U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 5 – Question 5 – Where Can I Turn
for Services?

Conference Call 1

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<u>PARTICIPANTS</u>:

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

MS. SHANNON HAWORTH, M.A., SENIOR PROGRAM
    SPECIALIST, ASSOCIATION OF UNIVERSITY CENTERS
    ON DISABILITIES AND CO-CHAIR, WORKING GROUP 5

DR. 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
    AND CO-CHAIR, WORKING GROUP 5

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

MS. LAURA KAVANAGH, MPP, DEPUTY ADMINISTRATOR,
    MATERNAL AND CHILD HEALTH BUREAU, HEALTH
    RESOURCES AND SERVICES ADMINISTRATION

DR. LAUREN BROOKMAN-FRAZEE, PH.D., ASSOCIATE
    PROFESSOR, DEPARTMENT OF PSYCHIATRY,

UNIVERSITY OF CALIFORNIA, SAN DIEGO

MR. DANIEL DAVIS, HEALTH INSURANCE SPECIALIST,
CENTER FOR INTEGRATED PROGRAMS, ADMINISTRATION
FOR COMMUNITY LIVING

DR. PETER F. GERHARDT, ED.D., PRESIDENT, PETER
GERHARDT ASSOCIATES, LLC

MS. LISA GORING, EXECUTIVE VICE PRESIDENT,
PROGRAMS AND SERVICES AUTISM SPEAKS

MS. MELISSA L. HARRIS, CENTERS FOR MEDICARE &
MEDICAID SERVICES, DISABLED AND ELDERLY HEALTH
PROGRAMS GROUP

MS. LETICIA MANNING, MPH, LIEUTENANT COMMANDER,
UNITED STATES PUBLIC HEALTH SERVICE, MATERNAL
AND CHILD HEALTH BUREAU, DIVISION OF SERVICES
FOR CHILDREN WITH SPECIAL HEALTH NEEDS

DR. CATHY PRATT, PH.D., BCBA-D, DIRECTOR, INDIANA
RESOURCE CENTER FOR AUTISM

MS. ANNE ROUX, MPH, RESEARCH SCIENTIST, LIFE
COURSE OUTCOMES RESEARCH PROGRAM, A.J. DREXEL
AUTISM INSTITUTE, DREXEL UNIVERSITY

MS. JANE A. TILLY, ACL/AOA, ADMINISTRATION FOR
COMMUNITY LIVING, U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES

DR. JULIANN WOODS, PH.D., CCC-SLP, PROFESSOR AND
ASSOCIATE DEAN – RESEARCH, SCHOOL OF
COMMUNICATION SCIENCE AND DISORDERS, FLORIDA
STATE UNIVERSITY

PROCEEDINGS:

DR. SUSAN DANIELS: Thank you. Welcome to members of the public who are listening in, and to our working group members. This is a conference call of the IACC Strategic Plan Update Working Group for Question 5, which is a part of the IACC's strategic plan, "Where Can I Turn for Services?" And we are going to be discussing the update to the strategic plan today.

I'd like to start with some introductions. So our chairs for this working group are Dr. David Mandell and Ms. Shannon Haworth, who are both members of the IACC. And they will be helping us shape the written part of this update for the strategic plan.

I'd like to go through the list of members of this working group. And as I say your name, if you can then respond with a one- or two-sentence introduction to the group, so that everyone can know who's on the call. So, Shannon Haworth?

MS. SHANNON HAWORTH: Yes, I'm Shannon Haworth. I'm a senior program manager on the public health team at AUCD.

DR. DANIELS: Thanks, Shannon. David Mandell?

DR. DAVID MANDELL: Hi. I am on the faculty of the School of Medicine at the University of Pennsylvania, where I direct the Center for Mental Health Policy and Services Research. And my research is on improving quality of care for people with autism.

DR. DANIELS: Thanks, David. Samantha Crane?

MS. SAMANTHA CRANE: Hi, I'm Samantha Crane. I'm the Director of Public Policy, and Legal Director for the Autistic Self Advocacy Network.

And our focus is making sure that people across the autism spectrum have access to the services and supports that they need to succeed in life.

DR. DANIELS: Thank you. Melissa Harris, are you on the line? Laura Kavanagh? Brian Parnell? Larry Wexler? Next we have Lauren Brookman-Frazee.

DR. LAUREN BROOKMAN-FRAZEE: Hi. Lauren Brookman-Frazee. I am faculty in the Department of Psychiatry at UC San Diego. And my research is focused on mental health services for children with autism spectrum disorder, as well as implementation research.

DR. DANIELS: Thank you. Robert Cimera? Have you rejoined? So he was on the line, but seems to have gotten disconnected. Daniel Davis?

DR. DANIEL DAVIS: Hi, I'm Daniel Davis, Health Policy Analyst with the Center for Policy and Evaluation at the Administration for Community Living, with very strong focus on identifying services and supports that people need to live independently in the community. Excited to work on issues focusing on targeting services for individuals on the autism spectrum.

DR. DANIELS: Thank you. Peter Gerhardt? Lisa Goring?

DR. LISA GORING: Hi. Lisa Goring. I'm Chief Program and Marketing Officer at Autism Speaks. And as part of my role I oversee family services where we connect people with autism and their families to resources and supports to enhance their quality of life.

DR. DANIELS: Thank you. Leticia Manning?

DR. LETICIA MANNING: Good afternoon. I am at the Health Resources Services Administration in the Maternal/Child Health Bureau. I'm a senior public health analyst and a program director for

the Innovation and Care Integration for Children and Youth with ASD and Other Developmental Disabilities Program. I also serve as a project officer for the Family to Family Health Information Centers.

DR. DANIELS: Thank you. Cathy Pratt?

DR. CATHY PRATT: Hi, this is Cathy Pratt. I'm the director of the Indiana Resource Center for Autism. We're part of the AUCD network, the IICD for Indiana. And I'm also the coordinator for the AUCD Autism SIG, interest group.

And the focus of the Indiana Resource Center for Autism is really on building capacity to support families, professionals, and agencies in being able to better support and program for individuals across the autism spectrum.

DR. DANIELS: Thank you. Anne Roux?

DR. ANNE ROUX: Hi, I'm Ann Roux. I'm a research scientist at the A.J. Drexel Autism Institute at Drexel University in Philadelphia. And I'm a member of the Life Course Outcomes Research Team, and much of our research focuses on tracking whether we're moving the needle effectively on services and outcomes for adolescents and adults with autism.

DR. DANIELS: Aubyn Stahmer is not going to be able to join the call today, but she sent forward some comments that, along the way if it seems appropriate, I can share or share with you afterward. Jane Tilly?

DR. JANE TILLY: Hello, everyone. I'm Jane Tilly. I'm a senior policy advisor at the Administration for Community Living Center for Policy and Evaluation.

DR. DANIELS: Thank you. And Juliann Woods?

(No response.)
DR. DANIELS: Maybe on mute?

DR. JULIANN WOODS: Well let me repeat that, okay.

DR. DANIELS: Thank you.

DR. JULIANN WOODS: I'm Juliann Woods, and I'm a researcher at Florida State University, with a focus on early intervention, building capacity for caregivers. And I'm using a community-based implementation research approach. I also direct personnel preparation in the School of Communication Science and Disorders, with a focus on autism as a specialization for our students.

DR. DANIELS: Thank you. And I'm Susan Daniels. I run the Office of Autism Research Coordination at the National Institute of Mental Health, where we manage the Interagency Autism Coordinating Committee.

Most of you are probably familiar with what our committee does. It's a federal advisory body that provides advice to the Secretary of Health and Human Services and to federal agencies, about issues related to autism. And so we are in charge of helping coordinate the IACC's effort to create a strategic plan to meet the requirements in the Autism CARES Act.

So we're going to be looking today at the progress that's been made toward achieving portions of the previous strategic plan for the IACC. So the strategic plan that the IACC has in place was first developed in 2009, and it was updated annually.

There were - 2009, '10, and '11 the IACC created particular objectives to help describe priority areas that they wanted to target for future action. And those objectives were focused

on research, because the Combating Autism Act had asked for the strategic plan to focus on research.

And so we have a strategic plan with 78 objectives overall, and they're focused on various aspects of research including services research, which is in Question 5 of the strategic plan.

If you go to the first document that I gave you, giving you the structure for the strategic plan, the current IACC strategic plan is framed around seven consumer-based questions.

Question 1, "When should I be concerned?" which is about screening and diagnosis. Question 2, "How can I understand what is happening?" which is focused on the underlying biology of ASD. Question 3, "What caused this to happen and can it be prevented?" that is focused on both genetic and environmental risk factors. Question 4, "Which treatments and interventions will help?" which is focused on intervention.

Question 5, which is the topic here, "Where can I turn for services?" which is about services in the service system. Question 6, "What does the future hold particularly for adults?" which is focused on life span issues. And Question 7, "What other infrastructure and surveillance needs must be met?" which includes research infrastructure, surveillance research workforce, collaboration and outreach.

And as you can tell by the titles of these different areas of the strategic plan, your area, the Question 5 area, services, has some overlap with some of these other areas, because there are services that are related to some of those areas of research that are encompassed in your area. So you may find, at different times that you would want to refer to some of those other areas as well.

I've provided an outline for you for what the strategic plan for the next iteration will look like. We discussed this in previous IACC meetings. So the current strategic plan has a very similar structure, and our plan is to update the various sections. But in particular there will be new objectives in the strategic plan going forward.

So the current strategic plan and the upcoming one will have an introduction. There will be a description area for each of the questions, as well as the aspirational goal for each of the objectives.

And for Question 5, the aspirational goal is, communities will access and implement necessary, high quality, evidence-based services and supports that maximize quality of life and health across the life span for all people with ASD. And so that was the aspirational goal that the Committee felt, back in 2009, described what they wanted to see as a long-term outcome for the research that was recommended in the strategic plan.

The next section of the strategic plan update will contain information about progress that's been made toward the current strategic plan objectives, and that's what we're going to talk about on today's call. The middle section of the strategic plan update will be an overview of progress that's been made in the field. And in previous plans, we've done a research update describing science advances, practice to research, and gaps, opportunities and needs.

But under the Autism CARES Act, it required that we include more information about services and support, including service and support delivery. So we're going to include a new section that will be on services and policy updates.

So we'll have information about new programs and policies; new research evidence that may be able to inform policy; and services, needs and

gaps, as well as needed policy changes. So that
will be a new are that you'll be able to develop.

We also will discuss what progress has been
made toward meeting the Question's aspirational
goal, after we've talked about many of the
specific types of advances that have been made.

The Autism CARES Act also requires that the
new strategic plan include recommendations from
the committee on how to ensure that there is not
duplication of effort in the autism arena. And so
we want to look at the kinds of projects that have
been funded in research, as well as consider
various services activities. And if the working
group has thoughts and ideas about how to ensure
that there is not duplication of effort so we can
be efficient, you'll have a chance to provide
those ideas.

Next, the third phone call that you will be
having will be to discuss new strategic plan
objectives to replace the current objectives. And
so there are 78 current objectives for the whole
strategic plan, and the committee had discussions
at the last couple of IACC meetings and decided
that they would like to reduce the number of
objectives to make the plan easier to understand,
and to focus the efforts more.

So they agreed that we should shoot for three
broad objectives per question, which would give 21
total for the strategic plan. And each broad
objective may be accompanied by examples of
different types of research or services programs
that are responsive to that objective.

And we listed in this document some examples
of the types of broad language you could use to
describe an objective, and just used some examples
from Question 1. But it'll allow you to have a
broader category, and then think of particular
examples that might help us to be able to
understand what is included in that area.

Next in the strategic plan we also will be required to have some type of budgetary estimates that will be provided, because the Combating Autism Act required that the strategic plan include recommended budget estimates.

And so we will probably - we will be taking that back to the Committee to discuss how they want to do that. And if they need help from the working groups, we will come back to the working groups for additional information on that. But that will be after the objectives have been developed. And then we'll be writing a summary in conclusion.

But this group in particular, you'll be responsible for writing the section on overview of progress in the field, which will be somewhat of a review of progress that's been made, and needs that we have for the future, and developing the objective. So does anyone have questions about that? About the structure of the strategic plan?

DR. DAVIS: This is Daniel. I was wondering, have any broad parameters been set in terms of how budget will be allocated, say, percentage-wise?

DR. DANIELS: No, not at all. So the law is quite open about how we can do the budget estimates. It doesn't give us any particular process, or say that the budget estimates have to be related to objectives or questions or any particular part of the plan. So we will take the draft plan back to the Committee and ask them for - ask them how they would like to create budget estimates.

They could, do similarly to the previous plan, try to estimate budgets for objectives, although that might be challenging if these objectives are quite broad and include various categories of services and research activities. They also could, for example, look at the current research

portfolio and estimate a percentage increase that they would like to see over a certain period of time. So there are a lot of different options.

If people on this working group have ideas about how budget estimates could be made along the way, you can feel free to email us. And we want to present this to the Committee and give them an opportunity to decide how they would like to create those budget estimates. Any other questions?

DR. DAVIS: Thank you.

DR. DANIELS: Sure. All right, why don't we move on to the next question or next agenda item here? So I'm going to present to you some information that our office, the Office of Autism Research Coordination, has collected from federal agencies and private foundations who've provided information about what types of research they're funding related to autism.

And this is an analysis of the 2013 data set. So we have collected '14 and '15, but those data have not been analyzed yet. So we have the 2013 data available for you to review, to give you a sense of where the current objectives are now, and to be able to make some comments on those.

So in the first figure in the data analysis set, we've provided a figure that describes federal versus private autism research funding; what proportion of funded research in 2013 was funded by federal sources or private sources. And about three-quarters of the research was funded by federal sources, and one-quarter was funded by private resources, private sources.

But keep in mind that there are some private foundations that may not have been participants in this effort, and so there may be - there is more that is funded that was not captured in the analysis. But we had several of the large funders

as well as some small private funders involved who were willing to provide their data to us, and the total funding overall, so it's $308 million.

So in 2013 - on the next page we have a breakdown of how that funding was provided by a number of different funders. And so the NIH was the largest funder of research, with over half of the research dollars. And research was also funded by private foundations like the Simons Foundation and Autism Speaks, as well as some other federal agencies -- CDC, Department of Education, and many other federal agencies and private groups that participated. So you can see that there is a wide variety of participating funders.

On the following page we provided a breakdown of how funding is distributed across the various question areas of the strategic plan. And as a reminder, funding isn't coming in one giant bolus and being distributed across seven areas by any one group.

It's each separate federal agency or foundation has its own budget, has its own mission and priority areas, and funds research that may be coming in from outside investigators, different types of proposals. And this is just the summary of everything that is funded.

So with Question 5, about almost 6.5% of the overall research budget is devoted to services-related research by funding, and a little bit more if you're looking at it by project count.

On the next page, we just have some information about the alignment of funded projects with the IACC strategic plan. And with the IACC strategic plan, when the Committee developed the objectives that are in the strategic plan, they were trying to target areas that they felt were in need of more attention; were promising areas for future growth. They were areas that were not

already well-funded, but there were some areas that were established and already funded.

So our expectation is that not all of the research in the entire portfolio will be related to objectives, because there was some long-standing, ongoing research already taking place. And there also has been new and emerging research that wasn't taken into account at the time of the development of the strategic plan.

So as you can see from this figure, about three-quarters of the funded projects do have some relationship to the strategic plan objectives. And about one-quarter were outside of those objectives, and might represent ongoing, established research, or new and emerging areas.

On the next page, this describes the same information but broken down by the different question areas. And you can see in the area of life - or Question 5 services that a little bit over half of the portfolio was specific to question objectives. And maybe about a third was related to Core/Other, which is the designation that the IACC chose for the established and emerging research.

I'm going to skip the next page, because I'll go to it on the following handout. On the last page of this packet, you see the percentage of 2013 funding broken down into sub-categories for this research question.

So for Question 5, our office came up with research funding sub-categories for all of the portfolio to better describe the content of the entire portfolio, because if you break it down by questions, those questions are in targeted areas and might not cover the entire portfolio, and we wanted to provide a simple way to quickly understand the content of the overall portfolio, so we tried to develop some broad categories that are within Question 5.

And so we have five categories—Community inclusion programs; efficacious and cost-effective service delivery; Family well-being and safety; Practitioner training research, which in the past there had been questions about that; the portfolio has been refined to only include areas that are related to research- and evaluation-type activities; as well as services utilization and access.

And so this is the representation of what's in the portfolio. So you can see that the area on practitioner training research is the largest out of those. Does anyone have questions about those figures?

DR. MANDELL: All right, Susan, this is David. Just to clarify, for the practitioner training, that is not research - is that only research about practitioner training? Or is that all of the funds that are going to practitioner training?

DR. DANIELS: We redefined it or refined it after the 2010 portfolio analysis, to really focus on efforts to evaluate practitioner training, and to do research on practitioner training. So it's more finely focused.

DR. KAVANAGH: Susan, this is Laura Kavanagh. I just wanted you to be aware that I had joined the call late.

DR. DANIELS: Oh, thank you.

DR. PETER GERHARDT: This is Peter Gerhardt, and I joined the call late.

DR. DANIELS: Oh, great. Thank you.

MS. MELISSA HARRIS: And Melissa Harris from CMS as well. Apologies for joining late.

DR. DANIELS: Oh, no problem. Thank you for letting me know you're on the call.

MS. CRANE: This is Samantha Crane. I have another question about the practitioner training, which is, you know, I'm noticing in the portfolio that a lot of these practitioner training projects are actually more along the lines of training practitioners in screening and early intervention, which would be kind of close - not practitioner training in services and supports themselves.

And is there a reason why we're counting practitioner training on areas that are relevant to other questions under Question 5?

DR. DANIELS: So historically we had not had any practitioner training counted in the other question areas, although that will probably - I don't know if that will change in the next portfolio analysis. But certainly the discussion of practitioner training needs for particular areas, in terms of the text of the strategic plan, will be included in their respective areas in the upcoming plan.

MS. CRANE: Okay.

DR. DANIELS: In the past, screening and diagnostic services were focused here, and the Question 1 area was really only research on diagnosis and screening.

MS. CRANE: And the second question is, I'm seeing family training packages in here, too. And I'm not sure why they're being counted under Question 5.

DR. DANIELS: I guess I need to look at the packet.

MS. CRANE: So I'm - I've got, for example, a Web-based tutorial on how to parent an autistic child. That's on Page 5. It's like the second to

the end of the 5.L.A questions, the 5.L.A project. I'm sorry, it's on Page 5 of the project list. And it's a study on parenting your young child with autism, a Web-based tutorial. And so I'm not sure why that would be included in…

DR. DANIELS: So you're - is this the third project on Page 5?

MS. CRANE: It's the seventh project on Page 5.

DR. DANIELS: So I think I would have to get back to you about that, just to look more carefully at the abstract. But anything that was about training people in skills to serve the autism population would have been a best fit for this objective, compared to the other objectives.

MS. CRANE: So I would - I mean I would say that training parents in parenting skills or in behavioral management skills would be a treatment or intervention.

DR. DANIELS: There are many of those parent training interventions in Question 4. So without really looking at this more carefully, I can't easily answer it.

MS. CRANE: Okay.

DR. DANIELS: But once we have a chance to really look at it carefully, we certainly can get back on that.

DR. MANDELL: Susan, can I respond generally to that? This is David. This was an issue that came up before, where there are many grants that were really about community implementation -- that is, there's something we knew that works in the lab, but we have not been very successful in changing community practice. And so these were really more effectiveness trials or implementation trials that kind of blur the line between treatment and services.

And I think that we made a decision a couple
of years ago that they were really - because they
were really more about community practice, and
improving community practice, that they belonged
in the services category rather than the treatment
category.

MS. CRANE: And so the reason - this is Sam
again. The reason why I was sort of concerned
about that type of call is that it then makes it
really hard to evaluate how much - how many
projects and how much money are being applied to
what I would consider like the core issues for the
services category, which is let's see what kinds
of long-term services and supports are effective.

And we need to distinguish long-term services
and supports from treatments, and that treatments
are focused on trying to change an individual's
symptoms, or trying to manage behavior, trying to
target a particular autism-related issue; whereas
a service and support is trying to support a
person in the long term, trying to help them
achieve quality of life and community integration
outcomes.

And that's getting - it's really, really hard
to pick out those kinds of studies when they're
all mushed up together.

DR. MANDELL: I think that this is definitely a
conversation worth having at length. I think we
probably have different definitions of what
constitutes services research. But maybe we can
make sure that there's time to continue that
discussion without - because I know, Susan, you
have a kind of packed agenda.

DR. DANIELS: Yeah, no, I think that that is a
really important question. I think that you're
probably right that in the past a lot of this was
lumped together, because we were carving out this
services area, and things that didn't fit into

research came there, and they might not have been distinguished into more narrow or refined sub-groups in the past.

But I think this new strategic plan is going to be the opportunity for you all to make those observations. Plus, the research and services arenas have grown. Things have progressed and so new types of organization might be more appropriate now as compared to 2009.

So I think that that is worthwhile, and is something we certainly can get into in more detail in the next call. But appreciate hearing about that. Any other comments or questions about the information I've shared with you so far?

So I want to turn your attention to the packet that gives the information on the progression of funding over time, so our multi-year funding table. And this gives you information about the years that our office has been tracking the research portfolio and the content of the research portfolio, and trying to assess - along with funders who were partners in doing the coding for this work, to determine how we were doing on achieving strategic plan objectives, only in terms of what projects were funded.

So in the next call we'll be talking about what's been achieved -- what outcomes there have been, what types of research outputs and outcomes there have been. But this was one type of assessment that's just based on what has been funded by research funders.

So in the last column where it's labeled Total, you can see that we have some colors applied to those. So the green color highlighting indicates that the number of studies recommended, or the content of the types of studies recommended and the recommended budget were all achieved.

The recommended budgets were created by the Committee to estimate how much it might cost to do what was set out in those objectives. And as described by other IACC members in the past, that the recommended budget was a ceiling and not - I mean was a floor and not a ceiling.

So it was what they felt would be the minimum required to achieve the objective; although in practice what we found is that at times, because of efficiencies in the research system, and infusions of funds from unexpected places, that sometimes things got achieved without spending the full recommended budget.

The yellow highlighting indicates that part of the objective, in terms of the content, might have been achieved, some or part; and that within the recommended budget, only part of that was allocated. And in this question area, we don't have any that are in red. But if we had had anything where the total was in red, that would mean that no work had been done in that area at all.

So does anyone have any comments about some of these particular objectives and how you feel the progress has been in these areas? Also when you've looked at the portfolio of what's been funded, anything that strikes you as either a change in the field, or since the time of writing the strategic plan objectives, or things that are still gaps and might need to be emphasized in the next strategic plan?

DR. PRATT: This is Cathy Pratt.

DR. DANIELS: Yes. Hi, Cathy.

DR. PRATT: Shannon knows this. One of the things that we're battling in Indiana is the increasing number of kids who have co-occurring disabilities of mental health and autism. And as I'm going into schools and interacting with

families, it's not only what are good practices, but what are also the policies in states, what are programs that in states are being used. And it really is an area where I'm really seeing a lot of folks struggle.

DR. DANIELS: Thanks. Do you have any comments about how that relates to anything that is in the objectives that we have in front of us?

DR. PRATT: Well I think, you know, for me I notice that there was something in one of the objectives that did speak about kind of some of the mental health. But I think it could be - I think it could hit a lot of the areas. I don't know.

DR. DANIELS: This is - so more of a gap. So you're identifying more…

DR. PRATT: Yeah.

DR. DANIELS: …considering co-occurring conditions as the gap.

DR. PRATT: Right, right.

DR. DANIELS: Thank you.

MS. HAWORTH: This is Shannon. I was also noticing that it was yellow and then red on the last objective on health and safety.

DR. DANIELS: Yeah, so I didn't really go into the explanation of that. So if you look vertically at the columns for those different years, we tried to give, if you wanted to look at one year at a time, where we were with respect to achieving that particular objective. But we did it based on an annualized version of the budget. So we took the budget and broke it into a five-year increment, and it was just an estimate to give the Committee some kind of idea of whether we were making progress or not making progress.

However, at this point in time, now that we have several years of data, really the most meaningful column is the total column. But back when we only had maybe one or two or three years of data, the individual fluctuations were - I mean we wanted to represent what was going on in each year.

So with the objective 5.L.D, where there is a change from 2012 where there were some funded projects - in 2013 there weren't any funded projects. But overall there have been some projects, and there has been some funding allocated toward that objective. So that's why it goes from red to yellow.

MS. CRANE: This is Sam Crane. I'm also sort of looking at other things. I'm really - I agree that I'm very concerned about the health and safety issue. And I'm not entirely sure why they have one objective to study health and safety, and another objective to study health and safety. Does that also consider self-determination and personal autonomy? I'm not sure why you need two separate one. Why not just use the second?

But I'm really - it's troubling that the amount of funding that examines health and safety, but also autonomy, has gone down over the past three years, from almost $300,000 to zero. And there is not projects right now on self-directed services and supports. That funding has gone down from $450,000 to zero. And, you know, I think those are really serious gaps.

And then the final thing is that it looks like there's over $7 million and 57 projects that aren't specific to any objective, which suggests that maybe the objectives are just not sufficiently broad, or not sufficiently well- defined. Because if, you know, a third of all of the studies are not specific to any objective…

DR. DANIELS: To respond to that particular point, I don't remember if I had told you on this call. I did another call just a couple of hours ago. But with the strategic plan, when the objectives were being created, those were to target areas that were of particular need, and that the committee felt were of high priority. There were already ongoing projects in many areas.

And so the projects that fall outside of the objectives, we fully expect that there will be some projects that fall outside the objectives, because the objectives weren't meant to cover the entire landscape of research in this field.

MS. CRANE: It looks like it's increased almost five-fold since 2009, the amount of funding on things that are not specific to any objectives.

DR. DANIELS: Right, which can mean that either they were ongoing, or they might be emerging areas of newly funded things. So we do have - in the project list you can see what is in that other category…

MS. CRANE: Yeah, and I've been looking at them. And I just was - the only reason I mentioned it is that that just - when we look at revising our objectives, one of our goals might be, you know, trying to see if we can make it so that it encompasses any emerging areas that are not suddenly being not counted as being part of anything.

DR. DANIELS: That's true, and I expect that all of the different working groups are going to identify some of those emerging areas that now have a substantial enough a bolus of work that we want to grow - that the Committee will feel like those are areas they want to grow, and might be targeted in some of the new objectives. So that's a good observation.

DR. MANDELL: Susan, this is David. And I just wanted to echo what Sam said. I think especially in light of the concerns about wandering, and concerns about the relative effects of different kinds of housing, that putting more focus on health and safety, and on self-direction, would be, I think, things that should be very strongly emphasized in the next report.

DR. DANIELS: Yes, and we will want you to be - help in developing those kinds of major themes, because that will help guide you in coming up with your top three areas that you want to focus on for your new objectives.

DR. MANDELL: Yes.

MS. CRANE: This might be jumping the gun a bit - this is Sam again. But it's important to note that health and safety includes a lot of other issues. It includes, you know, the fact that autistic people are facing really dramatically poorer health outcomes across the board than people who aren't on the autism spectrum.

Seizures are one of the leading causes of death of people on the autism spectrum. So that would also be an issue when we're talking about health, safety and mortality. And in terms of wandering, that's just another reason why it's important that we, you know, focus on this objective to study health and safety while simultaneously considering principles of personal autonomy and self-determination.

Because when we're talking about, you know, wandering or other behaviors that are associated with safety risks, you know, it's important to consider those both things at once in all of our research.

MS. HAWORTH: This is Shannon. (Unintelligible) and to speak to Cathy's point, I just wanted to mention, when she mentioned about

mental health and co-morbidity, that's something
that we can consider as well, going on to health
and safety…

     MS. CRANE: Yeah, absolutely.

     MS. HAWORTH: …not just the health, but also
the high suicide rate for adults with autism. So
that's just something I wanted to bring up that we
can consider…

     MS. CRANE: Fine.

     MS. HAWORTH: …the two health and safety
categories. That's just something to think about.

     DR. ROUX: This is Anne Roux. And I had a
couple comments. I wanted to give a broader
perspective, too, for Samantha's comments about…

     MS. CRANE: I can't hear what you just said. Is
it my connection or yours?

     DR. DANIELS: It didn't come through, Anne. Can
you try again?

     DR. ROUX: Okay, can you hear me now?

     DR. DANIELS: Yes.

     DR. ROUX: Okay. I think it's worth noting at
the beginning of this chapter that there has been
an overall decrease in both projects and funding
for the services question, beginning around 2010.
And I don't know how much of that is possibly due
to redefinition of what is being included as
services research. But I think there's an overall
shift of funding that doesn't seem to match with
an increased level of demand over time.

     And then I think specific to Cathy's comment
about policy and practice, and deficiencies in
that, I think that that really speaks to this
objective about implementing and evaluating policy

and practice level coordination. When I look at this, I know that it was only specified on the base of two projects. But it seems to be a particular gap in light of need.

And when you look specifically at the most recently funded projects listed here, they seem to be focused more on early intervention and support for families, which fall under this services research and are important, but perhaps don't get at some of the huge deficits that we have in coordinating policy and practice for adolescents and adults.

MS. CRANE: I absolutely agree with that. And especially since even the description in 5.S.C it specifically calls out things to study like self-determination, economic self-sufficiency, transitioning youth, augmentative and alternative communication, and policy and practice level coordination among state and local mental health agencies, none of those seem to be addressed in the two most recently funded, or the two 2013 studies that are listed.

DR. ROUX: And, in fact, if you look at just the titles of all of the funded 126 projects, only four of those appear to focus on adolescents or transition-age issues. And none seem to focus on adults. I don't know if that's because more of those ended up under Question 6, but that was a question that I had, since this is a life span goal.

DR. DANIELS: Yes. A lot of the research related to adolescents and adults did end up in Question 6, although it's a small body of research nonetheless.

MS. KAVANAGH: This is Laura. I just wanted to piggy-back on some of the previous comments, especially related to the life span perspective. I think that part of this relates to how we

categorize studies, and there's been already some discussion about that.

But as we're moving forward and thinking about where there's potential gaps, I think that it would be helpful to have some specificity in thinking about expanding the targeted service systems that are - for which we're studying either clinical interventions or services interventions, to ensure that we're covering the service systems that will be important for both transition-age youth and adults.

Such as - there's been a lot of especially training related to education in the education system, but ensuring that we're also encouraging the development of interventions targeting vocational settings and other settings - mental health settings and other settings that may be relevant, particularly across the life span beyond education and early intervention.

I think that even within younger children, there could be potentially increased attention to other service systems that may be impacted by the number of individuals with autism who don't have capacity necessarily to, at this point, meet their needs -- just child welfare and so forth.

So I think that yes, there's been a lot of attention to practitioner training and so forth. But there could likely be some expansion to the service systems that are targeted.

And then I think somebody also touched on kind of that distinction between the testing clinical interventions and implementation strategies or service interventions. And I do think that that distinction is important, and it relates to those policy-level studies, different policies of ways to improve quality of services across different service systems, as well as really focusing on how do we sustain practices when we train people to use them, and what types of organizational

interventions may also be helpful in improving quality across service systems.

DR. DAVIS: This is Daniel. A couple of thoughts, I definitely agree with the past couple of speakers about a desire to get more focus on issues around transition services and transition age. I think that that's an area that is, I think, of emerging interest. And I think it's a core issue in terms of making sure the people maximize their opportunities to achieve success as adults.

I also wanted to make the point that ACL and CMS are continuing to build out an increased attention to quality measurement in general. And I think that in that regard, we may want to look at the sub-category of that efficacious and cost-effective service delivery, and see how we can enhance that work.

DR. DANIELS: Something that I might - this is Susan. Something I might add to that very last comment is we recently got (SICORI) to agree to provide their data to us for the portfolio analysis. So from 2014 or '15 onward, we will have 13 - oh, sorry, from 2013 onward, we will have their data.

DR. DAVIS: That's very helpful.

DR. DANIELS: Something that would be a bigger question for this working group is, right now we have most of the transition and adult services-related projects, and we have a whole separate chapter that's on that. Does this working group feel that that division isn't a good thing to continue? Because if we were going to change that, it would make sense to change it this year versus doing it in a future year.

We had discussed with the Committee keeping the structure the same. But does the group feel like it still serves a good purpose to have a special place for adolescents and adults in the

strategic plan that's separate? Or does it make more sense to have it altogether have all of the services together? David, you also - you've been on the Committee for a couple of cycles. You might have some thoughts on that.

DR. MANDELL: Yeah, I mean I think initially it served a really important purpose, was just getting the words adult and adolescent into the strategic plan, which really were remarkably absent, I think, from a lot of the discussions around autism.

So I guess the question now is, has it become unintentionally segregating? Because frankly the needs of adults and adolescents span the rest of the questions. And each of the groups, I think, should be considering the needs of adults and adolescents when they are talking about issues related to data infrastructure or services or treatment or biology, especially as we learn more about what happens to people with autism as they age.

So I would be in favor of considering taking that chapter out, but I don't think the idea is to merge it with services. I think the idea would be to create a structure where it's every group's responsibility to think about needs across the age span for their particular area.

DR. DANIELS: Any other thoughts about that? Pros and cons to doing something like that?

MS. GORING: This is Lisa Goring.

DR. DANIELS: Yes.

MS. GORING: This is Lisa Goring. I was just going to say I absolutely agree that it should be incorporated in each of the other question areas, because it really does have implications across all of the other questions.

DR. DANIELS: So I know that the - this is
Susan. I know that the Committee initially had
wanted to really highlight the needs of
adolescents and adults, and that was the reason
for creating that separate question in the
strategic plan. But do you feel like -- if, for
example, we do have a Question 6 working group; if
they were to come up with several ideas and
recommendations -- that it would be helpful to the
strategic plan to then divide that all up and move
it around the strategic plan to other areas, and
not have an area that's devoted to that?

MS. CRANE: I would - this is Sam. I would
really strongly object to that, particularly -
it's not that I don't believe that, you know, the
needs of adults should be considered with respect
to each question, but we've had long-standing
concerns that the research on the needs of adults
is dramatically underfunded.

And when it's chopped up - when that research
is sort of chopped up and put into all of the
other questions, it makes it almost impossible to
get an easy, quick number to put on the amount of
projects and amount of funding for the needs of
adults. So we don't - it reduces the visibility
and transparency of, you know, how much money is
getting spent on adults versus other populations.

DR. ROUX: This is Anne Roux again. I think if
a move was made in that direction, it would be
really helpful across questions if we could also
have a breakout by amount of funding that's
dedicated to each segment of life span research,
and then which questions go across segments. I'm
not sure how easy it would be to do that. But even
just in looking at Question 5 today, I think that
would have been really helpful.

DR. DANIELS: Yeah. Well to answer that
question - so this is Susan. Most of the
adolescent and adult research is in Question 6, so
you're not seeing it on this list very much.

Unless it was a project that included all age groups, it would have been in Question 5. But if it was really focused on adolescents and adults, it went into Question 6.

MS. KAVANAGH: This is Laura Kavanagh. I also think we should take into consideration Congressional intent when they reauthorized the Act. There was a heavy emphasis around transition as well. So thinking about the adolescent health and transition issues separately helps to address that, unless there's some way we can still capture that data, I think it was, as Anne just mentioned, too.

MS. CRANE: But the other thing that we need to keep in mind -- this is Sam -- is that, you know, services and supports and the needs of adults aren't necessarily always going to - you know, there can be - there's plenty of research on the needs of adults that isn't about services and supports.

And, you know, we might want to consider something along the lines of, you know, including - you know, research on services for adults could still be in Question 5. But then Question 6 would be focused on, you know, screening for adults; you know, developing diagnostic tools for adults; studying adult outcomes; studying, you know, to see what kinds of things adults need over time. And those aren't necessarily services-focused research.

DR. MANDELL: No, but they are diagnosis and screening-focused research, or…

DR. DANIELS: Right. And…

DR. MANDELL: …research.

DR. DANIELS: …this is Susan. The Committee went through different iterations of developing Question 1. And they initially developed it to

really focus on early childhood. And then there were questions about whether it should be expanded to include adults, and they really decided that they wanted to keep the boundary on that to be the early childhood area, and to have the adult section be in the Question 6.

Having particular strategic plan questions focused on the needs of adolescents and adults does make it a lot easier for tracking that information and seeing it as a whole. If it is distributed, it would be much harder to pull all of that together and, for example, we wouldn't have, probably, a working group that would be devoted to that particular topic. It would just be a little part of everything else.

So there may be some advantages, if you're trying to highlight those needs, to have them separate. But you would need to maybe see what the boundary is between the two, because I guess you don't want to be duplicative with that other group. Maybe you would want to see what their portfolio looks like as well, and be aware of what they're doing.

DR. PRATT: This is Cathy. I think that separating it out, though, gives the message that we think this is really important. And I think that it also shows the evolution since the services roadmap was first developed, is that there's a growing realization, based on many people's reports and fabulous research, that our adults are really facing high unemployment and not great outcomes. So I think that whatever we can do to really show how important we think this is, is really critical.

DR. DAVIS: This is Daniel. I would agree with that last statement.

DR. GERHARDT: And this is Peter. I would just add that I think it's important that we understand the complexity of what the word outcomes means;

that if we look at quality of life, which in and of itself is a complex term - but there's research on quality of life and whether or not people are employed, but no research on whether or not they're in jobs that they like, which really would be the quality of life indicators.

So I think that it's much more complex than we're sort of making it out to be in this discussion. And that would be, I think, a much more valuable question, is what are good outcomes for people? Like what does that really mean?

Man: Listen, I have to apologize, but I have - I thought this call was from 3:00 to 4:00.

Dr. Susan Daniels: It is supposed to be from 3:00 to 4:00, so we really should be wrapping up here.

Man: And so - and I think that this is - I mean this is a critical question that I think people have made really good points on both sides, and I don't think it's something we want to try and answer in the next…

Dr. Susan Daniels: Right. I think that we can certainly discuss that more on the next call. Just to quickly wrap up here, I do want to ask the group, that for whoever who can stay on a little bit, about duplication and then adjourn. So that's fine if you need to go. That's not a problem at all.

For those who might be able to stay for maybe an additional five minutes, can you give me any input on whether you have any concerns about duplication of effort across this area? This is an area that Congress asked us to ensure that the Committee provides any recommendations that are needed to improve efficiency and avoid duplication of effort. So does anyone see anything that concerns them?

Man: I think how we resolve the question that we were just discussing is going to be important in terms of that discussion, because I think we definitely don't want to duplicate, but we also definitely don't want to lose track of making sure that we're getting studies across the - and work that's being done across the life span.

Dr. Susan Daniels: Right. With the discussion we just had, it was really more about the strategic plan itself. And the portfolio and what's in it wouldn't necessarily be affected by the strategic plan structure exactly. So I think those might be a little bit separate issues. But we certainly don't want to duplicate the effort of the Committee either, and have two working groups producing highly overlapping areas. Anything else?

All right. So because we're over the hour, I'm going to try to bring us to a close. So on the next conference call, we're going to be talking about advances that have been made in research, and new areas of policy and programs to provide services, and what are the critical needs in those areas.

I'll be sending you an email that will have some discussion questions. And I'll also be sending out notes and a transcript from this call, so that you can have access to that. And we will be posting the transcripts online for anybody in the public audience who wants to see that.

So I will be in touch, and I really appreciate everybody being on this call, and for your thoughtful comments. Thank you so much.

Woman: Thank you.

DR. MANDELL: Thank you.

Woman: Thank you.

Woman: Thanks.

MS. HAWORTH: Thank you all. Good-bye.

Woman: Bye.

Woman: Thank you. Good-bye.

(Whereupon, the conference call was adjourned.)