

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 6 - Question 6 - What does the
Future Hold, Particularly for Adults?

Conference Call 1

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2:00p.m.

PARTICIPANTS:

SUSAN DANIELS, PH.D., EXECUTIVE SECRETARY,
IACC, DIRECTOR, OFFICE OF AUTISM RESEARCH
COORDINATION (OARC), NATIONAL INSTITUTE
OF MENTAL HEALTH (NIMH)

JULIE LOUNDS TAYLOR, PH.D., ASSISTANT
PROFESSOR OF PEDIATRICS AND SPECIAL
EDUCATION, VANDERBILT KENNEDY CENTER
INVESTIGATOR, VANDERBILT UNIVERSITY AND
WORKING GROUP CO-CHAIR

SAMANTHA CRANE, J.D., DIRECTOR OF PUBLIC
POLICY, AUTISTIC SELF ADVOCACY NETWORK

AMY GOODMAN, SELF-ADVOCATE

DAVID S. MANDELL, SC.D., ASSOCIATE PROFESSOR
DEPARTMENT OF PSYCHIATRY AND PEDIATRICS
CENTER FOR MENTAL HEALTH POLICY AND
SERVICES RES., UNIVERSITY OF
PENNSYLVANIA, SCHOOL OF MEDICINE

EDLYN PEÑA, PH.D., ASSOCIATE PROFESSOR,
EDUCATIONAL LEADERSHIP, DIRECTOR,
DOCTORAL STUDIES, CALIFORNIA LUTHERAN
UNIVERSITY

ROBYN SCHULHOF, M.A., SENIOR PUBLIC HEALTH
ANALYST, MATERNAL AND CHILD HEALTH BUREAU
HEALTH RESOURCES AND SERVICES
ADMINISTRATION

SCOTT BADESCH, PRESIDENT/CHIEF EXECUTIVE
OFFICER, AUTISM SOCIETY

VANESSA HUS BAL, PH.D., POSTDOCTORAL SCHOLAR
DEPARTMENT OF PSYCHIATRY, UNIVERSITY OF
CALIFORNIA SAN FRANCISCO

SOMER L. BISHOP, PH.D., ASSISTANT PROFESSOR,
DEPARTMENT OF PSYCHIATRY, UNIVERSITY OF
CALIFORNIA SAN FRANCISCO

LESLIE J. CAPLAN, PH.D., REHABILITATION
PROGRAM SPECIALIST, NATIONAL INSTITUTE ON
DISABILITY, INDEPENDENT LIVING, AND
REHABILITATION RESEARCH, ADMINISTRATION
FOR COMMUNITY LIVING

DR. NANCY CHEAK-ZAMORA, PH.D., ASSISTANT
PROFESSOR, DEPARTMENT OF HEALTH SCIENCE,
UNIVERSITY OF MISSOURI SCHOOL OF HEALTH
PROFESSIONS

DR. LAURA GROFER KLINGER, PH.D., DIRECTOR,
TEACCH AUTISM PROGRAM, ASSOCIATE
PROFESSOR, PSYCHIATRY, UNIVERSITY OF
NORTH CAROLINA

MS. JALYNN PRINCE, PRESIDENT AND FOUNDER,
MADISON HOUSE AUTISM FOUNDATION

DR. PAUL SHATTUCK, PH.D., ASSOCIATE PROFESSOR
LEADER - LIFE COURSE OUTCOMES RESEARCH
PROGRAM, A.J. DREXEL AUTISM INSTITUTE

DR. SUSAN WHITE, PH.D., FACULTY, DEPARTMENT OF
PSYCHOLOGY CORE FACULTY, CLINICAL
SCIENCE, CO-DIRECTOR, VT AUTISM CLINIC

PROCEEDINGS:

DR. SUSAN DANIELS: Thank you. Well, welcome to our public audience and welcome to the members of the working group of the IACC's strategic plan update for Question 6 of the IACC strategic plan, what does the future hold, particularly for adults. And this is a chapter of the IACC's strategic plan that is focused on lifespan issues. And so we have a group of -- who've volunteered their time to help with the update to the strategic plan. I'd like to do some welcomes and introductions. So welcome to you all. The materials for this call are up on the IACC website. So anyone from the public who's listening in, if you go to the website and to the meetings tab, if you go into the working groups, you'll be able to find the materials for this call and you can follow along.

I'd like to take roll and I'm just going to read the names. And if each of you can give a one to two sentence summary of who you are to introduce yourself to the group that would be great. So starting with our co-chairs and thank you to our co-chairs, Brian Parnell and Julie Lounds Taylor who will be especially working with helping coordinate the drafting of this chapter of the strategic plan update. So we'll start with Julie Taylor.

DR. JULIE LOUNDS TAYLOR: Hey, everyone. I'm Julie Taylor from Vanderbilt University. I'm a public member of the IACC and my research is focused on understanding how to improve the transition to adulthood and adult outcomes for people with ASD.

DR. DANIELS: Thank you. Brian Parnell, have you been able to join? So Brian is our other co-chair and hopefully is not having problems with the phone, but maybe will join

us later. So next is IACC member, Samantha Crane.

MS. SAMANTHA CRANE: Yes, I'm Samantha Crane. I'm the Director of Public Policy at the autistic self-advocacy network.

DR. DANIELS: Thank you. Next is Amy Goodman who's also a member of the IACC. Amy?

MS. AMY GOODMAN: Yes, I'm Amy Goodman and I'm a, I guess, independent individual on the spectrum,

DR. DANIELS: Thank you. So Kevin Pelphrey is not able to join us today because he's on travel. Edlyn Pena who's a member of the IACC also.

DR. EDLYN PENA: Hi, this is Edlyn. I am an associate professor at California Lutheran University and I'm co-director of the autism and communications center.

DR. DANIELS: Thank you. Robyn Schulhof?

MS. ROBYN SCHULHOF: Hi, good afternoon. This is Robyn Schulhof and I am an alternate member in place of -- on the IACC for Laura Kavanagh. We are with the Health Resources and Services Administration at HRSA.

DR. DANIELS: Thank you. Alison Singer? So she may join us on this call, although she is chairing question seven and that call just ended about half an hour ago. Scott Badesch?

MR. SCOTT BADESCH: I'm here. I'm the President and CEO of the Autism Society of America.

DR. DANIELS: Thank you. Vanessa Hus Bal?

DR. VANESSA HUS BAL: Hi, I'm an associate professor at the University of California San Francisco and my research focuses on symptom profiles of autism in adulthood and different factors in childhood and adolescent that predict longer-term achievement.

DR. DANIELS: Thank you. Somer Bishop?

DR. SOMER BISHOP: Hi, I'm also at the University of California San Francisco. I'm an assistant professor and I'm interested in phenotype and measurement issues across the lifespan.

DR. DANIELS: Thank you. Leslie Caplan?

DR. LESLIE CAPLAN: Hi. I'm an external participant. I'm a project officer at the National Institute on Disability Independent Living Rehabilitation Research, otherwise known as NIDILRR in the administration for community living.

DR. DANIELS: Thank you. Nancy Cheak-Zamora?

DR. NANCY CHEAK-ZAMORA: Hi, I'm Nancy Cheak-Zamora. I'm an assistant professor at the University of Missouri and work at the Thompson Center for Autism and Developmental disabilities. My research centers around how we can provide healthcare services to promote independence and appropriate transfer of care for young adults with autism.

DR. DANIELS: Thanks. Laura Klingler?

DR. LAURA KLINGER: Hi, this is Laura Klingler. I'm the Director of the Teach Autism Program at the University of North Carolina, Chapel Hill and my research is on a transition to employment and post-secondary education, and also looking at adult outcomes in a group

of 30 to 50 year olds with autism who were diagnosed as children here at Teach.

DR. DANIELS: Thank you. Ophelia McClain? She is not with us at this time. JaLynn Prince?

MS. JALYNN PRINCE: Hello, can you hear me?

DR. DANIELS: Yes.

MS. PRINCE: Okay. Thank you. I wasn't sure that my phone was working. I'm JaLynn Prince with Madison House Autism Foundation and we have been around for ten years working on the issues of those 21 and over and the issues facing adults and families that are on the spectrum. And I am also the parent of a 26 year old, Madison, who is profoundly impacted by autism.

DR. DANIELS: Thank you. Paul Shattuck?

DR. PAUL SHATTUCK: Hi, my name is Paul Shattuck. I'm the Director of the Life Course Outcomes Research Program at the A.J. Drexel Autism Institute at Drexel University in Philadelphia. Thanks for having me.

DR. DANIELS: Thank you. Nancy Spenser? Maybe will join us later. And Susan White.

DR. SUSAN WHITE: Hi, this is Susan. I'm at Virginia Tech and I do mostly treatment and transition prep research for adolescents and adults with ASD.

DR. DANIELS: Thank you. We have a terrific group of people together as we did for all of the other questions as well, and we really appreciate you all volunteering your time to do this. So I'm going to be talking with you today about past progress that's been made towards achieving the initial objectives

of the strategic plan that was put together by the committee initially in 2009 and then has been updated every year. And the committee, if you go to the first packet that I gave you, that is about the IACC's strategic plan structure, the committee decided to frame the strategic plan around seven consumer based questions. And so the first question is "When should I be concerned?" about screening and diagnosis. Question two, "How can I understand what is happening?" Which is about the underlying biology of ASD.

Question three, "What caused this to happen and can it be prevented?" That's about genetic and environmental risk factors for autism. Question four, "Which treatments and interventions will help?" Which is about a variety of different types of interventions for ASD. Question five, "Where can I turn for services?", which has some overlap a little bit with the area you all are looking at, which involves services and service systems. Question six, "What does the future hold, particularly for adults?" Which is the topic of this group, which is about lifespan issues and was created by the committee to focus attention on the needs of adults.

Question seven, "What other infrastructure and surveillance needs must be met?", and this question is a cross cutting question that encompasses research infrastructure, surveillance, the research workforce, collaboration, and outreach efforts. And so this is the structure of the plan. We have working groups for each of these questions so that's something to keep in mind as we operating through looking at the portfolio of research for Question six that there are smaller chunks of the portfolio that are divided across this entire strategic plan that capture other aspects.

So I provided an outline for you of the structure, the rough structure of what the IACC strategic plan update is going to look like and this working group is going to be involved in helping draft some of the language, especially in the middle of the strategic plan. So in 2016 and 2017, for this new strategic plan update, it'll be an opportunity for a significant refresh of the plan because the last time the objectives of the plan were updated was in 2011. And so the committee agreed in some of the previous meetings that have been held in the end of November 2015 through 2016 that it was time to create a new set of objectives.

And so one of the things that this group will be doing will be helping create those new objectives. So to go through the structure briefly, the new plan will have an introduction and it will have a section that describes the question area and the aspirational goal. And this might have evolved since the last time this was updated because I think out of the different question areas, this question six was probably one of the most rapidly evolving and growing. So you may have some important updates to make to the description of what this area encompasses.

The current aspirational goal that the committee developed for this question area is "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." And so you'll be considering throughout this process where we're going in terms of that aspirational goal and if the aspirational goal needs to be adjusted at all. We will have a section in the strategic plan update about the progress that's been made toward the current

strategic plan objectives and there are 78 objectives for the entire strategic plan. And our conference call today is going to be discussing this area. We'll be talking about progress made on the objectives for Question six and so that's going to be the focus of today's call.

For the next call, our focus will be to talk about progress that's been made in the field, which will be the subject of some of the writing that you're going to be doing. So that section will involve an update on research that has occurred in the last couple of years, so major advances in science, what has happened in terms of practice to research, and vice versa, and gap opportunities of needs in research, as well as a section on services and policy updates. And in the new law that reauthorized the interagency autism coordinating committee, the Congress wanted the IACC to include more information about services and supports issues in the strategic plan update.

And so the previous strategic plan was a strategic plan focused on research and now it's going to be expanded to give fuller consideration to services and supports needs. And so there will be an entire section to talk about new programs and policies, research evidence that can inform policy, and services needs and gaps, and needed policy changes. And so I know that you all will have a lot to contribute to that as well. And at the end of that discussion, we will also talk about the aspirational goal and whether you feel that it's still an appropriate goal.

We also are going to be talking about duplication of effort because in the new law, it requires that the IACC provide a statement about recommendations to avoid duplication of effort, and in particular to avoid various

agencies duplicating each other's effort or working simultaneously on areas without proper coordination. So we'll talk about whether you have any concerns looking at the portfolio about duplication of effort in this area.

The next section of the strategic plan update for Question six will be where you all will help devise new strategic plan objectives for the plan. So this will be replacing the current objectives. So there are 78 across the entire plan. The committee felt that with this refresh that they would like to limit the number of objectives to a smaller number so that it's easier to understand -- easier for Congress, and the public, and those who read the plan to really grasp what the major priorities are that the committee sees for the area. So we're going to be shooting for three broad objectives per question. So question six will have three new objectives and each of these will be a broad objective that may encompass both research and services types of goals. And under each objective, we can give examples of the types of projects that would be responsive to that objective.

The law also requires that the committee develop budgetary requirements for the strategic plan and so we will be bringing that back to the committee once the working groups have made recommendations about objectives, the committee can consider how they want to do their budgetary requirements, whether they want to do it similarly to last time and create individual budgetary requirements for each objective, or if they want to do it in some larger chunks or across the entire strategic plan. And then there will be a summary and conclusion to the document.

So it's quite similar to the current document but does anyone have questions about the structure? All right, so then we can move

onto the next portion of the call where we're going to look back at some of the data that we've collected about research that has been ongoing in autism. So my office, the Office of Autism Research Coordination annually collects data from across many different federal funders and private funders of autism research and we analyze the data according to the IACC strategic plan to help the committee better understand how the research landscape relates to their plan and what has been funded, what are the trends in funding, and hopefully can use that information to help inform them for future iterations of the strategic plan.

So we're going to talk about the question six area and I provided you with a data packet for this. So if you turn to the data analysis packet that I provided for you, I'm just going to briefly go over the figures in here and then allow you to have some time for discussion. So starting with the first figure, this one just portrays the distribution of funding across federal and private funders for all of autism research. And so as in previous years, this proportion hasn't changed too much. About three-quarters of the research that we capture in our portfolio analysis is funded by federal sources and about a quarter is funded by private sources.

And this is keeping in mind that the private sources, they include a specific subset of funders but may not include some family foundations that aren't a part of our portfolio analysis, or private companies, industry, that may also be funding some research that have not as yet joined our portfolio analysis effort. But we do have a significant representation of major funders in the field. So this is the proportion of funding as we have it right now.

On the next figure in our packet, we provided..

DR. TAYLOR: Susan, that's across all of the research questions, right?

DR. DANIELS: Yes, this is across all of the research questions. So on the next one -- again, this is across all of the research questions -- the percentage of 2013 funding by agency and organization. As you can see looking at this figure, a little bit over half of the funding total from the funders that we collect from, is from NIH and then there are several other funders that are involved, some that have large portfolios like Simons Foundation and Autism Speaks, CDC, and Department of Education, and then many other funders who fund a broad variety of various aspects of autism research. And in the table to your right, you can see the breakdown of that funding.

On the next slide, we have the percentage of 2013 funding as it's distributed across all of the question areas of the strategic plan. And as a reminder, there isn't a central brain that's getting all the funding and distributing it across these areas. It's -- this is the compilation of funding from many different organizations and agencies that have individual missions, and budgets, and applications coming into them. So when we look at it all together, this is what the picture is of funding for this area. And you can see that for question six, it currently -- in 2013 -- comprised 1% of the total research budget and by project counts, 2%.

MS. PRINCE: That's very sad.

DR. DANIELS: And any other particular comments about that?

MS. CRANE: Is there a breakdown -- I don't see further down here whether there is a breakdown for who's funding specifically the Question six.

DR. DANIELS: We have those data. I didn't provide it in the packets for you all but I'm happy to provide that separately after the call. We have the information. You can actually get a little bit of a sense of it when you go through -- if you look through the listing of actual projects and you just thumb through it, you can see the last column in that packet, which is the (unintelligible). You can see who the different funders but I didn't...

MS. CRANE: Yes, that helps to see it by number of projects but it's kind of hard to easily see the dollar amount per -- how much of the dollar amount is coming from each place because the projects vary so much.

DR. DANIELS: So you can...

MS. PRINCE: It's a small amount. It's very, very sad.

MS. CRANE: Yes.

DR. DANIELS: So these are the -- if you look at that last packet, you can see the funders and you can see the funding amounts for individual projects. But we don't have it compiled for you in a particular way.

MS. CRANE: And the reason why I asked is I agree it's really way too small of an amount and it might help to sort of see, well, who's -- are there specific funders that seem to be ignoring this question more than others and, you know, can we give that feedback to them.

DR. TAYLOR: Is it possible to know how much of the -- what is it, \$175 million from NIH -- is going to that?

DR. DANIELS: Yes, it is. It's not something that I gave you but we have that information.

MS. CRANE: I think it's in the dataset.

DR. DANIELS: If you look through the project listing, it would be hard for you to do that now on the fly, but we have that information. So something to keep in mind is that with the different funders, each one has a different mission. So because a funder isn't involved in this area doesn't necessarily mean that they're ignoring it. It might not be a major part of their current priorities or their mission area. So there are some mission areas that are covered by multiple agencies, some that are covered by very few, and some agencies that cover multiple areas of the strategic plan, and others that really focus on one or two areas.

So and that's something another kind of data that we have, but I didn't provide that for you specifically here.

MS. PRINCE: But if you take into consideration that some 21 and on that's approximately 60 years and the largest portion of life is the least represented on this, which really is tragic.

MS. CRANE: Who's speaking by the way? Who was that?

MS. PRINCE: JaLynn Prince, Madison House Foundation.

MS. CRANE: This is Sam Crane. I agree with you on that and I think it also means

that, you know, even if there is -- I don't know of any funders that will actually say we don't do adults but even if there are, that could be a reason to go back to the other funders and say, look, you know, these other research areas are kind of being covered by these other funders. Don't duplicate that. You really should be focusing more of your funding on adults because it's an area that -- of uncertain (unintelligible).

MS. PRINCE: Another huge question here too, it makes one wonder how aware funders are that autistic children become autistic adults (unintelligible).

DR. DANIELS: So who was speaking there? If people could identify themselves before they speak, that will help. It will also help our transcript be more accurate. So who was that?

MS. PRINCE: JaLynn Prince.

DR. DANIELS: Oh, hi JaLynn. Yes, so again, what was your comment?

MS. PRINCE: The comment is I wonder how much awareness even some of the funders are of this population becoming adults because there is a tremendous emphasis on children and there may not be that collective consciousness.

DR. DANIELS: So speaking in terms of the history of the IACC, this area of the strategic plan is the newest area and it's quite an emerging new area of research. So it has had the least amount of time to develop as yet but it is a new area of focus and priority for many of the different federal agencies, as well as private funders. So I think what you're noting here is that it is quite new but not that people with autism who are adults are new, but that there are -- this is new in

terms of an area of specific focus and that's one of the reasons that the IACC chose to create a specific chapter on this, to try to bring attention to this issue.

MS. CRANE: This is Sam, though, from ASAN and one of the things that really got to us when we saw this -- these numbers in the dataset that was released -- is they appear to go down since 2010. So it looks like they're not even increasing. If it were just because this is an emerging area, you would see a steady increase of funding. But I don't think that's what we're seeing here.

DR. DANIELS: You're correct about that observation to the time. For the '14 and '15 dataset, I think that there is going to be an increase but we haven't had a chance yet to analyze those data. So that will be coming to the committee at a later time after you finish this update, but it will be really interesting to reassess with the '14 and '15 data to see if there has been some increase in the area.

But so noted. That is obviously the smallest area of research.

DR. TAYLOR: This is Julie Taylor and some of the specific calls that have come up from NIH for research specifically focused on adolescents and adults with ASD are going to help that out too. So I would be really surprised if we don't see a slightly higher percentage. I think it's still going to be sadly low, but I think it's going to be higher than 1% the next time through, or let's all hope at least.

MR. BADESCH: This is Scott Badesch. I don't know -- I would just qualify this by saying this is not an accurate reflection of all the money that's in the system. I run an organization where none of our money is even

showing up there. You've got United Way has put up money. You've got foundations putting up money. I would just qualify it by saying that it's nowhere near an indication and the number is going to be greater. But there are other funders putting money into the system.

DR. DANIELS: So Scott, we have approached Autism Society before about research projects. So this is a research portfolio and in the past, Autism Society has not provided any document...

MR. BADESCH: I understand, but I think the question is, is what are you defining -- and I apologize, and I'll get it to you. I don't know why we didn't get it to you, but the question is, is what are you defining as far as the specifics of dollars being used for what.

DR. DANIELS: This is for research only. It's not for services efforts and general education dissemination types of efforts. It's for research so we've -- right now, Autism Society is not listed as a research funder. However, if Autism Society is funding research, we would be really interested in including you in the portfolio analysis in the future. I think we approached you all years ago and have kept in touch, but were not aware that you were doing research.

MR. BADESCH: Yes, and we have some money going to research, but I also would wonder how do we get other foundations that are putting money up toward research in that area too, and so I would just suggest.

DR. DANIELS: Yes, so we have a listing, as you can see, on that second page of the foundations and agencies that we receive data from now. There are some private family foundations we've approached that didn't feel

comfortable with sharing data with us. We'd really be happy to talk with you about other foundations, if you're aware of foundations who are funding research in this area, who would be willing to openly share their data, we're happy to include them.

MR. BADESCH: Okay.

MS. CRANE: Why would the other -- this is Sam Crane -- why would the other foundations not want to share information on what research they're funding?

DR. DANIELS: So there are some private foundations that feel like they would prefer to keep their information a little bit confidential about exact dollar amounts, who they're funding, et cetera. And for us in this endeavor, we really can't analyze the data unless we get a pretty complete dataset. Like if they can tell us the specific projects, the specific amount of funding, give us a description of the project, if we don't have that information it's pretty hard for us to include it.

MS. CRANE: Is there a likelihood that those private foundations are funding so much adult research that it would really change these numbers?

DR. DANIELS: Not having the information, I can't really speculate on that. But again, if you're aware of some foundations that you think would be interested, I think also we've now had a track record of doing this for many years and people have been able to see how the process works and the funders who have been participants, I don't think any of them have had really bad experiences with the community because they shared their data. And so now that this has been going on for many years, maybe there are some foundations that now

would be more willing to share. But it takes a lot of work on their effort too -- on their part as well. They have to spend the time to really look at their projects, and submit them to us, and go back and for the refining the data.

So we understand that some small foundations might find that very burdensome. So our office tries to offset that burden as much as we can. But yes, from all the people on the call, if you know of foundations that you think we should be including, please let me know.

MS. PRINCE: This is JaLynn Prince again. But this makes me concerned too, if there is a reluctance to share that bit of information that they are doing research, are they reluctant to share those findings as well. So maybe there's a relationship to something in there too, because how widely circulated would that information be if there's an initial reluctance.

DR. DANIELS: That's a very good point and there may be some groups that feel like that they're just happy that they're funding the work and that it's going on, and may not be as concerned with dissemination. However, with the IACC, dissemination is certainly one of its goals and so that's a really important point. Anything else?

DR. CHEAK-ZAMORA: This is Nancy. I was just going to say that even if we have holes, certainly, in the information, that just if we even though that most of the \$3 million was coming from NIH that's still less than 1% of the NIH's budget that it's spending towards autism research, which sort of puts it into context that no matter what, like, this is really a very, very low number.

MS. CRANE: I would agree.

DR. SHATTUCK: May I make a comment? This is Paul Shattuck speaking.

DR. DANIELS: Sure.

DR. SHATTUCK: So I would like to go on record as advocating that we include in the language of the next plan revision some discussion about research impact. So in the United Kingdom, there's been quite a revolution in funding from the national government for health economic and social research that's funded by taxpayer funds. And there's been really a huge shift in the discussion about return on investment and measuring research impact. And I think we really don't have a corresponding conversation so much in the U.S. and certainly not in the autism field.

And I think the take home point that I think about when I look at these numbers, this may sound ridiculous, but honestly I'm not so concerned about the actual numbers. I'm more concerned on the return on investment, which we have no metrics for and no way of really thinking about, much less measuring. So for instance, my sense from the data that we look at is that we're -- we have really poor outcomes in adulthood. And we could quadruple the amount of funding on research. I'm not at all confident that that would necessarily translate into improved outcomes for adults on the spectrum.

So conversely, I could imagine keeping funding levels exactly the same and if we could somehow increase the return rate in terms of impact for dollars spent, we might actually move the needle on adult outcomes. So I don't want to get too lost in perseverating on the numeric amounts of money being spent on

research because adding more research dollars to that kitty might or might not really improve outcomes for people living on the autism spectrum and their families. So I just -- I really want to be an advocate for adding in a thread of dialogue and discussion on the IACC and in the revised plan for taking even just some baby steps, like how can we start a conversation among ourselves and maybe be kind of a beacon of inspiration and light for other corners of the research world and the U.S. for being on the vanguard for thinking about social return on investments made in scientific research.

Because if all we ever do is count how many articles per year get published and how many projects get funded, that's a very circular and sort of inwardly referenced way of thinking about return on investment. And at the end of the day, what really matters? What really matter is whether the outcomes that we care about are improving -- is the employment rate going up, is health improving, are people having more success participating in their communities and so forth. So I just wanted to go on record for saying that.

MR. BADESCH: Paul, this is Scott Badesch. You said it much better than I did. That's what my point was. We're not spending money on research that may be more defined by what IACC has done. We're spending money on research of looking at quality of life indicators and what kind of mixture of services may increase someone's quality of life indicator. And that's where my confusion on this thing is. If I'm going to do it, what do we want whatever research money we're spending on to go toward and then let's look and see what's going toward it.

Because this number to me, it's great that we're spending that much money, but I

think you're right, if it's not helping -- well, it's helping everyone but if it's not really going at, you know, proving that people's life are improving, you know, through quality of life indicators or some measurement than we're not really going to move the needle.

DR. CAPLAN: This is Leslie Caplan. I'd just like to say quickly I think that's a really important point and thank you to Paul for bringing it up. My one concern is that I think we should think about, talking about impact and less about return on investment, because return on investment is an economic concept, might send us down a track we don't want to go down. But certainly to talk about impact, to talk about the effects on quality of life, I think. I think those are really important questions.

((Crosstalk))

MS. PRINCE: There's a couple of other things too that we may need to look at, or let me put a couple things out there. We are lumping together two different types of research. One is more of a scientific research because I see a lot of these things with biology, and diagnosis, and different types of things that are medical in nature. Now that we're working with an adult population, many more of those things are sociological factors and well-being factors.

And so we've got two different types of research and things going on here and that even divides this down even more so because we don't even know what the impact of various types of autism would be on the adult population. And I think to your point too that you were bringing up a few moments about research, as we're looking into this, there has been some fine research that has come out

of the U.K. and I think sometimes as Americans, we say that's them, this is us, what we are doing? And if we are at this particular point, do we need to make certain that we look clearly and closely at some of the things that (unintelligible) and others have done with this population so we build on some things that have been done as we move into the future.

DR. DANIELS: This is Susan. I have a couple of clarifications to make. When it was mentioned that there's research on things like quality of life indicators, if there were work that were specific to autism, we would be interested in counting it in these kinds of totals. But if it's something that's general quality of life for all people with disabilities or something, it's something we would note but we wouldn't be counting the dollars towards autism research. So we, in order to keep the analysis clean, we are only counting projects that are specifically focused on autism.

MR. BADESCH: That's what I was alluding to but I could get you our numbers.

DR. DANIELS: That is something I think that impacts the way we are looking at this for all of the services areas and for this area of adults. I think that there are many projects that could be out there that are looking much more broadly at people with disabilities or people with neural developmental conditions, et cetera, that include a lot of different conditions. And so those might not be captured here.

One other clarification I wanted to make is that the process for updating the strategic plan this year is a three-step process. So we're going to be today looking back at the portfolio from 2013 to see if it can inform us

about what's out there, what's been funded to date as of this analysis. The next call we're really going to talk about what has been the major breakthroughs or new things we have learned that can propel us forward as we think about what needs to be in the strategic plan, what are the most important areas that you all want to prioritize. And then on the third call, we're going to try to synthesize that information and come up with objectives. So this is not the only information you're going to be considering. It's just the first step and we wanted to do this in chunks to make it a little bit easier to manage.

MS. CRANE: This is Sam. I wanted to respond a bit to Paul's point on impact. I'm not entirely sure -- sorry, I've got a sore throat -- in this particular area, there's so little funding that I'm not sure that we would possibly be able to just say, well, we'll trim the fat and we'll cut out all of the research that's not having an impact and move it to other research that will, and then we can achieve better outcomes for adults without increasing the number of projects or funding. I just don't think in terms of the incredibly small amount of resources that's being spent on this, I'm not sure that's possible.

It's possible that we can -- considering what's coming out of the U.K. and other countries will help, but the U.K. and other countries are also researching plenty of other questions that are relevant to the other questions that the IACC is tracking. So that's not really unique to results. If we're going to really -- I'm looking through the list of projects and there are only maybe a couple that I am looking at and thinking, yes, this doesn't really have to have happened. And even when there is something like -- that hasn't really had much of an impact, a lot of the times in the context of adults services, the

impact -- if people aren't actually getting the right support, it's often not the fault of the research. The research is there. It's the political will to fund those support.

So that's another thing to consider when we're making impact based determinations of what research is worth funding or not.

DR. SHATTUCK: Paul here. Great, thanks for making those points, Sam. I totally agree with everything you said and I was not clear. I was speaking sort of hypothetically to make a point..

MS. CRANE: Yes, thank you.

DR. SHATTUCK: ...but I was not by any means recommending the static funding level of what we have now. And I entirely agree that the levels of funding currently in this arena are just entirely inadequate. And when I was talking about the U.K., I wasn't talking about U.K. autism research. I was talking about the U.K. health and social research funding agencies have metrics and they have requirements for funded projects to describe research impact.

MS. CRANE: Yes, I was thinking -- there was someone else that mentioned research in the U.K. That was what I...

DR. SHATTUCK: Yes, and they have -- they actually have these real cool, like, we actually use their work quite a bit at our research shop over the past few years. They have an entire service impact toolkit that they've developed for investigators to think about all the different ways that they can increase the dissemination and impact of scientific research, health research, and we've used a lot of their materials in trying

to rethink how we produce new knowledge and what we do with it.

And I think part of our problem in our culture of science in the U.S. is that we have this false belief -- or I think not a false belief, but a not productive belief that a scientist's job is done once the research project results are published in a peer review journal. And I think that if we don't encourage scientists to take more responsibility for generating impact and dissemination then that's a really big lost opportunity and I think that's a problem with our culture of science in our country.

MS. PRINCE: And so -- this is JaLynn Prince -- is it a role that perhaps coming to NIH or something else too that we may need to have more of a mechanism. We need a clearinghouse for some of this information with autism because it is very spotty in trying to figure out where you can locate information in the subject. And it comes from many, many, many different sources and there's not a clearinghouse and there's not a resource per se. That may be something that we all need to consider along with this as we increase the funding.

((Crosstalk))

DR. TAYLOR: This is Julie Taylor. It sounds like some of these discussions that we're having too, and (Susan), correct me if I'm wrong, a lot of these feel like they're more question seven type issues about infrastructure and surveillance needs, and collaboration and outreach is a piece of that. And so maybe we could at some point have a conversation or some of us with the question seven people. But I think, thinking about outreach for research findings, and collaboration in some of these, what you were

just talking about JaLynn, I think these things -- I think they would probably fit really nicely under question seven if I'm understanding it right.

But I think even in question six, you know, having something in our writing about the emphasis of research that will have -- that has impact and is probably defined pretty broadly, but that seems like that's something that most people here on this call feel is an important thing.

MS. CRANE: But at least that's addressed as an area of need that people are saying we are encountering this. Can someone research it. We don't know how to serve people in this context and we don't know how to help people with this and that. That's the kind of stuff that we can put a priority on.

DR. DANIELS: So taking note of the hour, I want to try to move us through the rest of the agenda here so that we can end on time in case some people have to leave the call right at 3:00. If you don't mind, I'd like to go back to the packet and just look at the next figure in our packet that was about the percentage of 2013 funding for new versus ongoing projects. And I included this in your packets in particular because I thought that one piece of positive information that you might be interested in is that of the different question areas when we looked at it by projects, that question six had the most new projects in it. So that was something interesting and it will be interesting to see how that looks in 2014 and 2015.

We also have a couple of figures that are about the alignment with strategic plan objectives and briefly, the IACC strategic plan when it was created, the IACC tried to focus the objectives on areas that they felt

were underserved that were not well developed and wanted to prioritize work on those particular areas. So areas that were kind of generally ongoing, well established, those were not targeted in the strategic plan objectives.

And so when we look at the objectives across -- or look at the projects across the strategic plan, when we try to understand whether they're related to the objectives of the IACC strategic plan or whether they're not specifically linked to the objectives, we found that about three-quarters of the research projects that we have in our analysis are related to the specific questions and objectives, and that there were about 25% of them that were not specifically linked to objectives. And those, again, encompass general foundational efforts like quality. They may be established in ongoing areas of research. It also might include emerging areas of research that have come forward since the time that those objectives were created.

And so for question seven that listing of projects that would be in that area are at the end of the funding packet or the listing of projects that you have. In the following figure, it just breaks that down by question and you can see with question seven, I mean, sorry, with questions six, that about a third of the projects or so were not specifically related to the objectives. And part of this for question six also might be related to projects that have multiple aims and were difficult to classify into a particular objective.

On the multiyear funding table, which is another packet that you have, the most important column to pay attention to is the last one and we had a color coding scheme here that we used green to indicate if according to

the way the objective was written, whether the objective had been met in terms of initiating projects that were indicated by the IACC and also meeting the recommended budget. And if that was the case they would have been listed in green. If only a part of the objectives in terms of its content was met and/or a part of the recommended budget was used for that objective, then it would be in yellow. And if there had been no activity it would have been in red.

And so as you look down the list of objectives for question six, you'll see that they're all in yellow so they all had partial progress toward these objectives but none were completed. So do you have any comments as you look through the content of the different objectives about how the field has changed and whether these types of objectives are still important, whether some of them -- maybe the field has moved beyond them.

DR. CAPLAN: Susan, this is Leslie from NIDILRR. I have a question -- I'm looking at the objectives on page two and I'm on the second to last one, which has been clearly edited recently. It's got a lot of content in red and I noticed there's a list of topics should include and the first one is community housing. I don't know if these are cast in stone yet so I'm asking -- topics should include community housing for people with ASD and I'm wondering if that bullet might be better phrased as community living and participation for people with ASD. That could include housing but it would include a lot of other sorts of outcomes that I think would align well with that aspirational goal. I don't see anything -- you can have a place to live but not be of the community and I would suggest that our ultimate goal is really to be of the community.

DR. DANIELS: And I would say that that is an example of possibly how the field has changed and our understanding of what this all means since the strategic plan was written. And so the items in red are just additions that were made by the committee after the initial objective was created. And so even the words in red are several years old now. So those were additions they made from the initial objective. And so that's something that we should take into consideration, the change that there's been in terms of understanding, especially topics like independent living, community living, and independence I think have changed a lot in the last several years.

MR. BADESCH: Susan, could you change that just to community integration or successful community integration?

DR. DANIELS: Well, these are old objectives. We're not going to be probably revising these ones. These are already done and so you're going to be creating a whole new set of three objectives. So these are going to be retired but this is what we had in the past and I was just asking you to comment on the information that's here, if you had anything to say.

Now, I know we're almost at the end of our time so want to be sensitive to that. A final question I have to ask you is as you looked through the projects that were listed here, did you have any concerns about duplication of efforts areas that you felt that we should be concerned to ensure that there aren't too many funders working in these areas and that there's duplications between them?

MS. CRANE: This is Sam. I am a little bit concerned for a couple of things in here. It's

less about duplication and more about that they're categorized in ways that seem a little weird to me. So it's hard to sort of immediately see all of the research in a single category. For example, there's a lot of research on teenagers in this portfolio analysis and I understand the transition to adulthood is a part of adulthood but it's -- a lot of these sub-questions say things like -- if you look at 6FD, it says they want to measure and improve the quality of lifelong supports delivered in community settings to adults. And the only research projects that's listed under that is -- appears to be on teenagers, people in secondary settings.

DR. DANIELS: So with the way that the strategic plan was written initially, the committee came up with these very, very specific objectives and the first go around when our office tried to categorize things -- categorize the projects to the objectives -- hardly any of the projects fit in the objectives because they were so narrow. And the committee asked us to be a little bit broader in how we do our categorization and really try for a best fit, but not be to the letter so that nothing fits in any of the categories.

And so that would be an example where that project may have met some of the other aspects of the objectives, but wasn't really specific for that one. This is a question area of course that doesn't have that many projects to begin with. And so in order to try to bring some meaning to the projects overall, we did try to categorize where we could, where there was a best fit. And we also didn't do subcategory coding for any of these projects so far because it was really difficult to break down into smaller categories, especially because some of the projects have multiple aspects and so it would be -- for example, if

there was supposed to be a subcategory on housing, there might be a project that includes housing but also includes employment. And so it wouldn't be very meaningful to attempt for a best fit there because you might miss a lot of really important information. So we have not done that to date.

MS. CRANE: That might be one thing that we consider when we're talking about objectives that going forward maybe we want to have one objective for transition to adulthood and another objective for adult services in general. And because I understand, I mean it's really hard to have certain kinds of research on adults. It's not going to be possible to say, well, this is housing or this is employment because they might be talking about the interaction of those two. So we might want to be using the objectives by overall goal rather than specific kind of service that an adult might need.

DR. DANIELS: And that's definitely something that we'll want you all to think about when you come up with your three objectives. And part of the reason the committee wants to go much broader this time and not make the objectives so narrow that they might indicate a single project, but rather think broadly about your overall goal and then you can just give examples of the kinds of projects that would be responsive. So that's -- keep that in mind as well.

MS. PRINCE: I see here as you're getting into this -- this is JaLynn Prince again -- as I go through this, this -- these are all very important questions and some stronger than others. But the quality of life issues are a lot of the things that I'm seeing here. But being married to a research scientist, I always go into looking at things with the science. We don't have anything really spelled

out in here about listing of research about what the processes are throughout life with autism. And we perhaps, again, have different autisms, but what does it mean at various stages in life, how do we prepare for those things? Are there different levels of care aside from getting somebody into the community, medical care that we need to address?

And I put this in a parallel to the Down's population because there has been a lot of interesting research and the things that have been happening with Alzheimer's, early onset, because of life expectancy changing because heart conditions are taken care of. Now, we do have some differences, granted, but do we know what those differences are and how can we treat and provide things unless we understand what the physiology of some of the individuals might be that we are working with.

MS. CRANE: This is Sam. I actually -- we come at this from very different perspectives but I would agree that we need, we really, really need health outcomes research over the course of life. And that includes -- and this is one of the things that is covered by our objectives right now -- that includes evaluation of the long-term effects of early interventions as well, that we have a lot of early interventions going on and we have very limited understanding of how they might (unintelligible) people over the course of many years and into adulthood. And some even people, like almost everyone on the autism spectrum has significant health problems later in life. It's almost universal.

MS. PRINCE: And we don't know how some long-term effects of medications that are taken to aid with various aspects of autism impact people after 30 or 40 years.

DR. DANIELS: We appreciate these comments. I think we're getting into the territory of the next call. So I hope that you all will keep some of those ideas in mind. I'd like to bring the call to a close because I know that we were supposed to end at 3:00 and I don't want to keep people past their time if they have to move on to another activity. But we really, really appreciate everyone's being here and the fruitful discussion. We will be giving you some follow-up information as well as information for the next call with some discussion questions and I hope that once you receive those discussion questions, you'll think ahead of time about some areas that you want to make sure get into the discussion and dialogue on the next call, where we're going to be talking about what have been the major accomplishments in the last couple of years and where the field needs to go. And so we'll talk a little bit more about this vision about where the working group and the IACC will want to see research progress to in the next few years.

So thank you all so much for being here. We appreciate it and we look forward to talking to you again soon.

(Whereupon, the conference call was adjourned.)