

INTERAGENCY AUTISM COORDINATING COMMITTEE
HEALTH OUTCOMES WORKING GROUP
CONFERENCE CALL
WEDNESDAY, SEPTEMBER 5, 2018
2:00 p.m.

The Interagency Autism Coordinating Committee (IACC) Health Outcomes Working Group convened via conference call at 2:00 p.m., David Amaral, Ph.D. and Julie Lounds Taylor, Ph.D., Co-Chairs, presiding.

PARTICIPANTS:

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JUDITH COOPER, Ph.D., National Institute on Deafness and other Communication Disorders (NIDCD)

LISA CROEN, Ph.D., Kaiser Northern California

SARAH GARDNER, University of California, Davis

PRESENT: (continued)

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Medical Center

CONNOR KERNS, Ph.D., University of British
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CLARISSA KRIPKE, M.D., University of
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BETH ANN MALOW, M.D., M.S., Vanderbilt
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MICAH MAZUREK, Ph.D., University of Virginia

DONNA MURRAY, Ph.D., University of Cincinnati

CHRISTINA NICOLAIDIS, M.D., M.P.H., Oregon
Health and Science University

KEVIN PELPHREY, Ph.D., University of Virginia

DORA RAYMAKER, Ph.D., Portland State
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SCOTT MICHAEL ROBERTSON, Ph.D., U.S.
Department of Labor (DOL)

MARCELLA RONYAK, Ph.D., LCSW, CDP
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ELLIOTT SCHERR, M.D., Ph.D., UCSF

STUART SHAPIRA, M.D., Ph.D., Centers for
Disease Control and Prevention (CDC)

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DR. SUSAN DANIELS: Thank you. Welcome everyone to this conference call of the IACC Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum. We are going to be talking today with members of this new working group that is formed for the IACC. We have a number of working group members and IACC members on the line. I would like to introduce first David Amaral, who is one of the co-chairs of this working group, and also Julie Taylor, the other co-chair of this working group. We would like to go around and have people introduce themselves. Maybe the most orderly way for us to do this would be to go down the list so we don't have people talking over each other.

Again, welcome to members of the public committee listening in as well. We would like to start with David. Would you like to introduce yourself?

DR. DAVID AMARAL: Good morning everybody or good afternoon. I am David Amaral, a member of the IACC, and I am at the UC Davis MIND Institute. Very excited about getting this working group going. Thank you.

DR. DANIELS: Julie, are you on?

DR. JULIE TAYLOR: I am. I am Julie Taylor, also a member of the IACC, at Vanderbilt University Medical Center, and really looking forward to having all of your expertise as we dig into some of these issues.

DR. DANIELS: Thank you. Beth Malow.

DR. BETH MALOW: Yes, hey, it is Beth Malow. I am also at Vanderbilt University Medical Center, where I am a sleep specialist and autism specialist. I am very excited to be part of this group.

DR. DANIELS: Thank you. Christina Nicolaidis.

DR. CHRISTINA NICOLAIDIS: Yes, hi, I am at Portland State University and Oregon Health and Science University, and co-director of ASPIRE, the Academic Autism Spectrum Partnership and Research in Education. I have been doing a fair amount of work in partnership with autistic adults about improving their health and health care, specially adults in the primary care system.

DR. DANIELS: Thank you. Tim, are you on.

(No response)

DR. DANIELS: We will come back. Greg Barnes.

DR. GREGORY BARNES: Yes, my name is Dr. Gregory Barnes. I am a pediatric neurologist and epileptologist at the University of Louisville Autism Center, where I serve as the executive director. I am excited to be here and be a part of this group.

DR. DANIELS: Thank you. Lisa Croen.

DR. LISA CROEN: Yes, hi, this is Lisa. I am an epidemiologist at the Division of Research at Kaiser Permanente in Oakland, California. Very excited to be a part of this working group.

DR. DANIELS: Thank you. Micah Mazurek.

DR. MICAH MAZUREK: Hi, I am an associate professor at the University of Virginia and a clinical psychologist focusing on autism. Really happy to be part of this group.

DR. DANIELS: Thank you. Sarah spence.

(No response)

DR. DANIELS: Kevin Pelphrey.

DR. KEVIN PELPHREY: Hi, this is Kevin Pelphrey. Faculty member at George Washington University - actually soon to be at the University of Virginia. Autism researcher, neuroscientist, and member of IACC, and delighted to be a part of the group.

DR. DANIELS: Thank you. Scott Robertson.

DR. SCOTT ROBERTSON: This is Scott Michael Robertson. I am at the U.S. Department of Labor's Office of Disability Employment Policy, (ODEP), on our employment-related supports policy team, which include health and community living as a focus, as it relates to folks being able to access competitive integrated employment and transition to that as part of being able to have health care services that ensure employment access.

DR. DANIELS: Thank you. Elliott Scherr.

DR. ELLIOTT SCHERR: Hi. I am a professor of neurology at UCSF and my labs studies both in genetics of autism, as well as its overlap with epilepsy. I am happy to be a contributor.

DR. DANIELS: Thank you. Donna Murray.

DR. DONNA MURRAY: Hi, I am Donna Murray. I am with Autism Speaks. I am a VP of a

clinical program here, Autism Treatment Network. I am really excited to be a part of this work group.

DR. DANIELS: Thank you. Connor Kerns.

DR. CONNOR KERNS: Hi, this is Connor Kerns. I am a clinical psychologist and an assistant professor at the University of British Columbia in the Psychology Department. I am pretty focused on anxiety disorders and sources of trauma and traumatic stress in people with autism. I am very excited to contribute today.

DR. DANIELS: Thank you. Matthew Siegel.

(No response)

DR. DANIELS: Antonio Hardan.

DR. ANTONIO HARDAN: Hi, yes, I am at Stanford University. I am the director of the autism program here. I am psychiatrist and a child psychiatrist. I do clinical work and I see kids and adults with autism. I do also

research in the area. I have been involved in the field for over 20 years. I am happy to be a part of this group. I am looking forward to working with everyone.

DR. DANIELS: Thank you. Dora Raymaker.

DR. DORA RAYMAKER: I am a research assistant professor at Portland State University Regional Research Institute for Human Services in the School of Social Work, and a system scientist and I do community engaged autism services research. I am also the other co-director of ASPIRE, along with Christina.

DR. DANIELS: Thank you. Joe Joyce.

(No response)

DR. DANIELS: Clarissa Kripke.

DR. CLARISSA KRIPKE: Hi, I am clinical professor of Family and Community Medicine at the University of California, San Francisco, and the director of developmental primary

care. I provide primary care for people with complex behavioral and who are conditioned and medically fragile. I run a consult service that does home-based consultations and work other members of this group on various research projects. I am a member of the ASPIRE team and on the advisory committee of Lisa Croen's work.

DR. DANIELS: Thank you. Jeremy Veenstra-VanderWeele.

(No response)

DR. DANIELS: Brian King.

(No response)

DR. DANIELS: Sarah Gardner.

MS. SARAH GARDNER: Hi, I am a parent of a young man with autism and our family was also one of the founding families of the MIND Institute. I am thrilled to be a part of the group.

DR. DANIELS: Thank you. Dena Gassner.

(No response)

DR. DANIELS: Daniel Coury.

(No response)

DR. DANIELS: Then we have a few IACC members that I know were supposed to be on the call. Diana Bianchi.

(No response)

DR. DANIELS: Or Alice Kau for Diana Bianchi.

(No response)

DR. DANIELS: Jennifer Johnson.

(No response)

DR. DANIELS: Nina Schor for Walter Koroshetz.

(No response)

DR. DANIELS: Patty Dietz for Stuart Shapira.

DR. STUART SHAPIRA: So good morning or good afternoon, depending upon where you are calling from. This is Stuart Shapira. I am

the IACC member from the National Center on Birth Defects and Developmental Disabilities at the Center for Disease Control and Prevention.

DR. DANIELS: Thank you, Stuart. Marcie Ronyak.

DR. MARCELLA RONYAK: Good afternoon. My name is Marcy Ronyak. I work for Indian Health Service in the Office of Clinical and Preventative Service. I am the director for the Division of Clinical and Community Services, where we manage, develop, and coordinate comprehensive clinical, preventative, and public health approach to clinical and community (audio cuts out). I am also a mother of a 9-year old son who is on the autism spectrum. Thank you.

DR. DANIELS: Thank you. Are there any other IACC members who are on the phone?

DR. JUDITH COOPER: Yes, this is Judith Cooper. I am acting director of the National Institute on Deafness and Other Communication Disorders.

DR. DANIELS: Thank you, Judith. Anyone else? Okay, we are done with introductions and we can begin. We want to talk about the first item on the agenda here is discussion of the purpose of the working group. I have a little preamble to give before I turn it over to David and Julie to lead the discussion.

This Working Group was formed by the IACC, the title is Improving Health Outcomes for Individuals on the Autism Spectrum to address the health needs of people on the autism spectrum. The work will be working from September 2018 through September 2019. We will explore topics such as health and general wellness for individuals with ASD, co-occurring physical and mental health

conditions, premature mortality, patient provider interaction, parental and family mental health, and other topics as time allows.

The group has now formed and we will be putting together a webpage that will list the entire roster, but many of those people you heard them called as we did the roll call. We would like to talk a little bit more about the purpose of the working group.

So David and Julie, go ahead and start that discussion.

DR. AMARAL: Thank you, Susan. First of all, this is a terrific group of people and I am really very pleased that everybody has volunteered their time to be on this working group, as well as the people who aren't on the phone call today. I think once we get all together later in the month it is going to be a very productive meeting.

I think, from my perspective, there are a couple of motivations for forming this working group. One of them is the emerging evidence from work by people like Lisa Croen and others that the lifespan of individuals on the autism spectrum is shortened, and it is shortened because they tend to be prone to a whole host of medical problems. The reason for their increased prevalence of all kinds of medical problems is not entirely clear at this point, but it is an issue that is only beginning to be addressed.

And I think the second motivation is one that we've talked about on the IACC and is a common experience of people working with families who have an affected individual, and that is oftentimes the medical problems of their children or adults even, when they try and seek help for them from the practicing clinicians in the community, oftentimes the

issues are not addressed and because the clinician suggests that is just part of the autism rather than attempting to deal with the medical problem, like gastrointestinal problems or sleep problems that have possible treatments.

I think the goal of this working group is first and foremost to identify the health challenges - and we probably won't be able to identify all of them. In some of the earlier discussion we have had about this working group we tried to come up with a series that we could address in this first meeting that we will be having in September. At that meeting maybe, we can end the meeting by thinking about other things we might want to address, but I think we have come up with a series of issues that are really important to individuals and families affected by autism and identify those problems. But more

importantly, try and come up with best practices in addressing those problems, with the goal in mind of developing a white paper.

So we want to have a useable document at the end of our working group deliberations that could then be widely disseminated and could be useful for clinicians all over the country, particularly those clinicians who may not have a lot of experience dealing with autism spectrum, in order to make them aware of these medical issues and then what would be the best possible ways to deal with those.

Again, there are a number of efforts - Micah Mazurek I know has been initiating the ECHO autism program, and that would be something that we might want to facilitate. But there may be other approaches to getting awareness and action plans to clinicians who are not associated with autism centers.

So I think that those are the primary motivations, at least that came out of the IACC. I will let Julie give her perspective on this, but then wanted to see whether others - how people think about those motivations and whether they think this is sort of a good basis to start the working groups. Julie, do you want to comment a little bit?

DR. TAYLOR: Sure. I agree with everything that you said, David. I am really excited that all of you were able and willing to collaborate with us on this. I think our goal in this project is to have some sort of product, some sort of white paper that is going to be really useful. If it is not really useful then what is the point? So having the input of everybody on the working group so that at the end of the day we can come up with something that is really

maximally impactful for care for individuals on the autism spectrum is something that is really important to us on the IACC, and also as chairs of the working group.

The other thing that David alluded to is that clearly, when we are talking about health and mental health, there are many, many, many different topics that we could be addressing here. In this first workshop this is really our attempt to pull out some of the topics that are coming up often in IACC meetings, or just are topics that really seem to be of great concern to individuals and to families. And I think we can have more conversation at the end of that about whether there are topics such as mental health problems, or things like that, that we should be thinking about addressing in either subsequent meetings or subsequent efforts down the road.

DR. AMARAL: Good. Thanks, Julie. How do people respond to those sorts of preambles of the goals for the working group? Do people feel good about that? Any concerns about those issues?

DR. ROBERTSON: This is Scott Robertson at DOL. I think that it sounds pretty good and I do like particularly the goal of having actual products coming out of it that we get discussion on the major focuses, but actually having something kind of tangible that comes out of the group I think will really be important for helping clinicians and other practitioners with the major health focuses since there aren't a ton of other products that are out there, say for instance on the adult space other than what ASPIRE produced with its tool kit, I mean there are not a lot of resources there yet. So that would be helpful to get that white paper.

DR. AMARAL: Thank you, Scott, that is a good comment. Other opinions?

DR. HARDAN: This is Antonio. I think that will be a very good first step in terms of developing a white paper. I think we would all feel good about having a measurable outcome at the end. But we might want to think a little bit beyond the white paper. I don't know if that is the right forum or not. Maybe the white paper is a first step, because if I think of the primary care physician out there who is trying to handle a non-verbal 25-year-old, trying to examine him or examine her, you want to have more specific guidance in terms of how to assess these individuals.

A white paper probably will go to people in the field, but people on the front line might not get the white paper. That will be

the scope of that effort but should be at one point the scope of an effort.

DR. DANIELS: This is Susan. When we discuss the golden products of the working group there are many options for different types of written products. I don't know if you want to discuss that now or wait until we are talking specifically about products, but you can discuss other things that can be done in addition to what has already been mentioned.

DR. AMARAL: Antonio, you are absolutely right. I think this is why we have tried to invite a very diverse group of people, both practicing clinicians and researchers, to this group because we wanted to generate more ideas about how to disseminate. I frankly think that dissemination is one of the most critical components of what we will be doing.

We have sort of talked briefly about going to various physician societies and trying to get the word out that way, but any input that you have on that - even suggestions that you have now about dissemination, but certainly once we get into the meeting and any subsequent follow-up we will be talking intensively about dissemination. Yes, if you write a white paper and nobody reads it, or specialists read it, that is probably not going to accomplish the goal either. We want to get it out to the folks in the trenches who, as you say, may not have a lot of experience dealing with the specific challenges of a person on the autism spectrum. That is the kind of input that we absolutely want for this working group.

DR. LISA CROEN: I wanted to echo both what Antonio and David, you just said. I can

see a kernel of an idea for dissemination would be teaming with some physician education experts. I am just thinking of people within my own organization, Kaiser Permanente, where they could help translate the contents of the white paper into some actionable physician education items that can be delivered in a way that will be received and acted on, and some picking up some bullet points and something very brief. I think Christina Nicolaidis will have a good idea of the kinds of things that we could do following her and Dora's work with ASPIRE.

DR. RAYMAKER: I am wondering if there has been consideration of dissemination to communities, to autistic people and families as well as to clinicians? Just as another dissemination vector where appropriate.

DR. AMARAL: Dora, I think it's a good point. I think that the initial starting

perspective was that it is the families that are experiencing it sort of on a daily basis, this problem and in a sense the education has to be more of the provider community. But I think it is a good point that making families aware that a lot of these issues are addressable. They probably should not be cowered, I guess, if they get pushback that a GI problem, for example, is just part and parcel of having autism, rather than a treatable problem. That is probably something that we should be trying to get out there as well.

DR. RAYMAKER: And also actual autistic people might be interested in being empowered by information.

DR. AMARAL: Sure, sure.

MS. GASSNER: This is Dena. I do agree that in terms of getting this information out to autistic adults, you know, YouTube and

Facebook have become a huge network for autistic adults to get information. So I think anything we could do related to video work that could be accessible, and also a specific strategy is to persistently advocate for just what you just described. We hear quite a bit about people who inherently have communication and anxiety issues having to persist at the doctor's office to get that delineated and teased out.

So I think just giving them the information that says, yes, you are right and your concerns are valid is stopping short. I think we need to take it to the next step in saying, and here is the information you can take and here is how you can approach your provider and here is what you can reasonably ask for.

DR. RAYMAKER: Yes, that is more what I was thinking.

DR. ROBERTSON: This is Scott. I want to say that I completely concur and I am glad that a lot of thoughts that come up as an autistic adult - from my perspective I am glad to see that a lot of adult focuses are in here and that there is a lot of broader focus on dissemination directly to autistic adults, because I completely agree that folks need to be able to access that information resources directly and a lot of adults feel kind of overwhelmed in terms of what to do in terms of accessing health care services. As we will find out maybe in some of our discussions, I know that we know that some of the disparities are partially because folks feel kind of intimidated by the health care sphere in terms of self-identifying and things like that, because of the barriers to access and communication and things like

that. So thanks others for bringing up those points.

DR. CROEN: This is Lisa Croen, again, just one last suggestion along the lines of what we are talking about, and that would be if we could produce sort of a video maybe that could be widely disseminated, a very brief video that would exemplify a successful office visit between a physician, a primary care physician, and an autistic adult, that would be really fantastic.

DR. TAYLOR: This is Julie Taylor from Vanderbilt. We have on the Vanderbilt website we have something called an IDD toolkit that has a whole bunch of videos, vignettes of physicians interacting with patients with disabilities, including autistic adults and young adults. We have some models that we could work from to maybe develop some videos that are more specific to some of the issues

that we will be discussing in the workgroup.
So I like that idea a lot.

DR. MALOW: I wanted to jump in as I was one of the actors in those videos. We might be able, as part of our work, we might want to look at what is already out there. Not that we are going to necessarily just use what is out there, but those could serve as models because I think there are other centers who also have similar things to what we have done at Vanderbilt.

DR. KRIPKE: When I am looking at the purpose in the outline, the things to me that is missing is that communication is the foundation of patient care and an emphasis on communication and communication supports and communication access I think is a critical piece, as well as social determinants of health and the systems issues that are driving these health disparities. There may

be some biological reasons why there are co-occurring conditions and associations, but I think a lot of it, perhaps even the majority of the health disparities, are really about workforce training, funding, access, employment, all the social determinants of health that we know are critical. I don't see where that fits in this agenda.

The Office of Developmental Primary Care has been working for 15 years at educating health care providers and health professionals and autistic adults and their families and service providers on these issues and has a lot of resources also to contribute on our website and would be happy to participate in creating new resources as well.

DR. ROBERTSON: This is Scott again. Can there be like a mechanism also to share some of these things around the group? Some of

the things that are mentioned at times I think would be good for us to make sure everyone has access over e-mail or whatever in terms of links to some of the different resources that have been mentioned.

DR. AMARAL: Susan, would it be possible to summarize, extract some of those things from this call and then send it out as an e-mail to all the participants?

DR. DANIELS: What would be helpful is if people who have mentioned specific resources, if you could send them to me that would be helpful and then we can compile them and share them with the group.

DR. KRIPKE Who are we sending them to?

DR. DANIELS: Susan Daniels.

DR. NICOLAIDIS: I agree with everything that has been said. Just to add to it, our APSIRE toolkit has half of the site is dedicated to information and resources for

providers about taking care of adults on the autism spectrum. We are happy to add that to the list.

Also, just an adding of the things that we would want for training, just in case it hasn't been highlighted, I think in addition to some of the videos and things that are very useful in terms of acting out and demonstrating interactions, I think also having some videos of autistic individuals or their stakeholders really talking about what it is like being a patient can sometimes go a long way in helping providers understand what the issues actually are.

MS. GASSNER: This is Dena. Another thing that I think we need to make sure we incorporate is inpatient hospital-based care. I recently had a knee surgery. Those were outpatient surgeries and the outpatient surgery holding areas before and after

surgery for recovery, are often just bed after bed after bed. There is no privacy, there is no wall. The people outside the curtained area are doing their everyday tasks. There are nurses that are just cutting up and having a good day, but for somebody whose sensory system is wired high that kind of cacophony going on right outside the curtain can be very overwhelming. And there doesn't seem in a lot of hospitals after you turn 18 or 21, there doesn't seem to be any kind of a care system where someone can disclose to anyone beyond their doctor what their hospital setting needs to be like for them to be calm and relaxed and less anxious. So I think we need to keep that in mind.

DR. AMARAL: I think that is a very good point as well. Even just starting this phone call, you appreciate how encompassing this problem is. It is all these different areas

that could be addressed. One of the things that I think we will have to do as part of the first meeting is develop a list of items that probably we won't be able to address in the first meeting but try and decide whether we should address them in further phone calls or in some other way.

There are limitations on working groups in terms of the logistics of it. So we are going to have to be smart in trying to come up with the highest priority issues, dealing with those, coming up with some solutions and putting it into the white paper. But also trying to identify areas that we might not be able to address but need attention in future meetings.

I am glad that everybody is endorsing the idea of getting a real product and something that will be useful. One of the things that I was impressed by was that when

we first started this new iteration of the IACC there was a previous working group on this topic, and it came just at the end of the last IACC. It was a very well-run meeting but unfortunately, because it was at the end of the last IACC, implementation of a lot of good ideas that came out of that didn't happen.

I think everybody is determined this time that there is adequate time to ensure that we get a document and that it gets into the hands of - and by a document I don't necessarily mean a written document. I think the ideas of using Facebook or using videos, those are really effective ways of communicating and I think we should explore all of those ways.

I do worry a little bit that we want to try and come up with priority areas to try and address and get some information out.

Otherwise the meeting might be so diffuse that we don't really have the impact that we are hoping to have.

Susan, should we move on?

DR. DANIELS: Sure, we can move on to the next section. We were just going to talk about the working group workshop. You all are aware that we are holding a workshop on September 27th for the working group. The topics that are covered were identified by the IACC in their last meeting as areas they wanted to look at. So we are going to be covering health epidemiology; we are going to have some introductory discussion with Jeremy Paar from the UK about some work that they are doing in this area with health and health care for adults on the autism spectrum; we are going to talk about patient-provider interaction; and then some specific co-

occurring conditions that were prioritized, including GI issues, epilepsy, and sleep.

So we will be covering those and you all received a draft agenda. A draft agenda is up on the website as well for anyone else who is listening in. We sent out the initial e-mail for this a few weeks ago and another e-mail blast went out today regarding this meeting. Any members of the public who are listening in, if you have things that you would like the IACC to know about any of these issues feel free to provide a public comment in writing or to sign up for oral public comments that will be happening at this workshop.

For members of the working group, think about questions you may have for some of these speakers regarding these areas and how that might impact the products you are thinking about.

In terms of what we just discussed with possible interest in producing videos, if there are any of you who have universities or organization that have a lot of experience with producing videos, and you want to send me some information about people that we can talk to, that would be helpful. I know that in our shop we do produce some videos, but we haven't done the types of videos that maybe some of you - others have done for their universities. Maybe we could be looking to partners or to get suggestions on how to do those types of things. So open to hearing about that.

DR. ROBERTSON: Susan, I can also send over an e-mail on what we do at ODEP because we do videos a lot with our outreach and communications policy team for like our campaign for Disability Employment and National Disability Employment Awareness

Month next month in October, et cetera. So we use a lot of videos and social media. I can get all that information gathered to send to you what we do here at DOL.

DR. DANIELS: Thank you. Is there any discussion about the working group workshop? Does anyone have comments about it or questions?

MS. GASSNER: I was just wondering if there was going to be any conversation around PTSD specifically as it relates to victimology? We are just seeing more and more dialog around sexual assault in people with developmental disabilities overall.

The other thing that I was wondering about is Ehlers-Danlos as a co-occurring condition?

DR. DANIELS: What was the last thing you just said?

MS. GASSNER: Ehlers-Danlos - it is a hyper mobility spectrum condition. I am on just one list serve and somebody posted how many of you who have EDS also have autism and 98 percent of the people said yes. And nobody is talking about it except their community.

DR. ROBERTSON: Can I add to that? Maybe even going beyond EDS and expanding to broader like connective tissue conditions? Because there is a lot I think in that area that is very much under-studied, so maybe if that gets mentioned in this group or something just for the future kind of thing, because I have tried to look at times for research in that area and, as was noted, the number is high for Ehlers-Danlos syndrome and it is possible that some other neuromuscular and connective tissue disorders are higher in prevalence, but they have not been researched

that extensively in concert with autism, even with the higher numbers. The literature is kind of lacking in there. Then some other things like vision and some other sensory things are somewhat understudied on autism, too.

DR. DANIELS: But we don't have any of these topics directly on the agenda. Although I don't know if Lisa Croen or Micah Mazurek or Christina Nicolaidis are going to touch on any of those. But certainly, we would welcome public comments on those and can keep those in mind for any future follow-up work that we might be doing. I don't know if David or others have other suggestions.

DR. RAYMAKER: This is Dora. Speaking of future follow-up work, is this the only meeting that will be had, or will there be more work groups? Because on of the things that I don't see on here, which somebody else

just brought up, is mental health. There is nothing that kind of goes deeper into things like PTSD and anxiety and depression and the co-occurring mental health conditions. Lisa touches on it a little, physical and mental health, but that just feels overly general. So I am wondering if this is the first meeting in a series or is this like the items that are on this list are all this work group is going to be addressing?

DR. DANIELS: This is the workshop that is planned by the working group and so we don't have any other workshops scheduled at the moment. We only have one year for this working group to do work. So it will be left under consideration whether there would be any future workshops. But if there is a future workshop it might be very late in the IACC cycle and we don't want to end up with a situation where we have it at the very end

and there is no chance to be able to follow up on it. So some of these other discussions might end up being phone discussions or webinars or things like that, rather than a full workshop. But we can talk about it.

DR. CONNOR KERNS: I just wanted to second the comment about mental health. I am sure mental health definitely interacts with many of the topics that are on the agenda list, but I feel like more could be done in terms of going in depth there. I also share the concerns about really looking into PTSD, but also not only PTSD but just adverse childhood experiences for people on the spectrum and how those may be contributing to really health disparities because there is some initial data coming out to support that.

DR. MALOW: I am sorry. Just as a general rule - I want this to be as productive as possible for the group. When, as a speaker,

what is it you would like us to emphasize? Because we could certainly go into like the whole history of our area and all, but I am getting the sense, based on the conversation, that we want to make sure we stay focused on solutions, dissemination. If you could give us a little bit of guidance so that at the end of the day we have a really productive meeting that will help us move forward toward those deliverables that you mentioned.

DR. AMARAL: Beth, I am glad you brought that up because the way the schedule is drafted currently - it was an initial draft - it sort of looks like there is a long lecture and then that's it. But in actual fact, I think, and Susan can correct me if I am misstating this, I think we are hoping that the speakers will spend really about 15 minutes just articulating how, for example, in your case, sleep is a disability and an

impairing condition associated with autism. The magnitude of the problem - how common is it? A succinct discussion of what is the comment? Is it that sleep bouts are short? What are the sleep issues?

Then the 30 minutes could be spent in the work group trying to develop a set of strategies with you that might go towards helping families and individuals with autism to deal with those impairments or disabilities. It is more discussion and less lecture, at least in my mind.

Just to go back to some of the other comments that were coming up, I think these were used as exemplars of things that are fairly common in autism, but by no means meant to be exclusive of the medical and health challenges. One of my research areas of interest is anxiety, and it is not really

articulated here, but that is a very common one as well.

I would hope that we use this as a sort of focused attempt to state a problem and try and come up with strategies that we could put into the white paper and disseminate in other ways that would be useful to physicians and families around the country. But consider that we will deal with other common co-occurring conditions, many of which were discussed previously and in further phone calls and stuff like that. So this would just be a start, not an end all.

DR. MALOW: Yes, that is really helpful. I would make sure that anyone who is not on the call today as a speaker gets that directive. Because even though I remember seeing an e-mail about 15 minutes, you articulated it really well, and just the idea that we will frame out presentations to be

more interactive, to pull in ideas, to spend time discussing our topic is something that I think is really important so that we can make the most of our time together.

DR. DANIELS: All of the speakers were instructed to give a 15-minute talk and then we do have 30-minute discussion times, just as David mentioned. And we have gone ahead and updated the agenda. However, since our servers are down we could not put it up on the web yet and we haven't been able to send it out. But we will be updating that so that it is more specific on the agenda, because that s how it was planned.

We are happy to have a phone call with speakers before the meeting to further elaborate but we just sent out an e-mail with some instructions already about the talks and exactly how David described it, that was how we were hoping to have this.

DR. MALOW: I appreciate that. So will it be the speaker leading the 30-minute discussion after our presentation or will it be you guys? How should we plan for that?

DR. DANIELS: The chairs will do that. We can talk about all the specific planning of the workshop maybe on a separate call.

DR. MALOW: That would be great, thank you.

DR. CROEN: I have a question. Is the focus mostly on adults, or are we looking across the lifespan?

DR. AMARAL: Across the lifespan.

DR. CROEN: Across the lifespan. Thank you.

DR. TAYLOR: Thinking about all of the topics that we will not be addressing, and clearly, as have come up in this call, there are lots of topics we haven't even talked about in this call, this is really just

sampling of all of the many important issues that we will be talking about. It might be worth some discussion, either in a follow-up phone call or maybe even a little bit at the meeting if we have time, which we probably won't, to really talk about what do we want to do about those other topics? Do we want to just put together a brief paper saying here are some of the other issues that are really important to understand? Do we want to do more than that?

I think we can have some sort of coordinated, purposeful way of addressing in some way the issues that we may not have time in the one year of the working group to go into great depth on, but I think to get some way to address those, even if briefly, I think that would probably be important.

DR. DANIELS: Some of those things are kind of overarching or underling things

behind a lot of these other parts, like the discussion on social determinants of health. Because that touches all of these other areas.

DR. KRIPKE: I am just listening, and the group comes from a variety of different background and even what paradigms we are operating under, medical model versus social model or neuro diversity models of understanding disability. There seems to be a range and in terms of what type of document we create I am just thinking, you know, to be concrete - the example of insomnia, when I am thinking with insomnia is we can't put out a paper saying should we give melatonin or a hypnotic? But we need to say is there something in someone's sensory environment that is keeping them up or did they have reflux?

I am trying to think about the whys of that, or psychological problems that are keeping them up because they are ruminating. There are so many different reasons why somebody may not be sleeping. So as a clinician, I am thinking about these issues in very different ways that some other people maybe thinking about them and I am just wondering how we, as a group, will figure that out to have a useful structure to move forward to make recommendations?

DR. KERNS: Just jumping onto that for a second, I think another example of that is sometimes kids aren't sleeping well because they don't have a clean cool sleeping space to sleep in, so that is where these social determinants are coming in as well. So how we work that all into one document I do think is something good for us to think about.

MS. GASSNER: To piggyback on that - this isn't a devil's advocate, it is just an addition - you know, when you live on \$800 a month as an adult, social determination also means you don't have a clean, quiet place to sleep at night. I would just add that. I would also add, critical to adults who are living without support, and in many states if you have an IQ above 70 you get nothing from your state, the executive function piece is a massive barrier to accessing health care services.

DR. AMARAL: I can see how people would think this would be a challenge, but I think this is wonderful. I love these kinds of brainstorming sessions where you hear different perspectives from different folks coming from different disciplines because that will make the document the richest possible document. In a sense, this is how

the IACC works to develop its strategic plan and gets a lot of input from lots of diverse voices and then Susan and her team always does a tremendous job trying to pull it all together. When we start developing the document from the raw information that we get at the working group meeting and from whatever phone calls we do, then the document will be distributed within the working group for editing. To the extent that you want to contribute to that editing we will invite that. Then ultimately, hopefully - and I am fairly confident of this - the document would reflect a lot of your opinions and it will reflect different opinions for different times of life.

So if you are talking about a three- or four-year old who is having sleep disturbances, a lot of the kinds of things in terms of the social dynamics are not going to

be impacting them as much as the biological factors. But that doesn't mean that we should focus only on the three- or four-years old to the detriment of dealing with these issues in adults.

I think we shouldn't shy away from the idea of giving our opinions and even if they only represent a component of the spectrum that will be important for you to articulate in the work group and in whatever phone calls we have. Let's gather data. Let's gather information, gather your opinions, gather your experience and not worry so much at this point in time about the final product, because I think it is an emergent process and that will happen.

I am actually looking forward to hearing the diversity of opinions on some of these issues because I suspect the final document

will be a different one than any one of us would be able to put together on our own.

DR. KRIPKE: David or Julie, can you describe what will happen after the one-day workshop when we are all together?

DR. DANIELS: This is Susan. We haven't planned all of that yet, but there will be future phone calls for this working group. So we will plan a follow-up phone call - it hasn't been determined yet what date. There is an IACC meeting on October 17th. I am not sure if it will be prior to that October meeting or after, but we will have follow-up phone calls to talk about any projects that you are undertaking to produce written or video documents or anything else. So we will follow up that way.

DR. KRIPKE: I guess my real question is the content of whatever we produce we are trying to lay out at the September 27th

meeting, or will there be opportunity after that to have discussions to further flesh out and integrate some of these other ideas that aren't directly on the agenda?

DR. DANIELS: Right, so we won't be doing any real structured - anything to try to write a document at the workshop. The workshop will be information gathering and you will be able to ask questions and get some ideas about the topics discussed, and if there are other topics you want to discuss, that you want to work into your product, we can discuss those on future phone calls after the meeting.

DR. AMARAL: And I suspect, practically speaking, that there will be a smaller subset of the working group who will develop a first draft framework for the document and then circulate that, through an iterative process, circulate that to the other working group

members. It will take some time to put everything together. This again is how the strategic plan gets developed. It takes months and that is why we are hoping to get started as quickly as possible with the process. It is a process that Susan and her team has run successfully previously. I am confident it will work again.

DR. DANIELS: There will be many opportunities for input and of course the working group was put together with the intent of diversity and a diversity of expertise, opinions and perspectives, and we really look forward to everyone contributing.

Are there further question or comments that people want to make before we will be adjourning in a few minutes?

MS. GASSNER: I have a request. As an accommodation support for some of the neuro diverse, and maybe some of the non-neuro

diverse people who live in the fantasy that you think you are normal - that was as joke - if we could ask the participants on this panel to submit a head shot then we could get a document with the head shot - where you work - so that when we are on these calls we can start to put pieces together. It is like talking into a black hole when you don't have that.

DR. DANIELS: We have that information together. I don't know if it is up on the web - are the bios up on the web site yet?

UNKNOWN SPEAKER: Not yet, no.

DR. DANIELS: So we are going to be putting that up on the web site. We have been working on that over the last few weeks and we do have the bios for the workshop already prepared. So that should be up shortly. So on future phone calls you will definitely be able to go to that page and look at everyone's

bio and head shot, and we will have that at the meeting in September.

MS. GASSNER: Thank you.

DR. RAYMAKER: This is Dora, and speaking of accommodation needs for the neuro divergent amongst us, who would I direct queries about that to? Because there are some components of this that I might need some help with.

DR. DANIELS: Susan Daniels. You can just contact me. I think you have my e-mail address. Happy to help.

DR. RAYMAKER: Thank you.

DR. AMARAL: Is there anybody we haven't heard from yet that would like to get a word in before we finalize?

Okay. I have enjoyed the conversation already and really look forward to the meeting. I think if you do have suggestions for resources, please, as Susan said, direct

those to Susan and she and her team can accumulate those. I guess if you have suggestions for other co-occurring conditions you could also send those to Susan and we will generate a list that maybe we can discuss at the end of the working group meeting and see how we could address them in the future. I think you have Julie's and my e-mail addresses as well so if you have any comments to us about how you think we should be chairing the meeting, I think both of us would be willing to get input on that as well. So happy to have to go ahead and send an e-mail directly to me.

Julie, did I misspeak for you?

DR. TAYLOR: No, that sound great. Me, as well.

DR. DANIELS: It has been a terrific discussion. In our office I am happy to collect any information that you have. We

are already putting together some resources that we'll have available at the workshop, but welcome additional input and if you have any further questions about the workshop let me know and we will be talking with the speakers about what to expect for the workshop and what we are planning. So we are really excited about this and looking forward to having you all participate and having the public participate by webcast, phone or in person.

So thanks very much.

DR. ROBERTSON: Susan, thank you and everyone else, in terms of spearheading the logistics. It is much appreciated.

(Chorus of "byes".)

(Whereupon, the Working Group adjourned.)