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 3

TUESDAY, NOVEMBER 1, 2016

11:30a.m.

PARTICIPANTS:

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

BRIAN PARNELL, M.S.W, MEDICAID AUTISM WAIVER ADMINISTRATOR, UTAH DEPARTMENT OF HUMAN SERVICES, DIV. OF SERVICES FOR PEOPLE W/DISABILITIES AND WORKING GROUP CO-CHAIR

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

KEVIN PELPHREY, PH.D., DIRECTOR, AUTISM AND NEURODEVELOPMENTAL DISORDERS INSTITUTE GEORGE WASHINGTON UNIVERSITY AND CHILDREN'S NATIONAL MEDICAL CENTER

PARTICIPANTS – CONTINUED:

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

SCOTT BADESCH, PRESIDENT/CHIEF EXECUTIVE OFFICER, AUTISM SOCIETY

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

DENISE JULIANO-BULT, M.S.W., PROGRAM CHIEF, DISPARITIES IN MENTAL HEALTH SERVICES RESEARCH PROGRAM

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

JALYNN PRINCE, PRESIDENT AND FOUNDER, MADISON HOUSE AUTISM FOUNDATION

ROBYN SCHULHOF, M.A., SENIOR PUBLIC HEALTH ANALYST LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL AND RELATED DISABILITIES, MATERNAL AND CHILD HEALTH BUREAU, HEALTH RESOURCES AND SERVICES ADMINISTRATION

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

PROCEEDINGS:

DR. SUSAN DANIELS: Thank you. Well good morning everyone. Welcome to the conference call of the IACC Strategic Plan Update Working Group for Question 6 which is on the topic of what does the future hold particularly for adults.

We welcome our co-chairs, members of the working group and our public listening audience. All the information for this call is on the IACC Web site if you go to the Meetings tab and Working Groups you will find the Question 6 Working Group and conference call number 3.

The materials are at the bottom of the page. So anyone can feel free to access them. So we're looking forward to talking today about the objective that we're going to create for this chapter. But before we get started I'm going to go though and do a roll call so we can hear who's on the phone. So Brain Parnell are you with us?

MR. BRIAN PARNELL: Yes. I'm here.

DR. DANIELS: Oh hi, Brian. Julie Taylor?

DR. JULIE TAYLOR: Here.

DR. DANIELS: Samantha Crane?

MS. SAMANTHA CRANE: Here.

DR. DANIELS: Amy Goodman? David Mandell? Kevin Pelphrey?

DR. KEVIN PELPHREY: Here.

DR. DANIELS: Thanks. Evelyn Peña?

DR. EDLYN PEÑA: Here.

DR. DANIELS: Robyn Schulhof?

MS. ROBYN SCHULHOF: Here.

DR. DANIELS: Alison Singer? Scott Badesch?

MR. SCOTT BADESCH: Here.

DR. DANIELS: Vanessa Hus Bal? I know that she joined the call so might be on mute. Somer Bishop?

DR. SOMER BISHOP: Here.

DR. DANIELS: Oh great thanks. I know, sorry, it's a little difficult unmuting yourself and getting on. Leslie Caplan is not going to be with us today and Nancy Cheak-Zamora is not going to be with us today. Laura Klinger?

DR. LAURA KLINGER: I'm here.

DR. DANIELS: Thank you. Ophelia McLain? JaLynn Prince? And Paul Shattuck and Nancy Spencer are not going to be on the call. Susan White?

DR. SUSAN WHITE: Here.

DR. DANIELS: Robin Harwood? And Denise Juliano Bult?

DR. DENISE JULIANO-BULT: Here.

DR. DANIELS: Thank you. So we have a good group of people on the call today. We appreciate you taking the time to do this. So the first order of business is I want to turn your attention to a draft chapter outline which is not really an outline at this point.

It's kind of a list of topics which you've seen before but we've added to it based on the last call. But these are some of the topics that you have discussed that probably will - you'll want to cover in your chapters.

So if you look at this list the topics we have are transition to adulthood, secondary education, locational services and employment and financial planning, housing, community integration, social and recreational opportunities and inclusion. Long-term supports, especially for high needs individuals, caregiver supports across the lifespan, health and healthcare and covering a range of different health needs, safety issues including laundering, self-harm, victimization, etcetera.

Adult diagnosis and we had a discussion on the last call about that. And I think the consensus of the group was that they felt that adult diagnosis overall is beneficial to individuals to help them realize that they may be in need of services and be able to access them. And within those different topics you'll have an opportunity to flesh them out a little bit. On the last call you talked about the importance of adult outcomes and developing quality of life and outcome measures that include the perspective of individuals on the autism spectrum and trying to define what a successful outcome is.

We also talked about personalized and individualized services, self-direction and autonomy, person centered planning and (unintelligible), creating a supportive environment for individuals on the spectrum, coordination of care across service systems.

The importance of assistance to help people navigate across services systems and the role of technology to enable access independent living and other important things. So those are some of the topics we have identified through our calls. Is there anything that working group members don't see on this list that you want to make sure are covered in the chapter you're going to be writing?

MS. CRANE: This is Sam. Can I ask if adult outcomes is going to include long term outcome

studies for interventions that might not necessarily be on adults in and of themselves?

So let's say you have an intervention on a, you know, person who's not yet an adult but you want to track the effects of that intervention through adulthood. Did we decide whether that was going to count as an adult outcome or if that should be in like the early interventions question?

DR. DANIELS: That can be included here. And based on going over the notes from the previous calls I think that the group seems to want to move in the direction of kind of keeping the lifespan as a whole.

And, you know, we can talk about that more on this call. But if we do I think that will make it easier to fit, things like that. And I know in the IACC meeting that happened last week we did talk about the importance of being able to perhaps capitalize studies that have already been done in children. And see if we can reuse some of those data or re-consent people to be able to track long-term outcomes. So that's certainly fair game to discuss in this chapter.

MS. CRANE: Exactly. Great. Okay.

DR. DANIELS: Anything else?

DR. TAYLOR: This is Julie Taylor. The other thing that I would like to make sure that's reflected in here I think is to understand all these different topics taking into account the range of ASC. And I'm not just talking about sort of IQ and symptom severity but also thinking about differences, your economic needs, you know, folks who are nonverbal versus not. Thinking about even differences by, you know, sex or gender. But that, you know, each of these different areas becomes much, much more complicated when we start to really drill down and figure out what might be

helpful for whom and to see a reflection of that in the - within the topics.

DR. DANIELS: Okay. Great. We can add that to the bottom list as kind of looking at the range of ASD including different special populations, underserved groups, various subgroups of ASD. So we can add that to the list. Anything else that others want to make sure...

MS. CRANE: I have one.

DR. DANIELS: Sure. Is that Samantha?

MS. CRANE: Someone else was talking and then I'll go.

DR. DANIELS: Okay.

DR. KLINGER: This is Laura Klinger. The other thing that I was thinking about is this issue of health and healthcare seems to be a very broad topic. And I was wondering whether it would make sense to separate out some of this, whether aging itself would go into a separate category or whether we would separate mental health from physical health. It just seems like this issues of comorbidity is not the same thing as aging.

MS. CRANE: Actually that was almost exactly what I was going to say that for example aging could also be relevant to, you know, the housing, long term support, categories, not just the healthcare category.

((Crosstalk))

DR. TAYLOR: This is Julie again. So maybe separating out - I'm sorry. You were still talking Sam. Go ahead.

MS. CRANE: As people age their support needs are going to change.

DR. TAYLOR: So maybe separating out aging which I would see as being its own section. You're right. That would encompass a lot of these things. And separating out sort of physical health and healthcare with more kind of mental health, quality of life, happiness type issues. Is that kind of what we're thinking?

DR. KLINGER: Yes. So we just took that one item and made it into 3.

DR. DANIELS: So that's fine. You can separate them out how you want. I guess the main thing will be trying to make the document readable. And so in places where you can combine things a little bit it will make it a little bit easier to follow.

Because if you have 10 different headings it might be confusing for reader. There's certainly a lot of choices of how you could organize the information. Anything else that you want to add to this?

(No response.)

DR. DANIELS: So I will be working with the chairs trying to flesh this out a little bit more. And then the co-chairs will be asking for assistance from the working group to help draft some text to go with some of these topics.

And so if there are particular topics that you're really interested in contributing on you might want to shoot me an email or myself and Julie and Brian an email just to let us know. And then we can try to make sure that you have a chance to help draft them. I mean everybody on the working group will be able to review the entire document. So you don't have to worry that you won't get a chance to see the other parts.

But if there's something that you in particular would like to help with writing then let me know. Let us all know.

DR. KLINGER: Susan do we want to add legal issues?

DR. DANIELS: You can add legal issues.

MS. CRANE: What do we mean by legal issues?

DR. KLINGER: Well I guess mostly I'm thinking about interfacing with the criminal justice system or even, you know, or even more civil issues. But for our...

MS. CRANE: I think that's - yes.

DR. KLINGER: ...adults that get in trouble.

MS. CRANE: That makes sense.

((Crosstalk))

DR. DANIELS: I wonder if...

MS. CRANE: I mean I think that that...

DR. DANIELS: …have something about criminal justice issues. But I was - when I put that in there I was thinking more like these interactions with law enforcement but not necessarily other kinds of legal issues. So I don't know if legal issues might be something that also might spread out across different areas. It might be more cross cutting because you might have legal issues associated with appropriate housing, appropriate education, etcetera.

So, but we can add it onto the list and you can decide how you might want to incorporate that. Other topics?

(No response.)

DR. DANIELS: Okay. So let's move on then to talking about the objectives which I know you've

all been looking forward to. I put together a straw man based on some of the discussions you've had on previous calls. But you can feel free to propose other ideas about what kinds of - what three areas you want to focus on in developing objectives.

And so some themes that I saw in what you discussed were talking about development and coordination of services for transition, improvement of health safety and wellbeing of individuals on the spectrum and increasing acceptance, accommodation, inclusion, independence and integration. So those were some themes but you certainly are free to propose other themes you want to go with to help build your three objectives. So do you have any thoughts about this?

(No response.)

DR. DANIELS: Julie as you looked at it do you have any suggestions about what you would like to do for objectives?

DR. TAYLOR: Yes. So when I was just looking through this and I was thinking - the thing that popped up to me right away - I'll be interested to see what you guys all think. Is when we talk about development coordination of services I think I'd like to make that a little bit broader?

Because that's really I mean sort of a transition from, you know, school based services to adult services. It's certainly one critical component of that. But we're seeing, you know, difficulty coordinating adult services across different types of services and agencies throughout the entire lifespan.

And I think we have no idea really what that's going to look like as people with ASD age and look at that piece too. So right at first glance I'd like the piece about coordinating services and

understanding how to make our services more effective to maybe fit in that too. But I'd maybe like to broaden that out to not just be transition to adulthood but really kind of throughout the adult lifespan.

DR. DANIELS: Okay.

MS. CRANE: So this was - this is Sam. One of the things I was wondering is, you know, are we going to have each objective be sort of have a component that's about services and a component that's about research. Because if that's the case then we could have that be kind of the services component of both 2 and 3 would be, you know, for example we need services that help this health, safety and wellbeing of individuals on the autism spectrum.

And, you know, do we need to develop more infrastructure there could be part of the - part of the objective from the services standpoint. And then, you know, from the research standpoint it would be things like what are the effective ways to do this.

DR. DANIELS: So with the objectives - this is Susan. They don't necessarily have to call out research and services really specifically because we're assuming that projects that are related to both of those will fall under these. But once you've decided on the objectives you can provide some examples of things that you think would be responses to help the reader further understand what you mean. So you could put examples that include research or particular services.

MR. PARNELL: This is Brian. When Sam started talking I initially agreed with that. That sounds like a really good idea to address people's overwhelming desire to have things be practical. The other side of me is sort of cautionary thinking that we need to be careful about bifurcating research from services because I

really would like to see us deliver the message that research drives towards good services. So...

MS. CRANE: I don't think I mean that we should bifurcate them. I'm just thinking that those could both be under the same objective.

MR. PARNELL: Okay.

DR. DANIELS: Yes. And we intend for that to be for all the objectives across the strategic plan that they will have room to be associated with projects that could be addressing services needs or research needs. Now in places like question 2 that's pretty much all about research. There will be mostly research. But some of these questions that may encompass both, there probably will be projects that we can associate with these broad goals that either are research or services.

((Crosstalk))

DR. TAYLOR: This is Julie.

MS. CRANE: I think that falls - oh go ahead.

DR. TAYLOR: Oh this is Julie. So I might lean towards although I think we could certainly pull the first question into question 2 and 3. I might argue to try to keep it its own question for the same reason that we keep the adult question its own question.

So a lot of things that we're talking about in the adults in question 5 we could fold into other questions. But because there's so little research on this area we really want to pull it out and emphasize this as an area in its own right that we need to be thinking about more research and understanding more about how to support adults in particular.

And I kind of feel the same way about this first objective. We could fold it in. But I think

there's something to be said for pulling it out as its own objective to really make the point that we really need to understand from a research perspective but also from a service provision perspective how to better develop and coordinate services to help youths and adults with ASD.

So just in the framework of trying to emphasize that as an area of significant need that I think would be really responsive to the public comments that we've been getting. I think it maybe makes sense to keep it its own question even though logistically it would work just as well to fold it in. So I don't know what you guys think about that.

MR. PARNELL: This is Brian. I agree with that. I also want to jump back to what Julie initially said about fleshing out the first one because there are so many different transitions within adulthood. So many people that have autism and are living with parents or other caregivers, relative caregivers, they have face that transition of what happens when those caregivers pass away or aren't healthy enough to provide for them.

So I think there are a lot of transitions I'd like to see us address.

DR. TAYLOR: So this is Julie. I feel like I'm talking a lot today. I also think this is a way that this strategic plan will really kind of move beyond the last strategic plan for the adulthood issue is to really kind of broaden the (odd). I think the last time around there was a real focus on the transition to adulthood. And I think that's important. And I think it should still be in here. But because of that focus I actually at least in part we've learned a lot about the transition to adulthood.

Not that there's not more that we can learn. And I think, you know, sort of saying in that in

the plan and then saying now we're really - we're also still worried about the transition to adulthood. But we're really broadening out to think about sort of issues in adulthood more generally all the way up through aging and parents who can no longer provide care and everything in between I think can be a way that we can really show the advancements that we have made since last plan and where we still need to learn a lot.

DR. DANIELS: So for - just to - this is Susan. Just to see if this might help a little bit. So if we change the first objective to say support development and coordination of services to help youth make a successful transition to adulthood and to continue to provide appropriate supports or something throughout the adult lifespan would that cover what you're talking about?

DR. TAYLOR: I think so.

((Crosstalk))

DR. DANIELS: Then that would expand it to cover the whole lifespan.

DR. WHITE: I'd like to suggest that the last clause, the parenthetical clause of number 2 that says "the need for healthcare providers who are trained in addressing needs people" on the (unintelligible). I think that should be moved up to number 1 because it seems to me that's more about the infrastructure and lifespan transitions. I would also like to suggest to the group - I don't think I introduced myself. Sorry. This is the other Susan.

That we have treatment, be very clear in here nowhere in here do I see any mention of treatment. And a lot of folks view that somewhat differently from services. So development of treatments and dissemination of effective treatments.

DR. DANIELS: So the development of treatments is in question 4. So that whole chapter is about that. So that's why it's not really called out here. I mean you could mention it kind of in passing. But there's - that question 4 is going to focus on development of all kinds of interventions.

MS. CRANE: So would that include ones for adults?

DR. DANIELS: It can include ones for adults. And that has come up on the question 4 call. I think that that's recognized as a major gap that there aren't enough different intervention options for adults. So that's been a topic of discussion.

DR. TAYLOR: And Susan in some of our last - I'm sorry. Go ahead Laura.

DR. KLINGER: Can it not be in both places? Because I do think this issue of treatment for adults is really important. And if you look at this without reading question 4 I think there will be some concern that this is isn't addressing issues of treatment. Can it not be in both sections?

MS. CRANE: What do you mean by treatments for adults?

DR. KLINGER: For example I'll give you a - an example would be a mental health treatment for comorbidity. Or it could be a medical treatment for health concerns.

MS. CRANE: Wouldn't that count under number 2?

DR. KLINGER: Well but the question was whether the word treatment should be specifically mentioned or not. And I heard you Susan saying that that's in question number four. But I just - I think it's kind of a glaring absence in the area of adulthood.

MS. CRANE: I've got it now. You just cut me off.

((Crosstalk))

DR. DANIELS: So you could say something like the availability of the appropriate interventions for adults or something like that?

MS. CRANE: Yes. I would say that for adults like the thing that you're talking about as saying that that's what you mean by treatment, you know, that's something that the adult autistic community, you know, definitely supports and wouldn't see as objectionable. I don't think we would use the term treatment though. It can be...

DR. DANIELS: Right. So we could use the word interventions. And so I wouldn't recommend in this chapter trying to go into the actual development of all those treatments. Because - or interventions because that's going to be covered in more detail in question 4.

But you could mention that the availability of appropriate interventions that will meet the needs of adults is an important aspect of improving health, safety and wellbeing.

DR. TAYLOR: And I think...

Ms. Crane: But I would consider them healthcare services actually. Like the ones that you were just using as examples. We would probably call them healthcare services.

UNKNOWN FEMALE SPEAKER:Susan could there in this section be a refer people to look at the other question for more detail on treatment.

DR. DANIELS: ...that's really necessary. I mean anybody who's really reading the strategic plan, you know, they may go to one chapter and just read the one chapter. But most people

probably will skim through the entire thing. So they're see that there is an area that talks all about interventions. And so somebody who's really interventions would go there.

MS. JALYNN PRINCE: Susan this is JaLynn Prince. I was just blocked for the first half hour. So if I'm asking a question kind of going back but I think it pertains. One of the things I'm very interested in is looking at the research that happens with the lifespan.

It's not just the transitions. It's the sociological types of things and not just mental health as a general thing although those are very important. We have seen indicators in other populations. Though this is different we don't know with the different types of autisms that there may be if we're looking at different types of things with life trajectory.

If we look into the Down syndrome population there had been certain types of things that could be addressed to increase life but at the same time there is an increase of Alzheimer's on the far end when people seem to be aging or getting to that point.

We don't have information medically about any portion of adults with aging and what are the other things that might be underlying things as even morbidity or research into these things. Some of the things that have been happening for children but I don't know if we've got any research happening for adults even if it is gut issues on some types of autisms or whatever.

I'm concerned that we're not addressing opening the door for medical research with implications of the medical component that may accompany some types of autisms.

DR. DANIELS: So to respond JaLynn on the number 2 area improvement of health safety and

wellbeing of individuals on the autism spectrum that would - that could potentially cover those issues that you're talking about. I don't see - I guess aging is not on that list but it could be added to that list.

MS. PRINCE: Okay. If we could do that, if we can cross over there I'd hate to have the adult population not addressed with the medical components.

DR. DANIELS: Right. So this is - actually has quite a lot of medical components including premature mortality which was an issue that we talked about at the IACC meeting last week. And I thought that especially members of the IACC may be interested in that. Chronic health issues, comorbidities and so we kind of grouped different things in there. But you all can put more things in there if you want in your writing.

((Crosstalk))

MS. PRINCE: (unintelligible) thank you.

MS. WHITE: Some of what the (unintelligible) collected that's all. Thank you. Was some of what Jalynn was saying also the need for epidemiological studies kind of along the line of what Paul Shattuck did for transition age youth?

That really was a foundational set of papers that led to the research that we're seeing now.

DR. DANIELS: Right. And so I think in these objectives we're not going to try to get into something that detailed. We could provide that as an example. For example under improvement of health safety and wellbeing we could include an example research epidemiological research that shows what some of the needs of...

MS. PRINCE: Right. Yes.

MS. WHITE: Okay.

DR. DANIELS: Something like that we could provide that as an example. And so you all once you've decided on the actual objectives then we can provide some examples and you can curate instead of - you know, I wouldn't recommend putting more than five examples because it would get kind of long to read. But just to give the gist of what you're looking for.

MS. PRINCE: Yes. I think it's just keeping the door open that people are seeing that this an avenue.

DR. DANIELS: And I think that the...

MS. CRANE: I would say that that's - that sounds like it would be under comorbidities. I don't want to be saying - calling out very specific comorbidities under there like gut issues because I think that would be making it sound like we care more about some than others but...

MS. WHITE: Oh right.

MS. CRANE: I think that would be clearly under comorbidities.

DR. DANIELS: I agree.

DR. TAYLOR: But I think the general issue of a better understanding through large cohort studies or epidemiological studies of the needs of adults and aging adults with, you know, on the autism spectrum I think is something that we can fit into the questions.

And I think it's important as examples. So I think the broader issue is a good one.

MS. PRINCE: Yes. I just brought that up as an example but not necessarily to put that into this but for conversation. Thank you.

DR. DANIELS: Sure. So it sounds like the group is somewhat comfortable with the idea of possibly just developing number 1 and number 2 more. What do you think about number 3? And those were just some of the themes that I heard on your calls. But do you like that? Or do you - is there something different that you would prefer to do for an objective?

MS. CRANE: I like I t.

DR. DANIELS: It seemed like with naming a number of those different issues that you all talked about that you could potentially fit a lot of different types of projects under it.

DR. TAYLOR: I mean it's really - this is Julie again. It's very broad which I think is actually kind of nice right? So work to understand, you know, what is going to be most effective for people with ASD in these areas, what would be desired, how these things might differ for people in some of these different underserved groups.

I mean there's a lot of different really I think important questions that could fit under this broader objective. So I like it.

DR. DANIELS: Oh good. So we - it sounds like then we're kind of coalescing around these ideas. And so then what we would need to do is just further develop them into nice statements that kind of would explain what the goal is overall.

So if we did that for number 1 so we, you know, just to throw something out there. And if you have other suggestions feel free to suggest them. Support development and coordination of services to help youth make a successful transition to adulthood. And I don't know about the wording of this.

And continue to succeed throughout the adult lifespan or something along those lines of something basically you want to see more positive outcomes across the entire lifespan.

DR. KLINGER: So this is Laura. And I'm wondering if by only talking specifically about the transition to adulthood it somehow emphasizes that that's the most important of the developmental phases of adulthood.

So either we ought to list transition to adulthood, transition to living independently , transition to aging. Or maybe take out that transition to adulthood and just say development and coordination of services across the adult lifespan.

DR. DANIELS: Okay.

DR. KLINGER: I'm not sure which is the better one. But by only saying transition adulthood I think it focuses - even though you're adding that qualifier I think it still tends to focus on that one developmental age.

MS. CRANE: And, you know...

MR. PARNELL: This is Brian. Maybe we can just change it to say transitions throughout adulthood.

DR. DANIELS: So do you feel like that would capture the youth transition though? Because I guess they're not quite adults yet.

DR. TAYLOR: So this is Julie. So can we put - can we have the objective and then have sort of a qualifier sentence or something afterwards that says something to the effect of, you know, this across the lifespan includes, you know, key transitions such as the transition to adulthood. Transition to independent living or to, you know, living outside the family home.

You know, aging, transition of care givers, etcetera and sort of flesh it out a little bit more kind of below the main big sentence?

MS. PRINCE: And I think you have something important there in saying - at the transition of caregivers. Do we need to also have something at least implied in there about caregivers because the health of the caregiver is going to impact greatly many of these individuals? And we don't have a lot of data on that.

DR. DANIELS: So I think of that - this is Susan - as more of an example than what you want to put in an objective. You want to keep the objectives really tight in how they're worded because in the last strategic plan we did have some objectives that were entire paragraphs.

And it was really confusing and kind of hard for people to follow what the point was. So I would recommend coming up with a single statement and then just providing examples of things that you think are responsive.

You could for example put a bullet underneath that says, includes X, Y, and Z kinds of transitions or something like that but to keep the factual statement itself kind of a single sentence if possible. So we have support, development and coordination of services across the adult lifespan. Is that capturing what - is that broad enough an umbrella you think that we could put examples underneath that that would kind of clarify for people what was meant?

So in terms of things that we could include as examples we could say something like research and services that address various transition periods including transition to adulthood. And I don't remember what all the other transitions you mentioned were.

MS. PRINCE: And there's an interesting thing through with the transitions that are happening with caregivers having implications on the individuals that are living with them. And I think that's critical. We encounter that so frequently I mean daily. And it is really affecting the quality of life. If we can mention something there that also - because services are different than living in the same home with aging caregivers and how they're dealing with things and what they need to have as well to provide a good environment for their adult child. And we don't have any research on that.

DR. TAYLOR: Hey Jalynn this is Julie Taylor. I wonder if that could fit in as an example under objective 3 about increase in acceptance, accommodation, inclusion, etcetera in terms of employment, housing, recreational. And maybe we can make mention of the role of family providers versus formal service providers in these things with - in which we're kind of given that to understanding the roles family.

MS. PRINCE: Good.

DR. TAYLOR: Which I think is really important as well. Without getting too specific into that what do you think?

MS. PRINCE: That's fine. That's fine with me. As long as there's a mention there so if somebody's looking at things and they want to take that type of research that there's at least a little bit of a nod.

DR. DANIELS: So and remember you have an entire chapter to just write more prose about these topics. And so I don't think you have to throw everything and the kitchen sink into the objectives themselves. Because you'll have plenty of time there to kind of, you know, flesh out more of what you mean by more of the areas that you want to make sure are priority areas. So I don't

think that you have to necessarily throw everything into the wording of the objectives.

But, you know, provide examples. Because just because you have five examples doesn't mean there's not going to be more. In fact we're assuredly going to be categorizing more under those objectives. But as long we make them broad enough that things will fit and that there's not so much overlap that it gets confusing trying to figure out where projects fit.

MS. PRINCE: Good.

MR. PARNELL: Yes. This is Brian. I think that's good. We don't want to include our entire narrative in our outline.

DR. DANIELS: Right. And I think on - yes. On our outline we do have caregiver supports across the lifespan. So you certainly could write, you know, an entire paragraph or something about the needs of caregivers across the lifespan. Right?

DR. KLINGER: So this is Laura again. Maybe in the top one I think one of the things is that it doesn't quite have the oomph of number 2 and 3 does when you take out the transitions.

And I was trying to figure out what else needed to go in there to make it look sort of - I don't know. That has that emphasis and I'm wondering about something like integration. Is it - would we say something like development coordination and integration of services across the adult life span? Because the idea around the transition points is really integrating across service types.

I don't know if that wording will help but it just felt like I know I'm the one who suggested taking out the focus only transition to adulthood. But I think it lost some of its eloquence.

DR. DANIELS: Yes. We could do that.

((Crosstalk))

DR. TAYLOR: So Laura to follow up on that, in coordination of integration services?

DR. KLINGER: There we go. That's nice.

DR. TAYLOR: I like that too.

MR. PARNELL: Yes. Sounds good.

DR. DANIELS: All right. Other comments about some of these?

DR. TAYLOR: This is (Julie) again. Just going back to - I've been thinking about this issue of overlap. And that's something that we talked about in our last committee meeting.

So we know that there really is going to be - these are not, you know, distinct silo questions. And we're definitely aware of that. So what I'm envisioning throughout the narrative is kind of working with some of the other question chairs who have some similar topics.

And making sure that we clearly make nod to the places where there's overlap in drawing the reader's attention if we're not covering things fully and just mentioning them in our chapter.

Just I don't think we'll be treating these questions - and correct me if I'm wrong Susan. As being completely distinct in the sense that there will be crosstalk between the questions to make sure that it's clear to the reader that if a topic isn't - a relevant topic isn't being covered fully here, here is where they can go to look to make sure that it is covered in detail.

Is that right Susan?

DR. DANIELS: Right. So, you know, we will try to add an opportunity for you to be able to refer to other areas. But again we don't want to get too wordy to the point where it's just every chapter you read and it's referring you off to a different chapter and it gets confusing. So but certainly these issues overlap and connect with each other. And so you can't necessarily separate one from the other in reality. In a document it's important to have some sort of organized structure so that people can read it.

So we'll definitely do that. So it sounds like we have some pretty good feedback about the objectives. I think that we could - I could work with the chairs on trying to come up with some language that will reflect the discussion and we could then provide you back with the actual text of these objectives. Is there anything else somebody wants to bring up that we want to make sure that we address?

MS. CRANE: Is there like a way to sort of cross - put pins in things that let's say for example the treatments issue where we said, you know, the - this is sort of about adults but we think it's going to belong in a different question.

Can we sort of keep track of the things that we identify that are important but belong in an - a different question to make sure that the working group for that question includes it or considers it?

DR. DANIELS: I'm a little confused about what you're talking about. Are you talking about the portfolio analysis in particular projects that are…

MS. CRANE: Well so for example I mean if we're talking about things that we want to be, you know, part of a goal let's say identifying treatments for adults. But we decide that treatments for

adults are not in this question. They're going to be in - I'm sorry I can't remember the number.

Was it question 4? Then, you know, make sure that question 4 when they're developing their outline, you know, maybe put something about adults in their outline.

DR. DANIELS: So I think adults is already in their outline.

MS. CRANE: Okay. Yes. I mean I was just using that as an example.

((Crosstalk))

DR. DANIELS: They've been discussing it and they have - Nancy Minchew she was on that working group and she works on adult interventions. And so we have - we tried on purpose to make sure that adult interventions was going to be covered.

And question 4, which in the previous strategic plan wasn't really covered as much.

MS. CRANE: Okay.

DR. DANIELS: So we were hoping that we'll develop that more. And I think the working group is interested in it. So I think that they're already doing it.

MS. CRANE: Yes. I was just using that as an example because it sort of keeps coming up and I just wanted to make sure that there is like a process to make sure that whenever something's identified as being part of a different question it actually gets taken up by that question's working group.

DR. DANIELS: So in terms of the projects when we do the portfolio analysis we'll be coding them according to these objectives and the way that we code the projects. We only assign one code per

project just to make it so we're not double counting money and we can get a clear idea of where these projects fit.

But on a practical sense if somebody wanted to identify any projects that had to do with adults and interventions the Web tool that we have, the database you can do keyword searches. And so for example if the office here had to identify projects having to do with adult interventions we would probably look through the questions we know about. Plus do a keyword search to make sure we didn't miss anything.

But that's kind of a separate issue from writing the text of the strategic...

MS. CRANE: Yes. Now I mean I was really thinking about the strategic plan. So, you know, if one question group thinks, you know, we really, really need more research on X, Y, Z, something they decide that that's actually not in their jurisdiction. It's under a jurisdiction of another question's working group.

DR. DANIELS: I see.

MS. CRANE: To make sure that that recommendation gets conveyed to the other question's working group.

DR. DANIELS: So I've been doing that.

MS. CRANE: Okay.

DR. DANIELS: So for example so the question 3 working group had some recommendations that effect question 7. So we've taken note of those and then we share them with the other working group. And so...

MS. CRANE: Okay. So exactly what I was trying to explain.

DR. DANIELS: Yes. So I've been trying to share suggestions from different...

MS. CRANE: All right.

DR. DANIELS: …groups. Because sometimes, you know, one working group will come up with a great idea that's not quite in their topic area. But...

MS. CRANE: Exactly.

((Crosstalk))

DR. KLINGER: So the other thing kind of related to that discussion - so this is (Laura) again and I've really been thinking about how in the service delivery arena thanks to, you know, some of the new (unintelligible) funds or certainly some additional federal funding directed towards services and coordination of services.

But there's really not a link between the - those funds and any evidence or research based that the services are effective for adults with autism. And then so even though the idea that treatment or intervention research goes with category four I want to make sure that we're focused on not just creating services or making sure that coordinated services are available but making sure that there's a strong evidence base.

And that is incredibly lacking right now around services for adults with autism. So I don't know how to put that in there. And I think that's more than just an example. I think we really need to make sure everything we just mentioned in questions 1, 2 and 3 are done in an evidence based way.

DR. DANIELS: So I would recommend putting that in the part where you're just writing more narrative about the question. Because if you put evidence based as a qualifier in these objectives when we're looking for projects.

It might make it a little bit narrower and more difficult to figure out what constitutes anevidence based practice. And when people are looking at that they might think that that then we must - we might want to exclude services that don't really have that much of an evidence base but might still be needed and the best thing we have available now.

DR. KLINGER: Right.

MS. CRANE: I think that's really critical.

DR. DANIELS: I don't think that you want to limit yourself. But I think that talking about the need evidence based services and supports etcetera is something that's really important that you could talk about in the chapter as you develop it. These are great comments. Thanks for sharing.

MS. CRANE: One of the things that people do in the services arena is, you know, we can't do RCTs or anything but we definitely can encourage service providers to collect data on outcomes of the participants and their programs.

And that really helps, you know, to ensure accountability while still ensuring that people can get services that are sort of the best that people know how to do right now. And you can just sort of collect that data and use it to evaluate and refine those service programs even if you don't have necessarily an RCT.

DR. DANIELS: Right. So I'm going to add that to the outline. So let me make sure that we cover that. So strengthening the evidence base for various services and supports and...

MS. CRANE: I mean you have to do that even if, you know, even if you have the world's most evidence based service you still need to collect that data because you have to check, you know, see

if it's being implemented faithfully. And, you know, sometimes you end up with a program that for one reason or another even though it's based on some, you know, an evidence base it's not working for that population or in that circumstance.

DR. DANIELS: Right.

UNKNOWN FEMALE SPEAKER:I think we have such an opportunity with this document to move that forward in the sense that we have an opportunity to really emphasize the need for an evidence base. Because I think that the - as I said earlier the funds flowing for intervention services around adults and the funds flowing for research on adults are not necessarily integrated.

And writing both kinds of grants in my daily life they're very different. When I write a grant for funds for service delivery versus a grant for funds for research. And I just think we have a really nice opportunity to word this in a way to emphasize that those two mechanisms needs to be linked if we're really going to get good quality programing for adults with autism.

MS. CRANE: So as an advocate for more services I just would really be cautious about anything that could be used to say oh no we're not going to fund this because maybe, you know, it's evident. And we don't have enough studies and we're going to wait for years and years until someone can publish an RCT about it. It can be a barrier.

MS. ROBYN SCHULHOF: Hi. Hello? Can people hear me?

MS. CRANE: Yes.

MS. SCHULHOF: Hi. This is Robyn from HRSA. I just wanted to comment on the issue of evidence base. And I'm not sure who the last person was saying that this could - I'm sorry. I don't know who the speakers are.

MS. CRANE: It was Sam. I was the one talking about barriers.

MS. SCHULHOF: Oh. Hi, Sam.

MS. CRANE: Hi Robyn.

(Robin Schulhaus): Hi. Yes. I would totally agree with that. I think that there are issues around putting evidence based practices in a report like this. And one is that you have to have some kind of review process to determine what's evidence based. And that costs a lot of money. And so you have to have a way of writing funding in and for the process of determining what's evidence based. The other is what Sam was alluding to.

I know our home visiting program restricted themselves to only evidence based programs. And they did reserve like 25% of funding for where states could choose promising practices. But in reality no state did that. And so basically you have, you know, what 13, 14 models now that programs across the country use. But the problem with that is that it squelches creativity and innovation for new and promising practices.

DR. DANIELS: So one - this is Susan. One other issue is that with question 5 they've been talking a lot about successful implementation of interventions. And I think that building the evidence base is kind of a part of that. And so that might be more covered there. It doesn't mean you can't mention it. But it might be something that fits a little bit more with what they're trying to do. And they are interested in the dissemination and access to evidence based practices including underserved populations.

So they have some aspect of this in their area as well. So once we have the other call which is this afternoon we'll find out. But we'll put it on the list for now. And then maybe the chairs of

this group can coordinate a little bit with the chairs of the other group. So you're all doing very well on time. Are there more issues you want to bring up in terms of objectives?

(No response.)

DR. DANIELS: So then let's move on to talk about the discussion of aspirational goal and title.

At the last meeting we talked about the aspirational goal which currently is worded as 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 we talked about changing the word necessary and something else I would propose is possibly just getting rid of the word necessary if you are concerned that it might be limiting. You could just say access to individualized services and supports without qualifying it.

MS. CRANE: I like that better. This is Sam.

DR. DANIELS: So the same reason we...

MS. CRANE: Yes.

DR. DANIELS: …may not want to narrow down to evidence based practices because that might limit what people think should be...

UNKNOWN FEMALE SPEAKER: That's because everybody may be different. And what is appropriate for one may not be for another. And it has to be geared on that individual.

DR. DANIELS: Right.

MS. CRANE: And you have to think necessary for what, you know? I mean maybe something might not be necessary for survival but might be necessary for an optimal outcome.

DR. DANIELS: Right. And I think at the time the committee there were members that were concerned that people could be requesting services that aren't required or something. And so they wanted to put that in there.

But it probably gives it a little - gives you a little more freedom if you leave that out because that...

MS. CRANE: I think that - sorry.

DR. DANIELS: No. Go ahead.

MS. CRANE: I mean I think that like those just as a matter of pragmatics. I don't think anyone's going to be reading this and think that we're saying, you know, services and supports that are completely useless and unhelpful.

DR. DANIELS: Yes. We want those. So...

MR. PARNELL: You make a point.

MS. PRINCE: And Susan this is kind of a big reach on this. And I don't know if it's appropriate or not but I do have the question. As we are putting this together and we're making recommendations or asking questions can we request more government agencies to be around the table?

Because sometimes we have HHS but I don't see anything with HUD. And I don't see a whole lot with transportation and also labor. And these are all areas that we need to have cooperation and coordination with.

DR. DANIELS: Right. So the reason that they're not at the table at the IACC is they're not

specified in the law as being member agencies of the IACC. But we are always free to invite them for discussions that we might be having.

And so if we for example want to discuss housing we could always invite HUD in to talk with us. Us meaning the committee. So it's not really any particular effort to not include them. But since they weren't...

MS. PRINCE: And so only particular agencies were specified. I didn't see that particular component in the law.

DR. DANIELS: Yes. If you read that law it specifies which agencies should be part of the committee.

MS. PRINCE: Wow.

DR. DANIELS: And those particular...

MS. CRANE: I thought that there was...

((Crosstalk))

MS. CRANE: Isn't there like an option for other agencies to join as sort of optional members?

DR. DANIELS: There is if the secretary of HHS is fine with it. And so if one of the other agencies requested that the secretary of HHS add them and she wanted to add them she could.

MS. PRINCE: Okay. Because it seems like that could be good. And so we can - can we ask that? Could we say that some of these things, especially involving adults would be benefitted by having deeper conversations with other government agencies and would welcome them to be around the table? Would that be too bold on our part?

DR. DANIELS: I don't think that's really appropriate to put in the strategic plan. But I think people who are members of the committee who are on this call if you're interested in that I would recommend bringing it up in a meeting or asking for us to invite those agencies in to talk to us about particular topics.

And I always take suggestions from the committee topics we'll discuss at meetings. So we're definitely open to hearing from you.

MS. CRANE: I don't know who was asking about that but if you contact me online I would be really happy to talk to you about that.

MS. PRINCE: Okay. It was Jalynn.

MS. CRANE: Because we agree. What?

MS. PRINCE: It was Jalynn.

MS. CRANE: Okay. We totally agree. We've been - we even tried to get them added as mandatory agencies in the Autism Cares reauthorization. And one of the reasons why it wasn't included as a mandatory agency was that they figured, you know, that they're optional and they can join if the secretary of HHS wants them to join.

So, you know, if we can capitalize on that option and try and add them in.

MS. PRINCE: Okay.

MS. CRANE: That would be great.

MS. PRINCE: Good. Good. I'll see what we can do.

MS. CRANE: Thanks.

UNKNOWN FEMALE SPEAKER: I have a question about this aspirational goal. If I was to be a

pessimist and read it I would say we're already there. And I don't think that's the case. I think that there's issues related to long waits, time, financial burden and untrained kind of providers and too many hurdles to jump through.

So I think of the words opportunity and access. And it's like okay at some level it's already there. But it's like oh but you have to drive two hours or you have to pay this amount of money. Or you have wait for a year to get through this list. And...

MS. CRANE: Like five years.

UNKNOWN FEMALE SPEAKER: I guess it is - yes. I pose it to the group do we need to add anything in there about things like at a reasonable cost or without undue waiting or anything like that?

MS. CRANE: Meaningful opportunity.

UNKNOWN FEMALE SPEAKER: I've been struggling with it. I'm not sure. Okay. I think for me it just boils down to a person of reasonable means or something like that.

MS. CRANE: All adults will have the opportunity not just some.

DR. DANIELS: We say all people with ASD.

MS. CRANE: Okay. Yes. Sorry I forgot about that.

DR. TAYLOR: How about reasonable access or no maybe that's - because I think with the access piece comes at the end of it. But you're right. You could argue well someone does have access to individual supports they just have to drive for two and a half hours to get to that.

So maybe you sort of - that's the place to put the word is in that - in front of the access. If it's reasonable access or...

MS. CRANE: I would say meaningful access because reasonable can actually sound like a downward qualifier in my experience.

MS. PRINCE: And going along with this...

MS. CRANE: And you're like well we tried.

MS. PRINCE: This is another kind of reach but maybe we put this in because I could see that there is a possibility of health consequences on portability of services. Because right now if somebody has supports from family and community in another state they have very little if any opportunity to cross those state lines and take any of their funding without going back on sometimes 12 to 15 year waits.

And that issue perhaps being addressed nationally because it can have health implications on the individual, on the families that may - where it may be selected that they remain with family and being able to go where there are additional supports.

We may be kept - costing the country more money by not trying to grapple with this particular problem. And to also increase better outcomes if there is a support situation. I know that's been...

((Crosstalk))

MR. PARNELL: This is Brian…

MS. PRINCE: But it's interesting. Yes Brian.

MR. PARNELL: Yes. I'm glad you brought that up because it's a huge issue when it comes to people's ability to choose even where they're

going to live. I think it's more of a state issue than a federal issue because it probably doesn't cost the federal government much different as a person who's from one state to the other.

But it affects the state's allocations towards people with disabilities when you've got a finite amount of dollars to spend and if you couldn't control how many people move into your state and therefore have a right to services if some law like that were passed.

But I do think it's a great lead in. It would be nice for us to recommend that it get explored.

MS. PRINCE: Because in your state especially because there are so many of the Mormon population that goes out and has their professional life that wants to return back to where the families happen to be and aunts and uncles and grandparents when they reach a particular part of their professional life or retire.

And they're not able to do that because they have to stay in Indiana or Alabama or Alaska or Washington. And it divides families. And it divides healthcare as well.

MR. PARNELL: Right. And…

MS. CRANE: And you end up having situations - oh sorry.

MR. PARNELL: No. I was just going to say the needs of military families comes to mind because you have no choice when you're being moved from one state to the next. And if you have a child in services in Utah and you move to New York then, you know, your job as a person in the military may be requiring you to take your child out of services.

MS. PRINCE: And it also pertains to people in the State Department. Because there are some

people that don't have a state registry necessarily or it's the wrong state that they're not returning to when they come back from Foreign Service. We do have those implications, those military state department and others that are in our public service.

MS. CRANE: We also have that situation in some urban populations where there are - where the metropolitan area crosses state lines. So for example the...

MS. PRINCE: Minneapolis/Saint Paul?

MS. CRANE: Yes. You could have someone or New York City for example where, you know, you're priced out of New York City and maybe want to move to New Jersey where you can get affordable housing and you simply can't. Because, you know, that affordable housing option stops being there. We're in DC. DC is completely unaffordable. But there is - there are a few ways to, you know, if you move to a Maryland or Virginia suburb in order to find affordable housing then you'll lose access to whatever you've gotten through DC.

MS. PRINCE: Yes.

MS. CRANE: And so on.

DR. DANIELS: This is Susan. I think that the portability issue just sounds like an issue in itself not necessarily something that you would want to put into the aspirational goal. But it's something that you might want to discuss in your chapter. Although it might be something that crosses over with question 5 so I think that's another issue that maybe the co-chairs of this group should discuss with the co-chairs of the other groups.

Because they may want to talk about that in theirs since they're talking about services and

service systems. The portability issue is relative TO THAT.

DR. TAYLOR: Brian can you carry that forward for us?

MR. PARNELL: Absolutely.

DR. TAYLOR: Okay.

DR. DANIELS: So in terms of the title, "So What Does the Future Hold Particularly for Adults" the group didn't suggest anything last time. Something that I wanted to throw out for consideration was whether based on your conversations about the full lifespan is whether you might want to change the last phrase particularly for adults to something like as individuals on the autism spectrum progress through the full lifespan.

To kind of broaden that a little bit or if you don't think it's necessary that's fine too.

DR. TAYLOR: That sounds good.

DR. DANIELS: What do you think?

MS. CRANE: I don't know. If we remove adults would the lifespan thing make it sound like we're including children and people who aren't adults?

MS. PRINCE: Yes.

DR. DANIELS: I think that in the number 2 objective with health, safety and wellbeing across - of individuals on the autism spectrum across the lifespan something that occurred to me anyway is that it might make sense not to repeat safety in two different places.

Because right now what we have is we have some safety issues in question 5 and some in 6. And if we just talk about the full lifespan and all

lifespan issues it could encompass lifespan issues that affect children as well.

Although really the, you know, when we're talking lifespan we're usually talking more about adults.

MS. CRANE: I just would really be very worried about having question 6 include people who aren't adults or at the very least transition age youth because it's so - we're so underrepresented in research funding that I just don't want to - I don't want to dilute it at all.

DR. DANIELS: Other thoughts?

DR. TAYLOR: I tend to agree. I really like keeping in the adult part in the title?

((Crosstalk))

DR. DANIELS: Okay. So then we'll stick with that. In terms of the next steps are there any other comments before we talk about next steps?

DR. TAYLOR: Just really quickly going back to the aspirational goal. I think that unless I missed it and we had closure on the issue I brought up about cost and time, etcetera, I think adding a clause at the end that says without excessive burden might work.

DR. DANIELS: Or you had brought up - somebody had brought up meaningful access? So I would recommend keeping it short. Because if you start adding another entire clause it's already kind of long and hard to read.

So unless (unintelligible) to something else and it can make it a little tighter.

DR. TAYLOR: I think meaningful is fine.

MS. CRANE: And can I actually - this is Sam again. Can I actually say something else about titles? But the word future kind of implies that - I mean it's - the titles are sort of aimed at, you know, stakeholders in the community.

And I think the word future in some ways makes it sound like the stakeholder is either a child or is a family member of a child. And, you know, maybe if we're, you know, going to include, you know, something about adult services I mean we might want to reword it in a way that acknowledges that, you know, for some people asking this question the relevant individual is already an adult.

DR. DANIELS: So do you have a proposal for a different title?

MS. CRANE: You know, perhaps something like what - how can, you know - what are the needs across the lifespan particularly for adults or, you know, what - how can, you know, what is in store for an adult. I mean I can keep thinking about it. But I just wanted to...

DR. DANIELS: Does anyone else have a suggestion there?

MR. PARNELL: This is Brian. I like the way that it's worded right now. But I'm certainly willing to look at anything that somebody's got to offer. So really Sam is kind of on the spot. Maybe if you have some time to come up with some ideas we can take a look at those through an email correspondence.

MS. CRANE: I'd be happy to do that.

DR. DANIELS: All right. Any other thoughts there?

(No response.)

DR. DANIELS: So then the next steps will be - I will be working with the chairs on kind of finalizing the outline and then the chairs will be contacting various members of the working group to assist with drafting various parts. And so if anyone is interested in particular topics and you want to write something about those topics please email Brian, Julie and myself to let us know so that we'll know who to call when we need something in that area. So you'll be working on this writing task over the next couple of months. And once we have a good draft we can circulate it around to the entire group for comment. I will also be working with the chairs on finalizing proposed wording for the objectives for you.

And then we will discuss these chapter drafts at the next IACC meeting that's happening on January 13. So we hope that we'll have a full set of drafts for all the chapters at that meeting so we can have the committee review. And hopefully if they're in good enough shape be able to approve the draft. So are there any questions that anyone has? Okay. Well we really appreciate everyone participating in this call and offering your suggestions and ideas.

We'll be in touch and we'll be sending around materials as needed. So but in the meantime if you have any questions feel free to reach out. Thanks everyone.

((Crosstalk))

DR. DANIELS: Thank you. And you'll be...

(Whereupon, the conference call was adjourned.)