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INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 7 – Question 7 – What other Infrastructure and Surveillance Needs Must Be Met?

Conference Call 3

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PROCEEDINGS:

DR. KAREN MOWRER: Thank you. So welcome to our chair working group members and members of the public listening in the day. This is the third conference call of the IACC's Strategic Plan Update Working Group for Question 7, what other infrastructure and surveillance needs must be met.

I’m Dr. Karen Mowrer. I’m a Health Science Policy Analyst in the Office of Autism Research Coordination. The Director of our office Dr. Susan Daniels is unfortunately under the weather today and unable to speak very much so we thought it was important that the working group continue with work so I’ll be walking us through the agenda today. Dr. Daniels is going to be listening in and following the discussion on today’s call. She just was worried about her voice and was not feeling like she could do the speaking required to walk through the agenda.

So to go ahead and start I’ll go ahead and take a roll call first off. So if you could just indicate if you're on the line. Alison Singer?

MS. ALISON SINGER: I’m here.

DR. MOWRER: Thanks. Daisy Christiansen?

DR. DAISY CHRISTIANSEN:Yes I’m here.

DR. MOWRER: Thanks. Samantha Crane? David Mandell? Robert Ring? No? Adriana DiMartino?

DR. ADRIANA DIMARTINO: Here.

DR. MOWRER: Thank you. Maureen Durkin? Michelle Freud?

DR. MICHELLE FREUND: Here.

DR. MOWRER: Dan Hall?

MR. DAN HALL: Yes present.

DR. MOWRER: Thank you. Robin Harwood? Paul Lipkin? He's not going to join us. Gretchen Navidi?

MS. GRETCHEN NAVIDI: Present.

DR. MOWRER: Thank you. (Jessica Raft)?

MS. JESSICA RAST: I’m here.

DR. MOWRER: Thank you. Catherine Rice? Michael Rosanoff?

MR. MICHAEL ROSANOFF: Here. Thank you.

DR. MOWRER: Thank you. And Andy Shih? All right so we had a very productive discussion on our last two conference calls with this group and so you should have seen in the materials that were sent in advance of the call we’ve included notes from the previous two calls to jog your memory about those discussions as well as an outline of topics which was included which we'll discuss next.

As you can see the outline is really just sort of a rough list of topics organized into the three overall topic buckets you had discussed on the last call which made it, you know, very easy to organize. I think we all agreed that we liked that organization. But if you can take a look at that outline now I can walk us through it quickly. So we had the first bucket, develop the bio repository infrastructure. And that included brain banking such as the Autism Brain Net and the NIH Neuro Bio Bank and that also included other bio repository systems that collect fibroblast, blood, saliva and other tissue samples such as the repository NIMH and (Agree) Resource.

The second bucket we discussed was developing the data infrastructure. And that includes surveillance and the various networks and studies focusing on that question, databanks and especially regarding data sharing. And that included NDAR as well as the genetics and genomics databanks. And there was an issue raised on not only in this working group but in the Question 3 working group about the need for stronger efforts to avoid resequencing the same individuals by encouraging more data sharing and transparency.

And there was also the discussion of building cohorts and adapting surveys to better collect data to facilitate sharing as well. And that included a couple of the surveys, the IAN network and then standardization of measures. And then the third bucket we had was developing the human infrastructure to support research and service delivery. And under that we included training and workforce development efforts, collaboration both in the US and internationally, the dissemination of science and using technology to enhance dissemination and then efforts to educate the public about autism services, best practices and as well as educating the public about the importance of research participation.

So this outline is by no means set in stone. We wanted to have it to reflect the discussion that happened. It can certainly be revised reorganized and we want to open it up for discussion now. If you have any other topics you feel are missing or should be organized in a different way we'd like to hear your feedback on that.

MS. NAVIDI: Hi. This is Gretchen. First of all thank you for doing all of this work. I’m not sure who really synthesized all this but I think this is really capturing what we’ve discussed for the most part. I had a couple of comments if you don’t mind. And some of them I don’t know if we want to consider some kind of for lack of a better term cross cutting bucket. I was thinking along the lines of how we would want to promote linkages both within and across infrastructures and registries. And I see that sort of as a way to capture this avoidance of resequencing the same individual. That's just one element of it. But I think the providing some kind of cross cutting category to link all of these together might be something that we could discuss.

DR. MOWRER: Any other thoughts on that?

DR. FREUND: This is Michelle Freund. I agree. I think that's an important thing that we should do and would save duplication of effort.

DR. MOWRER: Other comments on the outline?

((Crosstalk))

DR. DIMARTINO: Okay go ahead. This is Adriana DiMartino. Sorry I interrupted someone trying to…

UNKNOWN FEMALE SPEAKER: Go ahead.

DR. DIMARTINO: Okay this is Adriana DiMartino and I'm sorry I could not attend the prior two calls so I was just wondering in what ways was the data sharing effort articulated if there was time to discuss about this? Obviously I'm heavily involved in data sharing particularly with the effort that we beside the NDAR and being in supportive of NDAR but have been leading the autism brain imaging data exchange and there are lots of issues and challenges and realities related to data sharing. So when we talk about the promoting data sharing I was just - there are several things that need to be considered and I was wondering whether this topic was unpacked in details?

DR. MOWRER: I think we did have a robust discussion about it but now is certainly appropriate time to mention some of your thoughts, you know, in case those weren't covered.

DR. DIMARTINO: Okay I - now or later?

DR. MOWRER: Now is fine.

DR. DIMARTINO: Okay so well one thing obviously everybody likes the idea of being in that in share data but it's very hard. I can tell you that there are many colleagues out there who want to share the data and have shared the data but there are also many colleagues who felt it there wasn't a good timing for them to share the data.

As a result Abide has given data promptly and timely available for the scientific community but these data not necessarily - many data are not available in NDAR and that one of the things I noticed that frustrates me is that there are so many projects there in NDAR and many colleagues don't feel comfortable to share their - for example they share their clinical data. They don't share the imaging data.

So I know that this is a delicate topic and I understand the view of some colleagues to feel the need to protect the scientific productivity. But I'm wondering what is the explicit policy of NDAR about releasing the data, timeline for releasing publicly the data? I feel that it's nice to respect and it's good to respect the need of scientists to have the time to analyze their data before being so-called scooped. But I also think there should be some monitoring on how long does it take for a lab to publish. And if that timeline is not met ten the data should be released and should not be kept in a lab for five years, seven years, ten years or forever.

MR. HALL: I probably can speak to that topic. Essentially for all human subjects projects we have very precise data sharing language included into the terms of award for NIH funded autism research. The data is expected to be shared at the end of the funding as well as program and investigator agreement over the course of the project. So demographic information is shared early and often typically. And then analyze data is shared either at the end of the project or at time of publication.

We’ve implemented new technology to allow records to be shared specific to in an aim so that if your first aim you publish on a cohort of individuals that are say 3 years old we can share just those aims or that information precisely at time of award. And we’ve put that in to all of our well, you know, into all the NIH terms. So, you know, I think we have a pretty good perspective, you know, policy for that data to be shared, you know, appropriately given the respect for doing the analysis. So once the analysis is done and the paper's published we would expect that data to be shared. And if it’s not shared, you know, certainly we invite inquiries into the NIH and then can share all the investigator data if some of that information's been published and is still embargoed.

MS. NAVIDI: Hi Adriana. This is Gretchen.

DR. DIMARTINO: Yes.

MS. NAVIDI: So after Dan has given an explanation about how we sort of approached things are you thinking that there needs to be more effort efforts implemented that - I think of the way to describe this, to enforce or encourage people to share data? Are you seeing that there are gaps in what is expected and what’s being done and if you’re thinking that we could think about ways to encourage people more?

DR. DIMARTINO: Yes so there are two immediate thoughts. One is the embargo I think that it should be again I am not against the embargo I understand the colleagues. It happens also to me so I understand what happened that you spend so much time collecting the data then the grant finishes, then you no longer have funds and you still have to analyze all the data so I understand. I don't want to - I don't blame those colleagues who feel - I do at the same time believe that there is enough scientific discoveries for everybody but that's another - anyway. I would try to have a more concrete determinant of embargo because I know of many labs who have data partly in NDAR and not all the data, not the images for example, the raw data images for more than beyond the timeline of when the grant finishes. So if there could be a way to follow the embargo timelines and follow-up with the PIs and ask what is your timeline for the publication of XY?

I don't I - maybe I'm wrong, maybe I missed this but I wasn't under the impression that there is such a strict follow-up on those aspects for the data in NDAR. And then the other thing but I don't know if it has something to do - if it can be done here is also about the problem of data sharing is big because institutions, many institutions do not support, do not promote a scientist for having shared the data. Actually I do have in my mental - in my (unintelligible) committee I am pushed to publish as with as many (altos) as possible. And I am said one of those who publish many (altos). So, you know, this is probably going beyond the - this strategy plan committee.

But in terms of data sharing if we can do something that helps that makes it easy for the scientist to share the data and so don't feel that NDAR is obstruct - is disturbing the productivity that it would be nice if we can think about something. I don't know - I think already NIMH by pushing for data sharing is making it easy but it's still not part of what institutions see as critical for promotion.

MS. NAVIDI: Right.

DR. DIMARTINO: And before, the junior scientists are afraid and then the depression, you know, it’s a vicious circle.

MS. NAVIDI: Right. So I mean maybe that's sort of where I was going with the whole idea of crosscutting themes or whatever you want to call them. We do have somethings in place here that, you know, we have the very clear timeline for when data are expected to be submitted and shared, you know, down to splitting it out by clinical, individual clinical assessment imaging genomics, et cetera.

And you do have the NDA study concept. And one of the sort of carrots that we put out there is that we provide a digital object identifier for each one of those studies. So a publication ends up getting to DLIs. Recently there’s been talk about this concept of an F index which is similar to the H index I think it is that publications have, you know, ways to encourage more data sharing, you know, to get more feathers in your cap and, you know, things along those lines. So maybe what I’m hearing you say is that there could be a more organized effort to provide encouragement and reward for - to promote more data sharing in a more timely manner. Is that what I’m hearing you say?

DR. DIMARTINO: Yes, yes, yes.

MS. NAVIDI: So…

DR. DIMARTINO: It again it’s not just about uploading the data because now again after many - and autism researchers are well educated about the fact that it needs to be done they complain. But they do it through NDAR because they have to do it. It’s more about the idea once the data uploaded when can they be open to the scientific community?

MS. NAVIDI: Right, right.

DR. DIMARTINO: So two different - two steps.

MS. NAVIDI: Yes so I don’t know. I mean are we allowed to have something that’s sort of - I’m keep using this term crosscutting. Maybe that’s not accurate but, you know, ways to link all the information ways to encourage more, you know, more timely releasing of data to provide data to junior investigators to help them get a leg up, you know, which sort of goes to this third bucket that we’ve identified, you know, to expand in efforts and encourage reuse of data.

DR. MOWRER: Yes. This is Karen. I think that that’s appropriate. We just I think will want to have the working group think about how we want to weave that in the chapter in terms of, you know, you'll have a narrative portion of the chapter where you, you know, can write, you know, this type these types of thoughts and whether you want to sort of include that within each of the buckets or, you know, have a separate section that addresses that is, you know, sort of has to do with the outline and how we organize it. But, you know, some of those recommendations could speak to the as you'll remember the plan this time around includes not only research but services and policies so it could speak to some of the policy recommendations that might encourage more of this crosscutting. But if want to see if anyone has any other topics at this time for the outline otherwise I think I want to move on to the discussion of the objectives themselves which is related very similar to the outline as you can see.

DR. CHRISTIANSEN: Hi. This is Daisy Christiansen at CDC. I mean I would just have an organizational comment.

DR. MOWRER: Okay.

DR. CHRISTIANSEN: I would move the National Survey of Children’s Health and the National Health Interview Survey from the third bullet under develop the data infrastructure up to the first bullet under Surveillance. I mean these are established government surveys that do collect information on prevalence. And in the case of the National Survey of Children’s Health characteristics of ASD. And I think that they are should be considered as part of the overall approach to surveillance of ASD. You know, we at CDC are looking at, you know, we consider that the information that's contributed by the Adam Network and by the surveys is complementary and we're currently taking a look at the best way to use information from these different modalities of conducting ASD surveillance to the best provide information to the public and to stakeholders.

DR. MOWRER: Okay, anything else? Okay well let’s move on to talk specifically about the strategic plan objectives you all will be crafting. So you’ll remember that each working group is - the goal is to identify three objectives. And again you’ve made this sort of easy by identifying the three general buckets.

And so you can see on the agenda again we’ve just written very simple phrases there, develop the bio repository structure, develop the data infrastructure and develop the human infrastructure for research and services. So we can talk about each one here now and how you might want to word that or what all you would like included under that. Remember that for each objective you want to keep it relatively simple, the objective itself. And underneath we can include examples of projects or efforts that would be responsive to that objective. And then you'll also have the narrative of the chapter to go into more detail to make sure, you know, you can hit on all the points you would like. But I - let’s jump right in and start with the develop the bio repository structure.

MR. HALL: My initial comment here is that this, you know, the this task which is develop the infrastructure isn't a task because the infrastructure is developed. So to me, you know, we're not breaking any ground here. All these things exist and the real challenge is integrate the bio repository infrastructure. And I think that was what Gretchen was alluding to earlier. If it's just develop it it's developed so you could take this off the list at this point.

DR. FREUND: Right so this is Michelle again. I just want to confirm that Dan's correct. The infrastructure for the neuro bio bank already exists, is very functional. I'm happy to provide any written comments about the neural bio bank but I don't know how to address the develop since it's done.

DR. MOWRER: Okay so what sorts of words would we want to use instead? I heard integrate?

DR. FREUND: We'd want to just provide the evidence that that infrastructure is existent and ready for people to use. People are currently using it with great effect. So I think we'd want to say we have achieved this aim although there's also Autism BrainNet and autism BrainNet and neural bio bank work together and we should continue to work together to have the resources in one place so that an investigator who's looking for postmortem tissue doesn't have to search in multiple places.

MR. HALL: Yes I agree with Michelle. I think if you just changed it from developed it to integrate the bio repository infrastructure that would provide the benefit that should be focused on in this next part of the strategic plan.

DR. MOWRER: So…

MS. SINGER: This is Alison. And I would just - I would ask whether you think that it’s fully developed and that you don’t need any more donations.

DR. FREUND: Oh we need we need tremendous numbers of donations Alison absolutely. So if there's …

MS. SINGER: (Unintelligible).

((Crosstalk))

DR. FREUND: …to, you know…

MS. SINGER: …(unintelligible) mean so we have additional people to donate tissue. So I didn’t feel very strongly that we should keep the words develop otherwise…

DR. FREUND: We need to populate but the infrastructure exists. We have sites. We have capacity but, we don’t have enough donors. So I think the word is to increase the outreach to increase awareness and registration but the infrastructure exists.

MS. NAVIDI: So it’s more of an improvement or an enhancement than a development. If you think of development as starting from zero and getting to something…

DR. FREUND: Well we continue to develop, we continue to improve. There's no doubt. We cover a lot of different disorders as well. And the program continues to change over time but the infrastructure if I interpret the word infrastructure the capacity to be able to take postmortem brains exists.

DR. DIMARTINO: Can it be worded as promote promoting growth of the existing bio repository infrastructures?

DR. FREUND: I think that would be great.

MS. NAVIDI: Yes. And so that would include increasing the number of donations that would include integrating each of the already existing infrastructures.

DR. FREUND: And including distribution of the tissue which is the most important thing.

MS. NAVIDI: Yes.

DR. DIMARTINO: Can I ask of what if integration what is how are these women reported integrated right now?

DR. FREUND: They're integrated on paper. There is an agreement that we will work together to collect the highest quality tissues and work together to distribute them to researchers. The NIH neural bio bank has an inventory that anyone can search and requests are made through that inventory for those tissues. At some point we discussed with Autism BrainNet to make their inventory available through the same mechanism. But I would say that it’s not gone beyond that at this point.

MS. NAVIDI: I mean similar to the way that NDAR works we’ve federated with EN and other repositories it would be great if a person could go into one interface, one portal if you will and search all of these different tissue repositories at one time. So that would certainly be an improvement, an enhancement of growing of the infrastructure that currently exists.

DR. MOWRER: Any other thoughts on that wording of promoting growth or enhancing or promoting additional development?

MR. HALL: Yes so I guess in summary it's promote the growth and integrate the infrastructure and that should be done not in piece parts but as a whole.

DR. MOWRER: Okay and we can also as a reminder as you all think about this more you can certainly email Susan and Alison additional thoughts about the wording on each of these. It doesn’t have to be set in stone today. So then maybe we should move on to the second objective. So maybe some of the same questions around data infrastructure then would exist whether we want to talk about developing that further or what the needs are there. Thinking towards what are the next steps is really what we want to - and the needs is really what we want to target in the strategic plans.

MS. NAVIDI: Yes I think we can fall back on this - same place that Michelle made at the beginning of our first bucket and that is to my knowledge all of these systems or infrastructures are already developed and we're - what we want to do is make sure that they’re all linked together and grown in a similar fashion as opposed to, you know, expanding the width by creating more and more databases or whatever, you know, just linking everything together making sure that surveillance information is coming into NDAR or, you know, there’s standardization across the board as much as possible in the type of measures and data that’s being collected within surveillance and research and, you know, service delivery, et cetera. So…

((Crosstalk))

DR. FREUND: So I'm a little bit unclear about how the surveillance information would come into NDAR. So the surveillance information from say the Adam Network or from the surveys. Can you elaborate a little bit about what you mean?

MS. NAVIDI: Well can - maybe I’m not clear on exactly what surveillance information is collected. But, you know, the way that NDAR is set up we can really pull in almost any kind of data. So maybe you give me a better idea of what the surveillance data actually looks like?

DR. FREUND: Right. So I mean the surveillance data looks like I mean for the out of network the surveillance data looks like, you know, the number of I mean in basic terms of prevalence it's a numerator and denominator of children who are, you know, determined to be ASD surveillance cases by our methodology across the population under surveillance in the ADDM Network. And then for the surveys again it's the, you know, it's the sort of, you know, based on parent response of, you know, whether the child had been diagnosed with an autism sector disorder. So those data are not - I mean there's nothing else attached to them other than, you know, sort of ASD status.

MS. NAVIDI: Okay. I get that. I don't know and sort of on the fence here. And so in my mind it's similar to the, you know, taking blood or saliva and - or tissue and putting it in a repository but may be a GUID could be associated with that individual and then if they show up in other studies we can get a clearer picture of that individual as they move through their life. But I…

DR. FREUND: Right. That's something, okay so that's something that would need I mean that's not something that is part of our protocol right now and so that's something that would need to be sort of under discussion in terms of the procedures for confidentiality, et cetera.

DR. DIMARTINO: This is Adriana again. I also think that the best way to integrate all these databases would be an NDAR GUID. I don't know all about the issue of surveillance per se. I'm not necessarily pro a single database because different database structures can provide different information as long as they're not redundant. But the NDAR GUID would link all these different efforts easily.

MS. NAVIDI: Yes.

MS. SINGER: Well this is Alison. I just want to make a general point that I think as we're talking we need to keep in mind that the audience for the strategic plan is the Congress. And if we start to say things like the infrastructure that we need for autism research is built we no longer need to develop it, we just need to federate it and populated then you’re risking a cut in funds for these projects. I think what we have to emphasize is that we’ve invested in building them and now we need to really grow them and develop them. But some of the terms that I’m hearing are very concerning from the standpoint of those of us who go to Congress and lobby for these funds.

DR. FREUND: But we need to be specific then Alison what exactly is needed. I’m perfectly happy to read and contribute to the actual document but if we say we need to build an infrastructure then we're ignoring what we’ve done so far. So if we have…

((Crosstalk))

DR. FREUND: ...specific plans of what exactly is needed we should put it in there.

MS. SINGER: Here’s a section of the document that talks about what’s been accomplished in the last few years and we should certainly talk about infrastructure that’s been built and how it’s being used and how it’s led to successful studies. But I think we have to talk about how those - how that infrastructure needs to be further developed and that additional infrastructure may be needed.

So for example in the last year new databases have been launched like the Autism Sisters Project Database, the Autism Sequencing Consortium has grown and taken - I mean there’s still - it really concerns me to say everything that we need from an infrastructure standpoint is accomplished. I think we should be bigger…

Dr. FREUND: I don’t think that’s what we’re saying though. We’re not saying it’s done and complete.

MR. HALL: Yes I…

DR. FREUND: But these databases and these autism sequencing consortium they work together and so what Gretchen’s point at the very beginning of the call was that we need to focus on how we can integrate all of the different efforts to make the most sense instead of dividing into a bunch of different avenues.

MS. NAVIDI: Yes I think we’re saying the same things that, you know…

MR. HALL: Yes. I think we just have a different understanding of what the word develop is. You know, it's really extend, leverage, you know, use those words because develop is, you know, it’s, you know, it’s just a poor word for what we're - what we really need to do next which is, you know, promote, extend, enhance, you know, integrate and so, you know, we just need to be clear on what these next steps are because, you know, the way I read it then, you know, maybe I’m just interpreting it wrong and I’m not, you know, certainly Congress but, you know, the ADDM Network exists. Now, you know, if it needs - if there needs to be surveillance for adults or something like that that should be put in here but actual infrastructure exists...

MS. SINGER: You don’t think it would be beneficial to have more sites in the ADDM Network?

MR. HALL: Yes but that’s what it should say. I mean I think the - if you’re using this word develop that’s just kind of a generic term, you know, we need to be very precise on that, you know, extend the Adam Network to include, you know, 20 additional sites and do an adult cohort it’s absolutely applicable but it should be stated here.

MR. ROSANOFF: This is Michael from Autism Speaks State but I’d also like to add that, you know, if we're getting to specifics about improving the ADDM Network or enhancing its reach I think we should also talk about the enhancement of networks methodology. We don’t have the results of the South Carolina Prevalence Study at this time but, you know, that the reason why that project was supported was to overcome some of the challenges of relying strictly on medical and education records mostly to (unintelligible) on prevalence but to understand why we might be missing some individuals and ensuring that they have adequate access to services.

DR. MOWRER: And this is Karen. This is just a reminder that with the objectives, you know, it’s okay to keep the objective a little broad and, you know, not very specific although you do want to be precise in your wording I understand. But remember we'll have those examples under each objective where you can sort of further define what you mean in terms of the terminology in the objective. So some of those projects there were just mentioned you could, you know, you could include those as the examples under the objective. Anything else on data infrastructure objectives?

(No response.)

DR. MOWRER: So again is the wording for that objective going to be more about enhancing and linking and maybe building upon what we have?

MS. NAVIDI: Right. Can I…

DR. MOWRER: Improve.

MR. HALL: Yes. Oh yes my...

MS. NAVIDI: ...move into the third bullet there that about building virtual courts? I see we’ve got absent devices in parentheses and if I recall correctly from our previous conversations we were talking about wearables, correct?

DR. MOWRER: That may have come up.

MS. NAVIDI: I don’t know if anybody has an example of what might be a more specific objective related to that. Anybody have any thoughts?

DR. MOWRER: And again I think that can be flushed out in terms of the examples that would go along with that objective.

MS. NAVIDI: Okay.

DR. MOWRER: Okay maybe we should move to the third objective then which would be around human infrastructure for research and services. But I realize based on the discussion there was a lot sort of included under that. So we might want to think about how to best capture the full range in that objective if that’s what you all decide because that included not just training but also collaboration, international collaboration and dissemination and outreach to the public.

So here we have the word develop again. And how do we feel about next steps for that infrastructure in terms of what we’re doing? Does that need to be developed more or enhanced more? Where are we now with that and what’s the next step and the really the critical needs that are needed?

MS. NAVIDI: So can I clarify so now that we’ve sort of got more discussion in place of about how we want these larger objectives or am I using the right terminology categories we're going to be filling them in with more specific objectives? Is that what the next step is?

DR. MOWRER: No so we need to start thinking about how to develop and word the three broad objectives that the working group will be identifying.

MS. NAVIDI: Okay.

DR. MOWRER: And then after sort of that step which is what we're talking about now later as people start flushing out each topic under the objective and the chapter is being drafted we can write examples underneath each broad - underneath each broad objective of projects that would be responsive to the broad objective.

MS. NAVIDI: I see. Okay and it - so it's the project that has sort of targeted dollar amounts associated with them am I right?

DR. MOWRER: So we're actually still in discussion with the full committee about the - how to satisfy the budgetary requirement recommendation that's mandated in the law. So there's a number of different ways that that could be addressed and the committee hasn't come to us a decision on how that will be done yet. So it won't necessarily be budget recommendations by project but since we're having broader objectives we thought having a little narrative or, you know, just examples of projects would help further fill in details if that makes sense.

MS. NAVIDI: Thank you.

MR. ROSANOFF: This is Michael. I would push just reading the bullet point there. I'd push to separate out dissemination of science and the including use of technology to enhance dissemination pieces. I would call attention to the dissemination objective a little bit more fully. I know this isn't a place to get descriptive but, you know, one of the challenges or and opportunities is, you know, to better train the investigators themselves to be, you know, the best advocates for their work specifically being able to better communicate the outcomes of their research to families but also to those who are the funders of research. So opportunities in training specifically in science communication I think is really important here. It would help everyone better understand the importance of the work, the outcomes of the work that applicability of those findings immediately and in the future. And, you know, frankly there aren't enough, you know, great scientific communicators out there in autism research. I think if we could enhance this it could really prove our efforts and our cause.

DR. MOWRER: So maybe in that objective we can think about including, you know, some sort of wording about human infrastructure for research services and scientific communication or outreach?

MS. NAVIDI: I think dissemination is a good word.

DR. MOWRER: Any other thoughts on the third area in the broad objective? Okay so we'll move on to discussion of the aspirational goal in title so we'll start with aspirational goal which based on the previous goal and the revision that was discussed on the last call we now have develop and support infrastructure and surveillance systems that advance the speed, efficacy and dissemination of ASD research and services. And the and services that the end is what has been proposed be added by the working group during the last call. So we wanted to check in on this call to see how you feel about this addition now and or if you have other thoughts on this in light of the additional discussion we've had.

DR. CATHERINE RICE: Hello can you hear me?

DR. MOWRER: Yes.

DR. RICE: Oh hi. This is Cathy Rice. Sorry I’ve called in a couple times and it just keeps me on the - on muted but you can finally hear me so I'm - I’ve been talking to myself. I definitely agree with that adding services and I did have a comment back about the human infrastructure to support research and service delivery.

And in that those are two very important human infrastructure but very different in many ways and that are really suggest that we pull that apart because supporting the research infrastructure is going to be very different than how we enhance the service delivery infrastructure and that the focus really should be on community-based service delivery versus I think as has been done in the past is focusing much more on the research and clinical sites university or specialty based sites with less focus on the actual community-based intervention. And I think we need to really highlight that need.

DR. MOWRER: Okay thanks.

MS. NAVIDI: So I think that given a large part of our discussion around the words develop and enhance and implement or expand whatever I think in terms of an aspirational goal I might be talked away from this position but I actually like including the word develop because there could be other things that we’ve not worked on yet. But I’d like to add in, you know, enhance or whatever the other word is that we’re going to end up using to sort of give a nod to what we’ve already developed in the need for improving and enhancing those. Does that make sense?

DR. MOWRER: Yes one option I guess would be to maybe replace support but if you like that word too I guess we could include a third word there.

MS. NAVIDI: Yes. I actually kind of like support so I don’t know maybe develop, enhance and support.

DR. FREUND: I agree. I think support is really important to include.

DR. MOWRER: Okay. Anything else on the goal?

(No response.)

DR. MOWRER: Okay and then we can also take this opportunity to revisit the title of the chapter which you want to keep in mind that needs to still be from a consumer perspective so what other infrastructure and surveillance needs must be met is the current title. And in our last discussion it was proposed that we change it to something such as how do we leverage the infrastructure system to meet the needs of the ASD community. And that was in large part to better reflect and focus on the ASD community rather than specifically sound more focused on the research community. So how do people like that and do we have other thoughts or revisions we want to discuss for the title?

MS. SINGER: So my concern with this is that -- this is Alison -- is that by saying how do we leverage the infrastructure implies that the infrastructure's complete and need only be taken advantage of. I think we need to add some additional words in there like continue to build, expand, enhance.

DR. MOWRER: Okay.

MS. NAVIDI: I agree.

DR. MOWRER: It sounds like people are in agreement on that. Any other thoughts on the title? Okay any other comments in general that maybe someone who was in the listen-only mode who is a speaker who now can be heard have any comments from previously in the conversation?

DR. RICE: Just a comment back on the discussion about developing and verses utilizing the data infrastructure that I think when talking about the objectives under there that it’s clear that part of the utilization is providing support to really analyze and make the most out of the existing data sets. So just really emphasizing the…

((Crosstalk))

DR. RICE: …developing the opportunity.

DR. DIMARTINO: Yes.

DR. MOWRER: Okay great. So what the next steps will be will Susan will be in touch with Alison and she’ll work with you to finalize the outline. We'll reflect some of the changes that were recommended during this call and come up with a plan for drafting the chapter. And this will likely include recruiting members from the working group to help draft certain sections especially in their areas of expertise.

So if you have a topic that’s in the outline that you really would like to take the lead on drafting please let us know, let Susan and Alison know so that they can take that into account when they are planning out how the chapter will be drafted. Then again if you think about any of these objectives the aspiration goal or title a little more and have some thoughts on it or want to propose some wording please feel free to email that as well.

And the plan is that once the first draft is done it will be circulated to the - all of the members of the working group so you'll have an opportunity to see the draft and propose edits and help work on that. And the plan is hopefully to have a draft, a complete draft ready for the next ICC full committee meeting which is scheduled for January 13 and there will be a discussion of the draft that we have put together by the full committee at that time.

So unless there's anything else that people want to bring up we will adjourn. And we thank you very much for participating and all of your efforts and for everyone listening in.

(Whereupon, the conference call was adjourned.)