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INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR
SERVICES RESEARCH AND POLICY

STRATEGIC PLAN QUESTION 5 AND 6 PLANNING GROUP
FOR FAMILY SUPPORT

CONFERENCE CALL

TUESDAY, OCTOBER 9, 2012

The Strategic Plan Question 5 and 6 Planning Group for Family Support convened via a conference call. Sally Burton-Hoyle, *Chair* presiding.

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PROCEEDINGS:

Dr. Roger Little: Good morning, everyone. Welcome to the conference call for the planning group to update Question 5 and 6 in the area of family support of the IACC Strategic Plan for ASD Research.

As you heard, my name is Roger Little and I'm acting as the designated Federal official on this call on behalf of Dr. Susan Daniels, who's currently out on maternity leave.

On today's call, please remember to identify yourself before you speak so that we know who's on the call, and thank you for joining us. I'll now turn the call over to the planning group leader, Sally Burton-Hoyle.

Dr. Sally Burton-Hoyle: Okay. Well, again, good morning. And if everybody could -- let's see, who do we have here this morning? Could you share your names?

Dr. Paul Law: This is Paul Law.

Dr. Burton-Hoyle: Good morning, Paul.

Ms. Lisa Goring: Lisa Goring.

Dr. Burton-Hoyle: Good morning, Lisa.

Dr. Ann Turnbull: Ann Turnbull.

Dr. Burton-Hoyle: Ann, good morning.

Ms. Alison Singer: Alison Singer.

Dr. Burton-Hoyle: Alison, good morning.

Dr. James Ball: Jim Ball.

Dr. Burton-Hoyle: And Jim, good morning, good morning.

Okay. Well, we're all here. And I thought that I would start with any questions anyone had regarding what the Strategic Plan looks like and if you had any questions over the diagram that was developed that showed how the questions related to the process.

And the Federal official also can answer any of these questions in case I can't. So were there any questions about that?

Dr. Turnbull: Sally, it's Ann. Is there a copy of the Strategic -- the most recent Strategic Plan on this topic or a strategic plan on another topic in terms of how you want this to end up? Like in the spirit of beginning with the end in mind could we have a --

Dr. Burton-Hoyle: Yes.

Dr. Turnbull: -- model of what that would be?

Dr. Burton-Hoyle: Yes. And if you go to the IACC Website, all the documents that have been developed are easily downloadable. So you could look at Questions 5 and 6 in that document to see how very simply they have presented the kind of what it is we're going to cover today, which is what are the needs, the gaps -- however you want to describe it -- and then what are the things that are known right now. So you can see a sample of how it is that that's written up -- which that will be -- David Mandell and Denise Dougherty will do that final piece after getting input from you all today, then the workshop and then -- and all that, putting together all that information.

Dr. Turnbull: Thank you.

Ms. Singer: So, this is Alison. I just want to reiterate that actually what we need to do is very similar to the section in the Strategic Plan that says "2011 Update." And that our mission is not to rewrite the objectives or the whole section but to just write a 2012 update similar to the 2011

update.

Dr. Burton-Hoyle: Thank you. Thank you for clarifying that. So, does anyone have any questions about the process? I sent you a sample template where you could fill out the topic of what you felt like there were disparities in, what we've learned and if it's something that's not a generally known idea, then the reference citation for that.

And that would be those things that you as experts felt were critical pieces. And they would be things that would have been published within the last 18 months. I wanted to make sure everybody was clear on that.

And I so apologize; it's a very tight timeline. So for you to put some things together and get them to me by Sunday is kind of when I'm going to need to, then work all night to get them to our -- the heads of the Committee so that then further work can be done on that. And I can get things written up.

Are there any questions about that?

Dr. Turnbull: Sally, this is Ann. When I look

at the 2011 Update, I think I'm looking at the right one IACC releases its 2011 summary of advances in autism research?

Dr. Burton-Hoyle: No. This is the Strategic Plan document.

Dr. Turnbull: Okay. Maybe after this call, if you could just send the key documents that we need.

Dr. Burton-Hoyle: I will; I absolutely will. I should have done that before, so thank you; I will.

Dr. Turnbull: But one thing I'm concerned about -- and I know from the outset I had stated that just I had really very limited time between now and the end of the month -- I did a quick literature search for 2011 to 2012 of just articles that included any derivative of the word "family," such as parent, mother, father, grandmother, sibling, and there are 260 articles. That was just one database, so, not a comprehensive search.

Dr. Burton-Hoyle: No, right.

Dr. Turnbull: That was only one that had the

words in the title but not in the article. And so what I really want to raise is, what is feasible to do given time constraints? And is there any staff help in reviewing this literature? And you know, how thorough can we be given that Sunday is five days away and we all have more than full-time commitments?

Dr. Burton-Hoyle: Right. Well, I think that why we pulled together you all as experts -- is for you to input what is critical to you. And, Alison, you help me out. You have more experience in this, but that is my understanding.

Ms. Singer: Yes. So the goal is for there to be an approximately 1,200-word update for all of Section 5 and 1,200 words for all of Section 6, of which the family services and supports, is one-sixth. So we're looking for about 250 to 300 words total.

So really what we're looking for in the update section is recognition of the growing body of research focused on the fact that autism affects the extended family, specifically with regard to stresses that families have identified, best

practices for supporting the whole family with regard to caregiving, things of that nature.

But this is not intended to be an exhaustive literature search. It's intended to just be really a very brief narrative.

And I think what the other committees have really found is that the frustration lies in paring it down and maintaining, sticking to that 300-word limit.

Dr. Burton-Hoyle: Thank you. So I think it really is what in your heart of hearts and as an expert researcher in your field, what do you think is the most important? And what do you think are the things that have been advances or things that we've learned and where are the gaps in what it is we need to know?

Dr. Elisabeth Dykens: So, this is Elisabeth, and that was my question exactly. Is this a snippet of 300 words or so of advances that have occurred or gaps that we would like future researchers to work hard to try to fill?

Dr. Burton-Hoyle: I think the answer is yes to both, because both of those questions need to be

answered. And so within the last 18 months, what are those things that have been advances or things we've learned and what are those gaps, what are those things that we do absolutely need to look at?

Dr. Dykens: Okay.

Dr. Burton-Hoyle: Okay.

Dr. Dykens: -- all within 300 words.

[Laughter]

Dr. Burton-Hoyle: Well, and you don't need to worry about the 300 words. You need to worry about the ideas and if there's a reference, a citation. And then we have to put that together. So, Alison, thank you so much for putting all that into perspective because that -- being newer on this committee I didn't have that part -- so that's really important.

Dr. Dykens: Yes, there's a lot of descriptive studies on high levels of stress but not much intervention work in terms of what to do about it.

Dr. Burton-Hoyle: Right. Okay. So, any other questions around what our job is, deadlines, kind of the format we're going to follow?

[Several speakers]

Ms. Singer: You know, Sally, what might be helpful -- this is Alison. I wrote up the 300 words of the final update for a subsection for Section 7 for workforce and infrastructure. I can send that to this group so you can just get a --

Dr. Dykens: Oh, thank you.

Dr. Burton-Hoyle: That would be helpful.

Ms. Singer: -- get a sense of the depth that you are able I think to go into in the 300-word limit. You know, we're not looking for heavy citations. We're really looking for one sentence identifying each of the key areas. So I'll send that around sort of as a sample.

Dr. Burton-Hoyle: And so for this group, I think -- as we talked about in our previous committee meeting -- it could even be things in bullet form that were presented by this group. So you know putting together your information would be the important piece and what you know already.

Ms. Singer: Right. So for example, a great piece of data from Dr. Law would be that 58 percent of parents supported that wandering was an

extremely stressful event. That's new data from new research.

Ms. Goring: Okay, excellent idea, excellent example.

Dr. Burton-Hoyle: Okay. So with that being said, what do you all think are, starting with that, with wandering, what are other things that are learned and what are things that you feel are gaps?

Dr. Law: This is Dr. Law. I do think that what is a very important topic and it's not one that I chose; it was one that the parent advocacy organizations really pushed me and my team at IAN to pursue. And we were always delighted to be involved in it.

But I think the thing that really stands out to me from that whole project and the whole way it happened was the way the community worked together very diligently to address an important topic.

And the way the different organizations were working together in unison. The way we do have some infrastructure that can investigate issues very quickly through engaging families was to me

absolutely amazing. I was blown away.

And I think it's -- you know, looking at the really big picture -- we should consider how, you know, what does community research look like for us and how does that directly impact family services.

Dr. Burton-Hoyle: Thank you.

Dr. Turnbull: This is Ann. Someone already said that there's been a lot of research on identifying the internal family characteristics that are associated with stress such as age of child and extent of autism and socioeconomic level and race/ethnicity and so forth.

And it seems to me that the major focus of what families are saying that they really need is a focus on what kind of support will make a difference in reducing their stress and improving their family quality of life. So that there will really be a shift from the descriptive demographic studies of families and negative outcomes to looking at positive support outcomes and what services do.

I mean, a mother was saying to me not long ago

"You know it's really not my child's autism that drives me crazy; it's the system that just will not cooperate in providing responsive services." And I think so many families feel that way, especially as their children move toward transition to adulthood.

Dr. Burton-Hoyle: Thank you.

[Pause]

Dr. Dykens: And I think as well, you know, it's again responsive services for the child. I think many of our interventions are child centric and focused on -- for lack of a better word -- the "identified patient," when we've known for decades that levels of stress and health and mental health, sequelae of stress are high in mothers and dads that are raising --

Ms. Goring: I'm sorry. Can whoever is speaking speak louder, please?

Dr. Dykens: Okay; I'm sorry. It's Elisabeth, and I will try to speak louder.

I was simply stating that I think that much of the work to date has really been focused on ways of helping families to get services, to intervene

in ways to improve their child's functioning, and really has done very little to directly address the stress that mothers and fathers experience.

So one of the things that we've done recently is to shift that on its head and do absolutely nothing with the children or the adult offspring and provide parents with tools that they need to live better, less stressful lives as parents but also as employers or employees, as citizens, as neighbors, really focused on their adult development and tools that they can use every day to reduce stress and to stay focused.

And again, the goal is not so much that that will enable better play or motor skills in their children. It really is to say how can we address the stress and depression and thought processes that many families have and tackle that directly? Instead of saying well, if we provide more support, if we provide more services, if our systems were more user friendly, if the state would fund this. That's not really the point. That will come and go, right? The point is giving them the tools they need for life to continue to

develop in a positive direction as an adult. And it's sort of shifting how we think about intervention. But, I think --

Dr. Turnbull: This is Ann. You know, building on that, Elisabeth, it would be great to really focus on research that would show positive child outcomes from family interventions.

Dr. Dykens: It would. And I think --

Dr. Turnbull: Because many agencies don't want to fund family work because they feel that the person with the disability doesn't benefit. But probably with the right study, it would not be hard at all to document that.

Dr. Dykens: Exactly.

Dr. Turnbull: Lower family stress, higher family quality of life has positive outcomes for the individual with autism.

Dr. Dykens: Sure. And I think that that trickle-down effect, as we call it, definitely exists over time. It's not immediate during the course of the interventions that we're using, but over time we predict that the whole family system will sort of settle.

And there is a body of literature that suggests that if you provide highly stressed parents with, for example, lessons or classes in behavioral techniques and managing their kids' behavior problems or whatever it is -- that if your stress is high enough, you're not very good at learning those lessons.

[Laughter]

Dr. Dykens: And really what you need to do first is bring the stress level down so that parents can take advantage of those interventions of how to better deal with your kids' temper tantrums or have them develop their language skills.

So if we're teaching highly stressed families these things, they're not going to be as effective in implementing them as if we first addressed their stress and then said, "Okay, now let's think about how we can think about your child."

Dr. Burton-Hoyle: That's wonderful. That makes so much sense.

Dr. Dykens: Well, I'm glad you think so. Hopefully, the reviewers will think so as well.

[Laughter]

Dr. Ball: Hi, this is Jim Ball, and I had suggested Mark Durand be on this, but I don't know if he could make it or not. But his research is into optimistic parenting and looking at how just impacting the family then impacts the child. So via giving the family what it needs and the strategies and looking at their lives in a different way, that then impacts the child and then they're learning and so forth. So his stuff has been really, really groundbreaking.

Dr. Turnbull: I agree. This is Ann. Another just huge topic is how parents can best learn to navigate the adult system. And what we've learned in our research is there are an amazing number of Federal benefits that adults with autism can take advantage of. But because it's such a well-kept secret that also not only families don't know,

Dr. Dykens: Yes.

Dr. Turnbull: -- but the transition coordinators advising families don't know. But, really excellent system navigation skills would go a long way in lowering the stress and improving

the quality of life at adulthood.

Dr. Dykens: And a challenge of course is that every state has a different, you know -- above and beyond the Federal benefits -- but every state system is different.

[Laughter]

Dr. Turnbull: Different on some benefits but not others. For example, there are a lot of housing benefits that could really enable people to have a home of their own rather than a group home or a congregate setting, and those are Federal.

You know -- so the Medicaid is state based but -- and there are also some principles of Medicaid such as participant selection of putting the money in the hands of the family rather than in the hands of agencies. And these principles of how they're distributed could be implemented consistently across states.

So the whole thing of policy, funding, services, how to navigate it, and how to put together individualized packages, there are many, many, many successful case studies. But research

hasn't -- these case studies are mostly very innovative families who had figured it out. And research hasn't aggregated the lessons learned and then taken those to the level of interventions.

Dr. Burton-Hoyle: Which goes back to -- if families are exhausted and stressed -- they don't want to learn anything new about their child who's turning 21 and what it is they could be getting.

Dr. Dykens: Yes, I agree.

Dr. Law: And if I may, most of -- IAN -- this is Dr. Law, by the way. Most of our contributions at IAN come in the form of contributing in some way to research.

And we have a lot of difficulty with students -- with individuals who are becoming adults. The -- I don't know what all the reasons are -- but families overall stop participating in research as they enter into the adult years. And perhaps that is because of the stress level, because the challenges are just too much, that there's just no discretionary time left. But it's a real problem because it makes it difficult to understand the problems that are out there or the supports that

are out there to know what to promote or what to deal with.

Alison and I are working on a project in New York to look for more creative ways to engage adults in research that's actually tied to interventions that will be used by the United Jewish Association to actually do interventions, but it's been a real problem.

And it's not just for us; it's for everybody to engage adults in sort of discovering problems and coming up with positive supports to overcome them.

Ms. Singer: This is Alison. Do you have any comparative data comparing the percentage of adults with autism who participate in research versus the percentage of adults with either other developmental disabilities or other types of special health care needs? Because I think sometimes that comparative data is extremely valuable.

Dr. Law: Who were you asking? This is Paul.

Ms. Singer: I was asking you.

Dr. Law: You were asking me. I was worried

about that. I think -- I can't cite any numbers. I think in general it's -- I just shouldn't say anything. I think it's probably poor across the board. Maybe Ann could speak to that.

Dr. Turnbull: I don't know of any data that compares the participation in research.

I do know that I really endorse what Paul is saying about so many families who are having problems at adulthood don't want to participate in research. But we have found that so many families who had found successful solutions are eager to tell their story. It would be a great qualitative study because they beat the odds and they would love to share with others how they did that so it would be easier for them than it was -- easier for people coming along behind than it was for them.

So I think a focus on family strengths would present a body of research that's along the lines of the positive psychology field of really looking at what's working well in families who have children with autism and how can researchers and families partner so that the knowledge of both can be brought to bear on the discovery of new

interventions that would be better than what the researchers could think of themselves or better than what the families could think of themselves.

The whole is not greater than the sum of the parts in terms of the knowledge of the different stakeholders right now, but that could certainly happen in the research agenda.

Dr. Dykens: And I also think that what limited data are out there do suggest that -- in terms of the sort of dropping off the cliff after 18 or 21 or 22 -- that if the child also has a co-occurring intellectual disability, it's much more likely that they'll stay within the system in terms of getting services and supports from state agencies and the like. But if that individual is a higher functioning, they sort of morph into the community in ways that make it hard to keep track of them. Like old mild intellectual disability literature from the fifties and sixties, they just sort of disappear into the community, and it's really hard to then pull them back to track or follow them over time.

We study a lot of adults with other

neurodevelopmental challenges and issues and syndromes, and we have absolutely no difficulty following them. I will say, echoing the prior concerns, that it is hard to find those higher functioning adults. Again, if they have intellectual disability, we're more apt to know about them, but we seem to lose track of those youth and adults that are higher functioning.

[Pause]

I love the idea of telling the positive stories. I think that's great and --

[Laughter]

certainly I worked a bit here with the Mental Health Court here in Tennessee, and I -- on the negative side and an outcome that we all want to avoid is that -- I think many of adults on the spectrum are in jail. So that's -- I was blown away by the numbers, and I think that that's an outcome that we want to avoid. But realistically, I think a lot of adults on the spectrum are in jail.

Ms. Goring: That is -- I think that is a very important piece. The juvenile justice system. And

there is one article --

Dr. Dykens: The adult justice system. I'm talking about the 30-year-old who does something really stupid and gets caught because of his autism and then ends up sitting in prison. I mean, yes. So I feel, yes, the juvenile justice system, I think, is one thing when we talk about youth. But looking at again the adult years, I think there's a huge problem there.

Dr. Burton-Hoyle: And we don't really have any good data on how many adults with autism are in the justice system, right?

Ms. Goring: No, no. That would be a need. In the article I just read, they said -- and it was more, it was on juvenile justice -- but they said schools were much more likely to press charges than if a person was in the community and got in trouble. And the sorts of things that they did were not premeditated. It was getting upset and acting out and doing something against a person. But that is an area.

Dr. Dykens: Yes.

Dr. Burton-Hoyle: What about some researcher

outcomes on successful transition plans that result in community integration? I know Paul Shattuck did some work in terms of what happens with adults with autism versus other disabilities after they exit the educational system.

But really more about what are the key components, maybe to a successful transition plan. And look at some of the outcomes. Because right now, I don't think we have any good outcome data on what happens when folks leave.

Dr. Dykens: And to what extent is this -- are we drifting a bit from the focus of this committee in terms of family? I mean, or is there a separate group within the coordinating agency that's dealing with adulthood?

Ms. Goring: We have Question 6, right?

Dr. Burton-Hoyle: Yes, we've got 6, right. So I think that many of the things that apply to young children obviously apply to adults -- with adults. But there is a committee on education/employment that would be covering transition.

But I mean, as it relates to family support,

how can the family be happy when they've got their 27-year-old at home? So I know from experience that it does figure into how a family functions.

Dr. Baden: And this is Elizabeth in the Office of Autism Research Coordination. And just to sort of clarify how the topics are divided, I think they decided that in each of the five topic areas each group will address transition from that perspective, so exactly as the last speaker just mentioned, that obviously transition is going to affect the family so you could explore how -- explore it in that context.

[Pause]

Dr. Burton-Hoyle: So I guess I wanted to clarify something. And Jim, you brought it up about the optimistic parenting. Is that something -- that's something -- we've learned, or is it still a gap area of research? Because I'm trying to kind of look at -- take notes on what you all are saying.

Dr. Ball: This is Jim. I think Mark did some on that, and now he's actually looking at optimistic teachers, special ed teachers. So he's

morphed that into other research because of the great success that he had with the optimistic parenting research he did. Now he's looking at teachers. So it's interesting.

Dr. Turnbull: Too -- it's Ann. He's trying to get more funding for his optimistic parenting work also. So I'm sure he would say yes, more research is needed.

Dr. Burton-Hoyle: Okay. So we've got things that we've learned about wandering, things we know about the stress level in accordance with the severity of the child with autism, ways for families to get services.

Elisabeth, you brought up -- Elisabeth Dykens -- about what you've learned about when you provide, you know, stress relief to highly stressed parents. Or no, you said that if you provide parents that have children with behavioral challenges, if they are highly stressed that they're not going to get anything out of it, out of that information.

And then interventions with adults, I don't know who had brought that up. And is that a known

thing or is that a research, to be researched?

Dr. Dykens: Interventions with adults regarding their stress?

Dr. Burton-Hoyle: Yes. And other -- I guess other areas, too. And maybe, Alison, you brought this up?

[Pause]

Ms. Singer: I'm sorry, what? I couldn't quite hear it.

Dr. Burton-Hoyle: Oh, I'm sorry. Had you brought up about the known research about interventions with adults? I didn't get who brought that part up. And was that a known body of research?

Ms. Singer: No, I don't think that was me. I think that was someone else.

Dr. Burton-Hoyle: Okay.

Dr. Turnbull: This is Ann. I was suggesting that there be research on how families can best navigate the system in order to get the support that their son or daughter needs.

Dr. Burton-Hoyle: Okay. Alright, parents needing support. And Dr. Law, you brought up about

how can communities' research better, how can they partner better? I'm trying to --

Dr. Law: I mean, I just think we need to -- to me there's translational research that -- to me translational research is how the community operates on the front line, to understand its concerns, to react quickly, and to monitor that reaction through services research. Because that's what changes people's lives, not -- actual interventions and the way those are tracked and monitored and improved that make the difference for families.

Dr. Ball: This is Jim. I couldn't agree more with that. And I think that as part of our summary, I think really for families, treatment-guided research is probably the most effective because I don't think we give them enough strategies and research strategies that have been proven to be effective for a certain population.

So when we look at it, I think that for our families, they need -- like on the front lines -- they need the hands-on strategies in order to have them to work with their kids.

Ms. Singer: So, this is Alison. I would just like to also suggest that we incorporate something about siblings. We've talked a lot about parents, but we haven't really talked about siblings.

And really, the only ways that siblings right now are engaged in research is with regard to the fact that they are a high-risk group. And so they are sort of a very ripe population in terms of early detection.

But I think one gap is sort of the psychological effects on siblings of growing up in a household that tends to be dominated by a family focus on the sibling with a developmental disability. And we don't really have any idea what the psychological ramifications are for those children, whether they emerge as highly empathetic beings or whether they emerge with psychiatric issues of their own.

Dr. Dykens: There have been some -- I agree that siblings are always the forgotten members of the family. And there is an emerging movement, I think, particularly within the UCEDDs to really better understand the sibling experience,

particularly as it relates not only to autism but other developmental disabilities.

And as you say, some of the earlier literature was overly -- it was either overly negative or overly positive in terms of, well, they all become empathic social workers or special ed teachers, or they become forever scarred by this. It's probably something in the middle. But I think having that be a priority would be fabulous.

Dr. Burton-Hoyle: I agree.

Dr. Turnbull: One thing -- this is Ann -- is the need for reader-friendly, family-friendly literature reviews, not only on the research in the field of autism specifically but other developmental disabilities.

Because there really have been a fair number of studies on siblings, but they're all spread out in so many different journals and it's really hard to bring that body of knowledge together and get a bottom line. And then once it is brought together, to have it in a family-friendly form so that families are interested and able to read it.

I think a wonderful contribution of this group

could be to really reap the harvest of knowledge available and to prepare it in ways that are meaningful to families.

Dr. Burton-Hoyle: And this is Sally. I agree, because that will address the destigmatizing thing that I think is so important for autism. Families need to hear autism and read about autism in a way that doesn't scare them to death. The more that we can do that about what autism is and what the family process has been, could be, will be, based on the tools that we give them. So kind of combining that optimistic parenting, how helpful that would be.

Dr. Turnbull: Agreed.

Dr. Dykens: I guess I just come back to ensuring that families are at a point where they're able to take that knowledge in. If you're under financial pressures, marital problems, Grandpa's in the hospital, and all these things are happening, it makes it all the more challenging for families to sit down and read even a user-friendly summary on things that they might be doing.

Dr. Turnbull: And maybe it's not in a reading format. You know, maybe it's what they can plug in in the car when they're doing errands.

Or maybe one of the consistent things in research on families has been that they really get a lot of informational and emotional support from connecting with a veteran family and getting information from them. So maybe a way to deliver the research is through preparing veteran families who have successfully dealt with autism and who are at a plateau period of their life when multiple crises are not happening -- how could they be a guide at a side, a research guide at the side of families who are needing information who just can't get it in traditional ways.

It's really the universal design for learning that we want for students with disabilities in schools; it's the universal design for learning for families. There are many alternative formats.

[Pause]

Dr. Burton-Hoyle: To you, experts, is there sufficient or any information, and I always get asked this so I've got the perfect group to ask is

divorce rate? Is that an area regarding family support that there is either known information on or is it needed?

Ms. Singer: I couldn't hear what the topic was. What was it?

Dr. Burton-Hoyle: I was asking was divorce an issue. Was this something that was known? If so, I get this asked all the time or is it something that needs to be studied? How do we keep marriages strong? Or is it if we keep families strong, we would keep marriages strong. I don't know if one would lead to the other, but I thought I had the right group to ask.

Ms. Goring: There was a study not that long ago -- I'm just trying to find where it is -- that the divorce rate is not higher.

Dr. Law: That was Dr. Friedman from Kennedy Krieger.

Dr. Dykens: And there was another one that said it was higher.

Dr. Turnbull: A couple of meta-analyses. George Singer did one of those. I don't remember the sample in terms of how many had autism versus

other types of developmental disabilities, but that meta-analysis showed that it was not higher, that in some marriages it made the marriage stronger; in others it made it worse. But overall --

But probably the research done on marital quality, if you went back and looked at all the studies, it might be, I'm just guessing, like all family research it might be about 80 to 90 percent from the perspective of mothers. You know, do fathers think the same thing? You know, or the extent of their challenges and what was the reason for their divorce.

Dr. Law: So this is Paul. We were looking at our data where we asked a few marriage-related questions, and we need to go publish this. But one of the things we saw -- or that all of us on our team are convinced might be part of what's going on -- is that kids with the stress that parents are under actually in some ways keeps them in the marriage. The stress of needing to take care of the child with autism, the impracticality of maintaining two households, the financial

pressures that they have been put upon actually makes it difficult. So even though their marriage is in significant stress and needs help, they actually perhaps don't have as high a divorce rate because of the practicalities of the issues.

[Laughter]

Dr. Turnbull: Unless they get a divorce.

Dr. Law: Again, coming back around to the theme of stress.

This goes back just a couple of minutes ago into our conversation, but we do a lot of presenting of -- distilling of -- information about autism and putting it on the IAN Website, which -- we get a fair amount of traffic. Families come and read articles.

The ones that really appeal to families -- because we track how each article performs whether it's an article on genetics, on research, or on how to drive or how to teach children with autism how to drive -- it's the issues that just are more related to the everyday goings-on of life, the stress, how to overcome certain barriers just to having a high quality of life. Those are the

articles that appeal to families the most and get read and shared the most, which again reinforces our topic.

Dr. Burton-Hoyle: Thank you.

[Pause]

Dr. Burton-Hoyle: I'm sorry, go ahead.

Dr. Law: Since there was a pause. So putting on my informatics hat, I think one of the critical things that we need to address is how to get information in the right people's hands at the right time. Because there is so much information and there is such a varied profile of autism, if you will, out there. There's different age groups and everything.

And I don't think we quite have a handle on this. If you have a baby and register in -- I think it's BabyCenter or something like that -- you get specific information for your child that's age specific over time. In autism, it's sort of like this flood of information, whether it's good quality or poor that families are dealing with. And it's like we need to maintain profiles or allow families to create profiles that allows

information to be filtered to them in a more efficient way.

Dr. Turnbull: I think that's really important. I was really struck by a comment I heard once that trying to get an answer to a question is like trying to get a sip of water from a fire hydrant.

[Laughter]

Dr. Turnbull: -- Certainly that applies in the field of autism as much or more than any other field with just the glut of information -- and knowing just how to get your question answered.

Dr. Law: The lost opportunity is our medical records that should be used I think to send information out to families based on what information we have on families -- or for that matter, our research records. So that is, you know, we have all this great information on wandering right now, but I feel a little bad that I'm not delivering more concrete useful advice to IAN families because we're not set up to do that.

Dr. Burton-Hoyle: So that would be a need. Because if 50 percent - Alison, you had said that 50 percent of families from Dr. Law's research. Is

that --?

[No response]

Dr. Law: I guess I'll answer for her. Yes, that is correct.

Ms. Singer: That's correct. I think now you're getting into very specific so I'm disseminating the policy implications of a specific study. Which you know, I think at the broader level, that's absolutely true. But there are other groups that are working to get that information out and to have specific toolkits focused on that.

Dr. Dykens: Lots of disorders, too.

Ms. Singer: I think we're in good shape on the wandering. You know, if we were -- I think wandering is sort of an example almost of best practice. Of how these issues are raised, the community mobilizes, we find the funding, we fund the research, we get the research published we get it out. We enact public policy change as a result of the research, and we help families -- so -- by creating these toolkits with very specific instructions.

So you know we are going to be including the

wandering as an example in the introduction and in Chapter 7 of an IACC success story. But I think if we wanted to talk about the broader implications of when we do get these findings and when we do have instances where we find out that families are stressed because of a specific stressor, how do we initiate public policy change to support families and how do we mobilize to make sure that that information -- to make sure that the process doesn't end at the point of gathering the information?

Dr. Dykens: Well, that's where I think the UCEDDs can be invaluable, because they, you know, it's their mandate to disseminate. And UCEDDs vary in how well they might tackle that core function, but it is the expectation. And so I think bringing in the UCEDDs and maybe the AUCD network is a way to assist with dissemination would be something to consider.

Dr. Burton-Hoyle: Excellent.

Dr. Law: I totally agree.

Ms. Goring: Nonetheless, what good will it do unless people know about it?

Ms. Singer: So while we're drawing to a close, what are the next steps? What are the action steps that you want us to take in terms of getting information to you, Sally?

Dr. Burton-Hoyle: Well, if you could look at the template, modify it if you need with the idea that seminal pieces of what you think are important in the area of what do we know, what are advances, and what are the needs. And get that quickly typed in and put bullets, you know, bullets for your topics and get that to me by Sunday. Email that to me. That's what needs to happen. That's the immediate next step.

Dr. Turnbull: Weren't we talking about getting a copy of one of the other sections?

Dr. Burton-Hoyle: Yes. Alison, you said that you were going to send out an example of what the endpoint, what it could look like. You had answered Question Number 7. Right, Alison?

[Pause]

Ms. Singer: Oh, sorry. I was on mute. I will send out two of the subsections from Section 7. The ones I have are communications, and I have

workforce enhancement, building a workforce.

Dr. Burton-Hoyle: Okay.

Dr. Turnbull: Can you give us a little bit of information about how this is going to be presented? Or do you want to wait and do that later?

Dr. Burton-Hoyle: Were you asking me or Alison? This is Sally.

Dr. Turnbull: Anyone who knows.

Dr. Burton-Hoyle: Okay. Alison has more experience with it. I can tell you what I'm going to try to compile -- yes, go ahead, please.

Ms. Singer: This group, the family support group, is one of six workgroups under the Services Subcommittee. And the Services Subcommittee is a subcommittee of the full IACC.

So there are two Subcommittees of the IACC. One is focused on services, and one is focused on basic and translational research. The Services Subcommittee is responsible for updating Sections 5 and 6, and the Basic and Translational Research group is responsible for updating Sections 1 through 4 and 7.

So the responsibility of this workgroup is to present ideas to Sally, who's chairing this workgroup, who then will give them to David Mandell, who is the chairperson of the Services Subcommittee. He'll then incorporate the material from all of the six subgroups, all of the six workgroups that are working on Chapters 5 and 6. And he'll write up some drafts.

Those drafts will be presented at the scientific workshop, which are taking place on October 29 and October 30 in Bethesda. So the first day, October 29, will be focused on services. So on that date, we'll be going through Sections 5 and 6 of the Strategic Plan.

And I'm not exactly sure how David plans to present it, whether the chair of each workgroup will present or -- but that's the date that we'll go through. And everyone on these workgroups will have a chance to comment on the work of all of the other workgroups.

And everyone from the Services Subcommittee will have a chance to comment on the work of the Basic and Translational Research Subcommittee so

that there's an opportunity for cross-fertilization between services and basic and translational research because we recognize that they both need to be part of all of the chapters.

Then the outcome of the two-day workshop will be presented to the full IACC, where members of the full IACC -- some of whom are participating in this process and some of whom are not -- will have the opportunity to weigh in and make suggestions. And then the IACC will take a final vote on the final updates to the Strategic Plan. The updated Strategic Plan is then sent to Congress on January 1st.

Dr. Turnbull: That was great; thanks.

Dr. Burton-Hoyle: Thank you.

Ms. Singer: That's why they have me do infrastructure.

Dr. Burton-Hoyle: Excellent. I can see why. That was -- thank you.

Ms. Singer: I can't believe I remember all that stuff.

Dr. Burton-Hoyle: Awesome. We're glad. So what else?

Ms. Goring: So Sally, once we send these bullets to you, then what happens? You send them off? Do we see them again, or you send them to David Mandell?

Dr. Burton-Hoyle: Well, you will see them. This is all draft, and it will be draft as David then tries to compile things. And as Alison just said, everybody will have a chance to comment on them at the meetings on the 29th. So yes, you'll see them again in some form, keeping in mind that I didn't even know that, that approximately 250 to 300 words would be what will be devoted to the area of family support just because it's one of several, which is why the lean and mean thing is important to us about what's important and what's needed.

Dr. Baden: And this is Elizabeth Baden in the Office of Autism Research Coordination.

And in terms of when you'll see it again, once Denise Dougherty and David Mandell have put the information from all the five groups together, we will circulate those drafts prior to the workshop on October 29th. So [Inaudible comment] week of

October 22, you will receive the drafts from all of the groups so that you will have a chance to review them prior to the workshop to help facilitate discussion and make any comments that might relate to both your topic area and other topic areas.

Ms. Goring: Great.

Dr. Turnbull: Good.

Dr. Burton-Hoyle: So, any further questions?

Dr. Baden: Sorry -- this is Elizabeth Baden again. Just a reminder to the group that one thing that the Co-Chairs of the Subcommittee as a whole have asked is for each group to address disparities issues. So any information that you might have that would pertain to access to family support or any data that you're aware of on particular issues that minority families might face in this area would be very useful to the Committee.

[Pause]

Dr. Burton-Hoyle: Okay.

[Pause]

Well, if there's nothing else, any more

comments or questions? I think does everybody have enough to get going?

Dr. Dykens: Yes.

Ms. Goring: Yes.

Dr. Burton-Hoyle: Okay, so thank you so much. Thank you so much for being participants in this and guiding us.

Dr. Dykens: Thank you.

Ms. Singer: Thank you.

Dr. Burton-Hoyle: And we'll be in touch. Thank you all so much.

Dr. Ball: Thank you.

Dr. Dykens: Take care.

Dr. Law: Bye.

Dr. Burton-Hoyle: Bye.

(Whereupon, the conference call of the Strategic Plan for Question 5 and 6 Planning Group for Family and Support has adjourned.)