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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 2

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10:30a.m.

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PROCEEDINGS:

DR. SUSAN DANIELS: Thank you. Welcome to everyone to this conference call number 2 of the IACC strategic plan update working group for question seven on the topic of what other infrastructure and surveillance needs must be met.

The IACC stands for the Interagency Autism Coordinating Committee, which is managed through my office, which is the Office of Autism Research Coordination at the National Institutes of Health.

So we welcome all the public - members of the public who are listening in, as well as the members of this working group and our chair, Alison Singer. I'd like to do a roll call to make sure that everybody who's listening to this call knows who's on the phone.

So after I speak your name, if you would also just provide a brief introduction of who you are -- just, like, one or two lines -- that would be really helpful. Thanks. So we'll start with Alison Singer.

MS. ALISON SINGER: Hi. I'm Alison Singer. I'm the President of the Autism Science Foundation, and I'm the mother of a 19-year-old daughter with autism as well as the legal guardian of my older brother, who's also diagnosed with autism. And I am a member of the IACC.

DR. DANIELS: Thank you. Daisy Christensen?

DR. DAISY CHRISTENSEN: Hi. I'm a Team Lead for surveillance activities at the Centers for Disease Control and Prevention in the developmental disabilities branch, where we do our autism surveillance projects. And I'm the mother of a 12-year-old boy with autism.

DR. DANIELS: Thank you. Is Samantha Crane on the line? So next is Robert Ring.

DR. ROBERT RING: Good morning everyone. I'm Rob Ring. I'm a neuroscientist by training. I work currently as a consultant, but previously was the Chief Science Officer at Autism Speaks, and before that headed up the autism unit at Pfizer.

DR. DANIELS: Thank you. Adriana DiMartino? Maureen Durkin? Michelle Freund is not going to be able to join us. Dan Hall?

MR. DAN HALL: Yes. My name is Dan Hall. I'm the Manager of the NIMH data archive, which includes the National Database for Autism Research. And I am also a father of a 19-year-old minimally verbal son with autism.

DR. DANIELS: Thank you. Romy Azuine?

DR. ROMY AZUINE: Hi good morning. I am Romy Azuine. I have a doctorate in public health, and I am the Division Director for the Division of Research in the Office of Epidemiology and Research at the Health Resources and Services Administration. Our office oversees the research programs for autism in our agency, and I am here in the place of Robin who is off sick today.

DR. DANIELS: Thank you. Paul Lipkin?

DR. PAUL LIPKIN: Hi I'm Paul Lipkin. I'm a development pediatrician at the Kennedy Krieger Institute. I'm a Director of the Interactive Autism Network, also at the institute, and have been an Assistant Professor of pediatrics at Johns Hopkins.

DR. DANIELS: Thank you. Gretchen Navidi?

MS. GRETCHEN NAVIDI: Hi. I'm Gretchen Navidi. I work at the National Institute of Mental Health on the NDAR project, which is the National Database for Autism Research, which is part of the

NIMH Data Archives. And I'm also the mother of a 16-year-old son with autism.

DR. DANIELS: Thank you. Jessica Rast?

MS. JESSICA RAST: Hi I'm Jessica. I work at the A.J. Drexel Autism Institute and I manage our National Autism Data Center here. I also work on one of our big projects, the National Autism Indicators Report series.

DR. DANIELS: Thank you. Cathy Rice is not going to be able to join us today. Michael Rosanoff?

MR. MICHAEL ROSANOFF: Hi everyone. My name is Michael Rosanoff. I'm the Director for Public Health Research at Autism Speaks. I've been with the organization for almost ten years. I'm an epidemiologist by training and also a family member of an affected individual.

DR. DANIELS: Okay thank you. Andy Shih? All right so we have everybody on the line. I don't believe we had any major follow-up from call one that we need to discuss.

We did some work offline just double-checking to make sure that the Autism Speaks portfolio was in line in terms of the portfolio analysis. And we checked on that with Autism Speaks and they confirmed that everything was fine with that. So that was the only follow-up I had from the previous call.

So the first thing I'd like to do today is to talk about the public comments that were received through a request for public comment that the Interagency Autism Coordinating Committee put out over the summer to collect input from the public about the seven areas of the strategic plan, and what they felt were the most significant needs and concerns and ideas that they have for the strategic plan.

And this will play into the work we're going to be doing today to try to gather information on what progress has been made and what needs and opportunities we need to address in the strategic plan, which will be the basis for the writing work that you're going to do on this chapter.

So I'd like to turn your attention to a list of themes that our office pulled from the public comments that came in. And we tried to divide this into a few major themes, but you also might have seen other themes that ran throughout the comments, that there were some comments on infrastructure and services.

There were some comments on collaboration and coordination among service providers. Also collaboration and coordination in research, research dissemination and translation of research into practice, workforce development, ASD surveillance needs, research including infrastructure such as databases and clinical trial policies to enhance research, the inclusion of people on the autism spectrum in planning research. Some comments that suggested that the current priorities that are covered in the strategic plan are appropriate and some comments about prioritizing services and interventions above research.

So those were some of the themes that we saw in there, but we wanted to get your thoughts about what you saw in the public comments and any important topics that stood out to you that you think that we need to consider in doing the strategic plan update. So do you all have any thoughts about that? Any comments on this public comment?

MS. NAVIDI: Hi Susan, this is Gretchen. I think that - I think they're actually very good comments and themes that have emerged from the public comment. And they seem to be pretty much in line with what we've been working through for the past few years since this question's been part of the strategic plan, so I don't see anything that jumps out as inappropriate. I think these are all actually very appropriate.

DR. LIPKIN: This is Paul Lipkin.

DR. DANIELS: Yes?

DR. LIPKIN: You know, I think through our network we have a lot of contact with families and, you know, I think these are the kinds of stories and things that we've been hearing as well.

DR. DANIELS: Thanks. That's helpful to know. Is there anything that you've been getting in terms of input to IAN that's different from what you see here in terms of what's needed for infrastructure to support research?

DR. LIPKIN: Well, you know, I think there's an ongoing call for things directed towards adults with autism. You know, so I think as we talk about infrastructure and services that one probably needs to think about an age continuum in some way.

And of course the children don't suddenly become adults, so there's that whole transition from adolescence into young adulthood and then full adulthood. So I think, you know, we're hearing parents having difficulty through all those age transitions.

DR. DANIELS: And so we collected information on adults and the transition period, and we categorized those to question six. But there may be some ways that that would influence what we're doing here in terms of talking about infrastructure, so appreciate that comment. Anything else that others wanted to highlight about the public comment?

(No response.)

DR. DANIELS: So we'll also have a chance for the Interagency Autism Coordinating Committee to look at these comments before their next meeting, which is taking place on October 26. And so those of you who are members of the IACC will have a chance to look at this again, and the committee will also consider this information and bring up any comments that we need to make sure we incorporate into the strategic plan. So thank you for having a look at those.

Next I'd like to turn your attention to a list of topics that our team put together that cover some of the things that were included in the previous strategic plans and strategic plan updates, as well as a couple of newer items that have been suggested by the committee. And so we wanted to go over this general list of topics and see if there's anything that you feel needs to be added, or if there are any changes we might want to make. Not saying that, you know, what you say on this call today is the end of that, but it's just to get an idea of the scope.

So in the past, the chapter seven has included information about bio banking and brain tissue collection to some extent. And in question two we previously had some information about brain tissue collection, although it might make sense to just consolidate it all in question seven since most of the information about bio banking is here. And some specific areas that we covered previously were the Autism BrainNet, the NIH NeuroBioBank, the (ATP) and the NIMH Repository. Is there anything else, kind of, in that category that we should make sure that we address?

MS. SINGER: Can I - this is Alison. So the way I started thinking about this based on our conversation on our last call and just reviewing the notes that I made on our last call, and being a crazy person who needs everything to be organized, I started to think about some - putting these ideas into different buckets as a way to try to organize the conversation. Because last time, you know, we were talking about gene banking and then workforce and then surveillance. So the way I started thinking about organizing this list was in three different buckets, as I said. The first one was developing the human infrastructure. The second was developing the data infrastructure. And the third was developing the biorepository infrastructure.

And I think all of these items that are on your list can actually fit nicely into one of those buckets. And I think it would just help to organize the conversation today if we could tackle them maybe in that way. So the way I was thinking of it, under human infrastructure, I included things like research training, workforce development, dissemination of science and efforts to educate the public, efforts to educate the public about the importance of their participation in research, and then global collaboration.

Under data infrastructure, I had surveillance, NDAR, AGRE, genetics and genomics databanks and IAN. And then under biorepository infrastructure, I had the brain banking and then other biorepositories like fibroblast, blood, saliva and other tissue collection. So it would just help me if we could go through them, sort of, in a logical order.

DR. DANIELS: I think that this makes a lot of sense. One thing I would - well I guess it could still be part of the human infrastructure. Something that we're - we've talked about changing in the strategic plan -- and we've already begun doing this -- is for each of the question areas, we're now going to have, for example, question one really address issues related to the workforce that's delivering services and screening and diagnosis.

And similarly, for interventions we're going to have some workforce issues directly in question four. And so we may not need to have all the workforce issues here in question seven. However, I know, Alison, that you had proposed doing something more on outreach and collaboration. I mean we had outreach before, but really talking about collaboration.

And something that our team threw into the mix here is talking about whether the IACC might be interested in expanding its thoughts to what's going on internationally, although the mandate of the IACC is domestic policy. But certainly the U.S. has to interact with other nations, so that's something that we potentially might add as a new thing to the strategic plan.

But in terms of research training and workforce, we can still talk about it here, but we may want to move some of that information to the other chapters. However, the rest of this human infrastructure, I think, makes a lot of sense here. We still have a lot of need for discussing dissemination of science and how to build these collaborations and networks. So does that sound like it would work?

MS. SINGER: To me - I don't know if you're asking me or the rest of the committee. It's...

DR. DANIELS: Anyone on the - in the group. But I think that these three buckets would definitely help organize it, and I think that they sound good. If others also feel the same way...

MS. NAVIDI: This is Gretchen...

DR. LIPKIN: This is Paul. I personally like that, and I think it's a way that the general public - it'll be much clearer for the general public as well in terms of their thinking about the efforts of the committee and NIH.

DR. DANIELS: Great.

DR. CHRISTENSEN: This is Daisy and yes, I agree.

MS. NAVIDI: This is Gretchen. I agree.

DR. DANIELS: Okay so we can do that. Since I didn't organize the notes myself this way before the call, I'll have to do a little bit of looking back and forth between some of the outlines that we have here. But maybe - so let's start as we just did with the biorepository infrastructure, which will include brain banking as well as other kinds of tissue banking.

In terms of particular items to highlight, we will probably want to talk about the Autism BrainNet, the NIH NeuroBioBank, the (ATP) and the NIMH Repository. Are there other major biorepositories we want to mention?

(No response.)

DR. DANIELS: Okay. So sounds like we may have those together. In terms of the data infrastructure piece - so I see - so you would have surveillance as a part of the data infrastructure, which is - that's fine. So with the databases and datasets that we need to discuss, we'll be talking about NDAR and AGRE.

Some issues that came up in other conversations with other groups were needs about access for researchers to education and services datasets -- which I'm sure that Jessica can comment on later as we're discussing that -- and increasing coordination between autism sequencing projects to prevent duplication and increasing research or access to data, which came up on a different call as well, so I think will fit in here.

I guess data sharing policies for genetics and genomics. And IAN will be part of the data infrastructure. Is there anything else that we will want to be thinking about in that area that wasn't mentioned?

DR. RING: Yes this is Rob here. I, you know, am thinking about, you know, the growing body of activity out there at the grassroots level where, you know, with each new, you know, genetic diagnosis being, you know, mapped into the autism spectrum, there's a - oftentimes a new community of activated parents that are organizing themselves around that genetic diagnosis.

And there are many of these who've actually, you know, grown to be larger than just grassroots -- you take the Phelan-McDermid Syndrome Foundation and other small groups like this. And like you see around the rare disease community, most of the activities that these smaller groups undertake right away is to build up these patient registries. And a lot of the organizing principles behind the registry are not unlike the different bins of resources and infrastructure we're talking about here, sub-serving a future improvement in clinical trial readiness for the field.

So you could really look at, you know, a lot of the activities across questions as really subordinate to a larger need to increase clinical trial readiness for the field. And readiness can be defined in - you know, from a regulatory point of view can be defined by a clinical trial network point of view, could be defined by the access to subjects or patients for research themselves.

And so registries themselves, whether or not they're being done at a small level in a small emerging foundation or they're being built out through massive projects like the Simons Foundation's SPARK Program or in, you know - as a result of programs like AGRE.

You know, I'm just wondering how we want to try to capture the need to look for solutions that begin to federate the data that is collected on patients that may not be, you know, associated with DNA or, you know, a particular layer of biological information, but it's just a point of connectivity -- a point of data connectivity, if you will -- with a population out there which collectively would be the future infrastructure for supporting research.

I don't know where to put this or how to talk about it, but I think patient registries of different sizes and looking to federate -- there's going to be an incredibly important thing to be talking about into the future.

DR. DANIELS: Dan or Gretchen, do you have any comments on that?

MR. HALL: Well we have done a fair amount of work related to that where the NDAR is - you know, has all of the NIH's research data, accepts some research data from a number of other funding institutions. And we are federated with the Simons Foundation and IAN and AGRE. So, you know, a lot of that work is out there. I mean certainly it can be expanded, but, you know, there is an infrastructure that does already exist.

MS. SINGER: This is Alison. I think the point that Rob is making, which is a really important one, is that these small, often parent-run groups are out there literally collecting skin fibroblast from families at their conferences. And they're building these registries that make them, as Dr. Insel used to say, sort of, "beaker-ready" for clinical trial.

And they are actively seeking researchers who want to use these registries. So I think that is a big change since the last time we wrote the strategic plan. So I - and I think it's going to be a major force in the field. So I'm in - definitely be in favor of adding that.

MS. NAVIDI: So this is Gretchen, and I think that's a great idea too, as long as we consider, sort of, an overarching theme, and that is regardless of what we put into this bucket, there needs to be linking mechanisms put into place. So I would just really advocate for linking mechanisms.

DR. DANIELS: Sorry, I couldn’t hear. What kind of mechanisms?

MS. NAVIDI: Linking.

DR. DANIELS: Linking mechanisms?

MS. NAVIDI: Yes. So for instance, the GUID would be a perfect example of that. Having, you know, certain information that allows us to link data regardless of where the data are reposited (sic), and including samples. So one of the things that we do with NDAR is we collect information on the location of any samples that have gone to any of the, you know, repositories so that the phenotype and sample data can be linked up for future results.

MR. HALL: As well as - if I can add onto that, is, you know, we've done a fair amount of work establishing autism data definition. And we should be encouraging these smaller repositories to, you know, do the upfront work to integrate the - their definitions with, you know, what's already been established, not to just, you know, create another repository. Because, you know, if you create another repository, sort of, as a standalone island, then it's going to be incredibly difficult to integrate those in the future.

DR. DANIELS: Sorry to interrupt, Dan. I don't know if you and Gretchen can hear it, but a fire alarm is going off in our building.

MS. NAVIDI: Yes we hear it.

DR. DANIELS: So I think that - unfortunately I think I need to get my team to leave the building. I'm sorry about this. I'll leave the call running and it will be recorded, but I think we have to exit when there's a fire alarm. So sorry about that.

DR. AZUINE: Please be safe.

DR. RING: This is Rob. I just wanted to...

DR. DANIELS: Hopefully we'll be back.

DR. RING: I just wanted...

DR. LIPKIN: Alison are you going to keep the meeting going then?

MS. SINGER: Well...

DR. LIPKIN: For a little bit, anyway.

MS. SINGER: I can serve as the moderator for the meeting so...

DR. LIPKIN: Okay. I wanted to - this is Paul. I wanted to continue along the - that lines of discussion that we were just having. So I think, as Rob pointed out, that the Simons Foundation is doing a lot of work now through its SPARK Program, as a lot of people know.

And fortunately I think Simons Foundation is working in collaboration with NDAR on it. There is a whole other pool of data that is - that we're probably on the cusp of gathering over the next year or two through PCORI. So IAN is essentially the autism node for PCORnet, which is the network of data research networks and patient-powered research networks being funded through PCORI.

This is a work in progress, but PCORnet is establishing collaborative research groups. And autism is being billed as a research interest group within the pediatric subgroup. The important point is that they are mustering the ability over time to collect large pools of data that comes from clinical entities -- whether it be electronic medical records, hospitals, healthcare systems and so on -- on patients all across the nation with multiple health conditions, and autism is within them.

And so I think - as we look at databases and databanks, I think PCORI at some point in time will have some really large and meaningful data that hasn't been gathered elsewhere on children and adults with autism, because it's rooted in electronic medical record systems and clinical networks. We are - we at IAN are, as the patient-powered research network for autism within PCORI, are making sure that the, sort of, participants' voices are being linked. And so I think the ultimate plan is to link participant-powered data or participant-derived data with clinically derived data into a large data pool around autism.

And I think, again, it's a work in progress, but I expect that - it's gathering a lot of steam very quickly and I think in the future that will need to be considered as well in terms of the data resources.

DR. RING: This is Rob. I just - building off of this, I think it's a great line of discussion and, kind of, reminiscing a little bit on some of the challenges we faced in standing up MSSNG, the large genomic sequencing...

DR. LIPKIN: Right.

DR. RING: ...database project with Google at Autism Speaks. Yes at the end of the day, you know, a lot of the success of our ability to ultimately federate all of these disparate data sources regardless of what they might be -- whether or not it's just patient, you know, information, or there's biological data associated, whether or not it's coming from samples that have in repositories and wherever they might come. You know, a lot of this is really going to come down to how well we - well, one, standardize the collection of that data and how well we standardize the sharing of that data. So that's already been said. I can't emphasize the importance of that enough.

You know, I think it's a bit of a stretch to just - from the top down just ask these small patient groups to just follow the standards that are being created. They're going to need some help. There needs to be more funding made available to smaller start-up foundations to not only give them the rulebook on how to do it, but give them some resources to help ensure they do it, you know, in a way that plugs and plays with the larger efforts to federate data.

So that's the first point I wanted to make. But the second point is really a lot of this is going to be, you know, live or die by how well we disrupt the existing ethical and legal frameworks around data sharing. Because you have a lot of differences in how consent forms have been used over the past - how they may be used now and how they could be used into the future. If there isn't some harmonization around common policies and common instruments -- legal and ethical -- used to move this forward, it's going to be very difficult regardless of how well you've created the ability to share data to actually share that.

And there are obviously organizations like the Global Alliance for Genomics and Health that are, you know, at the forefront of thinking how you develop these new policies to enable this. But, you know, whether or not that falls within the charter or scope of what we're talking about here or not, it's going to be an important part of realizing the promises of what we're talking about here. We can collect all the samples we want. We can talk about ways to digitally connect them. But if we've failed to really address some of the fundamental challenges inherent in the legal and ethical dimensions of this, it won't be possible. And I think we need to somehow reference that in our discussion moving forward.

DR. LIPKIN: Paul here again. And I just - and one more addition to that, Rob - what Rob brought up is that I suspect the NDAR people are no longer on the call. Is that true? Dan or others? But there actually is an active effort within PCORnet for creating common data models to work across research projects.

And it's not simply with autism as its focus, but they are looking to develop a data nomenclature. And so it's probably - will be ultimately important for the autism world -- you know, probably people at NDAR -- to speak to some of the leaders on that within PCORnet to make sure that that data that PCORnet is working on will be useful to NDAR and vice versa.

MS. SINGER: Okay so this is Alison. I think those points are well made and well taken. At this point I would ask if there are any members of the committee who disagree, who don't feel that we should include something new about federating these patient registries and the new diverse datasets? Does anyone want to speak to that or...

(No response.)

MS. SINGER: Okay. Are there other items that are not currently under the data infrastructure that we want to add? So just to summarize what Susan put under data infrastructure, she included surveillance, NDAR, the genetics and genomics databanks, and the need to improve data sharing, IAN.

We've now added these to encourage the federation of diverse patient registries and data sources. Does anyone have any other ideas for things to include under data infrastructure, or should we move on to human infrastructure?

DR. AZUINE: Hi this is Romy from HRSA. I'm new to this workgroup, but I just wanted to point out that for us here in MCHB, the autism research network that we fund - very big for us. So I was wondering where that falls under surveillance, because these are also infrastructure facilities that we established for across multi-site studies. So I wasn't sure where on this list research networks might fall under.

MS. SINGER: So what specifically do you mean by "research networks?"

DR. AZUINE: So these are a couple of multi-site studies that we set up -- some of them with Autism Speaks -- where investigators from across the country collaborate and then use that as a platform to conduct interdisciplinary studies, as well as also for opportunities for further funding opportunities and leveraging of sources from both foundation and other government agencies.

DR. LIPKIN: It's the (AIRP) and...

MS. SINGER: Right. So...

MR. LIPKIN: ...(AIRB).

DR. RING: Right.

MS. SINGER: So my understanding is that those will be included based on their topical area in other areas of the strategic plan, but that where we could include that in chapter seven is, I'd say, under issues of fostering collaboration, both national and international. So I would say we could talk about that under human infrastructure because the topical areas will be covered by the topical chapters.

DR. CHRISTENSEN: Hi this is Daisy at CDC. I'll just add that, you know, we're currently, sort of, evaluating the data that we get from the ADDM Network to which, since the last survey - the last strategic plan was developed, we've added surveillance in younger age groups, specifically 4-year-olds.

It's considering what it would like to add surveillance among some older age groups, adolescence and even, based on the availability of special education records, for you know, the 18- to 21-year-olds -- some very young adults. Although the ADDM Network methodology doesn't easily translate directly into adult surveillance, although there may be some opportunities for doing a linkage project to try to get some idea of, say, services and things like that based on linking from previous ADDM Network cohorts.

I'll skip over international surveillance. But also, sort of, looking at the landscape of other surveillance activities that are conducted through the national surveys, one of which is connected currently by CDC, which is the National Health Interview Study, which is a - it's a yearly survey that's nationally representative.

It has a relatively, you know, small sample of children. It's about 10,000 to 12,000 children across the United States. But the prevalence estimates that they get are relatively consonant with the prevalence estimates that were derived from a larger, also parent-reported survey, the National Survey of Children's Health, which is now - has been - was formerly a collaborative project between CDC and HRSA conducted on a CDC sampling platform.

That's now been moved to a Census Bureau-based platform and there's actually some exciting news to come out of that, though that will be fielded more - that survey, the National Survey of Children's Health, will be fielded more frequently and will also -- for the first time, I believe -- be able to produce at least every two or three years, by combining years, some state-based estimates of specific factors that they ask about, which I assume would include ASD prevalence.

And so, you know, we're in - you know, sort of, talking internally about, you know, what we - you know, where we're going with the ADDM Network and, you know, what the parent-reported prevalence surveys provide. The parent-reported surveys provide, you know, the level of data and the level of detail of data that we get from ADDM.

And, you know, we'll be interested in, you know, sort of, getting input from the committee in terms of - you know, there are certainly questions that can be answered only by the, kind of, detailed data collection that the ADDM Network is able to do. But the ADDM Network is not able to operate outside of, you know, a, sort of, 10, 12 communities in the U.S. and is not as timely as the surveys.

And so we really want to make sure that we are getting, you know, the most relevant data that we can out of, you know, that activity. And, sort of, using all - you know, these, sort of, two different methods that CDC is involved with, you know, as complementary to provide the best information out to researchers and the public and policymakers, et cetera. So interested in feedback and comments about that.

MS. RAST: This is Jessica. I think that's a great idea about the national surveys. One of the thoughts that I've been having is that we should take it beyond just the surveillance measure. There's a lot of good information that comes from these. There's a whole bunch of national surveys that collect information on people on the autism spectrum. And I think it would behoove us to include that type of information in these big buckets under the databases.

DR. CHRISTENSEN: Which ones are you thinking of in particular?

MS. RAST: Well there's the - like you mentioned there's the children's survey. So the National Survey of Children's Health and Children with Special Health Care Needs.

DR. CHRISTENSEN: So those two - so the National Survey of Children with Special Health Care Needs is actually not going to be functioning as a standalone survey anymore.

MS. RAST: Right.

MS. CHRISTENSEN: It's being combined...

MS. RAST: It's being combined.

DR. CHRISTENSEN: ...with the National Survey of Children's Health. And so, you know, both to, kind of, increase powers, I understand, and to allow it to be fielded more frequently than the every, sort of, you know, three or four years that, you know, they were, kind of, staggering the way that those were fielded.

And so, you know, as far as, you know, I know, the two surveys that include questions on ASD are now the National Survey of Children's Health, and that is actually in the field right now and should have some estimates by next spring, early summer. At least nationally -- national estimates -- for ASD prevalence, although I wouldn't guess that there would necessarily be state-based estimates. And then the National Health Interview Study.

MS. RAST: Okay. And I think there's other larger surveys that get at questions other than prevalence that are important. For instance, service use or educational experiences or, you know, whatever, kind of, information that you're looking for. There's also the National Survey of Drug Use and Health.

There's different things that we could do with these big surveys that already exist, maybe oversampling for autism or connecting them somehow or thinking about, you know, the infrastructure that already exists that all this money is spent on. I just think there's a lot of opportunity there to gather other types of information and get some really good data and some big numbers.

DR. CHRISTENSEN: Yes. I absolutely agree.

(Pause.)

MS. SINGER: Okay are there any other topics that are not currently on the list that people feel it is important for us to include?

(No response.)

MS. SINGER: Okay so let's move on to human infrastructure.

DR. DANIELS: So by the way, just wanted to let you all know I'm back on the phone with the team here at OARC, and I think the other NIMH people are probably back too. So apparently it wasn't a major fire. It was probably a fire drill.

DR. CHRISTENSEN: Good to know.

DR. DANIELS: So when we were talking about the databases just a minute ago, are there any current concerns about access to data from these - or these surveys in terms of researchers being able to get their hands on data? I know that in the IACC we've had some concerns shared sometimes about difficulty in accessing the data. Is that something that needs to be addressed, or are the data fully accessible and easy to register to obtain?

DR. CHRISTENSEN: Well the data for, you know, say, NSCH or NHIS -- I mean at least at the national level -- are simply available on a Web site. So there's not - at a certain level there's not even a need to register. There may be other levels of data access, and we'll see how that works out with, say, state-based estimates with NSCH that would require a little bit more, you know, sort of, steps to go through in order to use the data. But, you know, there certainly are absolutely public open-access datasets that are available, you know, sort of, as you consider on the Web.

I mean, you know, you need some level of sophistication and some access to the statistical software that would allow you to, you know, analyze and account for the sampling strategy. But there are also, you know - if you're able to, kind of, work through them, there are, you know, very detailed instructions about the methodology. And they have, you know, suggested software programs and things like that. But, you know, you're - you do need to have some basic level of experience in those areas, I think, to be able...

DR. AZUINE: I just want to add in a little bit more. I think that you are very correct. The National Survey of Children's Health is actually directed from our office.

DR. CHRISTENSEN: Yes.

DR. AZUINE: And the current one is on the streets now. Actually I took one two days ago for my household. Yes. And so I can speak to the questions that are inside there. I think we have a data on autism. We have for parents' information. We have for household demographics. We have questions on nativity. We have questions on access.

So I think the traditional questions that we had in the prior survey are still there and more. But I think, like she pointed out, the greater benefit of the survey now is that, as opposed to the four-year cycle, we will -- you know, fingers crossed -- be able to do them, you know, annually and rule out this data. But I just want to add about the technical assistance. We also have a contractor called Cami Now at Johns Hopkins University that is able to provide technical assistance to non-data-savvy people to be able to use the data based on different statistical softwares like SAS, Stata and SPSS.

In addition, our office is also happy to provide some technical support if people were to need - have questions. So we're excited that we are rolling out the survey in collaboration with the Census this time around.

DR. CHRISTENSEN: Right. Great.

DR. RING: So...

MS. NAVIDI: So this is Gretchen. Can I - sorry, we just got back on the call and I think that I missed where those data are being collected and how, and how they're going to be available. Can you repeat that?

DR. AZUINE: Yes. The datasets will be publicly available. You need regularly - you will need a thing - what we used to do before with the CDC. Or if you were going with the center for adolescent measurement and health information at Johns Hopkins, will need to register the normal traditional commitment that you make that you will respect the data used where you - to have access to private, you know, personally identifying information, you keep intended security of this data.

And also for us to know who is using this data purely for our own surveillance effort. Otherwise all the datasets are available free of charge to the members of the public on three software bases -- SAS, Stata and SPSS.

MS. NAVIDI: Okay. Oh that's wonderful. So, you know, one of the things that we do at NDAR is that, you know, we're all about standardization so that, for instance, we've got 780 different test instruments that have been defined, which constitutes over 114,000 different questions. And we try to, you know, reuse those so that it makes analysis on the back end much easier, and it allows researchers to compare apples to apples, if you will. So is that - and this has really been adopted as the standard within the autism research community. And is this something that has been considered as part of this project? And, you know, are item-level data available, or is it more at a summary level?

DR. AZUINE: Is this Susan?

DR.DANIELS: No, that was Gretchen Navidi.

MS. NAVIDI: No...

DR. AZUINE: Oh I'm sorry, Gretchen. So I think we are open to discuss questions. In the rollout for the National Survey of Children's Health we had this very nationwide consulting with stakeholders. And I'm sure Dr. Gandorada managed that effort, was able to get to our colleagues at CDC, our colleagues - I think some people at NIH as well in the questions.

But I'm happy for us to talk offline so that we can see those questions, if they are the same questions reflected in the survey, or what are you think - these are some of the questions we could ask as well, share with our measurement research network that is funded from the bureau here as well. So I'm happy to set up something for us to talk, Gretchen.

DR. CHRISTENSEN: And I'll just...

MS. NAVIDI: Okay that...

DR. CHRISTENSEN: Sort of in the broad landscape, the question - among the surveys, the questions have not always been completely comparable. And there's, sort of, been an evolution over the 2000s in terms of the wording of the questions on the surveys that, you know, it's - they, sort of, started out asking about autism, and then that expanded to include, sort of, the different subtypes under DSM IV.

At some point in the 2000s -- I think it was in the 2007 survey -- they included - compared to the 2003 survey they included a follow-up question. So the standard questions is, you know, "Has anyone - has a healthcare provider ever told you that your child had autism, autism spectrum disorder?" You know, and then they'll list a number of other conditions which, as I said, have, sort of, changed. The list has morphed over time.

But they followed that up with the question, "Does your children currently have" - you know, and then listing the same number of conditions. And they actually found, you know, a not huge, but not insubstantial difference in response in parental endorsement between those two questions.

And so there was a follow-up study that, you know, looked at that. And the - you know, the most common reason for endorsing lack of a current diagnosis as opposed to a historical diagnosis was presence of new information and new diagnosis. And so, for example, the - so the National Survey of Children's Health has had this follow-up question, which is typically then what's been analyzed. And the prevalence estimates have been based on the "current" question, whereas the National Health

Interview study still has just the "has anyone ever told you" question.

And they will include the "current" question on the 2018 version of the survey, and they don't have the same number of follow-up questions, including things that National Survey of Children's Health does, including questions like, you know, "How old was your child when someone first told you that they had, you know, autism?" You know, "What sort of practitioner was it?" You know, "Has your child received any medication?" "Has your child received any behavioral services?" Things like that.

There also was a paper that came out about a year ago from the National Health Interview study that showed the effect of actually just internally in the questionnaire changing the order in which questions were asked about different developmental conditions, like other development disorder, intellectual disability and autism spectrum disorder. And the wording of the questions and, you know - so comparing the 2011 to 2013 surveys with the old wording to the 2014 survey with the new wording, and they found a doubling of autism prevalence just based on - or apparently just based on changing the wording of the question and the order in which the questions were answered.

And so, you know, there's - I think to your point, you know, there - the surveys are still not quite standardized in terms of how they're answering - how they're asking even the most basic questions to get at prevalence. And I think it's, you know - it will go a long way when everybody's asking just the basic question, "Does your child currently have a diagnosis?" And then, you know, it's appropriate for different surveys (unintelligible)...

DR. LIPKIN: So we're really getting into the weeds on a lot of the details here, but I think this discussion really highlights the big issue --

this question -- and for our group, you know, clearly there are multiple sources of data going across agencies. So there's tons of data on children with autism and it's not well-harmonized. NDAR has made a great effort for that, but despite that, there are many other sources of data that are not harmonized.

And I think when - in terms of meeting the needs of the American taxpayer, I think it's created a large amount of inefficiency. And so I think in - for talking about infrastructure, I think this is something that needs to be tackled and addressed.

DR. RING: Yes and Susan, this is Rob. When you guys stepped out - at least I'm expecting you missed this part of the conversation, but bringing it back to your question about access, you know, it’s clearly there's the challenges that have, kind of, been laid out around access to the larger world of potential federation of data and the technical challenges associated with that.

But we did discuss while you were away -- and I still can't emphasize this enough -- that a lot of the challenges or obstacles, barriers to access are really going to be found in how the consents have been, you know, developed over time and how they are more standardized or made more universal moving forward. Because ultimately, you know, who has access to the data should not be, in my view, as limited as it has been or as narrowly defined as it often is to researchers, you know, at qualified universities.

That the universe of potential users of that data from commercial entities to researchers in non-autism spaces may bring a lot of innovation to the analysis of that data that isn't permitted by the way data sharing policies are designed. So we can build wonderful database infrastructure and harmonize data on a technical level, but if we still aren't able to disrupt the way policies define the sharing of data -- which will define the access of individuals to data -- whether or not even those who are parents own access to data -- their own data -- is an important part of the discussion that we touched on while you were away. Just to, kind of, finish that point.

DR. DANIELS: I appreciate that. That's helpful to know.

MS. NAVIDI: That's actually very - you know, you make some very, very excellent points there. And I agree with really everything that you said. So just to give you a little bit of context, for NDAR we currently have -- for only autism-related subjects -- about 90,000 different subjects.

And that represents almost $1 billion worth of research. And all of those data are broadly consented. So that means that it's not limited to researchers who are only looking at autism research in terms of accessing the data. So that's an excellent point in terms of writing the informed consents appropriately for broad access once data become available and shared with the research community.

It needs to be done in a broad way, and that's something that we've really advocated for along with the harmonization standards that you mentioned. And it should really be a focus throughout any of the data-related infrastructure that we discuss.

DR. DANIELS: Thanks. I don't know if this came up while I was off the call, but was there any discussion of databases on services and education and - are there concerns about access? I know that I heard this in an IACC meeting and I wanted to make sure we followed up, if there are things that we need to consider here. Are these data readily accessible to researchers and easy to use? Are there any particular issues or needs?

MS. RAST: This is Jessica. I do have a few thoughts on the access for those. The CDC and the MCHB surveys are really easily accessible, and there are great health resources for people who want to do analysis on those. But there's a lot of other ones out there that are hard to get. They're hard to find. A lot of people don't even know they exist, so I think there's a lot of access problems that exist out there through different sources. And I do think that there could be some way to, you know, again harmonize those, to get those all available, to get them known, maybe a way that we could you know, collect them just to tell our researchers that they're out there and what types of information is being collected.

That's you know, possible to do analysis on. So there's definitely, definitely problems with access and availability with a lot of national forces of surveys and services research and things like that.

DR. DANIELS: Do you have any suggestions of things that would make that better that we could actually address besides just maybe putting web links on a web site and saying here are a bunch of places you can contact for data? Are there things that the IACC could be doing to try to encourage more openness of the data or anything else?

MS. RAST: I'm not sure. I can definitely think about it. I know there's some problems with some of them aren't necessarily DA identified so it goes back to the same things we've been talking about as far as you know, (unintelligible) and success ability and consent and things like that. I'm sure that there is something that we could do beyond just collecting all of these but I'll have to think about it.

DR. AZUINE: Yes I think Susan, one way to be, actually reach out to owners of these datasets from an IACC point of view, reach out to them and ask them for their data governor's documents.

I remember one of the (unintelligible) databases I had, we took several months trying to create a data governing document that guided all of the people who contributed to the data and then provided a transparent approach so which external researchers could apply to use these data systems.

I just want to point out that having not easy access is not really bad in itself. It's just what that means. For instance, if somebody's asking you that we want to know who you are, what you'll be using the data for, and we want to tell us when you published with this data, I think those are not encumbering as they are that people are preventing access.

But I think if you reach out to them, see if they have any documents, see what the indicator they have in this database, those databases are actually whether they have autism questions, then that will be the beginning of the discussions to ask them and to disseminate you know, if they were not have the process in place maybe provide technical assistance on how to create a data governing document.

DR. DANIELS: Yes so that's an interesting idea. I think that we might need to circle back with some of the researches in this area that we're kind of you know, discussing concerns they had about difficulty in trying to access data and try to identify what the real issues are there.

MR. HALL: Yes. Our experience is that retrospective data sharing is nearly impossible and very expensive in that you know, the department of education and others should put terms in you know, requiring data sharing in some you know, in some form.

You know, whether, you know, we'll certainly set the research data and we have from I think, 20 different public and private institutions and so

NDAR available for that but you know, it might not work for all types of data however, if the agencies year mark put terms in for data sharing, I think that will go a long way and that's something the IACC can monitor.

DR. DANIELS: That has been an interest of the IACC. I think data sharing has always been on their agenda so certainly something that we can address in the update.

MR. HALL: But you know, and one thing that we do is I know at the NIH I think every grant before it's awarded is reviewed for whether data sharing terms are included. I don't think that is consistent in other agencies and that should be something that can be discussed.

DR. DANIELS: Thanks. Great. Well under the data infrastructure bucket that Alison has put together here, we have all of surveillance, have we yet had a chance to talk about what progress has been made in the surveillance arena in terms of the research? Daisy, do you have some thoughts about that, things that we would want to highlight in the strategic plan update?

DR. CHRISTENSEN: I mean, we have talked about some about for example the extension of the ADDM that worked into Alison's surveillance among four year old children. We also talked about the sort of, some exciting changes in the national survey of children health which is one of the largest national survey of children that produces both prevalent estimates.

And some characters of children with ASD that is, was formally run on a CDC sampling platform but is now being run on a census based platform out of HRSA and that will hopefully fingers crossed I hear be able to produce some annual estimates and then also possibly on an every several years basis be able to produce state based estimates which we have not ever had for ASD.

So those are some exciting new things that are potentially coming out, that have or are potentially coming out of this surveillance world. And then just in a nutshell, I said you know, we're sort of continuing to look at kind of the intersection between the Adam network and the surveys and other ways of collecting surveillance data on ASD.

And how they complement each other and what you know, what we should be focusing on in our work in the developmental disabilities branch to make sure that we're really getting at the right questions.

DR. DANIELS: Have we made some progress in terms of really understanding prevalence in the last couple of years since the last strategic plan update?

DR. CHRISTENSEN: Well, I mean, I think that we you know, we continue to have a prevalence estimate that is based on a very rigorous methodology that has been consistent since the conception of the Adam network.

And I think that you know, the importance of that can't really be overstated, you know, at a time when other methods of assessing prevalence has gone through different iterations of how they ask the question, et cetera.

As I said, we vote, you know, we've applied the methods to four year old children and found that that is not only feasible and doable but provides interesting information, especially as well move on through the consorts about the percentage of four year old children, you know, who are sort of identified.

And then hoping to see kind of the percentage you know, when we look at our eight year olds and we look back, you know, hopefully seeing the percentage that were identified at four increase over time as we you know, move towards our goals of earlier and earlier identification.

And then we also have the current, we have the current scientific priorities where the Adam is, because of the way we collected data, we're able this year to simultaneously produce a prevalence you know, to you know, define case status based on both DSM4 and DSM5 and so we'd be able to look for the first time directly at the effect of DSM5 on ASD prevalence and characteristics in the ADDM network.

DR. DANIELS: So I was sort of thinking more about what we've actually learned about prevalence itself through the study.

Is there any update on that that is going to be important to include I guess, the last Adam network paper had some new findings but are there any other major updates we have in terms of what we're learning about age of diagnose whether that's changing prevalence in various groups?

DR. LIPKIN: Yes has a success study read out yet?

DR. CHRISTENSEN: No. It has not.

DR. DANIELS: So I mean, we'll definitely be writing a section on that in the strategic plan update so we don't necessarily have to discuss it on the call but this is the only place in the strategic plan where we really talk about what's been happening in terms of research outputs in the surveillance arena so we'll need to be prepared to summarize kind of where that is.

DR. CHRISTENSEN: Right. I mean, we're very much anticipating seeing the results of the success study from South Carolina when they come out.

Dr. DANIELS: Do you have any sense of when that is? Is that this calendar year or next calendar year?

DR. CHRISTENSEN: I don't have a good sense. They published the message paper and that is really all the update that I've gotten.

DR. DANIELS: Okay. And in terms of adult prevalence, is there anything on the horizon?

DR. CHRISTENSEN: We've been talking about that. I mean, the Adam network methodology is not very well translatable to doing an actual prevalence study among adults.

I mean, I think there are some options that we could do in terms of linking previous Adam network cohorts to other databases that might cover services for adults and you know, getting some information about transition and about you know, sort of research needs and services. That way I think that a true national prevalence estimate of ASD among adults is you know a relatively major undertaking.

I think that if we talked about a little bit if I remember in this group or at least in the IACC that it's not you know, it's not clear that the national surveys of survey like the behavioral risk factor survey or SSS would necessarily produce a very accurate estimate of ASD among adults in terms of capturing the you know, the sort of spectrum of impairment.

And so if you think about doing some study similar to what was done in the UK, then you know, that's a more major undertaking. I mean, we would certainly be involved in looking at different, you know, what sort of sampling platforms you could at least initially start with.

It's such a project where you know, a thought to be a priority and you know, worse the resources that it wouldn't entail and be refunded and I think that it you know, other than you know, then in the meantime, there are sort of other ways that we can kind of get at some transition issues you know, through data linkages. But not necessarily, it's hard to think of using the education and health record system as it stands, you know, as we use it now for ADDM and just simply porting to adults.

DR. DANIELS: Right. So that's an area that's come up in the IACC before about wanting to know whether we, in the future, anticipate having a strategy to understand adult prevalence and I don't know if that's still going to be something that the IACC is interested in seeing in the future but something this group should keep in mind when thinking about future priorities and where that fits in.

DR. CHRISTENSEN: I agree. I mean, I think we're happy to contribute to that discussion and you know, I mean, this hopefully recommendations from the IACC about the priority of such a study you know, considering sort of what it would entail, you know, would be taken into account by people who make decisions about priorities and funding.

DR. DANIELS: Great. Does anyone else on the call have any thoughts about that, about interest in adult prevalence and where that fits?

(No response.)

DR. DANIELS: So well that might be something more for the full IACC to think about. Are there any other data infrastructure type issues that you all want to discuss before maybe moving on to another area?

DR. LIPKIN: Yes. One thing we'd like to bring up is this idea that and there was an old IACC item and we implemented this capability to associate all data with publications so that and we put that into our terms.

So now not only are we expecting all the raw data but actually the data specific to a publication to find out through a cohort and this is something that we are you know, we've done in beta for a year or two and now we are losing that into you know, to scale to support all of our research at the NIH.

DR. DANIELS: Great. That would be a good update to include in the write up.

MS. NAVIDI: Yes I mean, we really think the fact an appropriate way to disseminate research results you know, regardless whether you know, they're positive or negative results and the feature is called the NDA study by the way.

And this is something that's been used across all of mental health autism so it sort of loops back to that concept of you know, other research communities and the interaction and the influence that research in other areas can have on autism.

DR. DANIELS: Great thanks. So then why don't we go back to the biorepository infrastructure and just pick up anything that we think in terms of major accomplishments that we made in the last few years and remaining gaps and needs that we might want to address in the strategic plan.

Any comments on that in regards to any tissue banking, frame banking, certainly progress has been made in terms of trying to have more outreach to the community for brand banking. Alison, are you still on?

MS. SINGER: Yes I'm still here.

DR. DANIELS: Okay so I know that ASF has been deeply involved in those efforts and the autism Brain Net and NIH neuro biobank agreement also had some major progress updates that we would probably want to include but is there anything else that you can think of that is worth highlighting?

MS. SINGER: I think you've hit the major topics. The, basically federation of the banks with the foreign U.S. nodes and the one international node and just the consolidated outreach which is one of the objectives of the old plan that now we can report progress on so I'm happy to write that section and (unintelligible).

DR. DANIELS: What are the, what are the big gaps that are still left in that area? Are there…

MS. SINGER: I think a lot of the gaps have to do with public perception. We still have a lot of, a long way to go in terms of educating the public the fact that we're not asking for a biopsy of brains from their living child. So I think we still have, I mean, I think a lot of progress has been made in terms of coordination between the banks, they've now made agreements on how to run protocols for harvesting and collection and staining and sharing and distribution of the tissue.

And I think the biggest issue is still getting people to register and donate tissue. Because you know, we still have not recovered from the loss of the tissue in Boston. We're almost too covered but we still have a long way to go. In fact, in the last update, we reported that we're worse off in terms of brain tissue then we were in the 2000 plan. So I think there's good news to report here but still a lot of work to be done in terms of convincing people to donate tissue.

Just as I think if we're on this topic, there's a tremendous amount of work to still be done in autism about educating families and people with autism about the importance of their participation and research generally.

Our families and our individuals with autism participating research at a far lower rate than many other diseases than disorders and I think that is a critical goal if research is going to move forward. We see so often studies are not reaching their prescribed and their undersubscribed and we have to do a better job there.

DR. DANIELS: So what do we think are the barriers that are keeping families with a member with autism from participating?

MS. SINGER: So we're actually studying that right now, it's funny you should ask.

DR. DANIELS: Oh, great.

MS. SINGER: We are, we've been doing it sort of casually but we're actually looking to put a more formal and rigorous study together about what is it that prevents families from participating?

I can tell you just (unintelligible) analysis. There's no philosophical reason for people to want to participate. Most of the reason for people sites are very administrative, things like I have to part really far away. There's no babysitting for my other child. Things like no one's going to, they can't pay my train fare. These are very solvable problems.

But I think that that's really a disconnect because when we talk to the research community, their understanding is that parents just don't want to participate and that's certainly on the case. Parents would like to participate but we need to pay down some of the structural barriers that present a participation.

DR. DANIELS: Great. That sounds like something that would be really good to address in the strategic plan. Paul, do you have anything to add to that from your perspective at (unintelligible)?

DR. LIPKIN: Actually we've just completed a project that we got through some fundings from CDC. In fact, looking at people's willingness to participate in all sorts of online research and I would echo what Alison said. I think people are very willing and interested.

These were mothers that we asked and we actually dichotomized it based upon age of the children whether it be mothers of teens and young adults or mothers of younger children and all across the board, you know, there was very much a interest in participating and informing researchers.

Even, we took the next step to see how people would like, how far one would be willing to go in terms of providing information and even going as far as activity monitors, home monitoring and so on and so forth.

We'll get all sorts of different modalities and there was a, really a large willingness, larger than we expected and anticipated for sharing information. There of course, there's a certain amount of security in safety and amenity that people are, certainly are striving for but they are remain very willing to participate.

Interestingly, the younger parents are showing us some issues in terms of the changes that are occurring in terms of the use of the internet and other modalities so in fact, younger parents were more willing and able to consider smartphone technologies and other technologies for monitoring and actually we're a little less concerned around security issues than older families.

I think they're, you know, I think they've lived in, they've grown up in an internet open society and so they're a little less concerned about the security of their personal information then we expected.

DR. DANIELS: So are there some opportunities there? Do you see any ways that the IACC could make a difference to be able to further encourage participation based on the availability of some of these technologies?

DR. LIPKIN: Yes and you know, I think that's what we've been working together with the CDC on. That was, that was a whole concept around this was should we be look at new modalities for accumulation of important information on the child and the adult with autism.

And I think, I think the IACC should consider perhaps promoting pile up projects or programs looking at alternatives to historic ways of researching these questions.

MS. SINGER: One issue that came up with our families around this is one of the barriers that was cited was that families are asked to complete the same assessment over and over if they do research a different site so our families are saying if I get a (unintelligible) at Yale, why do I have to do another (unintelligible) at NYU?

Right, so I think that could be a philosophical question for the IACC to talk about is should we relax some of the restrictions that are currently in place that require the measurement tools to be repeated by clinicians at every site where research is taking place.

I mean, frankly if you have two (unintelligible) in the same year, I think it's not even valid but that's what, that's what's going on and that's a big barrier. People are, I don't want to do the (unintelligible). I feel that way, like why do I want to do the (unintelligible)?

DR. DANIELS: That's a really good point and I think that is something the committee would be interested in talking about. Great. Well those are some important areas. In terms of, so we've talking about research participation, do we have more that we want to talk about in terms of dissemination of science and efforts to educate the public?

So we've talked a little bit about that related to brain banking but in general, are there other things that the committee sees as good opportunities to increase the dissemination of evidence based practices and science?

DR. LIPKIN: I imagine Alison you have some great opinions around these issues. You know, certainly we at EAN have felt a responsibility for educating public around that and assignments foundation has been working that, on that as well through its, through its media opportunities.

So I think I think the public is yearning for the latest research information and you know, I think we, but I think few of them know about these places where they can go to get this information.

DR. RING: Yes this is Rob. I'd add to that I just you know, think this is such an important area for us to figure out how to develop guidance and priorities around you know, whether or not it's establishing some standardized framework for evaluating the evidence behind commercial products.

It could be apps running on you know, phones and iPads or it could be you know, therapeutic, nutrition, nutritional approaches to all the way to the use of medicines and medical practice.

I think families really struggle one, you know, the challenge of getting the disseminating the findings broadly is one thing translating that into a language that families can be a consumer of is another but creating sources of curated science resources that families can go to.

And be able to compare and contrast what, not just the evidence says from the literature but other sources of validation behind products and services that are emerge from the science couldn't be any more important you know.

And I see, you know, various organizations in a given autism species, tried to do this with the app space, create a framework for evaluating what data might be behind some of the apps that are commonly being used.

This could be applied anywhere and there just isn't a single place for families to go to get that kind of curated information and it's got to start with some standardization around how we evaluate the level of evidence behind certain science based products out there.

MS. SINGER: This is Alison. I totally agree. I would just add that in addition to the curated macrolevel data families are also interested in participant level data. They bring that up as well as the (unintelligible) to participation. They would like in many cases to get the results of, that are some, their personal participation.

I apologize, I have to get off the phone to deal with some hurricane prep for an event we have this weekend. Okay.

DR. DANIELS: No problem. Thank you for being with us and we'll fill you in after the call has ended.

MS. SINGER: Okay thanks. Bye everyone.

DR. DANIELS: Thank you.

DR. LIPKIN: This is Paul again. Just adding on to Rob's point you know, I think you know, certainly what NIH and IACC keep hearing is about concerns around services and other areas that have not been particular addressed over the past five to 10 years and I think there's good justification for that.

On the other hand, there's been a tremendous amount of investigation that's been on neurosciences and genetics and that is, that really has been landmark research and, but I do think that there's been a real, a gap or real problems in communicating that information to families you know, everybody when it comes to the health related conditions wants to know about causes.

And the achievements in neurosciences and genetics have really not been -- we have not found a way to communicate that information effectively to parents. I think there are researches now who are sort of delving into that and trying to get a better understanding of that.

So I think, you know, I think, and I think this whole communication around results ends up being really important as we, as the IACC continues to yearn to have, to gain, to earn the trust of the wider public.

DR. RING: It's a shame we lost Michael Rosanoff. I know he just sent us an e-mail and got bumped off but you know, this whole area of dissemination science is so incredibly important and many of the products of research, clinical research today are creating you know, tools that can be put in the hands, that's apparent you know, delivered services is you know, a very active area.

And certainly very important in developing areas of the world and underserved populations across their own country so parents skills, training, et cetera are areas where we, the science is there and you know, it's really a matter of helping to assist the dissemination on that.

I know it's a priority here but just want to, worry that that voice has been lost in this conversation right now because I know it would be for fronted of what he would have to say.

DR. DANIELS: Thanks.

MS. NAVIDI: Hi, so this is Gretchen. You know, I heard some really great concepts you know, for sort of coming through the discussion over the last couple of minutes, things like trust and you know, the public needing to understand how their participation is valued.

And how they fit into the overall you know, grouping of other families with autism and I think this is a really important concept in terms of dissemination of information and it kind of goes back to the whole concept of public trust but there's a large amount of funding both private and public organizations that's devoted to autism.

And in general, people want to know what is coming out of all of this efforts that's being put in whether it's actual dollars or whether it's you know, time and resources. One of the things that we've been able to determine from the data we get at NDAR is that it costs about $9 thousand per subject for data to be collected in a study.

And this is an important number to consider you know, what is the public getting out of it? So I agree that looking into how data are disseminated and how research results are translated into every day methods and standards is really an important concept that needs to be included in this overall area.

DR. DANIELS: Great. Some good comments on that. Do we have any more comments about dissemination of clients? I know that we've had some progress in terms of some of the private funders in particular that have really in the last few years increased their exposure of the public to scientific findings and trying to publish lay friendly articles about various scientific findings of course in the government agencies as well.

They are also trying to get more information out but there is a tremendous needs and there is a lot of research that's being done that's all that isn't being covered that way so there's still opportunities for more to be done.

So if we can, I'd like to change our focus to research training workforce development and any general comments that this group might have about needs for training the research workforce? We probably will have more specific information in the other chapters but in the past, this group has helped with defining this issue a little bit and reporting on it.

In terms of the pipeline of researches who will be carrying this work on into the future, are there particular concerns about gaps or areas where we need to have more efforts to ensure that we have the appropriate workforce in place?

DR. LIPKIN: You know, I'm not quite sure that the medical workforce around autism is really having its needs being looked or addressed in any particular way. There's you know, as we get better and better at our early identification, we still are dealing with an absence of adequate medical professionals for dealing with the special problem that children have with autism.

And then beyond that, the problems with 18 year olds and above or 21 year olds and above is disastrous. There's not a family that I've met with someone who has someone in the family who's over 21 with autism who is struggling to find adequate health care so I think there are huge workforce issues that are really only beginning.

Well, there not really only being addressed. In terms of child neurology research, there actually has been a large sum of money that's been put aside for training child neurologists and research not specifically autism but it will be nice if the IACC can have some input into those initiatives to book towards more child neurologists aiming towards autism and related disorders.

MR. HALL: If, this is Dan Hall. You know, if I can bring up you know, an area where I think the IACC could you know, provide some weight is that you know, we have now 90 thousand (unintelligible) shared across genetics, neurosignal recordings, MRI, clinical data. We're now you know, we've broaden from NDAR, we've expanded to all of mental health so we have you know, other data on schizophrenia, bipolar disorder that can be you know, translatable with you know, the research that's being done at autism.

And all that data is available so the opportunity to provide grants for secondary analysis to fund young investigators and research is absolutely possible now and I think the at least, the federal agencies and the private agencies still focus on the opportunity and I think it's an opportunity that's out there and can be capitalized on.

MS. NAVIDI: Yes I would agree with that because you know, there's a large expense associated with collecting data and it, what I personally say is that you know, some of the more genuine investigators still always get these huge grants with large amounts of funding and infrastructure associated with them.

So you know secondary analysis is probably the best way to start to get feet wet and get integrated within the autism research community and start to get some publications out there so I would agree with that. The secondary data analysis is a great opportunity for post docs and junior investigators.

And even down to the undergrad and grad level, you know, starting to get folks interested in this research domain area so that they would continue on into advance degree work and potentially get into the research profession.

DR. DANIELS: Thank you.

MR. HALL: Yes you know, secondary analysis, I mean, a grant for 25 thousand can go a very long way in you know, pulling down data, you know. Again, you know, we have, data on you know, genetic data on 31 thousand subjects right now.

And you know, MRI data on 10 thousand subjects and it's much you know, it would be hundreds of millions of dollars to generate that data yourself so you could do analysis on that for very little.

DR. DANIELS: That sounds like a great opportunity to highlight in the plan. Anything else on that before we move on to collaboration? I wanted to get your thoughts about trying to build out more of a piece of this chapter that would be focused on collaboration.

This is something that Alison Singer brought up in an IACC meeting and the committee seemed very enthusiastic about it about having the IACC see where they might be able to support and promote more collaboration among researchers or among researches and people out in the field so any thoughts about that and what is needed and what could possibly be done?

(No response.)

DR. DANIELS: Of course it's too bad we don't have Alison on the phone to comment on that. I'm pretty sure that she would have some thoughts. And even more broadly, another opportunity we have is to think about how the U.S. can be better collaborating with and working with the international community.

And this is something that isn't specifically within the IACC mandate but as it's obvious that the U.S. does have to interact with other countries and there is work that's being done around the world that's really important for autism and it's important to try to build on those opportunities.

Does anyone have any thoughts about particular areas where there might be an opportunity to build more collaboration with other countries in their, whether it's their nonprofits or other governments around autism?

DR. RING: I think, I think, this is Rob, I think you know, we've already touched on it several times in other areas. It's probably not surprising that it gets rigged here. But there are going to be I think some unique dimensions to navigating the challenges of sharing data across international boundaries that separate research activities of large consortia in other that emerged around autism, around the world.

EU Aims is a classic you know, example of a very large $50 million precompetitive consortia operating across the EU bringing academics and, academics that has a research excellence alongside you know, drug companies. They've built one of the larger clinical trial network structures and have partnered quite you know, effectively with patient groups and the EMA, the European equivalent of the FDA.

As these generate data, I think there's going to be some additional challenges that have to, may create barriers or obstacles to realizing that sort of collaborative potential of sharing data from these various places around the world.

It just needs to be you know an add on perhaps to the larger discussion about data access and data sharing.

The… you know, over that same bridge of collaborative connectivity between activities here in the states and globally, we'll probably travel the same expectations for data standardization, the standardization of outcome measures and other types of tools and pieces that support clinical trial readiness globally. So I think those are maybe checking the boxes of the obvious. We just want to make sure we have those on the table.

DR. DANIELS: Thank you.

MR. ROSANOFF: Hi guys, great news, it's Michael and I'm actually back on.

DR. DANIELS: Oh thanks.

MR. ROSANOFF: Reconnected. So I'd like to chime in here and I thank Rob for mentioning some of the work that we're doing around dissemination earlier.

But specific to this area of international collaboration and international outreach, you know, I think the IACC published a report a couple years ago that I think it was a publication analysis that looked at some of the global rates of publications on the topic of autism.

Although we've seen an increase in the number of publications coming from countries outside of the U.S., the U.K., outside of the Western world and more developed countries, there's still a great imbalance in the, in the number of researchers and research projects coming from other places around the world.

And I don't want to be quoted on the number but I think it's you know, four fifths of the world's population and is living low and middle income countries and certainly that segment is under represented in research.

Now, how that pertains to the work that we're doing here in the U.S. and how we can learn, how we can sort of enhance the work that we're doing, you know, through partnerships with country governments and local advocates, we have been able to really effectively advocate for the access to data that's being collected in countries around the world.

The use of that data in fact combing it with data from other countries in being able to look at some of the you know, the issues around autism media ology for example across countries.

So I think there is a place for conversation around partnership with not only international researchers but other advocacy groups, country governments, and establishing these types of partnerships at the community level but also at the government level that would allow us really not only better access to data but also to individuals with autism in those countries.

So it can really start to learn more about what autism looks like outside of the, where most of the research publications are coming from.

DR. DANIELS: Great. Thank you. Do we also have an opportunity to be disseminating up to date information both about the biology of autism and about services needs that we're learning here in the states to other countries that are still developing their definitions and understanding of autism in their communities.

We know that through the UN there's been some progress in that area trying to recognize it internationally but there's still many countries where they don't have a strong understanding what ASD and how can they support people in their countries that need help and IACC has some room to do something there.

MR. ROSANOFF: Yes sure. It's a great point. I wanted just to second that and emphasize that in the work that Autism Speaks has been doing in more 70 countries around the world, absolutely. Many countries are looking for more information around best practices in terms or diagnoses and treatment of autism and terms of building capacity for services in their countries.

And yet there's been some progress at the United Nations and world health assembly level and having resolutions passed that are encouraging country governments to look at this issue. I would caution the group though to not only think of this as a one way stream of information, in fact we can learn a lot from these international populations who have autism communities and don't have access to maybe some of the treatments of services that we have here in the U.S.

So they're using very unique strategies to help their populations and needs using community based solutions so there's an opportunity for us to learn from them as much as there is for them to learn from us especially when trying to increase access to services among our underserved and underrepresented populations here in the U.S.

DR. DANIELS: Excellent and I think this is something we're going to be discussing it at the upcoming IACC meeting on October 26 with some guest speakers from the U.K. and that might start a little bit of the international conversation.

But people on the working group can be thinking about this and as we build out the chapter, think about what kinds of opportunities may be around the corner for the IACC to have more interaction with international groups in the future.

So were there any areas? I think I've tried to hit most of the ones on our list here but are there any other areas that anyone feels like they need to comment on with regard to…

MS. RAST: I have another idea about collaboration.

DR. DANIELS: Go ahead.

MS. RAST: I'm thinking about researchers or international collaboration. I've been thinking a little bit about service system collaboration so within the united states, you know, you can think of a system as either you know, service system or the educational or vocational systems or even public support systems like social security.

So I think it could be a good idea to focus on the collaboration of these things within the U.S. so either in the way that we collect information which we've talked about in the context of research opportunities.

So we can compare across different populations or maybe even an aspirational goal of collaborating across systems to combine data from multiple service interactions for the same individual. Obviously that would be a long term pipe dream type goal but I definitely think that there's opportunity there at least beginning with the way that information is collected.

DR. DANIELS: That's true and the IACC always does try to be aspirational to try to aim high and see where we can go so I think that that's totally appropriate. So I'd like to spend a couple of minutes talking about the aspirational goal and the title of the chapters.

So the question, each of the questions in the strategic plan has an aspirational goal that describes a long term outcome that they'd like to see come from the research and services issues that are covered in that chapter.

So the aspirational goal for question seven is developing and supporting infrastructure and surveillance systems that advances the speed, efficacy, and dissemination of ASD research.

And so do you feel that there are things that we might want to add to this and we don't have to answer this all on the phone now but we've talked a little bit about outreach and collaboration as areas that we want to build in, dissemination was there. But we might want to talk about how we would reshape this to reflect where the committee things the feature is going in this area. Any immediate thoughts about it?

MR. HALL: Yes I think services is woefully not in this goal here so I think you should say ASD research and services.

DR. DANIELS: Okay.

MS. NAVIDI: Yes I agree with that. I think it's very limiting to just think of the infrastructure and surveillance as important research.

DR. DANIELS: Right and one of the reasons that was worded that way in the past is before 2014, the legislation that authorized the IACC required the strategic plan to focus on research and under the autism cares act now, that's been expanded to try to incorporate more about services and supports

And so throughout the strategic plan, we're trying to ensure that both research and services and supports are covered so that's a great point. Anything else?

DR. LIPKIN: Just for clarification, so it's not research on services, it's services as a sustained from research?

DR. DANIELS: Yes so service delivery, service provision. So the strategic plan now is going to be discussing major issues related to service provision and what can be done. So that's going to be a new aspect of the strategic plan and we've been working with all of the working groups to develop that area.

That will be a more comprehensive strategic plan. So those are some good comments. I think we can come back to this later and you might want to just you know, take some time to digest that and see what kinds of suggestions he might and we can come back to it on the next call.

The other question is whether the chapter title is still appropriate. So the chapter titles were based on consumer based questions that the public wanted answered and could be answered through research at the time and now you know, expanding that to research services and policy.

So the question that became the chapter title is what other infrastructure and surveillance needs must be met and do we want to do something different or broader than that in the future?

(No response.)

So again, I don't think that we have to think of anything specific right now. Does somebody have a thought about that?

MR. HALL: Yes I mean, I think it's, we've met a lot of these needs so it's really how to leverage.

DR. DANIELS: Okay.

MR. HALL: To me it's about how to leverage it, infrastructure as opposed to you know, infrastructure to meet needs because I think the infrastructure's now there.

DR. DANIELS: Okay.

MR. HALL: And it's the use of that infrastructure and dissemination of that infrastructure probably should be the focus but I don't have a catchy title.

DR. DANIELS: So something like how can we leverage the infrastructure system to meet the needs of the autism community or something along those lines maybe?

MR. HALL: Yes, yes, yes.

DR. DANIELS: And we can obviously play with words (unintelligible) but…

MR. HALL: Yes, I mean…

Dr. Daniels: …something like that.

MR. HALL: …even say, get back to the real constituency you know, those impacted by autism as opposed to community.

DR. DANIELS: So I didn't get the distinction. I guess when we talk about the autism community we kind of…

MR. HALL: Yes.

DR. DANIELS: …all of the community not just the people with autism but also the providers, families, entire community supporting people on the spectrum.

MR. HALL: Yes and I think that the distinction is focus more on those affected as opposed to the general research community.

DR. DANIELS: Oh I see.

MR. HALL: It's just a suggestion.

Dr. Daniels: You know, people on the autism spectrum and their families or something like that.

MR. HALL: Yes, yes I think we should you know, focus on that you know, to meet you know, to I guess better meet their needs.

DR. DANIELS: Great. Well we can start with this as a, as a possible suggestion and then work from there. So to get you wrapped up as we have only a few minutes left on the call, I think we've had a really productive discussion and this chapter probably more than some of the others had some big areas that we could add on that haven't been there in the past.

So I think that you've done a good job of covering some of those types of issues and if you think of other things after the call and you want to just e-mail them to us, we can try to get them included in notes for the write up. And so I'll be working with Alison to come up with an outline for the chapter and then Alison will be in touch with various members of the working group as well as I to help get some of the writing started and we'll try to have people with expertise in various areas contribute to developing the draft.

We're, our goal is to get a strong draft together and I understand that the people have various other commitments and so we'll work around people's schedules to the best of our ability and the IACC will be meeting October 26 and they'll be discussing some other areas of the strategic plan.

And on January 13, we'll be having a meeting and hopefully we'll have a good draft of the strategic plan to share with the committee at that time. So that's what's coming up. I will be in touch about preparation for the next call.

On the next call, you'll be talking about the three objectives, broad objectives that you'd like to create for this chapter that will capture priority areas that the IACC should emphasize going into the future, areas where more work needs to be done and these can be very broad type of objectives. And then we can provide examples of the kinds of projects that would be responsive underneath and so hopefully I think already even in just developing some of these buckets that Alison provided gives us some ideas and then some of the discussion we had I think will also inspire you to come up with some objectives.

So if you think of ideas for objectives in the meantime, feel free to send them my way and of course I'll be sending you an e-mail about the next call and soliciting your ideas and we'll talk about them on the next call. So any other questions before we adjourn?

(No response.)

DR. DANIELS: Well thank you so much for joining us. We really appreciate the thoughtful discussion and we will be in touch so have a great day everyone.

(Whereupon, the conference call was adjourned.)