crandy: More long-term outcome studies.

Mr. Robertson: Well, we actually do -- I mean, they're not necessarily to -- on this question. But the outcome studies related to long-term life and adults, et cetera, I mean, there have been a number of those that show a lot of problem areas when supports are lacking on these things, on employment and postsecondary Ed and things like that.

So there -- there actually are some studies like that that have been done over the last, you know, 10 and 20 years. But you know, they haven't been done with looking at, you know, exactly aligned to this of supports on each area where -- you know, what's been funded here and whether it's

making a difference in terms of outcome or not.

They haven't looked at that. It's mostly been just kind of broad outcome studies, you know, regardless of what support structures look like.

Dr. Burton-Hoyle: Right.

[Pause]

Dr. Daniels: Any other thoughts about the array of projects that was devoted to this area?

Ms. Abdull: I just -- I just have a question about the safety. I see a lot about the employment and postsecondary education, but especially safety in adults. I mean, we saw in the other chapter a couple of studies for safety or wandering/elopement for children. But the same can happen for adults, and I just wonder if I don't see it or if it's not here? I'm looking at all the years, and I don't see safety, looking at the adults with autism and their safety. So maybe we haven't met with the money, and we haven't met with every part of the objective is my take on it.

Ms. Crandy: Scott, and you probably know this area the most, do you feel like we've met this?

Mr. Robertson: Did you say Scott?

Ms. Crandy: Yeah.

Mr. Robertson: Yeah. I don't -- you know, I don't -- I mean, I'll be honest. On a lot of these, I don't think that we've met it, but you know, we're -- we're getting a little bit better. But, like, it's we're still -- we're still substantially off target.

So yeah, I -- you know, I'd say -- you know, but I do like to see on that first objective that there's the improvements on the -- on the funding -- the fact that it has been in the upward trajectory is a good thing. But it's still, you know, pretty substantially off -- off what it should be.

But you know, if it continued to go up like that in terms of, like, the -- the doubling seen between 2010 and 2011 and then the doubling again 2011 to 2012, you know, if it continues that and if it were to be, say, you know, $2 million this year, and I don't know what this year's funding looks like, then, you know, that would be -- you know -- that would certainly be a positive sign that it's going in the right direction.

Versus some of these other ones, you don't necessarily see this pattern of an upward trajectory on the funding. So that's a positive at least. I mean, it's a silver lining on this. Even when it's not even near adequate, it's starting to move in that direction.

Now if it levels off for this year and 2014, then you know, I get -- that upward trajectory would no longer hold, I guess.

Dr. Daniels: So, so then what I'm hearing is that you feel that this area is moving in the right direction, but much more is needed?

Mr. Robertson: Yes, yes.

Ms. Crandy: Yes.

Dr. Daniels: All right. Can we then wrap up that one and move on to the next, just in the interest of time? Ms. Crandy: Yes.

Dr. Daniels: "Evaluate at least one model at the State and local levels in which existing programs to assist people with disabilities -- examples, Social Security Administration, Rehab Services Administration -- meet the needs of transitioning youth and adults with ASD by 2013."

And the recommended budget was $5 million. About $2 million has been spent so far.

Really a very small number of projects. So it should be pretty easy to look through the project list.

Ms. Crandy: It seemed like we met what the question asked, but we've not spent the funds.

Dr. Daniels: So maybe they were smaller projects than what was envisioned by the Committee?

Ms. Abdull: But not the funding. I don't think we met the funding, right?

Ms. Crandy: But if we answered the question and saved money, that's a good thing, too.

Ms. Abdull: That -- is that a -- yeah, I suppose that's cost effective.

Dr. Daniels: So in 2011 and '12, it's the same two projects. One is a voc (vocational) rehab one from Department of Education, and oh, the second one is also voc rehab from Department of Education.

Ms. Crandy: But we said we would look at one model.

Ms. Abdull: So Social Security, do we have something for SS, Social Security?

Ms. Crandy: No.

Ms. Abdull: So we haven't met then all the --

Mr. Robertson: Yeah. We've only met -- we've only met, you know, half of it in terms of the areas because it was supposed to be Social Security and rehab, and we only did -- we only did the voc rehab part.

Dr. Daniels: Actually, it says "examples." So if they say examples are X, Y, and Z, that doesn't mean all. It usually means, you know, some examples of what could potentially apply. But -- but in any case --

Mr. Robertson: Well, yeah, but the only -- it was only two examples that were listed, Social Security and rehab. It's not like it was a list of seven things. So it might be nice to see -- have the intention to fund both of those?

Dr. Daniels: Well, it's --

Ms. Abdull: Plus, more people are on Social Security, I would say, that have autism. So I would think that would -- that would be the

priority if the two -- if only one of the two were to be done.

Dr. Burton-Boyle: I think that is so important. I think that that's a missing piece. That's very --

Dr. Daniels: Okay. So it sounds like partially met but has not addressed the Social Security aspect?

Dr. Burton-Boyle: Yes.

Mr. Robertson: Yes.

Ms. Abdull: Mm-hmm. I agree.

Dr. Daniels: Okay. Alright, let's keep moving. The next one --

Dr. Wexler: Susan? Susan, just remember that some autism-related work will be done as part of PROMISE.

Dr. Daniels: Okay.

Dr. Wexler: So that would be in 2000 -- fiscal year 2013. So, and that's potential --

Dr. Daniels: Okay.

Dr. Wexler: I have no idea how much money that is, but we'll be sort of figuring it out in terms of how many kids with autism are affected.

Dr. Daniels: Okay. That's great to know. We'll make a note of that.

Okay. The next one is 6.S.C: "Develop one method to identify adults across the ASD spectrum who may not be diagnosed or are misdiagnosed to support service linkage, better understand prevalence, and track outcomes with consideration of ethical issues, including insurance, employment, stigma by 2015."

There's only one project here and, you know, $8 million that was recommended, and $56,000 spent. So I think that one is pretty clear that you're far below the recommended budget and --

Mr. Robertson: Susan, I think this one is probably perhaps arguably, one of the most underfunded of pretty much any of the objectives, where we intended to spend $8 million on this and only -- you know, they only spent $56,000. And it shows up pragmatically that there's nothing -- there's not really anything -- really substantially fruitful in this area as far as really good standards for getting, you know, real innovation on getting autistic adults who aren't

already identified and diagnosed. So things are more done on an ad hoc basis, and that hasn't really changed in the last few years.

Dr. Daniels: Yeah, so -- and the project that's funded in 2011 and '12 is an Autism Speaks project called Development and Refinement of Diagnostic Instruments for Use with Adults with ASD. So that sounds like it is addressing this issue.

Cathy, do you have any comments from CDC about anything with diagnostics and adults? Or Laura?

Dr. Rice: Yeah, I would just say that really this is -- if we could give this one a red, that that would probably be most appropriate. For the end, because there's no funding continuing on, there's really not much going on that I know of.

Ms. Crandy: Is there a tool developed yet or not?

Dr. Rice: So I think -- well, this project that's mentioned here, I think this is refining current diagnostic tools, and there are some screening and diagnostic tools that are applicable for adults. Whether that's sufficient and really

addresses the issue of trying to identify those that may have been not diagnosed or misdiagnosed and don't have access to services, that I don't really know of anything specific to that that's unique to adults versus access to care for people that need that based on the symptoms that they have.

That would be part of the typical outreach for seeking health care. So it's not really anything that we have any projects on.

Mr. Robertson: Yes. And you know, just as a comment on that is that partly, say, revising -- and I know some instruments are sometimes applicable to adults like the ADOS, et cetera. But a lot of those instruments don't meet a certain subset of individuals who -- particularly individuals who may have adapted a little bit, so you know -- may still have really substantial challenges, but because of vocabulary or language or communication, you know, may -- some things may get masked.

And -- and I don't think that in many cases folks are going to show up, you know, well on the

diagnostic instruments like the ADOS that exist right now, and I don't know how much refining those instruments rather than creating, you know, new things is -- has been really, you know, helpful in that area.

Dr. Rice: Yeah, and I think, you know, with the change in the *DSM-5* criteria, there was some effort in trying to look, include history, and to make sure that the issue of level of support needed is included. So if there are specific projects about adapting the *DSM-5* criteria to adults in particular, that could be applicable here. But that's not something that CDC funds. So I'm not sure.

Dr. Daniels: Well, great --

Ms. Abdull: This is Idil. So is it safe to say then we haven't met the objective nor the funding for this one?

Dr. Rice: Yes.

Dr. Daniels: I think so. I think that's what I'm hearing.

Mr. Robertson: Yes, definitely.

Dr. Rice: Definitely.

Mr. Robertson: Definitely have not met it, yes.

Dr. Daniels: So this one needs a great deal more work?

Ms. Crandy: I think we should change it to red.

[Laughter]

Dr. Rice: Yeah, I mean, I think --

Mr. Robertson: Deep red, like a very dark red.

Dr. Daniels: I guess our -- our tool that we -- the indicator or system that we've used here -- the red, yellow, green -- has been helpful. And in this particular table, of course, we were using the colors based on just pure dollars, but in the previous phone calls as well with the groups, I think that they kind of almost thought of their own planning group's assessment of red, yellow, green that's based on multiple components, not just the dollars.

And so I hear that one loud and clear and I think that that's a good analysis. I think on the next call and at the workshop, you might have a chance to interact with some experts in the field

to try to understand better or talk with the rest of the Committee about what are the barriers here and why is this not moving forward at a faster pace.

So let's move on to the next one: "Conduct at least one study to measure and improve the quality of lifelong supports being delivered in community settings to adults across the spectrum with ASD through provision of specialized training for direct care staff, parents, and legal guardians, including assessment and development of ASD-specific training, if necessary, by 2015."

And this one also kind of overlaps a little bit with some of the other training things as well, so you might keep in mind what you've seen in those. But in terms of projects that were coded specifically to this objective, it's a very small number and certainly far below what the recommended budget was. So what do you think about this one?

Ms. Abdull: How much of the 785 -- $7.5 million did we actually do?

Dr. Daniels: What's your question?

Ms. Abdull: How much of the recommended budget has been used?

Dr. Daniels: Oh, $619,000.

Ms. Abdull: So, again, we're in the hole here. And then even if you look at the number of projects --

Ms. Crandy: So --

Ms. Abdull: -- go ahead.

Ms. Crandy: So Susan, like, the last 2 years, both have zero, but there could be some money that's spent on those, and that's why those are yellow and not red?

Dr. Daniels: So those ones had active projects, but the projects probably got their funding the previous year or something or 2 years ago. They're both Department of Ed projects, and I know a lot of the Department of Ed projects have frontloading.

So the first year in a 5-year grant will get the money, and then the rest of the years no new increments go in, but the project continues on.

Dr. Wexler: A lot also, they may be on a no-cost extension. So it may have been a 5-year grant

and the grant ended, but they still had money and activities to complete. So that would -- that's why that would look like zero.

Dr. Daniels: So that's another reason it can be a zero, but there was actually funded work going on.

Ms. Crandy: Okay. But that's why they're yellow instead of red?

Dr. Daniels: Right, because we were -- yes, if they were yellow because in that case, there were active projects.

Mr. Robertson: Sue, it's a problem that we allocated funding in 2010, I guess, for the future, but they didn't -- you know, didn't revisit this in terms of they didn't allocate funding again in 2011 and 2012 toward this -- this objective.

Dr. Daniels: I don't understand what you're talking about.

Mr. Robertson: Because you're saying the 2011 and 2012 funding is not new funding, right? It's the same funding from 2010? Do I understand that right?

Dr. Daniels: It's the same project ongoing. So there weren't probably new projects. I don't know what's in the 2010 --

Mr. Robertson: Okay. So we -- so we didn't -- so it means we did not -- did not establish new projects in 2011 and 2012 to be funded, right?

Dr. Daniels: Right. I think that those -- I know that the 2012 project is the same as what was in 2011.

Mr. Robertson: Okay. That's just what raises the concern for me is that there wasn't anything new, you know, being focused on in 2011 and 2012.

Ms. Crandy: And I would say the projects do not address everything that's in that question either.

Dr. Burton-Hoyle: Exactly.

[Several speakers]

Ms. Abdull: I think the way the question is written, it says conduct at least one study. So when the objective itself just says one study, then one could say, well, we did one study. But then if you read through all of these things, the self-direct care, the parents, the legal guardian,

the assess -- I mean, all of those things could be their own study.

So one could say, yeah, we did one study, even though the amount is not obviously not even touching the surface. I mean, I have so many problems with the way the objectives are written that some are just too broad and then if you do just one thing, a person could say, well, we met it because we did one study.

Dr. Burton-Hoyle: I think the age span that it's missing is older than transition age.

Transition age is, you know, getting out of public education, public school, and transition is -- you know, that's too specific.

So I think it -- again, it's looking at older adults. It should be looking at older adults, too, the way I read the objective.

Mr. Robertson: Yeah, especially since it says -- it says “lifelong supports.” I mean, I agree that that --

Dr. Burton-Hoyle: Right.

Mr. Robertson: -- you know, that goes way -- that goes way beyond, you know, education

transition funding. I mean, that should be -- that should be going many, many years after education.

Dr. Burton-Hoyle: So we skipped from transition age to then older parents. So it's like a whole lot of people that are actually suffering that are kind of in that middle part. So that objective falls way short for me.

Dr. Daniels: So I think what I'm hearing here is that this one is far below expectations that really --

Dr. Burton-Hoyle: Yes.

Dr. Daniels: -- the projects that are there are not really fully addressing this area, and there really just aren't enough projects. There's not enough funding. Does that -- does that capture it?

Ms. Abdull: I agree. Yes, 100 percent.

Mr. Robertson: Yes.

Ms. Crandy: I agree.

Dr. Daniels: The Planning Group's color would be red here.

Dr. Burton-Hoyle: Yes.

Ms. Abdull: I think all of Question 6 should

just be red. I mean, we're just lacking in adults, if you ask me. We're just -- and these children do grow up to be adults -- and we're just not ready.

We're not ready for it when they become adults. Somehow we seem to think they're going to all get recovered or cured, and that's not the case.

Dr. Daniels: Right. Well, this is the newest kind of maybe fastest evolving area. So, so we may need to stay tuned for a while on this one. But we can see some evidence of progress, and in a few areas, we do see some evidence in other areas really not. So --

Ms. Crandy: And Idil, I would say the majority of the population, they're going to grow up, and we're -- States are going to be providing some level of support for the rest of their lives. So we need to really address this.

Ms. Abdull: Mm-hmm, yeah.

Dr. Burton-Hoyle: Yes, very important.

Dr. Daniels: So let's go to 6.L.A: "Develop at least two individualized community-based interventions that improve quality of life or

health outcomes for the spectrum of adults with ASD by 2015."

And we have a few projects here. We have about $8 million in funding versus the recommended budget of $12.9 million. So what do you feel is going on here, as you look through what was funded?

Ms. Crandy: I think some good stuff was funded.

Dr. Burton-Hoyle: I think so, too.

Ms. Abdull: This has -- this has the most.

Dr. Daniels: And a number of different funders. We have DOD, Department of Ed, Organization for Autism Research, HRSA, Autism Speaks, and NIH, at least on the --

Ms. Abdull: I just wonder -- this is Idil. For the quality of life and health outcomes, there is a lot of good stuff being funded for this objective, but I don't see for older, nonverbal adults.

Like, so the ability to communicate through other means, and I said this in other questions, I think we're just assuming all these adults are

talking, and they just may need some social skills or training, what have you. But I think we have to concentrate on the communication method for adults that have autism that are still either low verbal communication or nonverbal communication.

Dr. Daniels: I think, though, Idil -- this is Susan. I think that it's possible that some of the communication interventions would have ended up in Question 4, especially since there's an objective that specifically addresses that. So that's one area that we might want to look at as well for those specific items.

Ms. Abdull: Right. Right. Right. For adults, so communication in Question 4, even though -- so it crosses over. I see what you're saying. A lot of these researches can cross over to many questions.

Dr. Daniels: Right.

Ms. Kavanagh: Susan, this is Laura Kavanagh. I'm going to have to sign off just a little bit early. I have to go to another meeting in the building.

Dr. Daniels: Sure.

Ms. Kavanagh: So let me know if we don't finish how we'll follow up.

Dr. Daniels: Okay.

Ms. Kavanagh: Thank you.

Dr. Daniels: I'll do that. I'll be sending out an email follow-up. Thank you.

Alright, so, so you see a variety of projects here. What -- if there are some areas that aren't addressed, what do you think is missing? You said nonverbal adults --

Ms. Abdull: Sorry. Nonverbal adults, and then I know we don't have the housing and the employment, but that really is so important to the quality of life and their health outcome for adults with autism.

And it would just be really good if we can get something from Labor and HUD, even if it's not research, per se, but even if they're doing other grants to help these adults with autism live in their communities, you know, as independent as possible. It would just -- it would just fit this health outcome objective very well.

Dr. Daniels: And I think that if we do find

programs like that, they would most likely go in a different kind of report. They probably wouldn't go in the portfolio analysis because many of the projects -- I mean, the general focus of the portfolio analysis tends to be toward research, although as I said a couple of times on this call, it gets really tough in Questions 5 and 6 because the definition of research, I think, becomes a little bit harder to pinpoint when you're looking at services issues.

Ms. Crandy: Susan, is all the money here? Like, in the last year, how that money has gone down, is there still more money that's going to be put in there or that is the money to date?

Dr. Daniels: This is -- this is pretty much it to date. There might be some small changes, but I don't expect to see a lot more go into here.

Ms. Crandy: Okay.

Dr. Daniels: Any adjustments at this point in 2011 and '12 would probably be pretty minor.

Ms. Abdull: This one looks the best, I would say, of all the ones we've read so far.

Mr. Robertson: Yeah, there are some good

projects here. I mean, it could use a little bit more funding, but, like, it's -- it's -- it's in a pretty decent state as far as I think the projects and the quality of the projects, as far as --

Ms. Abdull: I agree.

Ms. Crandy: I'd agree with that.

Dr. Daniels: So maybe we could say that this one is moving in the right direction, but needs continued emphasis or continued work?

Dr. Burton-Hoyle: Yes.

Mr. Robertson: Yes.

Ms. Crandy: I'm a little concerned that the money has decreased. I mean, it went from $2 million to $600,000.

Mr. Robertson: Yeah, I'd concur with that concern.

Ms. Crandy: Because I think that these studies -- it feels like that is building those community-based interventions.

Mr. Robertson: The problem also with the drop in -- in -- funding is how do you know if long term what the improvement of quality of life looks like if the project drops off because the funding

drops off? Because some of these are long-term things.

[Pause]

Ms. Abdull: Hello?

Dr. Daniels: Yes. So I was just trying to get a sense of what was going on in 2010. I don't have the information right in front of me to say what kinds of projects might have dropped out between 2010 and 2012. So, but we could say needs continued work, needs to be sustained?

Ms. Crandy: I like that, sustained.

Mr. Robertson: I like that.

Dr. Daniels: Because if we say sustained effort, we can't just say been there, done that, that's done. There's work that needs to continue to -- especially looking at long-term outcomes.

Alright, if you feel comfortable with that, let's move on to the next. I'm just trying to get you through all of your questions here, all of your objectives.

So 6.L.B: "Conduct one study that builds on carefully characterized cohorts of children and youth with ASD to determine how intervention

services and supports delivered during childhood impact adult health and quality of life outcomes by 2015."

And this one sounds like it may have some overlap a little bit with the previous one.

Ms. Crandy: And I do, I like these studies, and I think it's answering an important question for us. Do I think it's enough? I don't think -- I think that we need a lot more research in this area --

Dr. Daniels: So we --

Ms. Crandy: -- like studies that have happened so far --

Dr. Daniels: Mm-hmm.

Ms. Crandy: -- that we need those long-term outcome studies.

Dr. Daniels: And this one, I think -- when we were considering 6.L.A -- some of these studies may also be answering some of the questions in 6.L.A as well. Might be a little bit of crosstalk between those two.

Ms. Crandy: And we're closer on the money for sure. We're only like a small amount.

[Pause] Are some of those studies that are in 2012, is it still some of the leftover study from 2010 or --

Dr. Daniels: Probably.

Ms. Abdull: Hi, Susan. This is Idil. I have to go and pick up my son. But I apologize.

Dr. Daniels: Thank you. Thanks for being on the call.

Ms. Abdull: Oh, you're welcome.

Ms. Crandy: Always appreciate you, Idil.

Ms. Abdull: Oh, thank you. Same here, I never want to leave usually on just any Questions of 5 and 6, but I have to -- if I don't pick him up, it's $1 a minute. So I have to pick him up.

Thank you all very much. Hopefully, there will be -- there won't be any Government shutdown, and we can continue this next week.

[Laughter]

Dr. Daniels: Yes, hopefully so. So we do have a number of projects. It's possible that there is continuation of some projects from earlier years.

Ms. Crandy: I think that we have answered the question. We did one study for sure. There's more

than one study that's looking at this. I don't think that we've answered the question.

Dr. Daniels: Uh-huh.

Ms. Crandy: And I think we're close on spending the money. I hope that we'll recommend more studies in this area, though.

Dr. Daniels: So maybe it would be a similar answer to the previous one -- that it's moving in the right direction but needs to be sustained and needs further work?

Ms. Burton-Hoyle: Yes.

Mr. Robertson: Yeah, I think that makes sense. Yes.

Dr. Daniels: Okay.

Ms. Crandy: Because if we don't answer this question, we are not going to know how to have less supports -- need less supports, I should say.

Dr. Daniels: Mm-hmm.

Ms. Crandy: Because improve the outcomes.

Dr. Daniels: Great. Alright, so, so let's move on to 6.L.C. This one has very, very few projects. "Conduct comparative effectiveness research that includes a cost-effectiveness component to examine

community-based intervention services and supports to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2018.

Topics should include community housing for people with ASD, successful life transitions for people with ASD, including from postsecondary education to adult services, employment, sibling relationships, and day programs. And meeting the services and supports needs of older adults with ASD."

So recommended budget was $6 million. The amount estimated spent was $774,644, so significantly below and hardly any projects.

Ms. Crandy: I think -- I think this is red, red, red.

Dr. Daniels: Okay.

Mr. Robertson: Yeah. Yeah, what were -- what were those two? Because I don't have the tool opened. What are the two projects on that were funded?

Dr. Daniels: Hold on a minute.

Ms. Crandy: Family -- I can tell you. It's family-centered transition planning for students

with ASD. That's University of New Hampshire. And treatment as usual and peer engagement in teens with high-functioning autism, and that's Seattle Children's Hospital -- So really not addressing.

Mr. Robertson: Yeah, that's -- that --

Ms. Crandy: And I think housing is huge, such a problem.

Mr. Robertson: Yeah. That's -- I mean, obviously, housing is not touched. And then the service and support needs of older adults, which before you even listed the projects, I was guessing that one probably wouldn't be covered either. So both of those two have not been addressed at all by this, by the funding.

Dr. Daniels: Sorry, which ones? The housing and the service and support needs of older adults?

Dr. Burton-Hoyle: Yes.

Mr. Robertson: Yes.

Dr. Daniels: Okay.

Dr. Burton-Hoyle: Again, [Inaudible comment] it's just a very small piece of it.

Dr. Daniels: So I think that -- sorry, go ahead.

Ms. Crandy: I think there is some overlap with transition stuff out there that maybe could be included here.

Dr. Burton-Hoyle: Yeah. Yeah, I agree.

Dr. Daniels: So overall, it sounds like this is looking like the work that's been done is pretty inadequate in terms of covering the topics that you were hoping would be covered and to the level that they should have been covered, with only a couple of projects that were funded in 2010.

So we could say that the Planning Group's read on this one is red.

Mr. Robertson: And is this another case where you do want to double-check with HUD and other entities on the housing to make sure there wasn't something being done that we're not aware of?

Dr. Daniels: Well, the situation that we're in is that last summer the Committee was very strong on emphasizing that they didn't want us to be collecting as much information that might be less related to research, although the difficulty is that the Plan actually calls for things that

aren't exactly research.

So that's the question. Does the Committee want us to be collecting that information or not? And I think we might have to have a bigger Committee discussion on that. Because last summer, the verdict was really stick to things that are related to research, and so we tried to narrow it down.

But if you want to -- but then you'll have a hard time really meeting some of these objectives because the objectives aren't as strict about the definition of research as was intended by some of this wording from what I can tell. So we'd appreciate having more guidance from you on that.

And if the Committee's decision is that you would like us to be collecting kind of a broader set of information, we'd be happy to try to do that.

Mr. Robertson: So are you going to bring up -- are you going to ask for a discussion of that -- it sounds like two competing forces, basically, that would be good to discuss maybe at the next meeting?

Dr. Daniels: Yeah, we could put that on the agenda to discuss that, the strategy for dealing with -- I think this really comes up mostly in Question 5 and 6. We haven't been having trouble with any of the other questions.

But because 5 and 6 are about services and it's a research Plan, but you can tell by the wording of some of these things when they're talking about evaluating policy models, it's kind of hard to call that exactly research. I mean, unless --

Mr. Robertson: Yes.

Dr. Daniels: -- you're thinking about the experimentation and evaluation as being sort of a science. That's where it sort of is like research, but I think for OARC, we've been kind of stuck between a rock and a hard place with this. So I would appreciate any guidance the Committee can give to help clarify, and we'll put it on the agenda for future discussion.

Okay. So then the last objective here is "Conduct implementation research to test the results from comparative effectiveness research in

real-world settings, including a cost-effectiveness component to improve health outcomes and quality of life for adults over 21 on the ASD spectrum by 2023."

So that's definitely long term. This one also sounds like it has some overlap with some of the previous objectives. And we see that $4 million was recommended, $135,000 has been spent, and there is a handful of projects, 5 projects, over 2011 and '12.

[Pause]

In 2011 the two projects are both Autism Speaks projects on estimating the economic costs of autism.

Dr. Wexler: Susan, I'm sorry. This is Larry. I'm going to have to go right now.

Dr. Daniels: Go ahead. Thank you so much, Larry.

Dr. Wexler: Thank you so much, a pleasure. Good-bye, everyone. We hope we're at work tomorrow.

[Laughter]

Dr. Wexler: And we hope we get paid if we're

not. Thanks.

Mr. Robertson: I hope you get paid tomorrow, Larry.

Dr. Wexler: Yes, thank you. Thank you. Bye-bye.

Dr. Daniels: All right. Bye-bye. There is also -- there are a couple more Autism Speaks projects in 2012: economic burden of current and future autism and another one. And one of them is -- the PI is David Mandell, but I think he might have had to leave the call.

So he would be a great person to ask what his sense is of this, but I think based on funding, certainly very little funding has gone into this area. What do you all think? The projects sound like they're starting to try to address the issue.

Mr. Robertson: It's starting, but it's just massively, massively underfunded along the lines of the -- of the diagnosis of, you know, diagnosing autistic adults who haven't received a diagnosis accurately. This is of that same, you know, underfunding line kind of in terms of the large gap between what was recommended here and

what is actually happening as far as the funding for these five.

I mean, they're good -- they're good projects, but we need to do substantially more, I think.

Dr. Daniels: Okay. So the -- I don't know if anyone else has comments, but it might be fair to say that this would be a Planning Group red?

Ms. Crandy: Yes.

Mr. Robertson: Yes.

Dr. Burton-Hoyle: Yes.

Dr. Daniels: That's not to jump ahead if people have more comments, but -- and then in terms of the core funding for this area in the "Other" category, there was only $2 million. So that's a very kind of handful of projects. So there's not that much of a foundation then in this area, although there could be some overlap with some of the things that are in the Chapter 5, in Section 5.

So you've successfully gotten through everything. We're a few minutes over our time. The last item we needed to do is -- so we're going to need a volunteer or volunteers to write up the

kind of Committee findings on these two questions and then pass them around to the rest of the Group to review. So do we have volunteers --

Ms. Crandy: Susan?

Dr. Daniels: Yes?

Ms. Crandy: Will you give us the notes that were -- you know, the discussion that was taken today, or would we go off --

Dr. Daniels: We do have -- we do have some minutes. And as I've been going along, I've been kind of recapping what I hear the Committee saying, which would end up in the minutes. But then we need sort of a more narrative description from the -- from the Group. And so, someone would have to take that information, then make it into a narrative.

So is there anybody who would like to do either Question 5 or Question 6?

Ms. Crandy: What's our deadline?

Dr. Daniels: We haven't quite set the deadline, but it's probably around mid-October, a couple of weeks.

Mr. Robertson: I think I'd be interested in

doing Question 6.

Dr. Daniels: Okay. Great.

Ms. Crandy: I could do the other one then.

Dr. Daniels: Great. Wonderful. So then I will be in touch with you to give you more information and to make sure that you get the minutes that we're taking. And I'll be in touch with the entire Planning Group.

I commend you all for getting through two chapters. We gave you a little bit more time than we gave the other planning groups, but you know, not double the time. So you did a fantastic job, having a thoughtful discussion, but having it quickly.

And we just really appreciate all your work on this, and we will be sending out more information. And until midnight tonight at least, I will be in touch with you about future plans for other meetings. We'll try to set up the next phone call, and on that phone call hopefully, we'll have our external participants involved as well. So does anyone have any questions before we sign off?

Ms. Crandy: I do. Can – can – Scott, on your

Number 6, could you and I work together on both questions, too, and, like, share our narrative, and then I would love to have your input. Is that something that we're allowed to do?

Mr. Robertson: Sure. Sure. Yeah, I'd be happy -- I'd be happy to assist on Question 5 write-up, too. Sure.

Dr. Daniels: Great. Great, and then, of course, we'll pass it around to the entire Planning Group for comments, and people can make suggestions. And the goal is for each write-up to be one to five pages. So it should be short, which will be a relief for Jan and Scott. So we're not looking for a doctoral thesis here. We're looking for something pretty concise.

Mr. Robertson: Oh, that's good to know, considering I just wrote my doctoral thesis recently.

[Laughter]

When do -- when do we -- is this all happening before -- well, you know, I'm speaking as if the shutdown doesn't happen. But assuming the shutdown doesn't happen and we do meet on the 9th, do you

need this stuff in the next -- in the next couple days because the 9th is coming up or what?

Dr. Daniels: No, you don't need it for the 9th.

Mr. Robertson: Okay.

Dr. Daniels: So we'll need it before the next phone call, hopefully, at least a draft. It doesn't have to be perfect and complete. But if we have at least some kind of a draft by the next phone call, that would be helpful.

Mr. Robertson: Okay.

Dr. Daniels: And then we'll carry that into the October 29th meeting and hoping that we don't have too much disruption here from -- from the Government situation. So --

Mr. Robertson: Because I'll have more time to work on it, like, Wednesday and after Wednesday because I'm defending my dissertation on Wednesday. So, like, I'll have more time right after Wednesday.

Dr. Burton-Hoyle: Congratulations.

Dr. Daniels: Yes, congratulations.

Mr. Robertson: Thanks.

Dr. Daniels: That's going to be a big event. You'll have to let us all know how it goes.

Mr. Robertson: Hopefully, it will go well. One of my committee members has said that my thesis looks good so far. So that's a good sign, right? So --

Dr. Daniels: Excellent.

Ms. Crandy: Yes.

Dr. Daniels: Well, we're happy to hear you're at that stage, and it's very exciting. So --

Mr. Robertson: And I'm hoping that the Government doesn't -- doesn't shut down so when we do meet on the 9th, assuming that I pass my defense, that I can actually, you know, share good news at the 9th meeting.

Dr. Daniels: Yes, that would be great. So we will be doing a round robin on the 9th, and I'm going to be sending out a note to the Committee. But we can all share some updates. So we certainly will want to hear about that one.

[Inaudible comment]

Mr. Robertson: And just -- oh, okay. Sorry. Who else was talking?

Ms. Crandy: I was just asking when could we expect to get the minutes from you if you're going to be shutting down tomorrow? Would we still get them in time for us to utilize to write this or --

Dr. Daniels: So we will get them out as soon as possible. Of course, we're writing minutes for all of the groups. Hold on for just a second.

[Pause]

One of the complications, of course, is if we shut down, then we won't be able to get them out or done because today we will be starting to work on these, but they usually take at least a couple of days to finish. And if we're shut down, we won't be able to do anything further until we come back up.

Ms. Crandy: And I have to be honest, I -- because I did not take notes while we were doing this, that I won't be effective writing this without those.

Dr. Daniels: All right. So we'll just make sure we get them out.

Dr. Rice: Can they have access to the recording?

Ms. Crandy: Do we have that?

Dr. Daniels: Do we have what?

Ms. Crandy: Will we have access to the recording before then if you shut down?

Dr. Daniels: No. No, we don't have access to the recording. So --

Mr. Robertson: As far as drafts on these documents, even if you don't send out the minutes, I took some -- you know, my brain tends to record some things pretty well. So I took some mental, you know, notes. I was paying good attention in terms of mental notes on some of these things. So I think -- I think I could help a lot on 5 and 6 in terms of what we -- what we talked about in terms of what should be going into the two different documents.

Dr. Daniels: Right. And we'll see what we can do. I took very careful notes as well, but I'm running a number of different groups. So I don't know that I could get these particular ones.

Mr. Robertson: Just one other thing on as far as logistics is if they – like, if the shutdown does occur, like, and then maybe it's lifted, but

then there's a timeframe for getting things back up. Like, Tom will keep us abreast as far as he'll send out emails or something insofar is that how things will go?

Dr. Daniels: So I will try to send out an email to the Committee. If we are instructed that we need to shut down, I'll try to send out an email to the Committee to let you know that OARC is shutting down and that we will let you know when we're back up.

And then in the meantime, in the interim, if you have any pressing questions, you can contact Dr. Insel to get --

Mr. Robertson: Well, would I -- okay. Because what I mean also is because of the 9th meeting, you know, what happens if, say, things get up and running on the 7th or the 8th or something like that, what does that mean as far as, you know, being able to maybe still hold it? But, like, materials can't necessarily go out in time for us to take a look at them or something before the meeting, I guess, if that possibility happens.

Dr. Daniels: Right. For the 9th, we don't have

a heavy agenda. So there shouldn't really be any materials -- major materials -- to look at. We will try to process the travels today so that people could theoretically travel on Monday, if possible. And if the shutdown prevents us from being able to process travel, we'll send out instructions for a phone conference and hold it as a phone meeting.

But in that case, then we wouldn't be taking oral public comment if we're only a phone meeting. We would have to just do written and I might not be able to get you the written comments in advance if we're shut down because we won't have any time to receive them or process them because we aren't allowed to check our Government email.

Dr. Burton-Hoyle: This is Sally. I have a question. So the meeting, if it's held, would be Wednesday, right?

Dr. Daniels: It's whatever day -- I thought it was Tuesday. It's Wednesday? Oh, sorry. I'm getting confused now.

Dr. Burton-Hoyle: Oh, okay. That's good. That's fine. I've just been planning on Wednesday.

Dr. Daniels: We have Monday and Tuesday. So if we are back up and running by next week, we should be able to hold the meeting. But you know if we're still shut down on Tuesday and the meeting is the next day, then the meeting would be canceled. And I'm sure that Dr. Insel, if I'm unable to communicate with you, then Dr. Insel would communicate with you to let you know that the meeting has been canceled.

But if you don't hear that it's been canceled, assume that we're either having it in person or as a phone meeting, and we'll just get you the information as quickly as we can.

Dr. Burton-Hoyle: Okay. Thank you.

Dr. Daniels: And let us know, too, if you have any concerns. So thank you for bearing with us through all of these interesting times with the possibility of these disruptions, and we hope that we can continue our business as efficiently as possible.

So thanks again, everyone, for being --

Mr. Robertson: Well, thank you, Susan, also for helping navigate us through all this --

Dr. Burton-Hoyle: Yes, thank you.

Mr. Robertson: -- especially if we haven't experienced this before. Yes.

Ms. Crandy: Great job.

Dr. Daniels: Thanks, everyone. Meeting is adjourned. Bye.

(Whereupon, the conference call of the Strategic Plan Questions 5 and 6 Planning Group was adjourned.)