U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR SERVICES RESEARCH AND POLICY

CONFERENCE CALL

TUESDAY, AUGUST 27, 2013

The subcommittee convened via conference call from 2:06 p.m. to 3:59 p.m., Denise Dougherty, Ph.D., and David Mandell, Sc.D., Co-Chairs, presiding.

PARTICIPANTS:

- DENISE DOUGHERTY, Ph.D., Co-Chair, Agency for Healthcare Research and Quality (AHRQ)
- DAVID MANDELL, Sc.D., Co-Chair, University of Pennsylvania
- SUSAN DANIELS, Ph.D., Executive Secretary,
 IACC, National Institute of Mental Health
 (NIMH)
- IDIL ABDULL, Somali American Autism Foundation
- JAMES BALL, Ed.D., BCBA-D, JB Autism Consulting
- ANSHU BATRA, M.D., Our Special Kids
- SALLY BURTON-HOYLE, Ed.D., Eastern Michigan University
- JOSE CORDERO, M.D., M.P.H., University of Puerto Rico
- JAN CRANDY, Nevada State Autism Treatment Assistance Program; Nevada Commission on Autism Spectrum Disorders

PARTICIPANTS (continued):

- LAURA KAVANAGH, M.P.P., Health Resources and Service Administration (HRSA)
- JOHN O'BRIEN, M.A., Centers for Medicare & Medicaid Services (CMS)
- LINA PEREZ, Office of Autism Coordination (OARC), NIMH
- LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds
- CATHERINE RICE, Ph.D., Centers for Disease Control and Prevention (CDC) (representing Coleen Boyle, Ph.D., M.S. Hyg.)
- SCOTT MICHAEL ROBERTSON, M.H.C.I., Autistic Self Advocacy Network (ASAN)
- ALISON TEPPER SINGER, M.B.A., Autism Science Foundation (ASF)
- LARRY WEXLER, Ed.D., U.S. Department of Education (Ed)

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PROCEEDINGS:

Dr. Susan Daniels: Thank you. Welcome to everyone who's on the line, to our listeners out in the public, and to the members of the Subcommittee for joining us this afternoon, August 27, 2013, for this meeting of the Interagency Autism Coordinating Committee, Subcommittee for Services Research and Policy.

We're going to be having a call today to talk about some potential projects that the Subcommittee may want to work on. And I would like to go through the roll call first just so that we know who is here.

So, our co-chairs are Denise Dougherty and David Mandell. Denise, are you on the line?

Dr. Denise Dougherty: I am.

Dr. Daniels: Thank you. David?

Dr. David Mandell: I am.

Dr. Daniels: And then I'll call off the names of the other members of the Committee.

Laura Kavanagh.

Ms. Laura Kavanagh: I'm here.

Dr. Daniels: Thank you. John O'Brien.

Cathy Rice. Larry Wexler. And Idil Abdull is not joining us today.

Jim Ball - oh, wait - was that? I heard something. Who was that? Idil or Cathy? If you join the call later, speak up and let me know that you're on the call.

Jim Ball. Anshu Batra. Sally Burton-Hoyle.

Dr. Sally Burton-Hoyle: Here.

Dr. Daniels: Thank you, Sally. Jose Cordero.

Dr. Jose Cordero: Here.

Dr. Daniels: Thank you. Jan Crandy.

Ms. Jan Crandy: Here.

Dr. Daniels: Thank you. Lyn Redwood.

Ms. Lynn Redwood: Here.

Dr. Daniels: Thank you. Scott Michael Robertson.

Mr. Scott Robertson: Here.

Dr. Daniels: Thank you. And Alison Tepper Singer.

Ms. Alison Singer: I'm here.

Dr. Daniels: Great. Well, several of you are able to join us today, and we look forward to having this call. So there is a set of minutes that I will be sending out to you.

Unfortunately, we weren't able to get it ready prior to the call to send it to you, but we will try to get that approved by email and then put up on the Web site as soon as possible.

And then, I would like to turn the call over to David and Denise.

Dr. Dougherty: David, do you want to go ahead?

Dr. Mandell: So thank you everyone for joining us. The purpose of this call is to try and make some headway on the two areas that we felt it was particularly important for this Group to address as our next activities.

The first being issues related to adult services and the second being issues related to health disparities in the identification and care of people with autism.

At our last talk - last time we spoke we had talked a bit about the idea of an adult
services toolkit and had been less specific
about what the health disparities project or
activities might be that we would engage in.

And all of you should have gotten an email with attachments from Susan, one that lists current research-related activity that has anything to do with sort of characterizing or ameliorating health disparities and a second being a list of autism services toolkits and resources that are currently available to people.

Did everyone get that - who is on the phone?

(Chorus of "yes")

Dr. Anshu Batra: Hey, David. This is Anshu. I'm on the phone.

Dr. Mandell: Hello, Anshu.

Dr. Batra: Hi. How are you?

Dr. Mandell: Good, thank you.

Dr. Catherine Rice: Hi, David. This is Cathy Rice. I also joined.

Dr. Mandell: Hi, Cathy.

Dr. Rice: Hello.

Dr. Daniels: David, can I just add something really quickly? For those who are on the call listening in from the public, our materials are up on the IACC Web site.

So, if you go to the "Meetings and Events" page and click on the materials for this meeting, you'll find them there.

And I'd also like to remind everyone to identify yourself as the call proceeds so that the transcriptionist can catch who is making each comment and to turn your phones on mute when you're not talking so we eliminate the ruffle of papers and so forth. Thanks. Sorry about that.

Dr. Mandell: Thanks, Susan. And so, my hope is that we can use these documents as a starting point in our discussion about where we think the priorities and energy of this Subcommittee should go.

Denise, did you want to add anything to that?

Dr. Dougherty: No, you've done it well.
Thanks.

Dr. Mandell: All right. So, my hope is that we can start with the adult services project and spend about half of our time discussing that and then making sure we give some time over to issues related to health disparities as well.

So, when we spoke, we talked about a toolkit for adults attempting to access services and also sort of a system-level toolkit as well for best practices.

You'll note from the 10 pages of
hyperlinks and descriptions of toolkits, that
there are many out there already - some for
very specific things, as specific as getting
haircuts and others much more general in terms
of accessing services, some that are really
specific to children, some that have adults in
mind, and some that really don't have an age
band in mind.

Did anyone have a chance to look at these toolkits or even their description, and does

anyone have any comments or corrections or thoughts about issues related to toolkits and adults before we delve too much further?

Dr. Burton-Hoyle: Hi, this is Sally. I think that SSI and how the states have written theirs, you know, their Medicaid plans and access to SSI is really, really important.

And in some of that, there was one of the transition things that wouldn't open. Maybe it's in here and I missed it, but I couldn't find it.

And I think that's, like, that's the key to any of those base services beyond the family.

Dr. Mandell: All right. So you feel, in your read of these toolkits, that one of the really important things that was missing was how individuals, adults with autism, could access SSI. Is that -

Dr. Burton-Hoyle: That is correct. That is correct.

Dr. Mandell: Okay. Were there other things that - sorry, go ahead.

Ms. Kavanagh: Sorry, David. This is Laura Kavanagh. In preparation for this meeting, I asked some of our grantees to gather information about adult services, tools that they were familiar with as well.

Most of the ones that they submitted were state specific, and I don't know if that's something we want to consider, or we only want more national-level resources. So, I just want to put that on the table for discussion.

Dr. Mandell: Thanks. Other comments or questions people had about in their initial perusal of these toolkits or about the toolkit idea in general?

Ms. Crandy: David, this is Jan Crandy. Is that why we didn't include some of the other ones - the states? Because, for instance, Ohio has some really good transition information.

Did we not include them because they're state specific?

Dr. Daniels: So, this is Susan. The

Office of Autism Research Coordination put
together this list. We were just trying to go

through, you know, searching various Web sites, but we didn't try to cover every single state and look through every state's information. So, this is not meant to be a comprehensive list.

It was just, you know, a list of things that were easily accessible to us. So there wasn't any particular effort to avoid putting state information. In fact, there were a couple of things from the State of Missouri that we ran across that we did put in.

So state-level information generally wasn't included just because it would take a lot more searching to get that information.

Ms. Crandy: David, this is Jan Crandy. I thought that - and maybe my file didn't work well when I gave it to you, but - because I had done some of that research and looked at other states. Did you guys utilize that at all, or no?

Dr. Daniels: Jan, this is Susan. I don't believe I received anything from you. Did you send it to me?

Ms. Crandy: No, I did not. I gave it to - I believe I gave it to David directly.

Dr. Mandell: Jan, that was totally my mistake then. I apologize. I didn't realize I was the only one on that list, and I should have made sure that Susan and her staff had it. But for those of you who didn't receive it, and I guess I'm the only one who did, Jan had done a lot of work in pulling together some resources, online resources that were available for adults with autism, many of which were state based.

So, Jan, would you be willing to forward that to Susan as well? And I think that that's something that we could certainly merge with this -

Ms. Crandy: Right, just to save us time if we're going to look at states. If we're not going to utilize it, then it's fine. If we were going to utilize looking at states, though, some of the work is done. It's definitely not complete. It was a good start, I think, that's all.

Dr. Daniels: Right. So Jan, this is

Susan. We could certainly try to integrate

that information in. And I'm sure that the

Committee may be interested in best practices

that are occurring throughout the different

states. So if there are items that would be

considered best practice, I'm sure people

would be interested.

Ms. Crandy: Right. And my hope was, I just didn't want to see us, as our Committee, duplicate work that's already done well out there in other states.

Ms. Kavanagh: Susan, this is Laura. I'll send you the list of what I got in response to our call for materials. Again, it's not comprehensive, but it's what our grantees were familiar with.

Dr. Daniels: Sure. That sounds great. Thank you.

Mr. Robertson: So this is Scott

Robertson. Just a comment, I think, on - and I

don't know what it's ultimately going to look

like with the potential toolkits - is that if

it had kind of a national look in terms of best practices, supports, and things like that, I think that that would go well in terms of being informed by what the states are doing, but I think it might get too big.

And I don't know if there was any thought of going in this direction, but it might get too big to actually go through in the toolkit state by state for all 50 states. So just, you know, a thought on that, that it might - when informal, we have in the overall discussion - but it's probably, I think, too big a thing to do, you know, all 50 states equally in this toolkit in terms of going one by one.

Dr. Mandell: Although, if they were — this is David — if they were — if this were an online resource and people could choose their states, then it wouldn't be as unwieldy, although certainly, putting together the information might still be quite a task.

Mr. Robertson: Yeah. Yeah, David, that was my concern is that on a timeframe standpoint is that we'd have to kind of do

equal justice to each of the 50 states. Plus, you know, maybe if you went for all 50 states, you might even have to do the - probably might have to do the territories of the United States, too.

And that would, you know, that could get unwieldy pretty quickly in terms of the complexity and the differences that exist, you know, among the states. I mean, that's a pretty big scale, I think.

Dr. Mandell: Sure.

Dr. Daniels: So, this is Susan. Just to understand, it sounds like maybe some of the Subcommittee members are interested in expanding this list. And then were you thinking about trying to create a Web-based - I had thought that maybe a Web page could be put on the IACC Web site. I guess it sounds like you're talking almost like creating a database, and I'm not sure if that's very feasible. But what do you think about having a Web site or a Web page that lists links in, you know, in groups sort of like they are on

the list that you have currently?

Dr. Mandell: This is David. I think it would be a reasonable role for the IACC and this Subcommittee to have to create a repository of available information. And if there were specific pieces that we felt were left out of existing toolkits, like accessing SSI or other things, to attempt to fill them in. I think it's probably beyond the purview and resource of the Committee to do something much more substantial than that. I guess the other thing we could possibly do is annotate or index a lot of the toolkits to give people a better sense of what's available in each.

Dr. Daniels: Something like that might be possible, but one of the other issues that we would have to consider is that to keep something like that updated - if you're having state information, states change their information constantly. Anyplace can change their information. And so, we could create a list, but there's not a guarantee that it would be constantly updated. And so, it

probably would go out of date eventually.

Mr. Robertson: So, one of the things that

- this is Scott Robertson. One of the things

that, you know, concerns me a little bit on

just looking to resources, and I don't know if

that's necessarily doing it justice as much on

the topic as much as having, you know,

narrative discussions in terms of things like

best practices, et cetera. I mean, I don't

know if it's going to help it.

Things are already out there in such a scattered form that I don't know if just having a few pages that just link to, you know, 90 different things is going to be as helpful to folks as actually having, you know, discussions in the way that, you know, any other organization or entity might have, you know, several pages or whatever in terms of best practices that are out there and highlighting things in a narrative form.

And the other thing is that, if it's just going to be, you know, links to other outside entities/things, in some ways, you know, how

is this, you know, not doing the same kind of thing that sort of seems like the Autism NOW

Center is doing, which is already federally funded to be doing this, you know, resource kind of amalgamation kind of thing.

So you know, I guess when I thought of a toolkit, I didn't necessarily think of, you know, I wasn't necessarily conceiving of, you know - I guess I thought more that this was going to be more like a small kind of guidebook than to different things in terms of accessing services, resources, best practices.

Dr. Mandell: What would you want the guidebook to cover that you don't feel is covered well in other places?

Mr. Robertson: I guess, from my

perspective, I guess maybe it would cover
just kind of integrate some of those things in

terms of put it - you know, what's the best

things from each of the different areas.

Because I think the problem is, I mean, all these toolkits are, you know - that are out there - are fine and wonderful. But if

you're the average parents or families or individuals out there, you're not going to read all 90 of these things. I mean, it's like information overload. And I think that that's the biggest problem out there, and it's no different with any other things in some cases with autism. It's just too much stuff out there at times.

And, like, a guidebook would help kind of narrow that down into like a smaller thing that could be an overview of different kind of areas in terms of what best practices are from, you know, as I say, from things that are happening in certain states being done better and things that are happening overall kind of nationally being done better.

And maybe pull in information from some of these tools in terms of referencing them, but not necessarily just be, you know, a bunch of links, because I don't think that's necessarily helping, you know, folks from the information overload standpoint.

Dr. Burton-Hoyle: Hi, this is Sally. And

in working with families, there's kind of two tracks towards, you know, post-high-school transition, employment, college, whatever.

It's, A, they're eligible for SSI Medicaid, and then, B, all the things that are already covered really well in this toolkit.

So, it's kind of, like, if you wanted to do some of these things and you have a child or you yourself had needs for transportation and all these other kinds of things, the funding base for it would be however your state, you know, however they wrote their Medicaid plan. So maybe even just something, like, to what people have to identify where it is they could look.

Or if they needed to go on their own, find out what their Medicaid - how their Medicaid plan was written. Because, you know, in some states your IQ has to be, you know, 65 for you to get, you know, to get eligibility. So it's different in all kinds of places. So I see it as kind of two tracks.

Mr. Robertson: Well, one thing I just

wanted to add, again tied onto that also, is that there's also a lot of - there's a substantial portion on the autistic adult end of things that a lot of autistic adults who aren't eligible for Medicare, Medicaid, you know, Social Security, you know, some of these larger systems and no matter, even if there isn't an IQ barrier, for instance, in getting an entry into the system.

Like here in Pennsylvania, we don't even make it on IQ. We have a restriction on level of care, which is just a Medicaid home and community-based services restriction. And you know, that's a restriction on level of care because it's across the country. So I hope it would be - there would be information related to things like SSI and Medicaid that's HCBS, but not limited to that because of the fact that there are, you know, some individuals that, you know, don't meet those criteria.

Dr. Mandell: So, Susan, what are the potential resources that are available to us?

I mean, I think part of - we have a lot

of different ways to conceptualize the size of the task in front of us, right?

And so, at the most basic it could be just providing one single Web page as the repository of, you know, annotated repository of links to multiple toolkits and then it could become increasingly complex from there. Ultimately, some kind of metatoolkit in which we're extracting best practices from existing toolkits and adding our own.

But a lot of that will have to do with what kinds of time people can put into this and what kinds of resources are available.

Dr. Daniels: Right. Well, your main resource is the Subcommittee. And so, if you all have time to - if you want to - do, for example, a review of toolkits, it would be whoever has time to look through these toolkits and write the reviews, or if you want to continue adding whatever, you would be able to send over to us.

We can put up a Web site, but, you know, the Subcommittee would need to do some work to

put together some of this also and how much work the Subcommittee wanted to do in maintaining information as well.

For example, we don't have a resource, for example, to put out a \$1-million contract to have some company come in and start a new Web resource for you.

Dr. Mandell: You don't? (laughter)

Dr. Daniels: No. We didn't get that appropriation. So it would be whatever the Subcommittee feels they can do.

So, for example, you could have a phone call and have a discussion of issues related to some of the things that are discussed in these toolkits, or you could write a review, or write up some narratives that could be put on a Web site, or any other kinds of ideas you can come up with that you feel would be helpful to the community. And our office would do our best to try to assist you.

Dr. James Ball: Hi, this is Jim Ball. I've joined the call.

Dr. Daniels: Hi, Jim.

Dr. Mandell: Thanks, Jim.

Dr. Ball: Hello.

Dr. Daniels: So I don't know if that helps at all. Do you have specific things in mind?

Dr. Mandell: I didn't. I'm just listening to the ideas that people have and trying to put them in some kind of context. So, and I also - Scott, have you had a chance to go through a lot of these existing toolkits?

Mr. Robertson: I've skimmed a little bit.

I just also know even for the ones that I
haven't seen that I just know from an
information standpoint is what I mean that
it's just, you know, if we were linked to
them, there would be - I can't perceive a
family that's reading all of them.

Now, maybe if we suggested for this area or something on it, but, no, I haven't - I haven't looked through on all of them yet.

But do you think it's a bad idea to be getting into looking at the stuff at another level - like it would be unwieldy?

Dr. Mandell: I guess it's a question - again, it's sort of a question of how much energy we have to put into it.

So I know that in the short term, for example, I don't have the time to go through these in a meaningful way and do that kind of extraction. And I don't know if there are other people on the Subcommittee who would be willing to take the lead in doing that kind of activity.

And then I think it would, you know, based on what kind of person power we could put into something like this, then we could make a decision about what the best strategy would be.

Dr. Batra: David, this is Anshu. I don't really have an idea, just a comment, you know.

I tend to - not that this is, you know, the gold standard - but I tend to myself, as well as refer my patients to the Autism Speaks transition toolkit. And again, I find that it tends to be fairly, you know, fairly comprehensive enough.

And they have individual states that you can click on depending on what state you're in. And it gives you very, you know, specific sort of, you know, basically a synopsis of, you know, transition between 14 to 22, et cetera, et cetera, you know.

And I think it's a good sort of basic tool right now. It's what I tend to use, and my families tend to use it.

Maybe we could take that and see if there's something that needs to be sort of picked at and incorporated with some more research that may be out there that maybe people might be interested in adding into that.

I mean, I think it's a really useful tool. And I myself have used it, and it's, you know - my son is 16. And so, it was helpful for me to get up to speed on, you know, what are the expectations for school and the IEP process, you know. And as well as vocational routes, et cetera, et cetera.

Dr. Mandell: All right. So I think your

point about an existing toolkit that can be very helpful is well taken.

And how far did you have to dig to find out that that was a good place to refer people?

Dr. Batra: Not very far at all. I just, you know, I - Autism Speaks, transition toolkit, I mean, it's basically the link that Susan sent. And if you look on that page, on the side there is employment, there's housing, there's, you know, a variety of postsecondary options and things like that, so depending on what the needs are for emerging adult or the adult.

And again, I personally have found it to be useful for my, you know, for my needs, and I refer my families to it.

So I'm just not aware of all the other ones that have, you know, that Susan has compiled and has sent to us.

Dr. Mandell: We should also think about this in stages, right? So doing a first step is not mutually exclusive with some of the others.

And so, if as a first step we wanted to pull together the existing toolkits, organize them by topic, and provide some annotation about what's available, that might be a good first thing to put on the IACC Web site. And then we could see what kind of effort and how long that took us.

And then from that process, think about what the next steps may be. And it seems like the next steps may be to fill in things that we think are missing rather than necessarily put together a toolkit of our own.

Dr. Batra: And this is Anshu. I would agree with that. I think that, you know, there's a lot that's already out there. It's just a matter of, I think, just, you know, compiling it and putting it sort of in an organized fashion.

And I think, again, I think for families and individuals, you know, they're just looking for a place to get some information.

And I agree with - I think it was Jan who

said, you know, that it really has to be state by state because, you know, I'm interested in California because that's where I live.

But you know, someone in Pennsylvania may have, you know, different state laws that apply to them. And so it's nice to know overall what the, you know, overall, you know, sort of consensus is, but state by state things differ.

Mr. Robertson: This is Scott Robertson. I don't, you know, disagree on that. I was only suggesting that state by state it's just something you want to think through and do carefully so that you don't end up with lots of paragraphs on the bigger populated states like California and Texas and then have almost nothing on other places where there aren't as effective service systems or things aren't as well developed or for whatever reason.

I mean, that's the only thing that I just worry about - is to make sure that you do justice to make sure that each state, you know, has significant information on there and

that we don't end up with 15 states that are doing things well and maybe have more population and more resources, that kind of dominate the discussion on the state by state.

That's the only thing that I worry about.

Dr. Mandell: Well, that could - I think that could be once we begin compiling all of the Web sites and putting - and - toolkits and putting them in one place. That would be something that we could - that we'd be able to figure that out while doing some good, and then figuring out where we needed to go next.

Dr. Daniels: David, and Subcommittee, I think that it also might - this is Susan. It might be a good idea for us to touch base with Autism NOW to make sure that this, in fact, is not re-creating something they already have.

I didn't go extensively through their Web site to see whether they have a list of toolkits, but it could be that they have something like this already or that they would even want to post this type of information, because that is the purpose of their Web site

is to be kind of a clearinghouse of information.

So I think, you know, we certainly could touch base with them to try to -

Mr. Robertson: Yeah, to add to that,
Susan, they already have it kind of broken
down in some ways by categories for transition
and relationships and employment.

They already have - I mean, it's not necessarily one essential document, but their Web site basically is that kind of a setup in terms of how it's organized.

I mean, that was the reason why I also suggested the more metalevel kind of thing, because that is different than what they're doing right now.

If we're simply mostly linking to resources, then we're doing basically, you know, kind of about the same thing, maybe even less than they're doing, because they kind of have a little bit of narrative, like a page, I think, for each - on each kind of - set of resources that talks about the categories or

whatever.

It doesn't necessarily go into massive amounts of depth, but, you know, it's not necessarily just linking to resources.

And at the metalevel, overview of, you know, best practices and going through existing resources in a narrative, that would not be duplicating, because that would be new ground.

Dr. Mandell: Scott, is that something that you'd be willing to take the lead on?

Mr. Robertson: Possibly. So one of the things that I have on my time constraint right now is that I'm kind of working on finishing my Ph.D. dissertation.

But after - and I don't know what it looks like on timeframes, but I can certainly give more time to this stuff in pretty much October, November, you know, December, more so than September.

So, like, after I defend my thesis, like, I'll have a lot more time for this then.

Dr. Mandell: So I think part of our

challenge is, you know, trying to juggle exactly the challenge you've just described in sort of the time commitment we're asking of our Subcommittee members against what we think would do the ultimate good.

So in between your finishing your dissertation, do you think it's reasonable to at least begin to compile those toolkits and be able to present them in one place or for some kind of -

Mr. Robertson: Yeah, I could - I could start a little bit. I mean, I can't - I can't necessarily give, you know, a hundred hours or anything like that, but I could definitely within the next few weeks I could, you know, here and there, start digging into things.

The other thing, too - and maybe Susan can correct me on this - is that I think we're not under the same exact timeframe as the - as like the Strategic Plan needs to go in at December to Congress, but the materials we're developing here, those don't have to be completely finished by December.

There could still be work happening on them into 2014; is that not correct?

Dr. Daniels: Yes, that's correct. This is Susan. You can continue working on these projects until September 2014 at least.

Mr. Robertson: So that being considered, it's not necessarily like we have to hit some kind of December 15th, you know, drop dead and the whole thing has to be finished, I think.

Dr. Mandell: All right. So do people feel that it would be reasonable then to gather these toolkits and then also to add in others that people have identified, some that are state specific, some that are national, and collate them into one page where people can try and find what they're looking for through existing toolkits?

Mr. Robertson: And by that you also mean, for instance, for states, Medicaid home and community-based services, like, trying to pull in information as possible for each state, you know, in terms of what their resources look like specifically on that.

Dr. Mandell: Well, I think that if
there's something written that's available for
that. I think this first step would be what
can we provide, what can we pull together
where we would not have to do a lot of
additional writing.

And then I think the next stage would be to review that and think about where some additional writing would make most sense and be most beneficial.

Mr. Robertson: Okay.

Dr. Mandell: So other members of the

Committee, do you think that this is a

reasonable approach to take? Are we on the

right track? The wrong track? Are there other

places we should be putting our energy when it

comes to thinking about adult services?

Dr. Burton-Hoyle: This is Sally, and I think we do need to find out what Autism NOW has. Because, again, I'm looking and click - I live in Michigan. Clicked on Michigan's resources for adults, and it was very incomplete.

And also what happens, people then click on something and then they say, oh, I'm going to go there, and then it comes back to the eligibility issue.

So again, I guess my heart is in thinking with those folks that can't do any of these other traditional kinds of things, but they're going to have to be - they're going to have to be supported through Medicaid.

And again, every state has a state plan for this. And you know, that's got to be compiled somewhere. So I mean, is there somebody that would know where that is, so that maybe somebody who lives in Ohio, they could click and that would say this is the eligibility requirements for being eligible for Medicaid?

Dr. Mandell: I think that - so Doug

Leslie has a grant where they are looking at

some of the Medicaid eligibility requirements

for autism through Medicaid waivers.

And I know that Stuart Spielman at Autism Speaks has done a lot of work in this area.

And so, there may be things already in existence regarding state eligibility requirements that we could pull in as well.

I think that would be part of sort of our search and fact-finding mission here.

Ms. Crandy: Right. This is Jan Crandy.

And there's going to be some states that

aren't - because of the functioning level and

what the requirements are to get in those

doors - that folks aren't going to be able to

get served through the state at all.

I know our state, if you're a higher functioning, you can't meet the level of care for our MR waiver; you're not getting through the door at all. So there's nothing for that group of - that population of - medium to higher functioning individuals with autism - aren't going to be able to get served.

So we need a recourse for them to be able to --

Dr. Burton-Hoyle: Right. So, there's three types. Those that are eligible, those that have states that have very limited

eligibility requirements, and those that don't need it.

Mr. Robertson: Yes, well, this is also what - this is Scott. It's also what I was pointing out, is that there are - for all states for their home and community-based services - there's already the feeling of level of care, which in some cases is just a general Medicaid thing in terms of the broad national restrictions that, who knows in the future whether that may change or not, that at least right now exists in the full Medicaid rules.

So it's across the board nationally that there's a feeling with which, you know, many autistic adults will not meet that threshold no matter what state they are and no matter what their DD system looks like because of that level of care centered around ITF criteria, because of how the waiver systems, you know, were set up around originally in, you know, otherwise out of institutional models.

So you know, that's just something to keep in mind is that, you know, across the board you're going to see that as a general trend.

The other thing I just wanted to add just briefly was that is it possible also maybe to keep a list, maybe a running tally, because this is also where the document contributes — is that there are some certain areas that are already known of areas where there isn't much information written at all about life for autistic adults.

And I know that one of which is driving and transportation tends to be a pretty scant area. I know it's covered a little bit maybe in some of those other toolkits, but probably not, you know, in the depth that's helpful as much to folks.

And I know that comes up a lot when I'm at conferences and things like that in terms of transportation issues for autistic adults.

Dr. Mandell: So, I'm sorry. I want to make sure I understood your suggestion.

Your suggestion was to keep a tally of things that we think are not well covered in -

Mr. Robertson: Yeah, on the side keep a tally, like a running list of different topics that we already know are not covered as much in the guidebooks or that we find when we're looking through them that are not covered.

And that's, you know, another area where this toolkit can contribute is maybe helping to at least fill in the gaps a little bit maybe with some information that's not already there for some of these kinds of topics.

That's what I'm just recommending out there. I don't know if you want to necessarily go in that direction, but that is certainly an area where, you know, it could definitely, you know, be helpful for folks is that some of those topics like I know where they don't have, you know, good information at all.

Dr. Mandell: I think it makes a lot of sense to try and cover, you know, try and, like you said, keep track of things that don't appear in any of the toolkits.

Dr. Rice: This is Cathy. Would that be helpful for Phase 2 of saying - because we're thinking about toolkits and I think we're also then talking a bit more about resource and service guides that are a little bit more in depth and specific than some of the toolkits may be.

And if we look at what the - well, maybe not specific, but that are maybe more specific to state and local issues versus more general quidelines.

And if we start with the more general knowledge toolkits that are out there addressing the specific topics like on this list and then in some way think about what we can add uniquely is to describe the need for additional guidance, you know, it's somewhat along the lines of the Strategic Plan of saying, well, here are the gaps and the areas where we really do need some accessible, clear information about addressing these certain areas.

Maybe that's Phase 2 of this process.

Dr. Mandell: I like that idea a lot. All right. So if we were to agree that our first step would be to begin to collect these links to these different toolkits to go through them and have some brief description of what was available to families at each, what would be our next steps in order for that to happen?

Dr. Daniels: So David, this is Susan. I just want to get a little bit of clarification.

When you all were talking about resource and service guides and service eligibility guidelines and so forth, was the Group talking about trying to find out what states have available and simply finding that information or trying to actually develop that information?

Because I would say that to develop that information you'd have to be a real expert in that state, and I don't know that our Committee is really in the position to do that.

So I'm assuming that what they meant is going out and looking at various states to see if there is an existing guide to how to use the services that are in that state.

Dr. Mandell: I thought we were looking for existing information at this point.

Dr. Rice: Yes, this is Cathy, and what I was thinking was that existing information, but then the next step is to basically putting out more of the call for the need for certain types of additional information so that experts and groups could act and develop toolkits in those gap areas.

Dr. Daniels: Okay.

Dr. Rice: Not necessarily the Committee.

Dr. Daniels: Right.

Mr. Robertson: Yeah, Susan, one thing to add, too, is that - I don't know whether this is feasible or not - is that possibly if things can't be found as easily, say, online or otherwise, is it possible maybe to contact states and maybe they have them electronically, you know, available, but they

just doesn't post them online or circulate them, but maybe there's - in some cases states add guidebooks to their systems that just aren't, you know, that they could give us to make available that they haven't shared yet.

Dr. Daniels: Depending on what process you decide on, if you're going to assign each Subcommittee member a few states to go gather the information from each of those states, then that person could be in charge of calling up whoever in the state if the information isn't online.

Although, I would hope most states put their information on the Web.

Mr. Robertson: Yeah, this was just - this was in the event that for all 50, that one didn't, because you never know that there might be an outlier here or there.

Dr. Daniels: Or people would be welcome to use whatever means they can to get the information they need.

Dr. Mandell: All right, Susan. Do you

feel like you have the clarification that you were looking for?

Dr. Daniels: Yes, I think so, but you're talking about having the Subcommittee potentially split up and gather information from various sources on various topics and then put that together in some way.

Dr. Mandell: Right.

Dr. Daniels: And maybe even discuss it further.

Dr. Mandell: Right.

Dr. Daniels: Sorry. I know this is pretty simple. Just wanted to make sure that we all know what we are talking about.

Dr. Mandell: Oh, I appreciate it. All sorts of things that seem simple to people also, first of all, aren't, and then everybody hears very different things. So I appreciate your clarifying that.

So it sounds like the next issue would be, you know, the thing about how many volunteers we could get to do some part of this and splitting up tasks either by state

or by type of advice or instructions that we're looking for.

Mr. Robertson: Well, related to that,

Susan, is it limited to - like development of
this thing - is it limited only to

Subcommittee members?

Are we allowed to, you know, have any assistance from any other folks, or, like, what are the restrictions of it?

Dr. Daniels: This is really a task for this Subcommittee. So I wouldn't try to task another Subcommittee or the full Committee with -

Mr. Robertson: No, no, no, no. I'm saying are any non-IACC folks allowed to provide any assistance with this, or is it only limited to IACC folks that can create this?

Dr. Daniels: I guess if Subcommittee members feel that they have outside people they want to contact for assistance, you can contact people for assistance.

I'm thinking - these are my thoughts - I
know that through the fall the full Committee

is going to be really involved in updating the Strategic Plan.

Mr. Robertson: Yes.

Dr. Daniels: And so, you're going to already be having a huge series of phone calls and meetings. And so, I wouldn't advise convening another Group of outside experts to try to help you with this, because it will get really confusing if you have - you have - another whole set of meetings going on, on top of the meetings that you'll already have.

Mr. Robertson: Okay.

Dr. Daniels: So if you want to informally, for example, if you have three contacts on the outside that you think really know this area well and could help gather that information for you and are willing to help, you're welcome to contact them and ask

Mr. Robertson: Yes, yes, that was what - I meant it more informally, not necessarily like having a call for experts like we do with the Strategic Plan. I meant more of

informal assistance.

Dr. Daniels: Okay, yes. If you want to, that would be fine.

Mr. Robertson: Okay.

Dr. Mandell: So all right. So, people, you've got to stop volunteering all at once, because we can't get your names down.

But I do think if this is something we want to take on, then I think we're going to need people who have time and think it's important to step forward to provide some help.

It's certainly something that I could devote some time to. Are there others who would be willing to help?

Dr. Burton-Hoyle: Yes. This is Sally Burton-Hoyle. I can certainly volunteer.

Ms. Kavanagh: This is Laura Kavanagh.

I'll volunteer as well.

Dr. Dougherty: This is Denise. I'll check to see whether I can get some help here at AHRQ.

Dr. Mandell: That would be great.

Dr. Ball: This is Jim Ball. I can also get out to all of our hundred affiliates if we have something we're specifically asking and gather information as to each of the different states that we have affiliates in.

Dr. Mandell: That would be very helpful if we could do something state by state.

Would it be worth - Susan, do you think it's worth, given the time, for those people who did volunteer, could we set up a call just for those folks to talk about divvying out responsibilities and -

Dr. Daniels: Sure. We could have a follow-up call to talk about the project specifically.

Dr. Mandell: That would be great, because I am conscious of the time and want to make sure we also talk about health disparities.

Dr. Daniels: So I have David, Sally,
Laura, Denise, and Jim. Are there any others?

Mr. Robertson: And me. Scott.

Dr. Daniels: Scott. Anyone I missed?
Okay, thank you.

Ms. Kavanagh: David, this is Laura. I'm very interested in the disparities discussion as well, but unfortunately I have a conflict at that time, so I'll look forward to getting the notes.

Dr. Mandell: Thank you for letting us know. And thanks for being on the call as much as you could.

Ms. Kavanagh: Okay. Thank you.

Dr. Daniels: Thank you, Laura.

Dr. Mandell: All right. So the next - any final thoughts or comments about the toolkit with specifically a focus on adult services before we move on?

All right. So let's talk about health disparities. So also included in that email was a list of projects that some directly, some tangentially related to identifying, understanding, or ameliorating disparities among traditionally underserved groups.

Many international projects - some related to screening and diagnosis, some related to awareness, and some related to

intervention.

When we discussed the issue of disparities and taking a more proactive approach, the thing about disparities rather than just acknowledging that they exist, that there was not a lot of specificity in what we thought the focus of the Subcommittee should be.

I don't know if people have any specific ideas about what the Subcommittee's role could be in bringing attention to or thinking about disparities?

All right. I'm going to take that as a no.

Dr. Cordero: Actually, no. I'm sorry.

This is Jose Cordero. I was on mute and well, I think it's very important that the
Subcommittee looks at its part of the whole
thing of service. It's how do we ensure that
they're exactly reaching all the communities?

And the major health disparity we have with autism is, one, early recognition, and number two is access to service.

So I think that the short answer is I think we need to say something, do something. I'm not sure what that something is.

Dr. Mandell: I'm sorry. I didn't hear the last sentence, Jose.

Dr. Cordero: I say I think that we have to do something, and we need to address this, but I'm not sure what that something should be. I think that's what we need to talk about.

Ms. Idil Abdull: Hi, everyone. This is Idil. I'm sorry I'm late.

Dr. Mandell: Hello, Idil.

Dr. Daniels: Hello, Idil.

Ms. Abdull: Hi there.

Dr. Mandell: We're just about to talk about your favorite topic.

Ms. Abdull: Yeah, I know. I was trying to at least make it for that one, and I was on mute for the other one. So I can volunteer for the adult services as well and try to figure out what at least Minnesota and the Midwestern States do.

Dr. Mandell: Thank you.

Ms. Abdull: No problem. And then on the disparities, it's such a tricky, complex question, but everybody knows we have a problem with it, but we can't somehow seem to figure out how to address it.

And I think a lot of times it's what I find out in my minute and a half of advocating is that people know it exists, but they don't really know how to address it and because the research has not been done to say we need to do one, two, three to address it.

So we know research has been done to say the diagnosis for, you know, children of color and people of color is late, the services are less, but how do you address that gap?

Is it, maybe, making sure that several grants and aids that go to state health departments and state Medicaid agencies, make sure that they contract and share the resources with minority-owned organizations that's the parent's choice, or is it because

we may be training the pediatricians to know how to talk to families of color and give them the information and get the information from them?

But where I find it hard is that a lot of people - because research lacks - they don't really do anything about it. So I don't know if we can recommend on the Strategic Plan; we need to do research on how to decrease the gap. We know it exists, but how do you decrease it?

Dr. Dougherty: I think that's what David was saying. This is Denise.

Ms. Abdull: Hi.

Dr. Dougherty: I think he did a very nice analysis of what we have in front of us.

Dr. Mandell: So Idil, I, as always, agree with you. And I -

Ms. Abdull: I owe you a dollar for that now.

(Laughter.)

Dr. Mandell: But I wonder - certainly in the latest - in the update that we wrote

recently and in a lot of what there is —
there is, you know, general consensus that
these disparities exist, less work done to
understand why they exist, and even less work
done to ameliorate them.

And I wonder if — and I wouldn't say that our position on that and what we presented in that update was particularly nuanced. I wonder if there is the opportunity for us to take a more sophisticated and nuanced examination of existing research, published research, practices that may be out there that haven't been well studied, and research that's underway to examine more fully where we think the gaps are and the appropriate next steps are in disparities research in this area.

Ms. Abdull: Right. So how do we do that?

I mean, I have ideas and theories, but a lot of times it's because it lacks research.

Personally, I think there are not enough providers of color so parents can feel comfortable and go to an autism therapist who

looks like them and understands their culture. There are not enough pediatricians of color.

And then the resources that go to the states are almost never shared with communities of color, organizations or communities. So how do we - and when I try to ask CMS, they just say, "Well, you know, this is the way we've always done it. We just fund the mainstream agencies, and that's just it, the way it goes." And somehow somewhere, that needs to change.

And I don't know if you guys remember, but that the parent said when he was, you know, at our meeting last time, sometimes parents feel more comfortable if community-based organizations are giving them information about the early diagnosis, the early intervention, what they are, the comorbidities.

You feel more comfortable if you're
Hispanic and you're going to somebody who
speaks your language, who understands your

culture, but it doesn't happen. Those organizations don't get funded.

In Minnesota, we can hardly get minority organizations funded by the Federal or even the state, because it has never happened before, because there's no research that says that's what needs to be done in order to decrease disparity, because they don't - nobody says, like you said, Dr. Mandell, why is it high? We know it's high, but why is it high?

Dr. Cordero: Well, this is Jose, and I agree that particularly we need to find ways to develop more health providers for families affected by autism.

I think that there is, like, three different areas that need to be addressed.

The first one is, do we have a measure of the differences in terms of early recognition of autism among children of color?

And I think that one of the areas that we need to enlist is the programs like the surveillance programs that are funded by CDC

and others and that actually have sufficient numbers in terms of whether it's Hispanic,

African American, and so on and to begin to have some kind of national number on are we moving in the right direction.

So we need to have something that could measure whether we are just staying the same or making some progress or not. So that's, I think, that's one thing that can be done, and it's to encourage surveillance systems on a regular - basically on their regular reports once a year or whatever, that they are able to look at where are we in terms of recognition of autism in different racial and ethnic groups.

The second is a - how could we have some systems that measure how long does it take for children to have evaluation and getting services. And that's something that I'm not certain how we can do, but it's certainly something that we must encourage.

Dr. Mandell: Jose, are you saying - are you suggesting with the last thing - that

that's also a surveillance question, or were you thinking about it as more action oriented?

Dr. Cordero: If I could summarize one, I think we need to encourage the surveillance systems to keep track of age of recognition, diagnosis in all different racial and ethnic groups. I think that's surveillance.

From the other part in terms of the question of - it's really a question of access to service. And it's how we have some research going on in different parts of the country about what are the barriers to accessing service to all children in minority groups or communities of color. That's the question.

Ms. Abdull: I agree. I agree with the research question. We know there are barriers. So even if surveillance is done, we know. We don't have to ask Jack and Jill. We know there are barriers.

But why there are and research for that and also how to - so, ideas. Research to

have, like, solutions. This is what we came up with. We know it existed. This is why it existed, and this is what we recommend.

Because then people like me can take those recommendations and can go to agencies like HRSA and say, you cannot keep funding mainstream agencies to talk to minority families. It hasn't worked. You've got to have some collaborative and inclusive organizations helping these families, but without research, I'm just, you know, worried.

Mr. Robertson: So, I just wanted to add something to this discussion. This is Scott Robertson.

So one thing, you know, taking an idea from the broader DD community is that many entities have been developing guides and toolkits, et cetera, on cultural and linguistic competence to be helping to educate, you know, government agencies, private organization service providers, et cetera, on not only cultural differences with

respect to, you know, broad-based kind of thinking and also how they understand and think around disability, but also linguistic differences and language barriers that we have in different communities in terms of, you know, Spanish or any number of many, you know, tens of other languages that are in this country among different minority groups.

And so I think I should inform discussion on things, too, as what does it look like, you know, in terms of incorporating their DD broad-based toolkits or autism-specific ones or otherwise that can help with education around cultural and linguistic barriers.

And that may be one of the reasons why, you know, we see some of the challenges that we have right now, is that people just don't, you know - you have these gaps in both culture and language.

Dr. Mandell: I think these are all, I think, Idil, both yours and Scott, your thoughts are all very reasonable hypotheses about why these challenges exist, some of

which we have more evidence for than others, and some of which lend themselves to immediate study more than others.

I wonder if that would be a, you know, in terms of thinking about a document that this Subcommittee could come out with about what the next steps are in addressing issues with disparities. We could certainly present some hypotheses like that to be tested based on the existing literature or observations of existing practice.

I mean, my thought is that while we don't, you know, all we do is make recommendations to the Secretary as a Committee, but it's wonderful how often those recommendations then turn into a Request for Applications or Program Announcements related to funded research.

And so I think that this is one of the ways in which we can most directly drive the research agenda around autism.

Ms. Abdull: Uh-huh. Uh-huh. I agree. Go ahead.

Ms. Redwood: Hey, David. It's Lyn
Redwood. I just also wanted to suggest that
we think a little bit more broadly about
disparities and also include in that access
to health care for individuals with autism.
Because we know, you know, from all the
reports we have received from parents over
the years, it's been really difficult for
them to get health care.

I know that's even been reported in the research literature, and I think part of that is that we don't have as many people trained in terms of being able to evaluate individuals with autism for different comorbid medical conditions. So I just wanted to ask that, you know, we also think about including that as a health disparity as well.

Dr. Mandell: So are you thinking about that as a disparity that people with autism face separate from people without autism, or within people with - among people - with autism that certain groups experience barriers to access - barriers to health care

more than others?

Ms. Redwood: I think a little bit of both, David. I think overall every person with autism experiences some barriers to receiving appropriate health care.

But in terms of certain individuals with autism, people who are nonverbal who have difficulty communicating their health care needs, I think that's a segment of the population who oftentimes have their health needs overlooked.

Mr. Robertson: Again, this is Scott. I concur definitively with that. It's just that I agree that that may be a good idea is that there's two different, you know, areas.

So there's the other diversity aspects that in terms of, you know, autistic people who come from, you know, children, adults, and their families from minority populations in terms of gaps, you know, in gender or socioeconomic, rural, et cetera. But then you also have, you know, existing things around, as was said, in terms of folks who have major

communication challenges need to use augmented alternative communication or otherwise, for instance, sometimes -

(Telephonic interference.)

Mr. Robertson: - but I believe, offhand that the Aspire toolkit on health-care-related access for autistic adults goes into that.

I know there's an article that I am going to be — it's soon going to be under review on my end related to — that I coauthored on — on how autistic adults and children may have difficulties with interacting with health care providers specifically around issues of pain and pain management. That communication was definitely a major factor and discussion, you know, that some individuals may have a lot more challenge, you know, in the health care system because of communication.

Dr. Mandell: So I think that that's a critical issue. I wonder - so it's not the way that we sort of in our conversations at least implicitly as a Group conceptualized

health disparities or disparities in access as to care.

We've generally talked about subgroups of people within those who have, you know, among those who have autism rather than comparing the experiences of people with autism to others.

And I, you know, I don't have strong feelings about this, but I would like to hear from other people on the Subcommittee about whether we want to consider the issue of access to physical health care for people with autism within this context of disparities, or do we want to think about it as a separate issue?

Ms. Abdull: Hi, this is Idil again. I don't know if I understand you correctly. But just to be on the safe side, Lyn, were you talking about disparities for, like, more classic people, you know, people that have classic autism, or nonverbal, whose health care needs are not met often because they can't communicate?

And so, how do we make sure that there isn't a barrier for them just because they're not able to communicate?

Ms. Redwood: That's part of it, Idil. I think the lack of communication is there, but also I think there is overall sort of a lack of awareness with regard to health care providers of the underlying problems that individuals with autism can have whether it's GI or sleep or seizures.

And oftentimes, a lot of the behaviors get sort of grouped in as just being part of autism and that they're not adequately investigated.

I know when my son was little, you know, I had those problems when I would take him to the doctor. And if there was something, you know, that he was doing if he had pain and was doing repetitive behaviors, instead of investigating what could be causing that, you know, I was told, "Oh, well, that's what all kids with autism do."

So that's the point I'm trying to get at,

is probably education of health care providers more about looking more closely at the behaviors to rule out underlying medical conditions.

Ms. Abdull: I agree with that one. We need more - we need more awareness as we had on the last IACC that there were obviously a couple of doctors that said everything is not just behavior autism. There are a lot of medical underlying conditions, including my son. They would - you know, he would touch his tummy and the doctor would say, "No, no, it's his behavior. This is just the way kids with autism are." So maybe more training and more awareness that autism is a medical condition in addition to behavior concerns.

Dr. Burton-Hoyle: This is Sally. And when my brother died a couple of summers ago and he did not have the ability to explain what was going on, everything was written up as behavioral management sorts of things.

What I think should happen is that families or those closest to the individual

that will be going to the doctor with them become assertive, comfortable, whatever you want to call it, with explaining that - how the person, you know, what the person might be communicating so that they are taken seriously and it's not written off and that tests are given and on and on, because the person is not communicating verbally.

Dr. Dougherty: This is Denise. So this is a bigger issue that we were trying to get to, I think, in having Jim Perrin, the incoming president of AAP, come in July and perhaps have a special session at the AAP national conference in October.

Susan, is any of that happening, do you know? I know he came to the meeting. But as far as followup and working on these issues of how the medical pediatric community treats people with autism -

Dr. Daniels: There is another Planning
Group that's going to be set up to talk about
that. So I don't know if this Planning Group
or this Subcommittee also wants to take on

that issue, but there is a separate Planning Group that is going to be created to look at that with what the Committee decided they wanted to do.

Dr. Mandell: This is David - sorry. Go ahead.

Ms. Singer: Yeah, this is Alison. I was just going to say that in followup to Dr.

Perrin's visit, a group of us outside of the IACC is now planning - we've been invited to meet with the Community Relations Board of the AAP - and that's going to happen on September 11th.

So we can certainly use some of that time to bring up these issues as well.

Dr. Rice: This is Cathy. I think Dr.

Perrin had said for this AAP conference it

would be hard to get a whole new session

included in the program, but myself and Dr.

Georgina Peacock already had a session on

early identification of autism, and we've

added information about safety issues and

wandering in particular into that session.

That doesn't address all of these issues that we're talking about, but it was one step in trying to address one of the issues that we're concerned about.

Dr. Mandell: This is David. This seems like a really important issue that perhaps deserves attention in its own right.

And I would be concerned the more I listen to people talk, that combining it with the issue of disparities and access to care for particular traditionally underserved groups, that one of them will get lost or that the message will be diluted in some way in trying to combine these.

And they certainly intersect at important points but may be different issues. And I wonder if it's worth adding a third topic, then, in this issue of access to medical care for people with autism. Have you all talked about that?

Dr. Cordero: I think that that makes sense because it is - the access piece - is one that in itself is very complicated. And

then from there you can talk about access and then what are the different levels of issues of access that you may have in the population in general. You may have people with specific racial and ethnic groups or socioeconomic or in some geographic area.

Mr. John O'Brien: David, this is John O'Brien. I think you're right, you know. We've been struggling a bit here with thinking about access in a different way. And that is what's the - what we call the network adequacy.

And so, you know, some of the conversation that I have listened to today — I think of how do we use the research. And there's been a fair amount done in terms of do we have enough trained clinicians or practitioners that are delivering, you know, ASD-specific services.

And then, you know, do we have enough practitioners that are competent to provide medical services to individuals that have autism? And then even more complicated, you

know, individuals within, you know, certain subgroups of that group to be able to offer services.

So I'm not sure kind of how we take or how we harness the research and come up with some smart ways to give states or other payers some good ideas about how they think about network adequacy, but ultimately it would be helpful if the research were able to lead us there.

Dr. Larry Wexler: Hey, this is Larry
Wexler from the Office of Special Ed Programs
in the Department of ED. Can you all hear me?

Okay. I just wanted to just throw in an observation, and I have shared this in writing to some relative to the other
Subcommittee that I'm involved with.

The concept of autism-specific services is one that is somewhat troublesome to the Department of Education.

We, you know - under IDEA, every child is entitled to the services they need, and they're not label based, ever.

So I would just caution in any of these written - these discussions and that if you're talking about school-age kids with autism, that's an issue for us. That whatever the service is, if it's an ADA service, that can be just as relevant to a child without autism and speech language, you know, sensory integration, anything along those lines is not disability specific. It's service specific to meet the individual needs of the child.

So I just wanted to chime in as a caution relative to that characterization of services. Thanks.

Ms. Crandy: This is Jan Crandy. I want to follow up with a comment on that. And yes, it is individualized. That's why it's called the Individual Education Plan, but it is very hard to get a child ADA that has autism to think that they're going to provide that service to other disabilities.

In reality, that's probably unlikely because it's expensive.

Dr. Wexler: Let me just say it's not an issue of whether it's expensive or not. I mean, the position that OSEP would take is that we never talk of services specific to disabilities.

We've very cautious about that. And I can assure you that there are many services that parents obtain for their children that are immensely expensive that are not necessarily for a child with autism.

I mean, I don't want to in any way put a wet blanket on any of the discussion. I'm just saying that it's something that I would suggest you remain cognizant of. Because any document that comes through our Department that relates to autism-specific services, we would raise that issue.

Ms. Crandy: One more question. So for our children who are deaf, we do not say they need interpreters; that would be disability specific. So I'm just wondering why autism doesn't have disability-specific needs. It does.

Dr. Wexler: I'm not saying it doesn't, but we don't characterize services based on disability.

I mean, interpreters can be provided and can be characterized in many, many different ways. And even within the deaf community, there are many, many different approaches to communication.

So the issue becomes what service do they need? Do they need an interpreter? Do they need - does the child need an interpreter?

Does he need signing exact English? Does he need, you know, a variety of different things?

So I'm not sure what service you could say was autism exclusive. And I guess that's what I'm - it feels when you say "autism-specific services," that it's autism exclusive. And we would -- I'm sorry. Go ahead.

Dr. Mandell: Larry, this is David. If we were to talk about them as services that children with autism tend to require, would

that be -

Dr. Wexler: No. I would say that it would be, you know, I would characterize it as services that children with autism frequently need to meet their individual needs.

I just -that's, I mean, and I think
that's right. Yeah, most, you know, Braille
instruction is almost exclusively for kids
with visual impairment. Yet I could see
someone trying Braille with a child with a
whole variety of different disabilities that
weren't necessarily visual who somehow was
connecting tactiley to language as opposed to
visually to language. So I mean, that's - I
mean, it's not a huge, big deal. I just, you
know, I want us to be aware that our law is
the law.

Dr. Mandell: So why don't we keep that in mind as we move forward? It sounds like it would be an issue that we'd be able to address semantically in a document that we were -

Dr. Wexler: I totally - I totally agree.

It's just a word of, like you say, let's just
keep it - be aware of it.

Mr. Robertson: So David, this is something I've also wanted to add on this, you know, related to that on keeping cognizant, is that it seems very commonly at times when we talk about, you know, access to, you know, medical care and health services that the focus, you know, shifts to the word "children" at times or the focus shifts on pediatricians.

And I just want to also keep folks cognizant that folks, you know, across the lifespan, autistic adults across their lifespan, have trouble accessing health care services.

And sometimes some of the larger challenges actually sometimes tend to happen when folks shift into adult life, wherein some cases they're accessing health care services on their own or with less extensive support as they would when they were, say, 5.

So it's just something to keep in mind in

there. And that's one of the reasons why that toolkit, specifically around autistic adults accessing health care services, was needed because adults may not necessarily, you know, in many cases may not necessarily want to, you know, be bringing their parents, you know, into the waiting room or something like that or may live, you know, thousands of miles away from their parents or family members, but may still, you know, may have major barriers in terms of being able to access health care services that aren't understood that well and that aren't being researched pretty much, you know, at all.

There's almost no research around autistic adults having barriers to accessing medical services.

Ms. ABDUL: Hi, this is Idil. I have to say I agree with Dr. Mandell in his original statement of that. Apparently, there's obviously not a single disparity. There's disparity in adults, disparity in medical care, there's a disparity in racial, in rural

area, socioeconomical, people who are low income.

So I mean, there are just so many disparities, and I think we don't want to dilute - but each one deserves its own - and so, I'm not sure what to do here, but it just feels so overwhelming.

There's just disparity in every corner with autism. So how do we tackle it and not dilute, but then also not leave any one particular group, because every group is important and everybody with autism is important?

Dr. Mandell: So could I suggest that we it sounds like there are a number of people
who feel very strongly about the issue of
access to medical care for individuals with
autism.

And this is something we addressed in our update of the Strategic Plan briefly and may really be worthy of further explication and a call for both demonstration projects and research in this particular area.

And I wonder if we could split this so that we continue to think about disparities for traditionally underserved groups as one area, but then there's also a Group that's thinking about developing a statement regarding access to medical care for people with autism.

Dr. Cordero: I mean, I would agree. Just several comments on - I think that Larry brings a very good point in terms of what's the perspective for medication, but also what are the rules and regulations in terms of services that really are about educational services?

But also wearing my hat as a pediatrician, children with autism have a lot of medical issues that need to be addressed. And nearly half of them would have something else other than autism that needs to be addressed as a medical issue.

So I think that we need to balance both, one, be respectable in terms of how things need to be described in services in terms of

educational system, but also at the same time recognize the need to understand the issue of access to services, the quality of services that children with autism need that need to be addressed in the medical system.

Dr. Wexler: And this is Larry. I defer to you in terms of the medical system, because we don't - in education, we don't provide medical services. There's a whole world of policy on that. So I defer to you. Thanks.

Dr. Mandell: So Lyn, given your interest in this with regard to the issues related to medical care, if we were to come up with a set of recommendations specific to improving access to appropriate medical care for individuals with autism, is that something that you would be willing to take the lead on?

Ms. Redwood: Sure. And I also, you know, working with this, let's say, Workgroup that hopefully will be established soon, I could be sort of the segue between those two Groups, because I hope to serve in that

Gorkgroup as well.

Dr. Mandell: Great. Thank you. That would be very helpful.

Ms. Redwood: I would also like other

Committee members to work on that project,

too, like Scott who, you know, has a lot of

good information to share about the health

needs of adults with autism.

Mr. Robertson: Yes, I'd be happy and delighted to contribute to that.

Ms. Redwood: Great.

Dr. Daniels: So this is Susan. I just want to caution you that we don't want to have two different subgroups working on the same issue and start duplicating effort and having multiple phone calls going on that different people aren't listening to.

So Lyn, I know you volunteered to segue between this group and the other Group, but I'm not sure if - unless the Groups are really working on different things - if it makes sense to have two different Groups or whether this issue should be just sent over

to the -

Ms. Redwood: Well, I think one has to do with identifying what some of those problems are, which is the other Group, the Workgroup. And then the second piece is the dissemination of that information, which I see this Group or Subcommittee working on.

Dr. Mandell: Lyn, you'd see them as different issues.

Ms. Redwood: Yes.

Dr. Mandell: For those folks who aren't as familiar with it, can you briefly describe what the mission of the other Working Group is?

Dr. Daniels: David, that Group has not even formed yet.

Dr. Mandell: Ah.

Dr. Daniels: So I don't know if it would be appropriate for Lyn to describe the Group's efforts yet if the Group hasn't been

Dr. Mandell: Okay.

Dr. Daniels: - but it is a group that's

going to talk about comorbid medical conditions, and we discussed that at the last meeting.

So just be aware that we don't duplicate effort and start having multiple calls on the same thing in different places with different people.

Dr. Mandell: Okay.

Ms. Redwood: David, just to answer your question, I would see the information coming from that Workgroup then being fed into this initiative to deal with disparities to try to disseminate that information back out to the general public.

Dr. Mandell: Okay.

Dr. Daniels: So the other Group is under the BTR Subcommittee, so it's a different Subcommittee. So it wouldn't be coming to this Subcommittee.

Dr. Mandell: Although, ultimately we would have access to that information, right?

Dr. Daniels: In the full Committee.

Dr. Mandell: Yes. And Susan, when people

talk about - when these Working Groups are coming up with position papers or recommendations, can you give some sense of the scope, the length, the breadth of what they're covering? Is that too difficult a question?

Dr. Daniels: So who we're covering and what for this particular issue, or for the disparities for underserved populations, or what are you talking about?

Dr. Mandell: For any of the products or deliverables that are coming out of these Working Groups. I guess I'm trying to help - I'm trying to develop an understanding for myself and perhaps for others about what sort of scope and scale - do they vary tremendously by whatever the Working Group and deliverable is? Do these generally tend to be relatively brief documents with some very specific recommendations?

Dr. Daniels: The groups can really - they do have some freedom to develop what they want to develop. Most of the Groups have

developed fairly short documents, probably because I think short documents sometimes have more impact, because people are more likely to be able to read all the way to the end and get the main points versus a very long document. And some of it is time constraints.

So you don't have a very specific limit on page numbers, but the Committee has intended to do shorter documents kind of like these letters to the Secretary and statements outside of the Strategic Plan and some of the other long documents.

Dr. Mandell: Okay. So we're talking about a relatively circumscribed product often that's coming out, but it's at the discretion of the working group.

Dr. Daniels: If you wanted to write a 20page white paper or something, you could do
that or - I wouldn't recommend writing a 500page one. But if you all felt you have the
time and energy to do that, there's nothing
that says that you can't.

Dr. Mandell: If we used a really large font -

(Laughter.)

Dr. Dougherty: Sometimes it's easier to write a 500-page paper than a 50-page paper or a 5-page paper -

Dr. Mandell: So, maybe similar to the adults Group, Working Group, should we think about some Working Groups for these other two issues?

Dr. Daniels: David, now you're losing me a little bit. Other Working g
Groups?

Dr. Mandell: I'm sorry. If we have a Group that's volunteered to - and maybe I'm using the wrong terms, in which case, I apologize.

But if we have a Group that's volunteered to assist with putting together the adult, you know, the compilation of online toolkits that would be providing useful information for adults, and then we might think about a statement drafted about health disparities,

and a statement drafted about medical care for individuals with autism, what would we call the groups of people who would volunteer to lead putting those together?

Dr. Daniels: I guess you could call them Subgroups or whatever. We could just have some small Subgroups of the Subcommittee.

Dr. Mandell: Okay.

Dr. Daniels: They're not formal standing

Groups or anything like that. It would just

be -

Dr. Mandell: Right. Absolutely. I mean, think about them as sort of meeting in a bar, really, almost by accident.

(Laughter.)

Mr. Robertson: Yes, this wouldn't - I assume, Dave, this wouldn't be like the other Subcommittees, DSM-5 Group where that's more formalized, right?

Dr. Mandell: I don't know. So could I - so Lyn and Scott are going to work on the medical care one. Jose and Idil, I assume that you're both interested in the

disparities one if you have time.

Dr. Cordero: Yes.

Ms. Abdull: Yes.

Dr. Mandell: And clearly that's an area that aligns closely with my research and interests, and I'd want to be involved as well.

Dr. Daniels: So can I ask the Group: Is it possible for you to defer the comorbidities issue to the comorbidities

Working Group or the Subgroup there, because I envision this starting to proliferate more calls.

We're already going to be having seven other Planning Groups meeting multiple times this fall. And now we are having another Subgroup meeting for this adult services.

If we also have a separate meeting for the disparities and a separate meeting for the comorbidities on top of the other comorbidities Group, we're going to be talking about 30 or 40 calls this fall, and it's just not going to be feasible.

So could we have Lyn and Scott just join the comorbidities Group and work on that issue there?

Dr. Mandell: I'm comfortable with that.

Lyn and Scott, how do you feel about

incorporating this into -

Mr. Robertson: Well, I guess I'm a little bit confused, because I didn't think that this - I thought discussion was on more of the general access to health care versus medical care. I didn't think that this was focusing on identifying or describing, you know, specifically comorbidities like that other Group is doing.

So can someone correct me if I'm wrong in that? I mean, I'm a little confused.

Ms. Redwood: And, Scott, I agree with that.

Dr. Mandell: Susan, is this primarily a workload and organizational issue, or is this an overlap of content issue?

Dr. Daniels: I think both. I do think in terms of workload, if we now split the

Subcommittee into three different Groups that are going to have independent sets of meetings, you're going to be really overtaxing OARC.

(Simultaneous speaking.)

Ms. Redwood: I guess I don't see that we would really need to have separate meetings.

I would see us bringing this information back to this Subcommittee.

Mr. Robertson: Yes, that was - I thought it was going to happen more kind of informally that we would kind of look up this information maybe in the next, you know, few weeks and bring it back to the Subcommittee - a more informal kind of a group.

It doesn't seem to be the same process that's happening in the comorbidities Group, Subgroup, in that other Committee - other Subcommittee.

Dr. Daniels: So right now you're talking about - you want another call for the adult services Subgroup of this Subcommittee, plus you want to have another Subcommittee call in

which you discuss both disparities and access to care issues. Right?

Dr. Mandell: Is that what you're saying, Scott and Lyn?

Ms. Redwood: No. I was under the impression that this would just be something that Scott and I would work on and bring back to this Committee the next meeting.

Mr. Robertson: Yes, just to bring back information for the next time - that it can happen not necessarily in a formalized series of seven phone calls or something.

Dr. Burton-Hoyle: Okay, this is Sally.

That's fine. I had understood it differently,
but that's fine as well.

Dr. Mandell: Susan, how are you with that?

Dr. Daniels: So then we would be having another meeting of the Subcommittee, but then in addition we would be having another meeting or a meeting of the Subgroup on adult services.

Is it possible to do all of that in one

meeting rather than having it broken up?

I guess it seems like you have this Subgroup that's seven people that want to work on adult services.

Dr. Mandell: What if we - so and does

OARC have to - when a few members of the

Subcommittee get together to develop some

materials or pull the others some materials

to bring back to the larger Group, does that

require OARC staffing?

Dr. Daniels: Yes. So then we would have to set up those calls. So we could do two calls. I guess I was just trying to avoid us starting to make more and more Groups.

So that's essentially just - we're now splitting this into two different Groups.

Dr. Mandell: So right. So originally I think when we got on the call, we had listed on our agenda two Groups: one related to adults and the toolkit and the other related to disparities.

And now in this discussion of disparities, it seems like that a third

important topic has really emerged.

Dr. Daniels: Right. So there are three topics, but before we weren't really necessarily splitting into Groups to work on them. But it sounds like now we might be actually splitting into separate Groups that need some separate meetings.

But really the Subgroup for adult services wants to meet separately, and then the rest of the Subcommittee will meet all together.

Ms. Singer: Susan, can I make a suggestion?

Dr. Daniels: Uh-huh.

Ms. Singer: This is Alison. This is what we've done with the wandering issue. In order to avoid having all of these meetings, we work together offline outside of our capacity as members of the IACC, but as part of our capacity as autism advocates and researchers and professionals, and then we bring information back to the Committee.

So would there be anything to prevent Lyn

and Scott from working together in their roles as advocates and bringing material back to the Subcommittee for its consideration?

Dr. Daniels: No, they could bring back materials to the Committee for their consideration. It's more of a matter of if they're going to do substantial work to keep all the meetings open and as a part of the process.

But if it's really just gathering some information and bringing it back, they can work on that offline.

Mr. Robertson: I would go with that idea unless, you know, there's a thought of doing it differently, but that seems like what was intentioned to happen anyway.

Dr. Daniels: Okay. So then it would really just be an agenda item for the next Subcommittee meeting.

Mr. Robertson: Yes, that was what I thought would work best.

Dr. Daniels: Okay. Well, thank you for that clarification. It's helpful. Not that we

don't want to have separate attention on every different issue, but we're also just trying to be practical so that we can achieve the goals that you want to achieve.

Mr. Robertson: Well, we also don't want to wear out our OARC staff, too, so you don't all fall apart also.

Dr. Daniels: We appreciate it.

Dr. Mandell: So yes, I agree with Scott.

We don't want to overtax you. I think we - I

think it's pretty clear from this

conversation that we have this third area

that has arisen that's pretty important.

And so let's talk about next steps then for these three topics so that we can be really clear about what we want to do.

It sounds like we are definitely setting up another call around the adult services and the toolkits to divide up tasks and to see how we're going to pull that material together for the Web site.

And then, is it possible for - on the health disparities side - for us to take the

same - engage in the same process as we are
with the - as Alison suggested for the
medical care side - that people just in their
capacity, separate from their IACC membership
affiliation, pull together some materials for
consideration by the whole Subcommittee?

Ms. Abdull: I think that's a good idea.

This is Idil.

Dr. Daniels: So then, we will just have those two topics then as agenda items on the next meeting, and you'll bring forward any materials you've pulled together at that point.

But if you're doing actual coordination on behalf of the Committee trying to get things together for the Subcommittee, I'd appreciate it if you'd keep me copied on those emails, as the designated Federal official.

Dr. Mandell: Absolutely. Okay. And I certainly think that maybe Jose, Idil, and I, our day jobs would suggest that this would be a reasonable area for us to address.

I don't know if there's anybody else who would want to contribute also, and then we could put it on the agenda for the next meeting.

Ms. Abdull: I know that Laura is not here, but I'd like to volunteer CMS and HRSA, John and Laura, only because so much of the services, or lack thereof, is either not coming or should be coming from those agencies.

So I don't want to volunteer anyone, but
- and I don't know if they're on the phone
still - but I would suggest that.

Dr. Daniels: So this is Susan. So if Groups are going to be meeting and having discussions by email, just please keep me copied on those emails so that I can see what's being planned for the Group and I can also add in any input or extra help that you may need.

Dr. Mandell: Great.

Mr. Robertson: Susan, one question on logistics for like the next - the next

meeting of this Subcommittee would be another phone call, right?

Dr. Daniels: Right.

Mr. Robertson: Do you have any ballpark in mind as far as the timeframe on when the next call of this group would potentially happen, this Subcommittee?

Dr. Daniels: I guess I'd like to hear from the Subcommittee about that, but keeping in mind that we're going to be working on the Plan through the fall as well. So we will have a series of additional calls that you all will be involved in, as well as two meetings in October in person.

So given those things, when would the Subcommittee like to reconvene?

Dr. Mandell: Well, it would have to be soon, right?

Dr. Daniels: For the whole Subcommittee to reconvene, I guess we need at least a month of lead time to put something into the Federal Register. So we couldn't really be meeting sooner than a month from now.

Dr. Burton-Hoyle: This is Sally, and if we could do Tuesdays, Thursdays, or Fridays, that would be good. I'm busy in the afternoons on Mondays and Wednesdays.

Dr. Mandell: Is it possible - Susan, can we agree that it would be good to meet at the very end or very beginning of October as a Subcommittee and offline try to find a date that works for the most people?

Dr. Daniels: So basically, sometime in September or October. We can look for a date

Ms. LINA Perez: Sometime in October, because September's almost here. So he's talking about October 1st.

Dr. Mandell: October.

Ms. Perez: First.

Dr. Dougherty: Yes, early October.

(Unintelligible conversation.)

Dr. Daniels: We'll look into it. We do have a meeting on October 9th - a full Committee meeting. So that's going to be a priority to make sure we're ready for that

meeting.

Dr. Mandell: Sure.

Dr. Daniels: But we will - we'll be in touch then about setting up a meeting. It sounds like you want it to be in that timeframe somewhere in October.

Dr. Mandell: I think to be useful, it probably would have to be.

Dr. Daniels: Are there any other comments or things people would like to bring up?

(No response.)

Ms. Redwood: I guess the other thing too that would be - I wanted to ask for maybe the next meeting that we could also discuss some of the issues around safety with elopement and also the use of seclusion and restraint that sort of fell off the table from the last IACC when we had a Subcommittee that focused on that.

Now that it's been consumed into this Committee, I was wondering if we could get some updates on that and also try to hammer out next steps when we have our next call.

Dr. Daniels: We can add it to the list.

So David and Denise -

Ms. Singer: I would be happy to provide the updates. By then we'll have met with the AAP and should have more information.

Dr. Daniels: And on seclusion and restraints, I don't know who has an update on that. Is there anybody on this call who's going to have an update about that?

Dr. Burton-Hoyle: This is Sally, and I'm on the Task Committee for Human Rights and Seclusion and Restraints. And they're working very hard legislatively, but we've got a curriculum we're rolling out, as well as there are some videos and things like that of people that have been secluded and restrained, a movie done by Dan Habib. There are a number of things they're rolling out.

Dr. Daniels: Okay. So you might be able to give us an update on that area?

Dr. Burton-Hoyle: Yes, I would.

Dr. Daniels: Okay. So it sounds like you have five topics that you might want to cover

in a meeting. And so, we would be looking at another 2-hour meeting.

Ms. Crandy: This is Jan Crandy. I was waiting until people were finished, but can I bring up the Secretary's letter about the insurance coverage?

Can we address that so that we're ready for that - the next, you know - that we're prepared to be trying to push hard for global insurance coverage?

Dr. Daniels: Sure. We could put that on the agenda, too. So then, that's six topics for a 2-hour meeting, or did you want a longer meeting?

Mr. Robertson: Can someone clarify this?

Did that letter not already go to the

Secretary? What's the update? Is the update

regarding how the Secretary responded to that

letter, or what?

Ms. Crandy: She did respond to the letter, and it was not favorable.

Mr. Robertson: So she sent a letter back to us? Is that what it was?

Ms. Crandy: Yes.

Dr. Daniels: She did send a letter back, and it's up on the IACC Web site.

Mr. Robertson: Oh, okay.

Dr. Daniels: It was a response letter.

But Jan, you want to give an update from your state or -

Ms. Crandy: I want us to, as a Group, as this Committee, to still be urging for coverage, because that letter just said it's thrown back to the state. And I think it indicated something about 2016 is the next time that it might get addressed or something like that as a Federal issue.

Dr. Daniels: Okay.

Mr. Robertson: That's pretty far into the future.

Ms. Crandy: I don't want us to let it drop that because there are states that are not picking up a mandate for this that aren't going to have coverage.

We need some kind of consistency across states and some kind of statement about

intensity level, a baseline intensity level that's our recommendation, you know, like what we put in that letter so that children in states that don't have funding are going to be able to eventually get insurance coverage.

Dr. Daniels: All right. So it sounds like six topics. Is a 2-hour meeting going to be sufficient?

Dr. Mandell: That is a lot of stuff to cover in one meeting. And I think finding a 3-hour block of time for people to meet on such short notice is going to be pretty challenging.

And so I think I - Jan, I agree with you. That's a really important issue. I think it could potentially take up the whole 2-hour block, and I wonder if there's a way for us to communicate in a different way about it, because I'm not sure exactly what you're thinking about as next steps.

Ms. Abdull: This is Idil. Is it possible to maybe talk about the Secretary's response

in the full Committee? Because I think that's one thing we all agree, that children need to get the services that they are prescribed, either through CMS or through insurance.

Even though it's a services issue, it's sort of an autism issue. And I just wonder if maybe we can talk about that, you know, when we have those general discussions at the full Committee and see if there's something we can recommend.

I don't know how much more we can change her mind, because she said that it is up to the states for both the health care law and the 1915© or 1915(b). Each state has its own say, apparently.

Dr. Daniels: The topic can be discussed at the full Committee meeting during the open Committee discussion time, if you'd like.

Ms. Abdull: I would agree with that. I think -

(Simultaneous speaking.)

Ms. Crandy: - so it does get discussed, because we always run out of time at the full

meeting, and I don't know what the solution is.

I'm just saying that we can't just leave this off the table now that we've got that letter. That letter doesn't solve the solution.

Dr. Daniels: Well, if this Subcommittee would like to keep it on the agenda for the Subcommittee meeting and then bring it up at full Committee as you wish, we can do that.

So then there are six topics. We'll have a 2-hour meeting. And then if we need to plan further meetings after that, we will plan more meetings.

Dr. Mandell: All right. That sounds good, and maybe we can order the agenda items by priority for the meetings in October.

Dr. Daniels: That sounds good. Are there any other comments or questions that anyone has?

(No response.)

Dr. Daniels: Well, I think everyone covered a lot of ground. Thank you all.

Mr. Robertson: Well, since we just have a couple minutes, I just also just wanted to mention on a news item related to service system policy that I thought was important that came up in the news recently on the human rights end of things that the Department of Education sent out a "Dear Colleague" letter to school districts around the country saying that bullying of students with disabilities can constitute a denial of their right to a free, appropriate, public education.

This would include autistic students, who are more likely to be bullied than students in some other disability categories. So I thought that was just an important thing for just folks to be aware of that that's, you know, a developing thing happening.

That's, I believe, the first time that, if someone can correct me, that ED has ever, you know, taken that stance with guidance to schools, just saying that definitively that bullying - and laying that route really

specifically - that bullying denies kids with disabilities their right to appropriate education.

Dr. Wexler: Yes, from the Department of Education, bullying can deny. It doesn't -

Mr. Robertson: Yes, okay.

Dr. Wexler: - necessarily deny. But, yes

Mr. Robertson: Yes, I should emphasize the word "can" or "can constitute," yes.

Dr. Wexler: That was a 1-year, year-and-a-half effort on our part, although, it's hard to believe when you see the length of it, but we're pretty happy with it, and we hope it's helpful to the field.

Mr. Robertson: It's been well received by us in the advocacy crowd. I was very delighted to see it out there. And you know, it's quite timely, because I'll probably be able to maybe add it to my thesis dissertation project right before my final document goes to my thesis committee on bullying of autistic students and make sure

it's mentioned on the implications of this work.

Dr. Wexler: All right. Don't forget to do APA style reference on it.

Mr. Robertson: There's definitely APA style reference in my thesis, yes.

(Laughter.)

Dr. Daniels: Larry, can you send that over to OARC so that we could distribute it?

Dr. Wexler: Yes, it's on the Web - it's on our Web site. If you just - I think if you just Google "bullying, Department of Ed," it will take you right to it.

Dr. Mandell: All right. Thanks for bringing that up, Scott.

Mr. Robertson: You're welcome.

Dr. Mandell: Susan, any other things we need to do before we adjourn?

Dr. Daniels: Not from my end. Is there anything that you all need to finalize before we adjourn?

Ms. Abdull: Did I say that you guys from OARC do a wonderful job, Dr. Daniels? Just

saying.

Dr. Daniels: Thanks so much, Idil. We appreciate it.

Mr. Robertson: Yes, you do good work, everybody.

Dr. Daniels: Thank you. Thank you. Thank you.

Dr. Mandell: All right. Take care.

(Whereupon, at 3:59 p.m., the

Subcommittee adjourned.)