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INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR SERVICES RESEARCH AND POLICY

STRATEGIC PLAN QUESTIONS 5 AND 6 PLANNING GROUP

CONFERENCE CALL

WEDNESDAY, NOVEMBER 13, 2013

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

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PROCEEDINGS:

Operator: Thank you for standing by, and welcome to today's conference. I would like to remind all parties today's call is being recorded. If you have any objections, you may disconnect.

I will now introduce your conference host, Dr. Daniels. Ma'am, you may begin.

Dr. Susan Daniels: Thank you. Good morning to everyone listening on the phone, to our listening audience in the public, and also to members of the IACC and our invited participants. We're really glad to have you here for this conference call of the IACC Strategic Plan Update Questions 5 and 6 Planning Group.

Today we're going to be talking about progress that's been made on the Strategic Plan objectives and Question 5 and 6 of the Strategic Plan, which are focused on services and lifespan issues.

To begin today, I'd like to go through a roll call just so that everyone knows who is on the phone. And we will have posted on the Web site, on the IACC Web site, for all the people who are invited participants, and we already have bios posted for all the IACC members in case anyone is interested.

So let's start with the roll call.

Idil Abdull?

She's not here.

And Jim Ball will not be joining us today.

Sally Burton-Hoyle?

[Pause]

Dr. Daniels: Jan Crandy?

[Pause]

Dr. Daniels: Denise Dougherty?

Dr. Denise Dougherty: Here.

Dr. Daniels: Thank you.

Dr. Daniels: Laura -

Ms. Idil Abdull: Hi, Dr. Daniels, this is Idil. Sorry I'm late.

Dr. Daniels: Thank you. Laura Kavanagh is not going to be joining us today.

David Mandell?

Dr. David Mandell: I'm here.

Dr. Daniels: Thank you.

Dr. Daniels: Shantel Meek for Linda Smith?

Ms. Shantel Meek: I'm here.

Dr. Daniels: John O'Brien?

[Pause]

Dr. Daniels: Cathy Rice? Dr. Catherine Rice: Here.

Dr. Daniels: for Coleen Boyle, thank you.

Scott Robertson?

Mr. Scott Robertson: I'm here. Can you hear me okay? Because I've been on the listen-only line before, accidentally. You can hear me?

Dr. Daniels: Yes. I Can hear you.

Mr. Robertson: Okay, good. Okay, good. Thanks.

Dr. Daniels: Sure.

Alison Singer?

Ms. Alison Singer: I'm here.

Dr. Daniels: And Larry Wexler is not going to be joining us today for Michael Yudin; he had a conflict.

Brian Boyd?

Dr. Brian Boyd: Here.

Dr. Daniels: Thank you. And now I'm moving on to external participants.

Nancy Cheak-Zamora?

Dr. Nancy Cheak-Zamora: I'm here.

Dr. Daniels: Thanks.

Aubyn Stahmer?

Dr. Aubyn Stahmer: I'm here.

Dr. Daniels: And Zach Warren.

Dr. Zachary Warren: Here as well.

Dr. Daniels: Thank you.

I'd like for invited participants to briefly just introduce yourselves, just one or two sentences about where you work and what you do and how you relate to our Group.

Brian Boyd?

Dr. Boyd: Sure. I'm an assistant professor at The University of North Carolina at Chapel Hill. A lot of the work I do has to deal with school-based services for children and adolescents with autism.

Dr. Daniels: Thank you.

Nancy Cheak-Zamora?

Dr. Cheak-Zamora: Hi. I am at the University of Missouri and the Thompson Center for Autism and Neurodevelopmental Disabilities. I study health services research and specifically health care transitions for youths with autism.

Dr. Daniels: Thank you.

Aubyn Stahmer?

Dr. Stahmer: I'm an associate professor at UCSD in the Department of Psychiatry, and I do research looking at translating evidence-based practice into community early-intervention and classroom settings.

Dr. Daniels: Thanks. And Zach Warren?

Dr. Warren: Yeah. I'm a clinical psychologist and associate professor of pediatrics here at Vanderbilt University. My research is in designing service systems for early detection and intervention, and I have been involved with some of Vanderbilt's comparative effectiveness for use of services and intervention programs.

Dr. Daniels: Thanks. And we will -- Jim Perrin and Paul Shattuck are also a part of this Group, but they weren't available for today's call, and they hope to be with us on Friday at the workshop.

So today's task is for us to look at the objectives in each of the Questions 5 and 6. So Question 5 -- I apologize -- I'm having some issues with my materials. So Question 5, "Where can I turn for services?" And Question 6, "What does the future hold, particularly for adults?”

So we're going to go through a table. There are two tables that I sent you that are labeled the Conclusions Tables from the previous call that we had. And in this table, we've listed all of the objectives in each of the questions and given a brief summary of what the conclusions were of the Group that met last time.

And their task was to go over what has been funded and to look at the Strategic Plan objectives. What kind of progress has been made purely in terms of funding? And what kinds of projects have been launched?

And on today's call, we're calling especially to the experts in the field to tell us more about what's actually happening in the field, what kinds of advances are being made, what are the remaining barriers, gaps, and new opportunities in the field?

And so we're going to go systematically through each of the objectives. We have, I believe, 17 to go through on this call. And so we'll need to keep the discussions slightly brief.

I mean, it doesn't have to be super brief, but we can't spend 15 or 20 minutes on each objective or we won't get through them.

So I'd like to start with Question 5, unless anyone has any questions. Oh, the other materials that you have, and for those who are listening on the phone and would like to follow along, we've posted all these materials on the IACC Web site at -- if you look for this meeting that's happening today for Question 5, 10:30 a.m., if you click on Materials, you'll find all the same materials that we sent out to the Committee members and our invited participants.

The other main document I sent you all was a Cumulative Funding Table. And this is what was used by the Committee members on the last call to look at funding and look at it as a reference. I also included projects listings, which were materials for the previous call on Questions 5 and 6. And the only reason I included those this time was on the last call we had with other groups, some people wanted that information available. And so it's not something we're going to go through, but we wanted you to have it as a reference, if you need it.

So are there any questions before we start the discussion?

Alright, so let's start with 5-short-term-A, 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.”

The last time the Group met on the phone, they felt that the recommended budget had been met because the recommended budget listed at the bottom of the objective is $1 million over 3 years. And funding over 2008 through 2012 was about $5 million.

They felt that the initial target of supporting two studies had been met, but that more work needs to be done in this area and that the projects that are assigned to this objective cover several topics related to family functioning and health disparities. But the full breadth of the gaps mentioned in the objective has not been covered. And they also thought that perhaps the objective as written might be too broad.

So can you all tell us a little bit about what is happening in this field? What have been the advances made, or what are the remaining gaps? What are the needs in this field? And are there any particular barriers to being able to move forward here?

[Pause]

And if you're speaking, please identify yourself. That would help the transcriptionist to keep track of who is on the call.

So does anyone have any thoughts about this area?

Dr. Stahmer: This is Aubyn Stahmer. It seemed to me it was kind of a long way in figuring out that we have the gaps in service, but understanding why we have the gaps and what to do about them seems to be the big gap. So, for example, we know underserved populations aren't being identified until older ages and not accessing care. But it doesn't seem really clear, to me, why that's happening or how we're going to fix it. So that seems to be sort of the next step.

Dr. Boyd: This is Brian Boyd. I think the other thing that we're learning, there's been some recent work I found in Paul Shattuck’s work, I think, also ties into this, that we are seeing perhaps differential outcomes for minority families and for families from low -- and from kids from lower income families. And so what's leading to those different outcomes?

And I think the service piece is also -- there are so many different service delivery systems with which families interact. So a lot of those families are getting the bulk of those services through the school system. Yet we know very little about what makes for a high-quality classroom for kids. What are long-term outcomes when kids are tracked into self-contained versus inclusive classrooms early on?

So some of those -- so breaking down what we mean by "services" and which services that families are interacting with, then understanding why we are beginning to see some of these differential outcomes for minority families [Inaudible] families.

Dr. Daniels: Thank you. Others?

Dr. Warren: This is Zach Warren. So Dr. Stahmer's comments resonate with me. I mean, we've had a lot of information really documenting sort of the disparities, but we have very very few sort of advances in understanding how to -- how to address these across the diverse service systems that Brian was talking about as well.

So, certainly, the work in terms of, how do we move service systems to address the documented disparities from identification of service delivery -- we've apparently just kind of highlighted the gap more so than identified the programs that reduce the gap.

Ms. Abdull: Hi. This is Idil. I want to just reiterate on what I said at our last call, Dr. Daniels and that is that objective questions are too broad. I resonate with the people here who are saying that we know disparity exists in communities of color and low income. But we don't have research that tells us why do they exist and what do we do about it?

So unless we are able to specify the

objectives, we're always going to get the same answer and we're never going to get to the solution. I mean, I can have – we all have theories as why they exist, you know, not enough outreach, not enough professionals of color, diagnosed later because they have Medicaid as opposed to private insurance, which is very difficult to get diagnosis because they don't pay well, so you have a wait list of 1 or 2 years.

I mean, there's a lot of theories, but unless we can somehow figure out a way to input into that objective and say, okay, so how disparities and how to address it, how to fix it, why do they exist, I think we're always going to just be chasing our tail here.

Mr. Robertson: I wanted to also add something to that. This is Scott Robertson. Is there any fruitfulness in the -- if researchers were to find out that, you know, the whys and the hows is to maybe add in some mixed message or qualitative research that could maybe, you know, understand some of these conceptual factors that are not being necessarily found for the existing studies that we've already been doing.

I mean, is there any fruitfulness in some qualitative research in this area?

Dr. Daniels: How do others feel about that?

Dr. Mandell: This is David Mandell. So I think that there has been some really good qualitative research that's done in this area. And I think what our invited experts are pointing to is the need to move beyond observational studies, whether quantitative or qualitative, toward more experimental design.

That is, we need to start, rather than documenting that disparities exist or even perhaps delving into some of the mechanisms that we ought to be moving toward experiments to improve access to care and outcomes for traditionally underserved families.

[Pause]

Dr. Daniels: Great. I think that's a good summary. Is there anything else that anyone wants to add before we move on to the next one?

Ms. Abdull: I'm sorry. This is Idil again, if I could just add the “class.” A lot of people always think that class guidelines help out with all the disparities, because information, education, diagnosis, everything should be culturally and linguistically appropriate.

But if you read the class guidelines, they are merely recommended. They are just recommending. Even getting interpreters, it's sort of required, but if providers don't follow, it doesn't matter. They still keep getting funding, they keep getting paid.

So it doesn't really -- we need, like, more concrete ways of making sure providers and professionals are following the class guidelines.

So I just wanted to let people know that. Class guidelines are there, but they're not -- you don't have to follow them. You should, but you don't have to.

[Pause]

Dr. Daniels: Is there anything in terms of the Strategic Plan that could be done to help that situation? I understand that it's a concern, but is there anything actionable there that the Committee could be doing?

Dr. Mandell: This is David again. And I would really like to hear from some of our experts on the Group. But I think one of the questions we have is whether there are specific programs that need to target specific ethnic or racial groups, or whether, to a large extent, what we're looking at is system-level and geographic disparities. So does a rising tide lift all ships? And that is, if you, as Idil suggested, went into some of these places where interventions traditionally are not delivered with fidelity or in the quantity desired and you worked with them to improve the quality and the quantity of intervention that's delivered, would you ameliorate these disparities? Or do you need to do something that's specific for specific groups?

And so I think making -- and this sort of ties the disparities work to some of the dissemination and implementation work that is one of the other areas of concern for this Committee -- but looking at it specifically through the lens of ameliorating disparities may be important.

Dr. Daniels: Thank you.

Let's move on to the next one, 5.S.B: “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.”

The last time the Group met, they determined that the recommended budget was partially met, that more work is needed in this area to achieve the goals set forth by the objective. And while more than the number of studies that were initially called for has been supported, the area is underfunded. All of the projects -- Many of the projects are small, and the projects do not examine all the areas that were targeted in the objective.

Then I provided a few examples that were discussed at the last meeting.

So what do you all think about this one? What is the state of this issue? What are some happening in the field? Are there any advances? What are the remaining gaps? And are there particular barriers that need to be taken into consideration?

[Pause]

Dr. Mandell: This is David again. Is there anyone on the call who has done any research or work in self-directed care?

Dr. Stahmer: This is Aubyn. No, but what occurred to me when I read this was, because I work with very young families, young kids, is that -- and maybe this goes somewhere else -- but self-directed care for very little kids may be helping parents be empowered to direct the care. I don't know if that's covered in a different objective.

Dr. Cheak-Zamora: This is Nancy Cheak-Zamora. And I don't focus on this area either, but I would actually support what she said even for youths and adults. So a lot of the young adults that I work with and that I've done research on, the parents are still very much involved in developing housing opportunities and employment opportunities for their even older adult children -- I'm sorry, older adult whatever. Excuse me.

And so it's not extremely self-directed, if we're talking about self-directed being from the person with autism.

Dr. Boyd: This is Brian Boyd. This isn't really my area as well. I'm not sure this quite falls into self-directed care, but there seems to be some more work going on around looking at employment for students who are transitioning out of high school.

Though, I know there are some people who are doing some work around the use of Project SEARCH and those kinds of models that allow students to sort of choose their own internships, to have some work experience before they get out of high school. So the employment key seems to be coming along.

But other things, sort of other community-based things like housing and those kinds of issues, and quality of life, I don't think -- I don't know if there's much of that work going on right now.

Dr. Warren: This is Zach. Yeah, in similar sort of form, I think there’ve been, you know, some work that's focusing on thinking about employment as the primary outcome. I think there's some fundamental work that needs to be done here in terms of understanding outcome itself, particularly, you know, with the words across the spectrum, you know, when we think about traditional markers of employment as being the one definition of outcome in some of these community-based service programs, I think we may be missing the boat a lot.

You know, we've done -- you know, we haven't done direct work, necessarily, but in reviewing the available literatures for transition-based programs, intervention programs, self-directed community-based programs, I mean, there's not a lot.

Our constituency, even the call tells us that this hasn't been the primary focus of most of our intervention research. But I don't know if it fits into this item or other items. But this definition of "service outcomes" is an interesting one for consideration, I think.

Dr. Cheak-Zamora: I agree. This is Nancy. And voc rehab and some other state-based services seem to be making an effort. But it's often very piecemeal. And they really lack an understanding of autism spectrum disorder. And so implementing services for those groups in particular has been extremely challenging.

Dr. Daniels: So this is Susan. What in terms of the types of research that should be done in this area -- what kinds of projects are lacking? If you were going to be recommending something back to the Committee about trying to focus a little bit more in this area, and what kinds of research should be encouraged?

Dr. Mandell: This is David. And I wish Paul Shattuck were on the call, because I think he thinks very clearly and well about this. But since he's not, I'm going to steal some of his ideas and share them.

I think one of the big issues is scale. So that often, when we talk about these self-directed programs, especially for adults with autism, we talk about assisting a very small group of people. Most of the studies in this area have really small samples. They're very intensive.

And we are sort of in a midst, as we always are in this country, of a massive reorganization of labor markets. And how we can take advantage of that to create programs that are scalable and help thousands of adults with autism at a time, rather than nine, I think is really important.

One way to do that may be partnering with existing programs in the community that are already doing this kind of work, and doing practice to research rather than research to practice.

And then again, I would also put the emphasis on scale that we have to rethink some of our self-directed strategies and vocational strategies so that we're helping a much larger group of people at a time.

Dr. Daniels: Can you elaborate a little bit more on practice to research?

Dr. Mandell: So in the absence, or maybe even in the presence, of good research on this, there are programs all around the country that have started or are starting soon that are already thinking about less traditional ways to provide support to families that are specific to the needs of the family.

There's Extraordinary Ventures in North Carolina. There's the work that SARRC is doing in the Southwest. There are states like Pennsylvania that has a mini-grant program for families, which is the equivalent of self-directed care.

But none of these has been studied in terms of what services that those funds are used for, how successful these are compared to other forms of care. But they're already in the community. They've figured out how to work within the constraints of existing systems and therefore potentially have much more generalizability or replicability than more university-based programs.

And so I think that for some of these issues, like self-directed care or vocational support or things like that, we are going to have to learn from what's already being done in the field rather than create de novo things in an academic environment. And that's what I mean by practice to research.

Dr. Daniels: That sounds like a concept that might apply in many places throughout both Questions 5 and 6.

Dr. Stahmer: Yes, this is Aubyn. I totally agree, because I think part of the dissemination issue is that we need to figure out what's going to work in the community rather than try to get out there what we think is working.

Ms. Singer: This is Alison. I also agree. And when we have asked researchers about doing this type of research, the concern has been to there are not places to actually do it. And I think part of it is going to be encouraging sites like Extraordinary Ventures to embrace research.

[Several speakers]

Dr. Boyd: This is Brian. Also extending that down to what's going on at the high-school level, because there are some high schools that have restarted their vocational training programs, because parents didn't feel that kids were getting enough training within the context of high school to then have any job skills.

So even thinking about, are those programs then producing better, getting more gainful employment or allowing students to gain better skills that lead to better outcomes? So also at the high school training level as well.

Dr. Stahmer: And this is Aubyn. I think that we found community agencies to be -- if you involve them from the beginning as much as possible and really develop a partnership where the grant includes some benefit for them, as well as the research, they are relatively open to participation over the long run. And even if it isn't -- even if it's costing them in terms of time.

And so I think some objectives around engaging the community in the dissemination and implementation research would be good.

Dr. Mandell: Susan, this is David. There are two specific mechanisms that exist or have existed before. So one is the Institute of Education Sciences has a partnership collaborative funding mechanism or did last year -- and hopefully they'll reissue it this year -- for academic centers to partner with local education authorities to create research infrastructure and address very practical questions like the ones we're discussing.

And then, NIMH used to have the RISK, the Research Infrastructure-something program, which did the same thing on the mental health side. And it would -- you know, I think there's the potential for tremendous advances if those kinds of mechanisms are in place to incentivize community settings and researchers to form lasting partnerships.

Dr. Daniels: Great. Thanks for sharing that. We'll take note of that.

Good. So if there isn't anything else that's pressing on that one -- of course, there are lots and lots of pressing things --

[Laughter]

Dr. Daniels: -- but we could spend all day talking about one objective here. But if it's okay, we'll move on to the next one to try to make sure that we touch each of these today. "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 AAC, 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 the last time the Group met, they felt that the recommended budget had been partially met and that the work that's been done has been good, but the objective is not fully achieved, and it's underfunded. They also discussed that HRSA does fund some state demonstration projects that may be related to this objective, but they're not reflected in the funding numbers here because of the decision to remove those from the portfolio analysis last year.

Dr. Stahmer: This is Aubyn. Was the decision to remove those because they are demonstration projects that aren't -- that don't come out with a lot of outcome data? Like, I feel like those demonstration projects partnered with some researchers might give us more information, but maybe it's just because I don't know enough about them.

Dr. Daniels: At the time, I think the concern -- and Laura Kavanagh is not on the phone -- was that the goal of the state demonstration projects was not -- in HRSA's view, it's not research, per se, although the way this objective is worded, it's not exactly, you know, a traditional look at research either. It's implementing and evaluating five models of practice-level coordination, which isn't what you'd think of as a standard research project.

And so because they weren't sure of whether the research link was there, the decision was made to remove them from the portfolio analysis.

So we know about the projects, but they're not being counted in the numbers here.

But on the last call, Laura discussed that there are some things that those state demonstration projects are doing that do apply to some of the goals here.

But overall, what do you all feel is going on in this field? Is this field moving forward? Is there good work being done in places? Certainly if there are state projects that are going on that are not federally funded, they would not be reflected in our portfolio analysis here.

And same thing -- you know, what are the gaps, barriers, opportunities?

Dr. Mandell: Zach, I hate to put you on the spot, but would you mind sharing -- no, actually, I don't hate to put you on the spot.

[Laughter]

But would you mind sharing some of your experience in Tennessee in improving early identification and quality of very early intervention for kids with autism and whether there's a research component of that or whether there could be one?

Dr. Warren: Yeah, sure. Whether I want to or not, I will share, right, David?

One of those things -- in Tennessee we've been trying to pull -- I mean, studying coordination across such diverse state agencies is a really, I think, challenging endeavor, and challenging in that it's not necessarily going to present us with all of the research-based outcomes that we'd like to be able to have.

And in part, I think what we've seen is that the programs that are most successful are those that are really pulling, not just from one specific targeted research intervention, but are really reliant on infrastructures, grants, system of support for numerous agencies to push forward this common agenda, right?

So, you may have a targeted project within that, but the idea of being able to really pull those things together. And the thing that I think that is really lacking here is that, one state to another, the communication across these coordinated sort of endeavors is lacking. I would say that I had a very, very poor understanding of how that happens in Pennsylvania, North Carolina, California, Missouri, et cetera, although I have some inklings from our colleagues.

So I think not only is one of the pertinent issues about trying to support these projects, but also sort of the dissemination of those across states. I'm not sure what’s the right mechanism for that, how that is to happen. You know, we've been partnering and trying to pull together our early-intervention systems, our, you know, pediatric societies, our academic medical research communities, all around the idea of, can we come up with a program for early identification?

If you ask me to identify the one person who -- or the one grant or the one mechanism that supported that, I couldn't tell you what it was, right? So there are some pretty complex issues. And even though many systems are pushing and seeing some progress there, measuring those things, communicating about those findings is something that's still quite challenging.
So that was a lot of words, but my initial response, David.

Dr. Mandell: Thanks. And, Aubyn, you've been doing some similar work at the preschool level in San Diego, as well, right?

Dr. Stahmer: A little bit, yeah. So at the early-intervention level, trying to get some policies in place within San Diego and Imperial

County through our one regional center. I think one of the biggest challenges, at least in a state like California, is that state policies, even national policies, really, trickle down locally in very different ways. And so, depending on where you were in the state, how things are interpreted really makes a difference for your services, even over and above, you know, issues, of course, in rural areas and access to care and things like that.

But how the regulations are interpreted changes what you can get for services for -- not quite neighborhood to neighborhood, but certainly county to county. And so I think understanding -- so studies, I guess, of a statewide policy don't necessarily tell us that much about what's happening in a particular community, and I think that is a gap or a challenge in how we look at autism services in general. Does that make sense?

Dr. Boyd: This is Brian. Also, it seems to me that there could be some methodological questions here, too, around, what are the most effective methods to sort of engage and sustain partnerships with local agencies? Like, do methodologies like participatory action research make sense here? So what are the most appropriate methods to sustain and engage partnerships?

And then how do you best build and sustain local capacity so there could be larger implementation science questions as well, like, do trainer of trainer models make sense? Once the researcher is sort of removed from the partnership, how do you make sure that the local agency is able to sustain what has been built up over time?

So it seems like there are some methodological and implementation science questions here that could be asked.

Dr. Warren: Then it gets to a really important point -- this is Zach again -- in terms of, does the science of actual practice change on the local level, right? You know, all autism seems to be local, right, to sites, state and Federal sort of guidance and policies of these things. But really, truly understanding what are the methods and approaches that could actually be potentially transportable across systems that really, you know, push practice change, that really actually sort of see a sustained difference over time in some of that is lacking.

Dr. Cheak-Zamora: This is Nancy. I just wanted to also point out that we're discussing a lot of early intervention. But part of this policy or recommendation is about use and self-determination and economic self-sufficiency, which isn’t seemed to be addressed within the funding and hasn't been addressed in the literature to a great extent.

Dr. Mandell: That's a really good point.

Dr. Cheak-Zamora: Um-hmm.

Dr. Daniels: So what kinds opportunities are needed here in order to stimulate the kinds of research that would be desirable?

Dr. Sally Burton-Hoyle: Hi, this is Sally Burton-Hoyle. I've been on sort of awhile. I was on late. I'm so sorry.

Dr. Daniels: Thanks for letting me know.

Dr. Burton-Hoyle: Yeah. I think that in light of the last comment, that there are many people, unfortunately, that don't think their child can ever have a life of self-determination. And so some of it goes back to -- and don't know [Inaudible comment] to go anywhere. But parents' appreciation of who their kids are and that they can have a life of self-determination regardless of the severity of their autism.

So self-determination begins, you know, at diagnosis or birth or whatever. So I think that -- I don't think there is anything much on that, because parents get to 18, and then they start thinking about it. But early on, it needs to be addressed, that people can have self-determined lives regardless of what their abilities are.
So I don't know how. I mean, if studies were to address that, I think that could help.

Dr. Stahmer: I completely agree. There has been one study that did show that successful employment is more likely if the youth or young adult had some jobs, some kind of job skills or job training. So they had a part-time job or they at least had some kind of work requirements at home.

And then actually, so that's increasing

independence sort of early on, and then that continually sort of multiplies and allows them to start thinking that they can be individuals.
But we're working on two programs at the Thompson Center on life skills and one on using photo-voice to increase self-determination. And I mean, a lot of our youths have the ability to do amazing things. But, yes, they completely lack the self-determination, and their parents haven't even thought about that because they're sort of living day to day or year to year.

Dr. Burton-Hoyle: They're living day to day and waiting for language. And that's not going to come. But that should not be the barrier for, you know -- parents need to look at the communication aspects.

But I spoke with parents last night who said their kids were not ready for any sort of self-determination until they could, you know manage a checkbook and things like that. And I'm like, "No, no, no. Don't think that way." So I think we need to do more. And so that's wonderful that there are studies that are beginning to address it.

Mr. Robertson: One comment that -- this is Scott Robertson. Does that mean maybe, if a potential element of expanding area in this research for the future would be maybe having something where training is for parents to help them understand the roles of determination across the lifespan and scaffolding that from a young age, you know, forward as their child grows up and grows into a teen and an adult?

And considering the diverse aspects of communication, et cetera, in what self-determination may look like differently for different individuals. I mean, do you think that's a kind of component of what needs to be in the research then?

Dr. Cheak-Zamora: Absolutely. And I would say it needs to go further than just the parents. Because our caregivers aren't initiating that either. And I don't know about the school level, but certainly when we're looking at health care settings, they constantly defer to the parents even when the youths have the ability to answer on their own and provide more self-determination or be more independent.

Dr. Boyd: Yeah, this is Brian. The other thing, too, I think is, how do we work with youths themselves to be better self-advocates? Because they start participating in their individual lives, transition plan around 14. And even for students who are capable of doing so, they often don't participate or don't know how to participate.

So are there effective interventions or strategies we can put into place to help them be better self-advocates as well, early on?

Dr. Cheak-Zamora: I would go back to -- I'm not sure who said something about projects of scale. But that's another area where this would be great. Because, you know, we're doing relatively good work with 10 to 15 youths at a time, but that's not going to solve the problem.

Dr. Daniels: So just to go back to the question that I posed earlier -- this is Susan. What kinds of opportunities are needed to encourage the kinds of research that you'd like to see here? Are all those opportunities there and they're just not being taken?

Dr. Stahmer: This is Aubyn, and I think if we could somehow add some research pieces into things like the state demonstration projects, where you've got already engaged and funded programs that are trying to do these things, that we could, you know, infuse some funding for some systematic evaluation, that might help move things forward in a direction that we know is effective, and then spread the information more broadly.

Ms. Abdull: Hi. This is Idil. I want to add also, in Minnesota, we were able to pass a legislation which is now a part of the -- this year, which basically mandated that state agencies or the health department, the Medicaid agency, and the employment, along with the education, to coordinate the services for children from birth to 18. So from diagnosis to high school to youth to getting -- either going to college or getting the job after high school.

And it's sort of at the starting point, because we were just able to pass this in May. But I think it's a really good idea. And somebody was talking about how it's very difficult even in San Diego, which California has at least regional centers.

But I think it would be very helpful if we're able to coordinate services and interventions and diagnoses from across the intervention. So not just the education talks to education, but the education -- there are interventions like speech and behavior therapy or developmental therapy, and then also employment, and that regardless of what a child or the person is on the spectrum.

So I think maybe starting with saying that sometimes people have nonverbal or classic autism, they are just -- their parents are told, they're told, "You know, you're just not self-determined. You're not able -- going to do this, that, or the other.

But these children and these people are able to do a lot of things, even the opportunities. So if there is a way to kind of replicate what Minnesota is doing in other states so that professionals and providers and systems are able to collaborate and work together, in the long run, and that would benefit.

And so we'd have children that are graduated from high school that are ready to go to college if they can and want to, or are ready to enter the employment workforce if they can and want to. We just don't have that on the national scale.

Dr. Boyd: This is Brian. But it seems like the other thing, and just based on the previous comment there, that there are some states who are beginning to implement some policies, in particular around transition age. And so can we study the facts of some of these policies that are being implemented? Are they actually leading to improvements in outcomes? So that's just what I was going to say.

Dr. Cheak-Zamora: This is Nancy. So this is sort of my area. And we will get to that, I think, in Question 6, too, a lot more. But a lot of other disease groups that work with children and youths with other disabilities have been doing this for 15 to 20 years, and they do have some good research in that.

But we also struggle with that sort of

research in making sure that we're looking -- we're not just implementing services and new programs, but we're actually evaluating it. So that the data on how effective on a lot of these programs isn't great, but there is a lot of history, if that helps at all.

[Several speakers]

Mr. Robertson: This is Scott. I'll be brief. I know that David wants to ask something, too.

Is it possible to incentivize some of these things like the self-determination, economics, self-sufficiency, like, embed that into other existing growths in terms of maybe some of the problems and some of the suggestions at times is that we have it full specialized in 15 different objectives. And maybe we should have some of these outcomes that we want to see more added to, you know, other objectives that look at, say, you know, different things in education, supports and things like for younger children.

Maybe some of these things like self-determination and parental training should be, you know, already components of - parental training around self-determination should be already components of some other existing research, but not, you know, part of that. Is that some of this, maybe? Is that taking what's in here and not just having it separated out into these special quote/unquote "demonstration projects" and putting it in other areas of research.

Dr. Cheak-Zamora: I completely agree. I mean, you can't achieve the 5.S.B that we were just talking about without self-determination in some of those, those aspects.

Dr. Daniels: David, do you have some final words on this one?

Dr. Mandell: Well, I don't know if they're final --

[Laughter]

Dr. Daniels: Well, for today.

Dr. Mandell: -- but it relates very much to what was just said about -- and it relates to some of the things we've talked about before. That is, often these opportunities come about in two ways. One is, they come about through longstanding partnerships between academic and publicly funded settings that lead to discussion and a trust and a willingness to experiment. So it goes back to the need to strengthen these partnerships.

The second is, they often occur because somebody's got to do something. So whoever has jurisdiction in a particular area is making a decision in the absence of information or with the best information available and sometimes with no real plans to study the outcomes.

I think about these state demonstration projects or other times when a state or a school district or city decides all of a sudden that they're going to implement X policy. And it would wonderful to have some kind of mechanism that would allow us to turn that into a natural experiment.

Because we're in the midst of hundreds of concurrent natural experiments about the best ways to care for people with autism at scale.

And so part of the issue here may be how do we take advantage of the decisions and the infrastructure that are already in place in some of these ways to study what the outcomes are, by having a rapid mechanism to pair the implementation of those decisions with research funds to evaluate them?

Dr. Daniels: Great. Well, thank you. That has been a good discussion for this one.

If you're ready, let's move on to 5.S.D: “Support two studies to examine health, safety, and mortality issues for people with ASD by 2012.” And on this one, the Group last time felt that the budget was partially met and that more work was needed on this objective, which I think is a recurring theme. But many studies, or some studies, have been funded in this area. Some examples are wandering and victimization, but they're small studies and do not address all the issues within the objective.

And it was noted that there are some projects that are probably coded elsewhere in the Strategic Plan, that are related to this.

But what is the state of the field in terms of these types of studies on health, safety, and mortality? And what needs to happen here?

Dr. Mandell: How soon does this relate -- how does this relate to the ongoing work that's happening with regard to wandering and elopement?

[Pause]

Dr. Daniels: Alison might have had to step off the call.

Dr. Mandell: Okay.

Dr. Daniels: She said that she was going to leave a little bit early.

Dr. Mandell: Well, then, we'll never know the answer to that.

[Laughter]

Dr. Daniels: Well, there's always Friday. We can bring up some of these issues on Friday if we need to.

Ms. Singer: No, I'm still here. Can you hear me? It was just on mute. Sorry.

Dr. Daniels: Oh, no problem. Go ahead.

Ms. Singer: I'm sorry. Could you just repeat the question for me?

Dr. Mandell: So we were talking about the studies related to safety, health, and mortality. And I was wondering how they relate to, if at all, the work that's being done in elopement and wandering and whether there is a research agenda around elopement and wandering that we ought to be exploring as part of this Plan.

Ms. Singer: So we are -- a group of advocates and we are working with Paul Law at the Kennedy Krieger Institute and the Interactive Autism Network to further mine the data that we've already collected with regard to wandering. But new questions have definitely emerged about best practices in terms of preventing wandering and, back to your practice to research, looking at some of the interventions that are being used to prevent wandering and for recovery after wandering takes place.

So we can determine which are the most effective and what the best practices are. So there's definitely more work to be done in this area with regard to research.

Dr. Cheak-Zamora: I would also say that health and safety are very important, since I think that 30 to 50 percent of our population has a comorbid condition. I've done several focus groups with parents of youth and young adults, and safety is one of their main issues that, as their child ages, they worry more and more about, of their child being taken advantage of or doing something that they would consider unsafe. But I don't know if there's any research out there in this area.

Ms. Abdull: Hi. This is Idil. I was just wondering about this Alison, or anybody can answer. So this is sort of like the disparity. We know how to name, but we're not really sure what to do about it and we don't know how to prevent it.

Wandering is just the biggest worry. I think the person before me just said that. It is the biggest worry, for myself and others for when your child, as your child gets older and they still don't have safety skills.

And then the even bigger worry is that, if he wanders, how will we be able to find him if he's not able to communicate? So the idea of just, you know, making your house look like, you know, a prison and just having so many locks, sometimes doesn't even work because that child in New York wandered off from school.

So I just wonder, what can we do about it? Is a bracelet a project, is that something that a lot of times CMS and Medicaid and private insurances don't pay, that you have to privately pay for that, or you have to have a waiver for it. Is it something in the research that can be done or has to be done that says -- because I would have to wait. While we're waiting, while we're waiting for this research, children are being -- they're wandering off and they're dying.

And so this is more like, I think, an emergency code red, that we need to have a prevention, even if we don't have the best way to prevent it. But we need some, much sooner than now, so that these children and youths, and adults even, are not wandering and then dying.

Dr. Rice: This is Cathy. I would add some more just to follow up. But I think what Idil and Alison are saying is we need to move beyond to have objectives that are much more about ways to prevent, address, and to respond to this important safety issue that has been identified.

So even though this objective has only been partially met, because it really has only addressed wandering and some aspects of victimization, there's a whole lot more that could be addressed about health and safety and mortality, but specific to this one key issue, recommendations for the future would be much more research-based ways of preventing, addressing, and responding to this so it doesn't happen.

Dr. Burton-Hoyle: This is Sally. And a huge piece of how kids with autism and young adults with autism are being hurt and killed is through the use of seclusion and restraint in school. You know, we see this policy that says it cannot happen. We've got policy now that says it can be done in case of an emergency, and emergency is still defined. So you know, kids are being hurt and killed every day.

So that is a huge piece of the mortality in health and safety.

Mr. Robertson: So, I also…This is Scott Robertson. I wanted to add also, in the context of adults, that I just wondered how it was more feasible to incentivize more research on health and wellness on what that looks like as individuals age from adolescent to adult life, considering that there's only been really about one good-quality study that looked at a lot of the barriers that autistic adults face.

And it found -- this is the study by Nicolitus Rainmaker and some others that found this through community-based participatory research, found greater odds of, I mean, health needs and physical health and mental health and greater challenges in -- like lower satisfaction in communicating with health care providers and accessing services.

I mean, a lot are challenges across the board, large barriers. That's like the only study in this area that has looked specifically at those specific challenges. And why can't more research be happening? So, what can be -- you know, I just wonder what can be -- incentivized by the end to improve the research on health and wellness challenges with autistic events facings comparison to non-autistic people?

Dr. Boyd: This is Brian. The other aspect of health, I would say, is sort of sexual health and decision-making because there's been a recent study around, just a descriptive study looking at having adolescents and adults sort of talk about their sexuality.

So I don't know if there's a lot of research around sort of how you inform them or talk to them about sexual health and sexual decision-making.

Dr. Mandell: Susan, this is David. I am mindful of the time. And I am noticing that we are halfway through Question 5.

Dr. Daniels: Right.

Dr. Mandell: An hour in, and we have not gotten to Question 6 yet. And I'm really enjoying the conversation, and I think people are being extraordinarily concise and thrifty in their statements.

But do we need to think about a different strategy to get through this by 12:30?

Dr. Daniels: Do you have a suggestion? But the only other strategy I have was to try to go through this, and if we run out of time, to have another call at some other point. You do have a larger number of objectives than some groups.

Although there were other groups that had almost this many and did get through the question. But there have been more people on this call as well, so more people that want to share their thoughts, which was why we invited people to be here.

Dr. Mandell: Right. Sorry. I don't have a great suggestion other than being a little more selective in which ones we spend a lot of time on. But I just wanted to be mindful of that.

Dr. Daniels: Thank you. I appreciate that comment. And it would be great if everyone could keep that in mind. We'll try to move through these a little bit more quickly so that we have enough time to go through them.

Alright, so let's go to 5.L.A: "Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013."

On this one, the Committee the last time when they met [Inaudible comment] recommended budget had been met. But it's a very broad objective, and there maybe be some overlaps with 5.S.A., that it was very broad, that more work was needed to cover the range of topics that are mentioned here. And specifically the requirement of projects looking at diverse community settings has not been met.

And so what do you think is the state of work in this area? And what are some needs or opportunities or ways that this could be improved?

Dr. Mandell: Aubyn, what do you think?

Ms. Singer: Well, Susan, I am going to have to drop off at this point. I apologize.

Dr. Daniels: Oh, no problem. Thank you.

Dr. Mandell: Aubyn, are you on mute? Are you still there?

Dr. Stahmer: I've been talking on mute. Sorry.

[Laughter]

Dr. Stahmer: Thank you. It's Aubyn. So I think there are a lot of studies in this area, which is good. But a lot of them are -- I would say a majority of them -- are not, I think, looking into the dissemination and implementation science literature in a way that's moving that into autism research quickly.

So I feel like we're trying some different things in community settings, sort of, but not -- most of them aren't using a model that I think is going to lead to sustainability, maybe just because that information hasn't gotten to the autism community quite yet.

So I don't know if there is a way to facilitate that, David. I mean, do you agree with that?

Dr. Mandell: Right. So that there's a lot of work that's been done in dissemination and implementation research in other areas.

Dr. Stahmer: Yeah.

Dr. Mandell: That is not making its way into autism.

Dr. Stahmer: Which then, I think, is slowing us down --

Dr. Mandell: Right.

Dr. Stahmer: -- because a lot of this work is people taking their particular intervention without much modification and just saying, "Let's try it in the community," which is going to take us a long time.

[Pause]

Dr. Daniels: How do you think you could encourage better use of those kinds of best practices?

Dr. Stahmer: Well, I think similar to what we were talking about before is really having some community partnership piece involved and some sort of understanding of community practice and how it will fit with whatever practice is trying to be implemented and really having some sort of a dissemination model as part of the project.

Dr. Mandell: I think also this is a great place for a training institute. So there are institutes on implementation -- research and implementation. And there are some people who are interested in autism who have started to attend these.

I wonder if one way to quickly advance the field is by creating those kinds of training opportunities and networks for people in autism who are interested in this area.

Dr. Cheak-Zamora: That's a great idea. This is Nancy. Just, I think --

Dr. Daniels: Great. Any other thoughts before we move on to the next one?

5.L.B: "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."

On this one, the Group felt that based on the funded projects, the recommended budget was partially met, but the ongoing projects under this objective with regard to efficacy, but not cost-effectiveness. And that overall more work is needed in general and that the intention of the objective has not been achieved so far.
So what do you see as some of the barriers that might be preventing this from moving forward in the way that it should?

Dr. Mandell: This is David. There are two things. One is cost-effectiveness. Studies work best when they are partnered with ongoing randomized trials or ongoing quasi-experimental trials.

And so it would be really cool to be able to supplement existing studies with a cost-effectiveness component that's built in from relatively early in the study. It's a great use of administrative supplements. And I wonder if there's even a potential for a call for administrative supplements on that.

Dr. Daniels: Okay.

Dr. Mandell: The second is that we have really lousy measures. We have really lousy autism-specific measures in this area. And so -- and I've worked with a couple of people who have done randomized trials where they've shown efficacy and then are interested in study cost-effectiveness, but they -- but the data collection is geared toward understanding clinical efficacy and not cost-effectiveness. So we need some additional, I think, measure development.

And the third thing is, in order to do this, you've got to follow people for a long time. And so it means being willing to invest in a cohort in a study that's showing efficacy or effectiveness, to be able to examine long-term cost-effectiveness. And I think that those three elements are sort of missing from research in this area.

Dr. Daniels: Great.

Dr. Warren: That's a great summary, I think, David, too. And that idea, I think that you're going to almost -- we're looking at efficacy, not cost-effectiveness right across this, because we're kind of looking at this within the trial itself. So I think that broader look I think is even further lacking.

Dr. Mandell: Yes, absolutely. There's also -- I think there's an issue of opening this to different trial designs, because if we want to do this as sort of the cost-effectiveness versus cost-efficacy, then sort of pragmatic randomized trials, which sometimes take a little more funding because you're having community stakeholders.

The community-based providers really do the interventions. So that sometimes it takes a little more funding than traditional RCTs.

Dr. Warren: This is Zach again. I think that's a great point. I think that's a point of tension that's probably run across a lot of these, is we've talked about that idea of potentially sort of, you know, practice research, right, or moving in the other direction?

You know, a traditional barrier to that is how these things are reviewed, really rely on tightly control designs, that if you're going to get aimed in that particular direction, it makes it hard to move there. So this openness of really understanding that new concept seems to me to be embedded within funding mechanisms itself.

Mr. Robertson: So, just wondered for folks -- this is Scott Robertson. It just points out in this objective, "of all ages." And we're certainly not, you know, meeting that by at least the projects that have been funded. Are there any, you know, specific reasons or anything that could incentivize to make sure this does occur in terms of this work in this area, across all ages with -- in coming years?

By not being “all ages,” I mean particularly -- I'm assuming it's particularly including adults, because it's saying "people of all ages," it doesn't say "children" in this objective. So...

[Pause]

Ms. Abdull: Hi. This is Idil. You know, I agree with David because it's very difficult to kind of separate the two. And we have a lot of ways of measuring this. But the efficacy and the cost-effectiveness, because if you're fighting to get XZY intervention because you're saying, you know, it's effective, then a lot of policymakers and a lot of people, or funders, are going to ask, "Well, is it cost-effective?"

But in order to say yes or no, you have to have research where people were followed for years, or even decades. And we just simply don't have that. And that's probably why a lot of interventions are not funded, because most policymakers, legislators, are going to say, "Show us the cost-effective research. Which one is going to work in the long term and that we will get our money's worth?"

So if there's a way to combine the two and make sure that there are incentives for these providers who cooperate with researchers, so we can find out not just, is it effective, but is it also cost-effective?

Dr. Daniels: So in terms of Scott's question about reasons why all ages are not included, it doesn't sound like anyone had any particular thoughts about that. But maybe just a note to say that there is a need to include all ages to do a better job in that area.

So let's move on to the next one, 5.L.C: "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."

And with this one, the recommended budget has been met. And there have been several projects in this area. However, there's a need to continue support efforts in this area. And that significant workforce needs remain, especially with regard to paraprofessionals.

And so with this one, I think that the Committee last summer had some issues about trying to understand what the research component is here. Because in terms of this, the funding and how it represented in the first -- in the third year -- of doing the portfolio analysis, the LEND programs, the HRSA LEND programs have some evaluation components in them. But since we don't -- we don't have a mechanism to tease out maybe little pieces of grants like that, the entire LEND programs were included in 2010.

And because the community felt that that might be over-representing the amount of evaluation that's been going on, now the LEND programs have been largely pulled out.

So the funding is probably not a great guide in this area. But, what can be done in terms of the research component of this and what needs to happen?

Dr. Mandell: This is David. I would -- and I think there are others on the phone that comment on this better than I -- but I think, similar to what we've discussed before, a big issue here is scale. So the LEND programs are highly selective. You have a relatively small cohort that it's going through.

And I think we need to start thinking about, how do you train, on a large scale, teachers or clinicians or other professionals coming into contact, or parents who are working with kids with autism, to improve the care these kids receive and their outcomes? And so I think that when we think about pre- and inservice training.

And then there's also the issue of which training models work best. And I think comparing additional training to nothing is not as useful as comparing training models in this particular area. So I would think the large-scale studies doing comparative effectiveness of different training models and examining its effect both on service delivery, but also, more importantly, on outcomes.

Dr. Stahmer: This is Aubyn. I agree. And I also think we need to understand better who needs to be trained in what. So there are some things that we can train paraprofessionals to do relatively easily and well, and then there are some things that need different types of stuff and interdisciplinary stuff.

And I think in some systems, like early intervention and perhaps schools, that's done -- it's built in relatively well. In places like health care, it's almost impossible, given the way funding is done.

So some of it is -- I guess that's service delivery, too. But that interdisciplinary -- promoting interdisciplinary practice, I think, is going to be very different depending on the service system.

Dr. Boyd: So this is Brian. I think the cost-effective piece comes into play here, too, because we know that sort of short-term trainings don't work. The people need ongoing support and coaching to sustain change and the change practice. So where some cost-effective means to support practitioners to sustain the training that we're delivering to them.

Dr. Daniels: Great. If it's okay, then, let's move on to 5.L.D: "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 the Group last time felt that this is a broad objective with a small recommended budget and that both the recommended budget and the intent of the objective have not been met at this time, and more work is needed.

But with you all, what do you think is desirable here? What would we like to see, ideally, in this area? And how might we get there?

Dr. Mandell: Can we -- this sounds so similar to some of the previous recommendations.

Dr. Daniels: There is overlap between some of these objectives.

Dr. Mandell: Is there a way to recommend that this gets folded in with other recommendations?

Dr. Daniels: Definitely. That could be a recommendation. That's something that has happened in various places throughout the Plan. There is some overlap in some places.

Where would you see this one tying in with something else?

Dr. Mandel: The other one on health and safety.

[Laughter]

Dr. Cheak-Zamora: Well, there might be an area in which self-determination and personal autonomy actually are, in and of itself, its own objective. Because I believe that those two are very important but are different than health and safety. But that's also addressed in 5.S.C, as well as 5.S.D.

[Pause]

Dr. Cheak-Zamora: This is Nancy still. But again, when you look at what's been funded for this, I wouldn't say that that it’s really meeting the needs of self-determination or personal autonomy. Somewhat -- bicycle safety and things like that seem to be certainly addressing some of the safety concerns -- but not much on autonomy.

Dr. Rice: And this is Cathy. This seems to address more of the issue we were talking about, that the earlier objectives need to, in the future, focus more on ways to prevent, address, and respond. And this goes into strategies.

And that given that -- even though we talked about, with wandering, we have some information on the scope of that issue in the earlier objective, there are a lot of other health and safety issues that really have not been addressed. So maybe it is still necessary to pull them apart or put them -- make sure that it's noted that they're related. One is to understand the problem, and the second is to figure out how to act on it in an appropriate way.

Dr. Burton-Hoyle: That's excellent, what you just said. That's absolutely it.

Dr. Daniels: So for this objective, are there different kinds of projects you would like to see here? Or do you really feel that this should be, at some point, broken out and integrated with other things that are already ongoing?

Dr. Rice: This is Cathy. I'd like to see them, 5.S.D and 5.L.D, tied together, in that the call to have studies to understand or examine health and safety and mortality issues are then quickly applied and tied into strategies to address those issues.

Dr. Mandell: That sounds great.

Dr. Cheak-Zamora: I agree.

Dr. Burton-Hoyle: Yeah.

Dr. Daniels: Okay. Great. So this will be the last one, then, for Question 5: "Support three studies of dental health issues for people with ASD by 2015, including:

The cost-benefit of providing comprehensive dental services, including routine, nonemergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with ASD as compared to emergency and/or no treatment. One study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with ASD.

And one study 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 this is one, the recommended budget has been met, and there are some projects in this area, but the projects are mostly focused on children, and that was one of the things the Group mentioned, that adults seemed to be a gap here. And that the funded studies focused on behavior management, but a more comprehensive health focus might be desirable to address the needs, the dental needs of children and adults with ASD.

Do you all have any thoughts about further work that needs to be done in this particular area or other projects that might be ongoing that we don't know about?

Dr. Mandell: This is David. I would much rather -- I would much rather see something like this come under the umbrella of an objective related to preventive health care and primary health care in general. And --

Dr. Burton-Hoyle: Yes. It does seem awfully specific.

Dr. Mandell: Yeah. And I know that there was a particular interest in this issue when the Plan was first created. But I would like to say that we've met the specific requirements of this objective and that the broader issue of primary care for children and adults with autism, whether -- regardless of the kind of health -- is still a pressing concern.

Dr. Warren: We agree.

Dr. Cheak-Zamora: I would also add mental health services. I mean, just personally, I think that's more of a priority than dental health services. For some of our youths and young adults.

Ms. Abdull: Hi. This is Idil. I think a lot of us on the last call were saying this is -- we want to see the specificity of this question or this objective carry over to most of the other objectives. It's very, very specific, and I think you said, Dr. Daniels, you said it was because Ellen Blackwell was part of team that created this Plan.

And so, I'm not sure what the process is, but it would be really, really nice -- and I agree with David and all the rest -- if we could make the other objectives as this specific. Because the more general and broad they are, the less likely we're going to have research that actually meets them and comes up with concrete results.

Dr. Daniels: I don't know if that's absolutely true. It is one of the challenges of getting overly specific in objectives is, basically if you're saying, "We want this project to be funded," but there's really no way for the Committee to control that. There's no way for a funding agency to really control it, unless they're going to put out a very specific initiative for that particular project.

But they can't do that for 100 different things. So you know, there is some benefit sometimes to having a little more generality to give broader guidance and then allowing the community to be able to, from that, come up with ideas that they think will work versus the Committee being overly prescriptive. But it's a balance.

So I think that we've gotten through Question 5. I'll just point out that the "Other" category, the funding there is for all the other projects that are related to services that didn't fit into any of these objectives. And the objectives were created by the Committee to address gap areas that they perceived in research and projects that needed to happen.

And so what was already ongoing in the research portfolios were coded in "Other," which on previous calls we've discussed with other folks in the Committee, and they all, I think, agree that "Other" is a very bland and non-descriptive term that doesn't help things. So we may be talking with the Committee about changing the name to something like "Core Activities" because it really represents the foundational other work that's going on in the portfolio.

So let's move on, then quickly to Question 6, and we will see how many of these we can get through. But we've definitely gained a lot of efficiency so hopefully, we can get through most of it.

“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. Examples are 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, 6.S.A.”

And with this one, the Group felt that the recommended budget had been partially met and the area is moving in the right direction and projects have increased over time. But what are the possible remaining gaps? What progress has been made in the area in terms of what's happening in the field? What are some of the opportunities or barriers?

Dr. Cheak-Zamora: This is Nancy. I just wanted to point out that, just thinking about this actual objective, there are, like, six different examples of how we could be working on service delivery here. So you have safety, employment, education, community inclusion, self-determination, relationships, health.

That's a lot going on in here. And so I don't know how we could actually address these recommendations within just one objective.

Dr. Daniels: And that is characteristic of a number of these objectives. The Committee comes up with a lot of ideas. Sometimes they really do just get lumped into a group in order not to lose anything. Go ahead, whoever that was. Did someone have a comment?

Does anyone have a --

Mr. Robertson: This is Scott. I just wanted to concur that I did also feel the same, that it was kind of -- it went past your -- where you had said that you wanted to find that balance point between not being too specific, but maybe being general to have more flexibility, I think this one is maybe way too general.

Dr. Daniels: Right. The balance is pretty tough sometimes, I think.

Any thoughts on the kinds of projects that are needed in this area?

[Several speakers]

Dr. Mandell: Sorry. Please go ahead.

Dr. Cheak-Zamora: Thank you. This is Nancy. So I would say that we definitely need more projects on employment, education, and health services. Those are key areas in which we don't really have a consensus on best practices.

And then also, how do we summarize this research? Because you have funded quite a few things that look like great studies here. But I don't know of a community -- like a real great way for me to understand what we learned from this and where do we go forward.

Dr. Burton-Hoyle: I agree.

Dr. Daniels: I guess that's where we were looking to people that have some expertise in the field that might be knowledgeable about that, because we don't have the time, unfortunately, to be able to go through the literature and summarize it for each of the areas across the whole Strategic Plan.

But we were hoping that there would be experts across many of the different areas on the groups. And on Friday, we'll have all of the experts together, and I think there are people that have expertise that's quite broad and hopefully might be able to weigh in on some of those things.

But do you all -- does anyone have any particular thoughts about things that need to happen here? So we have some comments about health services and employment projects and best practices. Anything else?

Dr. Mandell: For people who study this area, do we have an agreed-upon definition and measure of quality of life in adults with autism?

Dr. Cheak-Zamora: No, not that I know of. And I don't even think we --

Dr. Warren: Not yet.

Dr. Cheak-Zamora: Oh, go ahead.

Dr. Warren: David, this is Zach. Yeah. I mean, I think I was talking about that point earlier. I think that idea defining quality of life across the heterogeneity of the disorder is a really essential thing for us to be able to move forward with understanding intervention and outcome research over time.

I think that's a huge gap. How do we assess quality of life for individuals with severe cognitive impairment where employment ain't going to be the marker for one individual versus another probably in that particular way, right?

So I think really thinking about quality of life measurement for individuals with ASD is essential.

Dr. Burton-Hoyle: And this is Sally. And perhaps something specifically in people living with support, semi-independent or whatever.

Whatever terminology you want to use because it's, you know, just again these things are general, and they're looking at what are the factors, all these studies, but to specifically look at where people live and how people live and the number of choices they have in their lives. The “where people” live really matters.

Dr. Daniels: Alright. Good. In the interest of time, let's move on to the next one, 6.S.B: “Evaluate at least one model at the state and local levels in which existing programs to assist people with disabilities -- examples, Social Security Administration, Rehabilitation Services Administration -- meet the needs of transitioning youth and adults with ASD by 2013.”

And in this one, the recommended budget was determined to have been partially met, and there were -- there was more than one project funded, and one was recommended meeting the initial target. However, little to no work had been done on Social Security, and this was still needed. And the Group also thought that it might be possible that this objective could be achieved with less than the recommended budget. Any particular thoughts about what could be done here?

Dr. Cheak-Zamora: You know, I just think that within our population, or at least the parents that I've surveyed, there is a great lack of coordination between a lot of these services, and it gets really complicated, particularly for the young adults, as parents don't really know where to go or how to coordinate all of these activities and then also think about guardianship is very difficult.

Dr. Mandell: So this may be -- in looking at the two projects that this may be one of the places where we get closest to evaluating existing models, which is -- which is -- very promising. I wonder -- I wonder again if this is the issue of evaluating one model as opposed to comparing different models, given that so many states are doing different things, that it may be more efficient to do that.

Dr. Daniels: To look at one model at a time?

Dr. Mandell: No, looking at one model at a time is not efficient. And that what we ought to be doing --

Dr. Daniels: Is look at multiple models.

Dr. Mandell: -- is looking at, you know, given that so many things are going on across the country that we ought to be doing some comparisons.

Dr. Daniels: Okay.

Dr. Warren: David, I think that's a great point. I mean, this does get closest to what we were talking about in great detail. I think previously it seems like there is so much that's ongoing as well, thinking about just one model seems a bit limited in scope.

Dr. Boyd: So this is Brian. I may be perceiving this incorrectly, but it seems like people are also trying to get at cost-benefit kinds of issues here. Is that correct, we're thinking about?

Dr. Daniels: I think so.

Dr. Boyd: Another place to --

Dr. Daniels: -- know what others here think? Is this another one where having more effective partnerships would be helpful?

Dr. Mandell: Absolutely. Always. Just put it for everything.

Dr. Daniels: That seems to be a good recurring theme throughout all of this.

So, good. Alright, let's go to 6.S.C:

“Develop one method to identify adults across the ASD spectrum who may not be diagnosed or misdiagnosed to support service linkage, better understand prevalence, and track outcomes with consideration of ethical issues, insurance, employment, stigma, by 2015.”

On this one, the recommended budget had only been partially met, and one small project has been funded in the area. But one project would not be sufficient to meet the needs of the goal of developing a new diagnostic instrument. This is still a significant need.

So what do you think is lacking in this one and any possible suggestions about how that could be ameliorated?

Dr. Mandell: This is David. We actually just got this spring an R34 to develop a screening tool to examine, to look for the prevalence -- to look for adults with autism in community mental health settings who may have been misdiagnosed with other psychiatric disorders. And one of the things that became pretty clear as we were doing this is that its relevance is questionable unless it's really linked to changes in treatment plans and service delivery for these folks.

So I wonder if we -- if we need to link the methods for identification with -- with different models of care? Because I think it's an important -- I mean, it's an important exercise to be able to identify them. But to do it on a large scale, we then have the issue, well, what are we going to do with them? What additional support are we going to provide?

Dr. Cheak-Zamora: I completely agree. So I've heard quite a bit about having -- diagnosing people later in life, but then not doing anything about it. So "then what" related to this issue is huge.

Mr. Robertson: David, this is Scott Robertson. I concur that, you know, what use is having a clinical diagnosis if you can't actually access supports and services that go alongside it.

But I just was wondering related to the funding you had just gotten recently and, you know, other potential in this area for the -- for the long term. Does your project and do other projects consider the fact that some folks who are either misdiagnosed or not diagnosed at all may, because of adaptations or other reasons, may not be as easily "diagnosable" through, you know, instruments like the ADOS, et cetera. So this is taken into consideration that you may have to be creative and think a little bit differently about how you go about the diagnostic process so you don't miss folks who already have been missed by the system previously.

Dr. Mandell: Well, I like to think that we're doing that. I guess the jury is out. You'll have to see when we -- when we --

Mr. Robertson: I'll have to see your journal article when you publish it.

Dr. Daniels: Any other thoughts about this one?

Dr. Boyd: Just echoing what David said, I think it's all about linking to services here. Are we actually going to change services based on someone receiving a diagnosis in adulthood? Because that would lead to differential outcomes.

Dr. Daniels: Great. Alright.

So then let's move on to 6.S.D: "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."

And for this one, the Group felt that the recommended budget had only been partially met through funded projects. But there is not enough funding or enough projects for this objective and that the projects that are here don't address the full range of issues.

They said that, for example, older adults are not considered. The projects that are funded are focused on secondary students and transition-age youth and that there were no new projects funded in 2011 and '12 in this area. So, so what are the needs here, and what could be done to make this better?

Dr. Mandell: So this looks very similar to the pre- and in-service training objective for Question 5.

Dr. Daniels: Uh-huh.

Dr. Mandell: And I wonder if we should think about the same kind of approach that as we -- and it relates to the previous objective, too. As we identify more and more adults with autism or as individuals with autism age into adulthood, they're entering some kind of care system. That care system generally is not particularly prepared to meet the needs of adults with autism.

And so how do we, on a large scale, think about providing training and support to those professionals so that they're better equipped to help these adults with autism?

Dr. Daniels: So would you envision comparative effectiveness or what other, what kinds of research would be helpful for this?

Dr. Mandell: Well, we may not be at

comparative effectiveness yet --

[Laughter]

Dr. Mandell: -- but --

Dr. Cheak-Zamora: I was -- oh, go ahead -- sorry.

Dr. Mandell: No, please.

Dr. Cheak-Zamora: This is Nancy. I was just -- I agree. I don't think we're at the comparative-effectiveness level. Just trials on how to educate them the best and quality improvement efforts within the health care system I think would be really effective and needed at this time.

Dr. Daniels: Okay, any other thoughts about that one?

[Pause]

Okay. Let's move on to 6, long-term, A, 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 this one also has a little bit of overlap with some other objectives here.

The recommended budget was partially met, and there were 11 to 18 projects depending on the year that were supported between 2010 and 2012. And the Group felt that while good work is being done, that sustainability is important in order to fully achieve the goals that were set forth by the objective.

And they also noted a trend of decreasing funding over time that they felt was a concern.

Dr. Mandell: I wonder if, given the concerns that have been voiced about especially the first objective and the similarity across many of these objectives with quality of life or health outcomes as the primary outcome of interest. And they all seem to be sort of taking a different slice at the same question -- whether it's worth recommending that these objectives be turned on their head, or turned sideways at least, and that the outcomes of interest identified in the first objective be separated and that the objectives relate to the outcome of interest rather than these slightly different methods of getting at the same issue.

I don't know if that made any sense, but you could still look at local practice models to test the effectiveness and cost-effectiveness of these different types of interventions to address a more specific objective, which also gets at Idil's concern that when they're so diffuse, it's very difficult to judge the progress we've made.

Dr. Boyd: Yeah, I agree with that. Because I think the overlap in the objectives is leading us to make similar recommendations on all of them. Because all the things David just said, I would say, oh, well, all the things we've already said for other objectives. How do you engage community stakeholders and get them involved? And I think that they overlap with other objectives we've already discussed.

Dr. Cheak-Zamora: And just a point on what you've actually been funding. It looks a lot like these projects have been mostly on teens and adolescents. So you're not actually getting so much at the adults, although I think that we need a lot more on adolescents.

But just a point of clarification: It doesn't seem like we're addressing a lot of adults with ASD within this -- within at least what's been funded.

Dr. Daniels: Okay. Thanks. Anything else here? Okay. Let's move to 6.L.B: "Conduct one study that builds on carefully characterized cohorts of children and youth with ASD to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes by 2015."

And on this one, the Group felt that the recommended budget has been partially met, and there was more than one project. But the projects have not addressed the questions in the area satisfactorily and that more research is needed regarding long-term outcome.

So what, how do you feel about this one?

Dr. Boyd: Something would have to be put into place to allow you to follow, allow you to follow kids who perhaps participated in some RCT to look at later outcomes. Are we funding -- can some funding mechanism be tied to an RCT, the funding that allows you to follow that cohort of students for a long time?

Dr. Warren: I think you would really want to sort of invest in multiple cohorts to really go after these issues that keep hammering home lifespan issues, right? Rather than just identifying an EI sample and following them for 25 years, which seems unrealistic.

You know, I think across some of these issues, you know, as much as we would like to think that we have this defined and understand that we really lack actual fundamental natural history studies of carefully controlled cohorts at different time points. You know, what we have from the people who've done pretty exceptional longitudinal research is really research that, you know, is from a different era and a different time.

And as much as I, you know, value sort of this contribution, I think it's worthwhile in investing in what we truly know about individuals with ASD in different cohorts as they exist in our society today. But also I think it is an extremely important idea to really emphasize not just one, but multiple studies looking at sort of the benefit of EI later on.

I mean, I've heard that again and again from those folks who are telling us, you know, basically, what should we pay for across systems of care, you know? And we really don't have great answers for that yet.

Dr. Daniels: So one of the barriers here -- this is Susan -- probably is cost if you're talking about doing long-term and longitudinal studies that would allow this kind of work to be done, and so that might be one of the barriers at least in achieving this.

Dr. Boyd: Right. And being able to measure the variation in the quality of services they're getting when you're studying existing EI programs, and that looks so different than trying to follow a natural cohort of students who are receiving early intervention services through Part C.

I don't think we have great ways to capture dosage amount and variation in quality of services that kids are receiving and then follow them.

Dr. Mandell: That's a really good point, Brian. We don't know how to characterize what they got.

Dr. Boyd: Yeah, exactly. We can't even describe really what they're getting.

Dr. Mandell: Right. So, but I also think that to build on Zach's point, this is -- I think you want to, for something like this, you'd want to build on stuff you've already funded. And so thinking about how to take advantage of ongoing either observational studies or experimental studies, where you may be more interested in what's happening in the control group than you are in the intervention group for these for these longer-term -- for these longer-term studies.

But how do we -- you know, there's such great expense to field those studies. There is the potential for such wonderful data if we were able to continue to follow and carefully characterize the experiences of these individuals over an extended period of time.

Dr. Daniels: Any other -- any other suggestions for this one?

[Pause]

Okay. Let's go to 6.L.C: "Conduct comparative-effectiveness research that includes the cost-effectiveness component to examine community-based interventions, services, and supports to improve health outcomes and quality of life for adults on the ASD spectrum over 21 by 2018. And topics should include community housing, successful life transitions, including from postsecondary education to adult services, employment, sibling relationships, day programs, and meeting the services and supports needs of older adults with ASD.”

And on this one, the Group felt that the recommended budget was only partially met and there was not nearly enough funding or projects for this area. And that most of the projects focus on adolescents and that more work especially needs to be done on the services and support needs of older adults.

What do you think about this one?

Dr. Mandell: I think this is -- this is another example of sort of a confused objective and that, again, so much overlaps with the other ones. And again, I think it's a lot of the things that we've already said are the same kind of challenges and that the overall -- and I welcome other people's thoughts on this.

But the overarching recommendation here may be that we need to do some different splitting of these objectives so that they're organized either by the outcome of interest or the specific population of interest if we want to highlight the needs of middle-age and older adults, which has not yet really been done. But that the objectives seem to repeat in different ways the same method over and over.

Dr. Daniels: And so, through that, you can understand some of the difficulties that we've had and the funders have had in coding projects as well because of these types of overlaps?

Dr. Mandell: Yeah.

Dr. Warren: This is -- I just have a question for people who do adult work. I mean, do we even have enough empirically sound interventions to be doing comparative-effectiveness research? It seems like we need more empirically sound interventions for adults.

I mean, that's just the overall question I had about the objective.

Dr. Cheak-Zamora: I agree. And I don't

particularly work with adults more than adolescents, but I don't think that we're at a point where we could even do this effectively.

Dr. Boyd: I don't even think we know, you know? I mean, most of our research does not capture older adults at all. Researchers don't even know who they are, where they are, how to pull them in, and what's going on.

I mean, I think there is some even more basic research that needs to be talked about. I think it's -- I really hear what you're saying, David. These things tend to blend together in my ears and eyes at this point, and in doing so, I think it may miss some of those things that need to be extracted like that very point.

I think we see so much that's focusing on just this transition age, and then it doesn't go beyond that. So anyway, I'm rambling.

Dr. Rice: This is Cathy. One thing I think -- when these objectives were put together, part of it was the discussion was having some -- the sense of urgency -- about things are happening for some people with autism in the community now, and how do we understand what's happening there?

And one of the challenges is certainly identifying potentially who has autism, and are all the people with autism clearly identified within that community in a way that research can be done to draw any conclusion? But I think we shouldn't totally lose the fact that there does need to be some characterization of what is happening now, and is what is happening effective in any way?

For instance, housing options. People with autism live somewhere right now. So how do we find out where they're living now and what the different situations are, and are there models that exist within whether there are state systems or particular existing mechanisms that may not be autism focused or adult care focused that could be better understood?

So just don't -- don't want us to lose that point and that we need to -- we do need to look at the fact that some things are happening. Whether they are the most effective interventions and autism specific, we don't know, but that's what we need to find out.

Dr. Daniels: Cathy, this is Susan. Just there might be some overlap with Question 7. The Committee put the State of the States project in Question 7, and I don't know if the State of the States covers anything about housing. But it does cover a number of different services.

And I don't know, David might be more familiar with this -- but that report apparently is expected to be coming out sometime in 2014 and will be descriptive of what's currently going on in the states.

Dr. Rice: Yeah, that's a helpful reminder and so it could be taking from the State of the States, doing some comparative effectiveness of some of those models across states, for instance, although not clean and easy to do.

Mr. Robertson: So I just wanted to just add a couple of comments to what's been said. Scott Robertson.

You know, some of it, you know, when I constantly see the way things look in terms of the funding structures, et cetera, in this versus some of the other questions, some of it relates back to meeting that paradigm shift to be looking at and just considering, you know, over and over again that we need to be looking at things through a lifespan lens and not, you know, starting at, okay, most of the resources need to go only singularly toward childhood.

I mean, that's part of what's reflected here is this -- is the belief system that doesn't necessarily always encompass a lifespan lens that, you know, necessitates making sure that we look across all ages. And related to that, I had mentioned before at a previous -- I think it was at a previous IACC meeting -- mentioned to some other colleagues how we could be covering some of these areas in terms of unmet needs -- for instance, in finding out housing needs, et cetera -- and what things currently look like for autistic adults if we had more involved needs assessments going on nationally and regionally.

As some of our colleagues in other countries have done, like in England, where they mandated needs assessments actually 4 years ago, specifically for autistic adults in different parts of that country. And they've have been finding out some really interesting trends that we're not really doing here because we haven't taken a really large focus to finding out the unmet needs and the gaps and knowing where we should be creating, you know, evidence-based service supports for autistic adults because you can't really be doing that unless you're finding out how things are going on right now.

And I don't know, since I'm not on Question 7, I don't know how that's looking like in the State of the -- what is it? You said it's the State of the States in autism, whatever? Is that what was mentioned for 7, and adults are a part of that?

Is that the case, Susan?

Dr. Daniels: It's a study that's looking across all 50 states to look at services practices in all the states, and it's being funded through CMS. And so, that project is coming to completion, and they plan to publish a report sometime in 2014.

And John O'Brien or some other people from CMS will be coming to the IACC to give a talk on that, whenever the report is released.

Mr. Robertson: And it encompasses all age ranges? So it encompasses adults in that work?

Dr. Daniels: We assume so. It's supposed to be all services, so we imagine that a lot of the services are directed at adults.

Mr. Robertson: Okay.

Dr. Daniels: So then, if there aren't any further comments on 6.L.C, then we can move to the last one, which is 6.L.D: "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."

And that, again, has a lot of the same words we've heard in some of these other objectives, arranged differently. The recommended budget was only partially met, according to the Group that met last time. There is an inadequate number of projects and funding for this objective.

The funded studies are economic analyses but not implementation of comparative-effectiveness studies in real-world settings. And so what do you all think is needed here? Are there any particular barriers to getting to where that objective needs to go?

Dr. Cheak-Zamora: I think we've already sort of talked about a lot of this is just the data. So we don't have it to even follow to know where the young adults or the adults are in real-world settings. So even a lot of our mechanisms, like the AT and the LENS, they don't follow people past 18. So I'm not sure how to get in touch or contact this group of young adults or adults.

Dr. Daniels: Cathy, do you have any comments about future prevalence work that may be done in adults and how that could tie into any of this? Is it included in Question 7's area?

Dr. Rice: Yeah, not in anything else that we talked about in 7, except that that's a huge gap. And I know that David mentioned some funding for a partial project of looking at prevalence among psychiatric-facility-based patients. I think that's what you had said.

Dr. Mandell: Yes.

Dr. Rice: Something of that nature. But otherwise, not that I know of.

Dr. Daniels: Okay. So that's something that we can note here -- that it seems that there are a few layers of gaps. We don't know the prevalence. We don't know where the adults are, and then we don't really know what their needs are in the kind of detail that might be needed to move on to the next layers.

So you've successfully gotten through all of these objectives. I applaud you for doing that. We wanted to have a couple of minutes to talk about the aspirational goals. You might have -- I think that you've actually already summarized some of that in the discussion today.

The aspirational goal for Question 5 was "Communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD."

And we wanted to talk about where we are with that and what are the needs, although I think that you've already discussed a lot of what might -- what you might be interested in here. But do you have any comments about that?

Dr. Mandell: I think, as you said, Susan, I think we've covered a lot of it. I think the aspirational goals are wonderful, and I aspire to them.

[Laughter]

Dr. Mandell: I think that one of the things that has come up in our discussion is the need for the objectives to perhaps line up more clearly with the aspirational goals. And that we use them to sort of unpack what we mean by maximized quality of life and health, that we -- that we unpack what we mean by self-determination, by participation in school, work, community relationships, and access to services and supports and that the objectives be lined up with those components of the aspirational goals, which I think would, in turn, also address some of the considerable overlap in the objectives as they exist now and allow us -- as has come up on this call several times -- to point out here is where we are in moving toward this aspirational goal within this specific area.

But right now, they are so general that in some places, I think we have good -- we know the best ways to intervene -- and it's an issue of getting them to the community. And in other places, we really don't even know the best way to intervene, and we're at a different place.

But because of the ways the objectives are glommed together, it's difficult to separate those things out.

Dr. Daniels: Great. Anyone else have any comments about the aspirational goal?

Dr. Burton-Hoyle: I think David summed it up perfectly. I think it's what I recommend.

Dr. Boyd: Yeah, I think just do what David said, yeah.

Dr. Daniels: Great. Well, on the Question 6 aspirational goal: "All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports.”

Do you have any comments about that aspirational goal beyond what we've discussed already today on the call?

Dr. Cheak-Zamora. This is Nancy. I just like this one very much because you are breaking it down a bit further, but we need to also think about, is this aspirational goal in -- does it work with the objectives in 6? And I would say that they are mismatched in some ways.

Dr. Daniels: Okay. Well, you've all done an excellent job of really providing thoughtful input on all of these. I think that all of this commentary will be really helpful to the Committee as they consider the update to the Strategic Plan, and we'll all be getting together on Friday.

We're going to be going through in order. I know that Questions 5 and 6, they always end up a little bit toward the end of the day, but we did try to schedule things so everybody would be getting out of the meeting by 5:00 p.m. And we're going to go systematically through the Plan and have 50-minute discussion blocks for each question of the Strategic Plan with an interlude for public comment.

And we will have a working lunch. We're going to have box lunches there for you. We'll have to ask you to pay for them because the Government can't provide those lunches anymore, and then we will sit down and eat our lunches as we continue through the rest of the questions.

And we really look forward to having you participate and feeling free to comment on any of the questions, not just be limited to these two. And we hope that there's a lot of cross-fertilization of ideas. And we know many of you have broader expertise than what you've been called to do on these particular phone calls.

So I will be sending out the agenda. The agenda is already posted on the Web site, but we will send out a PDF copy, as well as some instructions for Friday in the near future.

Do you have any questions before we conclude the meeting here today?

Dr. Mandell: Thanks for your stewardship in this, Susan. This was a lot of stuff to get through quickly, and I really appreciate how you helped us do it.

Dr. Daniels: Oh, well, thank you. I appreciate all your help with getting through this and for the really robust discussion we've had. We appreciate everyone's participation, and we look forward to talking with you on Friday.

So we're adjourned.

Dr. Stahmer: Susan, this is Aubyn. Is there anything in particular you want us, after this discussion, to prepare or think about for Friday or we're going to continue this?

Dr. Daniels: I will have some information in the email that I send out.

Dr. Stahmer: Okay.

Dr. Daniels: And, but you don't have to do any extensive preparation. So don't worry about that too much. I think your expertise will be what will be helpful to us.

Thanks so much. Have a great day. Bye-bye.

(Whereupon, the Strategic Plan Questions 5 and 6 Planning Group of the Subcommittee for Services Research and Policy was adjourned.)