INTERAGENCY AUTISM COORDINATING COMMITTEE
HEALTH OUTCOMES WORKING GROUP
CONFERENCE CALL

MONDAY, DECEMBER 17, 2018

4:00 p.m. – 5:00 p.m. ET

The Interagency Autism Coordinating Committee (IACC) Health Outcomes Working Group convened via conference call at 4:00 p.m., David Amaral, Ph.D. and Julie Taylor, Ph.D., Co-Chairs, presiding.

PARTICIPANTS:

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PRESENT: (continued)

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JOSEPH JOYCE, C.P.C.U., C.W.C.A., Keystone Insurers Group Inc.

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BETH ANN MALOW, M.D., M.S., Vanderbilt University Medical Center

MICAH MAZUREK, Ph.D., University of Virginia

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DORA RAYMAKER, Ph.D., Portland State University

SCOTT MICHAEL ROBERTSON, Ph.D., U.S. Department of Labor (DOL)

MARCELLA RONYAK, Ph.D., LCSW, CDP
Indian Health Service (IHS)

MATTHEW SIEGEL, M.D., Maine Medical Center Research Institute

SARAH SPENCE, M.D., Ph.D., Harvard Medical School

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PROCEEDINGS

DR. DANIELS: Welcome to this conference call of the IACC Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum. I thank working group members for joining us this afternoon, and any members of the public who might be listening into our call.

We are going to be talking today about the workshop we held in September, recapping that. Talking about activities that we would like to plan around mental health issues, and then talking about our working group document that we want to work on. So it is a planning call.

We are very happy that you joined us this afternoon. Are David Amaral and Julie

Taylor, the co-chairs of this working group, on the line?

DR. JULIE TAYLOR: This is Julie. I am here.

DR. DANIELS: Hi, Julie. David. David might be joining us in a minute. I am going to take a quick roll call just to see who is on the call. I already have Julie Taylor. Greg Barnes.

(No response)

DR. DANIELS: Tim Buie.

(No response)

DR. DANIELS: Lisa Croen.

DR. LISA CROEN: Yes, I am here.

DR. DANIELS: Hi Lisa. Beth Ann Malow.

(No response)

DR. DANIELS: Micah Mazurek.

DR. MICAH MAZUREK: Yes, I am here.

DR. DANIELS: Thank you. Christina Nicolaidis.

DR. CHRISTINA NICOLAIDIS: Yes, hello.

DR. DANIELS: Hi. Dora Raymaker.

(No response)

DR. DANIELS: If anyone comes off mute you can just chime in. Sarah Spence.

DR. SARAH SPENCE: I am here.

DR. DANIELS: Thank you. Dan Coury.

(No response)

DR. DANIELS: Orrin Devinsky.

(No response)

DR. DANIELS: Sarah Gardner.

(No response)

DR. DANIELS: Dena Gassner.

MS. DENA GASSNER: I am here.

DR. DANIELS: Thank you. Antonio Hardan.

DR. ANTONIO HARDAN: I am here.

DR. DANIELS: Thanks. Joe Joyce.

(No response)

DR. DANIELS: Connor Kerns.

DR. CONNOR KERNS: I am here.

DR. DANIELS: Brian King.

(No response)

DR. DANIELS: Clarissa Kripke.

(No response)

DR. DANIELS: Donna Murray.

DR. DONNA MURRAY: I am here.

DR. DANIELS: Thank you. Scott Robertson.

DR. SCOTT ROBERTSON: I am here.

DR. DANIELS: Hello. Elliott Sherr.

(No response)

DR. DANIELS: Matthew Siegel.

DR. MATTHEW SIEGEL: Here.

DR. DANIELS: Thanks. Jeremy Veenstra-VanderWeele.

(No response)

DR. DANIELS: Patty Dietz.

DR. PATTY DIETZ: Here.

DR. DANIELS: Thanks. Alice Kau.

(No response)

DR. DANIELS: Kevin Pelphrey.

(No response)

DR. DANIELS: Denise Juliano-Bult.

(No response)

DR. DANIELS: Nina Schor.

(No response)

DR. DANIELS: Alison Singer told me she was not going to be able to make it.

DR. LIZA LITVINA: Hi, this is Liza Litvina. I am calling from NINDS. I am calling on behalf of Nina Schor, in case she is not able to listen in.

DR. DANIELS: Oh, sorry, can you repeat your name?

DR. LITVINA: Liza Litvina.

DR. DANIELS: Okay, thank you.

Jim Ball.

(No response)

DR. DANIELS: Linda Birnbaum.

(No response)

DR. DANIELS: Sam Crane.

(No response)

DR. DANIELS: Geri Dawson.

(No response)

DR. DANIELS: Tiffany Farchione.

(No response)

DR. DANIELS: Melissa Harris.

(No response)

DR. DANIELS: Elaine Hubal.

(No response)

DR. DANIELS: Jennifer Johnson.

DR. JENNIFER JOHNSON: Here.

DR. DANIELS: Thank you. Walter Koroshetz.

(No response)

DR. DANIELS: I know that there was somebody else from NINDS on.

David Mandell.

(No response)

DR. DANIELS: Edlyn Peña.

(No response)

DR. DANIELS: Laura Pincock.

(No response)

DR. DANIELS: Louis Reichardt.

(No response)

DR. DANIELS: Robert Ring.

(No response)

DR. DANIELS: John Robison.

(No response)

DR. DANIELS: Marcie Ronyak.

DR. MARCELLA RONYAK: Present.

DR. DANIELS: Oh, you are, thank you. Robyn Schulhof.

(No response)

DR. DANIELS: Stuart Shapira.

(No response)

DR. DANIELS: Melissa Spencer.

(No response)

DR. DANIELS: Larry Wexler.

(No response)

DR. DANIELS: Nicole Williams.

(No response)

DR. DANIELS: Melinda Baldwin.

(No response)

DR. DANIELS: Judith Cooper.

(No response)

DR. DANIELS: I think that is all that I have on my list. So all of those people are not members of the Working Group. Some of them are IACC members who had joined us for the workshop. So I wanted to check is there anyone that I did not call that is on the call.

DR. BETH MALOW: Beth Malow.

DR. DANIELS: Oh, okay, I did call you. Thanks, though. Who else?

DR. DAVID AMARAL: This is David.

DR. CLARISSA KRIPKE: This is Clarissa Kripke.

DR. DANIELS: Clarissa Kripke. Sorry, and who else was that?

DR. AMARAL: David Amaral.

DR. DANIELS: Oh, hi, David.

DR. AMARAL: Hi, Susan, sorry I am late.

DR. DANIELS: Great. Anyone else?

DR. DORA RAYMAKER: This is Dora Raymaker.

DR. DANIELS: Oh, hi, Dora. Any other people? Okay, so now everybody knows who is on the call.

I would like to give some time to David and Julie to talk about the workshop that we had. Just as a reminder we had this workshop on the 27th of September, here in Rockville, Maryland. We covered the topics of Health and Healthcare for Adults on the Autism Spectrum, with a talk by Jeremy Parr from Newcastle University, about adulthood and his aging research program.

We had a presentation that David Amaral gave on behalf of Lisa Croen, about Physical and Mental Health Issues in Autism and the Epidemiology of Co-occurring Conditions.

We had a presentation on Epilepsy in Individuals with Autism: The State of the Science. That was by Greg Barnes and Sarah Spence.

We had a presentation by Tim Buie on Autism and Gastrointestinal Disorders.

And then finally, a presentation from Beth Ann Malow about Autism Spectrum Disorder and Sleep.

Sorry, the final presentation was the Patient Provider Interactions with Micah Mazurek, Christina Nicolaidis and Dora Raymaker. And we had a really robust discussion.

David and Julie, would you like to comment on it or provide some additional details?

DR. AMARAL: Julie, did you want to start?

DR. TAYLOR: Sure, and David, and maybe when I say a few brief remarks you can kind of talk a little bit about what you summarized to the broader group, to the broader IACC group.

But, you know, I think one of the things that I was really impressed by in the meeting was just sort of the robust engagement that everybody had with the topics. It was really exciting to hear about the work that everybody is doing. The thing that I really brought away from the meeting is that there is really a lot of good work going on in these areas, especially like in academic medical centers. One of the real barriers I see is how do we sort of get the uptake to that out into the community and to other physicians?

Other than just sort of learning a lot about the great work that is going on, a big take-home that I had was that there is a lot of great work going on and what can we do to sort of increase sort of the spread of that. Right, increase how that gets used.

DR. AMARAL: Yes, I think that that is right, Julie. I guess the take-away that I had was a comment that was made near the end of the session which said something to the extent that this was one of the first workshops or conferences on autism where everybody was in agreement that it was an important area.

Not only clinicians, but scientists, researchers, as well as people affected by autism and family members, were all consistent in their view that a lot of these issues like epilepsy or sleep disorders or gastrointestinal problems, were ones that really effect the families and individuals who have autism and that there is a need for broader dissemination, as Julie was saying about the data.

I do think that there were some questions that came up where it is clear that we need some more information. When we talked about epilepsy, for example, there is not that much information about what our predisposing factors of the emergence of epilepsy. There was some sense that epilepsy and autism of two types – not two types, but happens temporally at two different times, so that there is about 50 percent that happens before the age of 10 and then 50 percent that happens at late teenage and early adult years. What leads to those different patterns are not clear at this point. It would be helpful to have more information on that.

But I do agree with what Julie was saying that there has been a lot of work that has been done and one of the important questions is how to get it out – not to academic institutions or out into private practice and community providers so that they have greater awareness and can act on the information.

It was a terrific workshop session. I think everybody was engaged and energetic all the way to the very end. In fact, even after we adjourned, there were a lot of sidebar discussions. So I was very appreciative of the group that came together that day. To me it foreshadowed other interesting meetings and then the potential for having a really powerful document.

Remember one of the goals of this whole enterprise is to try and come up with a document that could be distributed on behalf of the IACC widely throughout the United States. I think we are on the road to coming up with that very powerful document. I am looking forward to the next meeting.

DR. DANIELS: Wonderful. Are there other members of the working group that have comments about the meeting? By the way, we are so appreciative of everyone who presented. You all did a wonderful job with your presentations and we appreciated having you there.

MS. GASSNER: This is Dena Gassner. I apologize, I am on my second round of bronchitis recovery, so I am a little breathy. But I did want to say that I appreciated the collaborative spirit that went through this process. I was also hoping as we dig a little deeper, that we will continue to pursue some of the evidence that was presented that started to reflect possibly some bias related to gender and diagnosis in these adult outcomes. We are projecting that more females participated in research, but maybe we just have more females than we thought.

Kind of questions that were brought up from the floor as we looked at the samples. I am hoping we can continue to pursue that as well.

DR. DANIELS: Thank you.

DR. SPENCE: This is Sarah Spence. I think the other thing that would be great to get some engagement would be from health insurers because I think that one of the things that these patients and individuals with autism are quite complex, so you tend to need slightly longer visits. There is a lot of different discussions. There is a lot of coordination, and I think we need to have some way, especially in the new realm of managed care and kind of accountable care organizations, I think there is going to need to be a way – there is going to need to be a way to document the medical complexity so that the payment reflects the work that the providers are doing.

I would really strongly recommend that somebody from CMS is there at the next meeting.

DR. HARDAN: Hi, this is Antonio Hardan. I want to echo what Sarah just mentioned, because that will be key to make our effort a little bit more successful and the recommendations to be followed.

I think if we can get someone from CMS, that will be key, because I think the way CMS and Medicare will go, the other insurance companies will go to make sure that if we recommend new codes for complexity for individual with autism or intellectual disabilities, they will be followed by other insurance companies.

DR. KRIPKE: This is Clarissa Kripke. I think that is a great idea for CMS but a theme that kept coming up was social determinants of health. So the funding is not just about funding for the healthcare services, it is also about developmental services and communication services and transportation and all the other things that enable people to make use of medical care.

So having people from ACL and Medicaid – it is not just a Medicare issue, too, and billing code, it is a developmental services issue.

DR. SPENCE: That is a great point.

DR. ROBERTSON: This is Scott Robertson. I wanted to concur on the social determinants of health and throw in like employment centered initiatives and transportation on there. Also, on the insurance end of things, I don’t know if it is something that we can explore for this or through other future avenues, it is how the possibility on what insurance can cover for autistic adults, the better insurer, quality of life, and kind of health and wellness. And what that means as far as being able to access the right occupational therapy, speech therapy, or whatever, due to be addressing things on sensory – is that kind of function, et cetera, that can get in the way of having a full health and wellness and quality of life.

DR. DANIELS: Thank you. We do have a member of the IACC who is from CMS. She wasn’t able to attend the previous workshop, but perhaps some of our other activities she will be able to be involved with.

Any other comments before we move onto the next section?

David and Julie can help us talk about this. At the last IACC meeting, the committee discussed the workshop. They also were really pleased. Many of the members were able to attend the workshop and thought that it was a really great workshop with excellent discussion.

They did talk about the need – this is something that came up at our workshop, as well – the interest in mental health conditions that affect people with autism. The committee discussed that and were in favor of potentially planning an activity, such as a workshop, around mental health. David and Julie and I have been discussing that and are interested in getting some input on that.

In terms of the discussions that we have had about this topic, we could do a workshop potentially this spring on mental health conditions. Some of the suggestions that have come up would be issues around depression, anxiety, and suicide. We are also open to other types of suggestions.

David and Julie, do you want to comment on this?

DR. AMARAL: Yes, I can. I think in the first workshop, anxiety kept coming up over and over again as an important issue. I think the whole workshop people were talking about mental health issues and actually encouraging us not to ignore them as we move forward in the workgroups.

I do think that it would be terrific to have a second session. I think one of the values of the first session was that we focused on three topics and tried to limit discussion on other things that are, of course, of interest, but were different from the three focal topics. I think the idea of having a session or workgroup meeting that deals with anxiety, suicide, and depression as three options would be good.

I think it would – at the first meeting, Connor was there and spoke eloquently on a number of topics. I would propose that we ask Connor to give an overview on anxiety.

Suicide was a little bit more difficult. I have become familiar – I am just mentioning this to get some feedback and see if other people have other suggestions – became familiar with Sarah Cassidy’s work, who was a faculty member at Simon Baron Cohen’s group, but now as an independent investigator at New Castle. Actually, she has written a very large report on suicide as an issue in Great Britain and really speaks eloquently and has done a number of editorials. She might be somebody good.

We were having a little bit more difficulty finding or thinking about people to represent depression.

From my perspective, those seem like three really important topics. I think we'll see what Julie thinks, but then also open it up to suggestions from the whole group, the workgroup, number one, on whether these are the three topics that we should focus on, and, number two, whether there are other people that we should invite to give short presentations.

Remember, for those of you who weren't at the first workgroup, we try to have the presentations limited to 15 minute presentations. These were like capsule summaries not only of the person's individual work, but of sort of the state of the field. Again, what made the first meeting so successful was that these really just launched people into discussion. There was this robust conversation with the whole workgroup. I think we would want to follow that same procedure for the next one.

Julie, I will turn it over to you. Then maybe we can open it up to get some comments on whether these are the topic areas we should be moving towards and whether there are other suggestions for the capsule summary speakers.

DR. TAYLOR: David, I think that accurately captures what we have been talking about here. I think those are the three sort of – suicide, anxiety, and depression are the things that, in our discussions at least, in what we heard both in the larger IACC meetings and in this first working group, were the topics that came up – seemed to come up the most often. I would be really interested to know if there are other topics that we should include.

I think the other thing to keep in mind is that just like in the first meeting, we would like to try to keep the number of topics relatively small so we really have some time to dig into them, which is always a balance. You want to cover lots of different things, but then you have so little time to spend on each one of them that you can’t really get into meaningful conversation. So, that would be the other thing to keep in mind as we are thinking about topics. Maybe limit it to – were we thinking maybe like four topics total is what we did the first time? Three or four within the realm of mental health just to make sure that we really have time to delve into them deeply.

DR. NICOLAIDIS: Julie, I think those three are really good topics. Another person to think about in terms of depression, who I am assuming you already know, is Brenna Maddox, who works with David Mandell. She has been doing some really good participatory work around mental health care, in particular, for autistic adults.

In terms of other topics – I mean Dora can speak to this more, since she is on the call, but we have recently gotten a small grant that Dora is leading around autistic burnout, which hasn't been in the literature, but which is a hugely important issue in the autistic community and, certainly, lots of folks I think have interest in this – the concept, which we, unfortunately, see often of people having a sort of almost complete life burnout from the challenges of trying to constantly cope, fit in, camouflage, function, et cetera, which sometimes leads to a burnout, depersonalization, loss of function type situation. I think that might be interesting to include, too.

DR. RAYMAKER: Thank you, Christina. This is Dora. Just following that, yes, Sarah, yes, Brenna, and yes to what Christina said.

Some of how I – so, there is a lot of connections between burnout, anxiety, depression, suicide, potentially. This is also coming at it from a services side. A lot of this came out in looking at employment services and learning that there is a mental health component to some of these services that isn't necessarily being met. So, that is another potential piece of approach.

I think that the camouflaging is something that in some of Sarah's work, she has found connections between camouflaging and depression and suicide and anxiety. So, there is a lot of kind of cluster of things.

I also would like to say that I would be very interested in being a part of that should it go further.

MS. GASSNER: This is Dena again. I just wanted to bring up Burke and Stoddart out of Canada, who has done a lot of research on health care access as a potential barrier to getting mental health support services. They talk about everything from having to make a first phone call, make an appointment, to people rushing them and not giving them time to process.

The other thing that I don’t think we are talking about enough is the years of medical maltreatment and delay in terms of getting a proper diagnosis and how that affects mental health. Many individuals come into their diagnosis of autism through the lens of depression. In fact, they may be presenting with depression, but they are not being treated through the lens of autism.

The medications they receive may not be effective or may be actually doing more harm. Sometimes they wind up getting a lot of repetitive, inappropriate treatment because they don’t know they are autistic and they don’t know to see an autism specialist. The people they see do more harm.

That may be best addressed through a lived experience share. I am all for the quantitative, but I think illustrating this through lived experience – I think most of our speakers last time, even though they came with research, spoke to it from some case experiences that helped to illustrate things. That would be something I think would be key is understanding the barrier to access.

Someone doing great work on that is Teal Benevides out of Augusta, with the AASET

Project. It is a PCORI funded grant program. We have already put in an INSAR proposal to present some of the data coming out of that.

Access is a huge barrier and they have identified systems navigation support as their number one most requested support to make a difference for them.

So there are just a couple of other ideas for you to think about.

DR. ROBERTSON: So I had a few different comments to share. One of which is to add to the comments on burnout to maybe couple that with discussion on resilience and the need for more of that in the research literature. A lot of the research literature on resilience has focused more on parents and family members and not as much on autistic adults and youth.

One of my other comments was it’s – in concert maybe with discussion on depression is to discuss a little bit on how there is a little bit of research literature that started coming out on substance abuse issues, which sometimes can go hand in hand with mental health-related adversity. Folks used to think that it was a lower rate. Now, we have a more comprehensive study that came out – I think it was like a year ago or so from I think it was Sweden or something like that where it found a rate that was two times higher.

It would be nice if – maybe to have SAMHSA – someone from SAMHSA kind of more engage some things. I happen to run – I don’t know if this is the person or someone else, but I happened to run into someone from SAMHSA and we were talking a little bit about autism stuff when I was at an interagency meeting on transportation and related kind of interagency focuses around that. He seemed of interest in terms of the cross-connection on mental health and autism.

There is not currently – Susan, correct me if I am wrong, but I don't think there is anyone currently from SAMHSA that is participating in the IACC at the moment.

DR. DANIELS: No. Not right now.

DR. ROBERTSON: Okay. So that would be – we could have like one person, either that person or maybe – I can put you in touch with him or maybe if someone else from SAMHSA could help participate because they are – I mean that is their focus on that area and substance abuse. I think they'd add a lot of value to the conversation.

And then the other comment was that we may want to integrate together like anxiety and depression kind of in hand, kind of a singular topic area, because they sort of cross-touch each other. They are not really separable. A lot of times depression comes for a lot of autistic people from repeated experiences of heavy anxiety from camouflaging, from a lot of social, cultural, just community-type barriers. The stress from all of the anxiety kind of adds up and that kind of fuels kind of depression. So it is kind of – there is a lot of cross-touching on there. It would be good to make sure that that overlap is covered.

DR. SIEGEL: This is Matthew Siegel. I would like to add just two comments. One is that I think a potential topic that underlies these is the challenges in where we are with psychiatric diagnosis. We may have topics on anxiety, depression, et cetera, but we have major challenges as a field in valid and accurate diagnostics for these conditions across the spectrum, including people who are more severely affected.

So someone who could – there is a number of people who could speak to that, but one of them is Carla Mazefsky from Pittsburgh, also Matthew Lerner from SUNY-Stony Brook. I am sure there are others – Emily Simonoff from the UK. Again, psychiatric diagnostics so that you can actually make a diagnosis and then treat.

The second thing is you might consider broadening the depression topic to instead of depression make it mood disorders. I say that for two reasons. One is that there is very limited information on depression, as you all know, perhaps because we have no good diagnostics that have been validated for the population. The second is that depression is just one end of the mood spectrum. A lot of what is seen and treated is kind of ill-defined irritability that is put under mood.

There is a lot of work that has been done and needs to be done in that area. Thank you.

DR. AMARAL: Matthew, stay on for a second. Do you have some recommendations of speakers for, whether it is depression or mood disorders, people who could give a good summary of the field?

DR. SIEGEL: Yes. I think Craig Erickson from Cincinnati Children's Hospital would be one. He is the person who is coming to mind at the moment.

DR. AMARAL: Okay. Thank you.

DR. SIEGEL: If I have another, I will certainly email it to you.

DR. AMARAL: Great.

DR. DANIELS: Thank you.

DR. KERNS: This is Connor. I was just thinking in hearing everyone speak, one thing potentially to consider is would it be worthwhile to have somebody do a kind of broad presentation to begin with about the specific public health cost associated with mental health conditions and some of these large kind of research and access to care issues that seem to be associated with many different disorders as a way to kind of start out the day.

I know that the material we had from Lisa Croen at the beginning of the last meeting was really helpful in that regard. And there are some real specific costs and difficulties associated with mental health, in particular, that might be nice to kind of orient everyone for the day.

Related to that, the other topic I think I want to mention, of course, is the idea of contribution of adversity, maltreatment, and trauma to mental health if there is any room for that to come up.

DR. NICOLAIDIS: We have some data around those interpersonal violence and mental health side of things if we have room for that. I know Julie had told us to list four topics and we have gotten way beyond that.

DR. RAYMAKER: This is Dora. I was also going to bring up the trauma and adverse experience and abuse piece because that is also very much connected to the mental health stuff that we have seen in our work.

DR. KRIPKE: This is Clarissa. I third that. I think any talk – discussion of mental health without trauma would be incomplete in this population.

DR. ROBERTSON: This is Scott. I concur also that trauma is a really, really major focus that autistic adults emphasize a lot that hasn’t been studied as much and emphasized as much as it should be. So that is a very important topic to be emphasizing.

DR. AMARAL: Could somebody unpack that issue of trauma a little bit more? What are we specifically talking about? And for people who are advocating trauma and adversity, who might be - who might we tap to be able to discuss this, again, broadly, not from an individual research perspective, but sort of where the field stands?

So if somebody could first unpack trauma and adversity a little bit more and then talk about potential speakers?

DR. NICOLAIDIS: This is Christina. I can try to unpack it. I am sure others would have other things to add, too.

I think there is multiple different types of trauma and adversity. One is the types of trauma that we see in general populations in terms of experiences of child abuse, intimate partner violence, community violence. Those things we know are higher rates in people with developmental disabilities than they are in the general population. So we have got that to begin with.

Then we have got disability-related trauma, where you might have people who are getting bullied or having – getting either neglect or taken advantage of or – you know, financial abuse, et cetera. That gets kind of added on top of what we would normally think of, where the perpetrators may not just be the typical players, but also you add in potential caregivers, peers, et cetera.

Then we have trauma that has to do with just the experience of being in a marginalized group, of getting – discrimination of – getting back to the trying and having really negative experiences repeatedly, some of our treatments. All sorts of things can potentially be increasing trauma.

Again, there are other ways to parse it out, but I think we are talking about trauma through multiple lenses and multiple different types of levels and perpetrators. All of it, there is growing literature that the rates are extremely high and the effects of trauma on mental health and health, overall, are very strong.

DR. ROBERTSON: To add to that - this is Scott. Like also, in particular with trauma, like adverse childhood experiences – so the ACEs – there has been looking at that among autistic children and adults. There has been a growing literature on that in the last couple years. I don’t know the names of the researchers offhand, but I know there is a bunch of papers that specifically looks at trauma and adversity among autistic people through the lens of the ACEs and found a higher number, of course, among autistic people.

DR. NICOLAIDIS: In our group – we partnered, again, Dora and I and many others. We partnered on a project funded by the CDC focused on interpersonal violence against people with developmental disabilities, including autism. So we can certainly help with that or put you in touch with others that we work with.

DR. KERNS: This is Connor again. I just wanted to – I did publish one of the papers on ACEs and mental health in the National Survey of Children’s Health. The other person who has worked on it is Kristin Berg at Temple and there is one other individual. I am happy to chip in there, as well.

I think the whole concept of trauma is very, very complex. So, you know, for me, one element of it is how is adversity and the social determinants of health being brought up mindfully and considered when we talk about the high rate of comorbidity in autism, since you have to be a part of the conversation.

The other part of it is actually looking at a lot of the research data where every psychiatric comorbidity appears to be higher in autism except for PTSD. There is like one paper that shows a high rate of PTSD. I think it is from Turkey in its population. But many, many other studies that have looked at comorbid psychopathology in autism don’t measure PTSD or they actually find the rates to be quite low. That was even true kind of coming out of some of these inpatient samples, where there is a high rate of abuse that has been reported for the kids coming in, but rates of PTSD are quite low.

It just goes back to this issue of assessment and operational definitions and diagnosis, but I am happy to contribute to that topic if it is something we decide to pursue.

MS. GASSNER: This is Dena. Can I just like – call me crazy, but what if we were to focus this first workshop on trauma as the foundation for then later looking at mental health? It sounds like we could do a whole day workshop on trauma.

Again, I go back to the medical trauma that many people report. Through our AASET study, people are talking about being physically restrained the first time they went to a doctor for a urinary tract infection. We are talking about people who will not go to the dentist because they were physically restrained when they went to the dentist. The fact that they can’t get nitrous oxide to relax them for their anxiety for those appointments without paying an astronomical amount of money.

We are talking about, like I said, the medical maltreatment through misdiagnosis that we talked about earlier. That we are just not doing a great job.

These people ultimately wind up without trusting relationships with providers because of their first bad experiences. And that results in them ongoing not having good medical or mental health support.

So I don’t know. I was just throwing that out because we have so many layers to trauma. I believe, as the earlier speaker said, trauma is the foundation for understanding mental health needs.

DR. AMARAL: This is David. Let me – so it has really been interesting hearing people talk about trauma. I appreciate everybody providing stuff and unpacking and emphasizing the importance of it.

I just want to remind everybody that one of the goals of these workshops is to not only articulate problem areas, but to also come up with solutions. So part of the reason for picking gastrointestinal problems and epilepsy and sleep disorders for the first workshop session was because each of those have some practical solutions if they could be implemented. Part of that is getting the knowledge out to, for example, primary care physicians that people with autism do have gastrointestinal problems and they should be treated.

Listening to the discussion about trauma, it seems to me like it is a really important issue to raise awareness. But in terms of finding some low-hanging fruit in terms of getting to treatments, I do think that certainly anxiety, where there is really good treatments for anxiety – if you can actually distinguish anxiety in autism, it is a treatable component of the whole disorder. Similarly, there is probably some good suggestions on how we can reduce suicide through earlier interventions and perhaps depression.

I think trauma is a really important topic, but I think it is because of the complexities that you all have been talking about, it is probably one where it is going to be harder for us to come up with some suggestions for ameliorating the problem. It is not to say that we shouldn't discuss it and it should be included in the document, but probably it is a topic area that is emerging, needs to be further researched and discussed, and then, hopefully, there will be some policy or some procedures that can be put in place.

Just listening to you, it seems to me like it might be a little premature to focus everything on trauma because it really is just beginning to emerge. I am happy to get arguments on that if other people feel strongly. We are really looking for sort of low-hanging fruit of how we can bring some relief for both physical, medical, as well as mental health issues to the autism community.

DR. DANIELS: Can I make a comment here? Sorry. This is Susan. Just responding to Dena in terms of like the idea of having multiple workshops.

The IACC is set to – there is a sunset on the legislation next September. We anticipate that this IACC is going to complete its work by September. We most likely will not have time to do two more workshops in 2019 for this particular working group. So we probably should just be planning one and then see where we go from there. Just wanted to throw that out there.

DR. MAZUREK: This is Micah. I just wanted to add just a couple of comments. I certainly think the topics that have been raised already are probably the most important in terms of priority mental health issues. But I would also raise a possibility of ADHD symptoms as a really common co-occurring condition that probably does present for treatment quite often. It might be something else to consider if we have time.

DR. HARDAN: Hi, Antonio Hardan again. I think as we are talking about the different options, it would be good to keep in mind those who are severely affected and think about the disorder or problem behavior that we see very frequently with the most severely affected. I think ADHD is one of them. Mood dysregulation is the other one, aggression and self-injurious behaviors. From a medical point of view, we see these problems very often and they are very hard to treat.

DR. SCHOR: I think it will be very important to consider presenting something about the appearance of these symptoms and these conditions in childhood. I think if we focus as much of the discussion I have heard on adulthood, we may have missed an important window to make a difference very early in the lives of individuals with autism.

DR. KRIPKE: This is Clarissa Kripke. I wanted to respond about low-lying fruit, in terms of addressing trauma. I think there is a lot of low-lying fruit and, in fact, I think a lot of the trauma – I am not sure if it was Dena or somebody else who said it – a lot of the trauma is actually iatrogenic.

It is coming in medical and schools in the form of isolation and restraints. It is coming from people being underestimated. And a lot of the aggression and self-injury is a reflection of it. And what Christina said about trauma coming actually from the therapies that people are being offered in early intervention and elsewhere.

So we could just – one very low-lying fruit is we could stop traumatizing people. And there is already work being done on isolation/restraint in schools. So there are very practical things we could be doing to dramatically reduce trauma in this population.

MS. GASSNER: I would say, too, if you overlay the ACEs research on top of the autism research in terms of mortality, the same things that are killing non-disabled people prematurely due to high ACEs scores are happening exactly the same way, but much younger, in our population. So I think when we look at this if we look at it from that ACEs foundation or that early trauma foundation that is the most effective way to address the needs of children and, inevitably, will lead to benefitting adults.

But I don’t know. We can do a part of that in a day. I am glad to know the framework and the timeline. That was very helpful.

DR. RAYMAKER: This is Dora. I also wanted to respond to the low-hanging fruit idea around trauma. This is not my area of expertise, but there is a growing body of work around trauma-informed care. There is even a whole Institute of Trauma-Informed Care Oregon that is a state-funded partnership with my university. So there are actually things that are beginning to come in place that are solutions to addressing trauma in healthcare and service settings that could potentially be tapped.

DR. KERNS: This is Connor. I think another low-hanging fruit here, in terms of trauma, is - maybe we don't have to make it the whole topic, but it is something that is considered in each of the disorders that is brought up or in the discussion throughout. So that we are sure when we are talking about mental health conditions that we are not just attributing to them to, oh, this is autism and this is what inevitably happens in autism. It is going to unfold this way. But also kind of considering the interaction of the person in the world.

So having that perspective kind of going in. And that is sometimes how, in its most basic way, trauma-informed can be framed, which is kind of thinking about what has this person been through, what have they been exposed to when you are caring for them, as opposed to just kind of attributing everything to the individuals, themselves.

DR. ROBERTSON: This is Scott. I just wanted to respond a little also to the – one of the comments mentioned on not forgetting about children when you are considering focuses on adults. I think we are all in favor on lifespan things. It is just that adults tend to often be the part of the population forgotten about. When you are talking about research or practices, it is still overwhelmingly focusing on kids. That is one of the reasons that autistic adults regularly bring up adult-focuses.

You are not – for instance, a lot of the studies on ACEs or trauma – like some of those were done among kids or adolescents, but not done among adults. Like resilience studies – like those haven't been done among adults. A lot of the mental health literature has been done more among kids.

I know sometimes when I have to look up research literature on co-occurring conditions and chronic conditions, et cetera, for research papers, sometimes I have to use the numbers from adolescents because there isn't always the literature among adults. I just want to emphasize that.

That that is one of the reasons why that is – that is iterated a lot from folks is that adulthood focus is really important. A lot of – while it is true that a lot of the adversity, trauma – a lot of mental health-related barriers begin in childhood and adolescence, a lot of it also comes through young adulthood, middle adulthood, et cetera, and experiences folks have in the adult world and community. I think that that shouldn't be minimized.

The other thing that I wanted to make a comment on – is it possible for future calls to use some kind of tool? Like when I was on the – previously, years ago, was on an FCC subcommittee for – advisory committee there. They had and it is still available freely, anybody can use it, it is called a hand raising tool, where it helps with these phone calls, where you can kind of cue up people rather than having this free for all kind of jumping in.

Because I find it really hard at times – we have such resilient people on the phone at times – to jump in and make a comment. I just communication-wise find that really challenging at times. And when you have tools that can kind of help make it a little bit more organized – I can send the URL to you, Susan, and to others, if you would consider that. I think that would help a lot for me, maybe others, on anxiety. Where you basically go online and then you click on the thing when you have a question or comment and then the person managing the call will just sequentially jump person to person. That makes it easier for those of us with communication challenges who may find it hard to just jump into the fray of these calls.

DR. TAYLOR: That is a great idea, Scott.

DR. DANIELS: Go ahead and send me the information. That would be helpful. Thank you.

DR. ROBERTSON: Yeah, I will send you the link. And it is free. It is a free tool online that they just provide. You just click on make a meeting and stuff like that and then you can just stick people in the queues. It is pretty easy. But I will send you the URL for that.

DR. DANIELS: Thank you.

DR. AMARAL: We need to push the NIH into the 20th century.

DR. DANIELS: I actually haven't been on a call that used that type of technology before.

DR. ROBERTSON: So the FCC uses it a lot for devices. I think it is partly also because in their case, they have a lot of folks who are communicating through, you know, like interpreters and augmented communication and things like that. And so like it is like essentially critical there, but I think it would also be helpful in our space. You have a lot of folks like especially like autistic adults on the call who may find it hard communication-wise to just suddenly jump into things.

There is a universal aspect of it, too, but I – yeah, it hasn't percolated I think outside of the FCC – used as much. It was developed by folks for the Raising the Floor kind of cloud computing stuff as just a universal tool that I think – I think maybe it was Wisconsin-Madison, a computer scientist there, I think, put it online as a website.

DR. AMARAL: That is great. Susan, do we need to move on because we are –

DR. DANIELS: Yes. So we are getting toward the end of the time that we had set aside. It sounds like we have collected some useful feedback. So David and Julie and I can get together and talk about this and see what we can come up with for ideas for this workshop based on previous discussions and this discussion.

We are looking at a timeframe of having this around the end of February or the beginning of March. So we have some dates in mind and we will let you know what we are considering for that. Just in terms of the OARC schedule, we think that that is the time of year that is going to work best for us as by summer, you would not have much time to do much with the information you gained because the committee would be completing its work by September. So we will be in touch about dates.

So the last item on the agenda, which we won’t have a lot of time to talk about, is talking about the group’s written document. So David and Julie, if you want to say a few words about that. We don’t have to figure everything out on this call. We can certainly have another call to really talk about that in more detail, but at least we can get a few thoughts out on this call.

DR. AMARAL: I was going to suggest, Susan and Julie, that the strategy that we used for coming up with the IACC Strategic Plan was a good one. Just so everybody knows who is on the call, basically, what happened was there were sort of team leaders who came up with an outline for different sections of the strategic plan and then people would volunteer to participate in writing those subsections. Somebody would coordinate those, the team leaders of each section. So it was an iterative process.

But I think in terms of this document that we are thinking about, after the next meeting, maybe Julie and I could try and come up with a very rough preliminary outline of topic areas and then what we could do is ask for volunteers to take responsibility for different sections and give some timeline for getting drafts back for each of the sections.

From my perspective, I think we should probably wait until the end of the next meeting and get the minutes from both meetings together and then we can come up with an outline and then distribute – make sure that everybody has the minutes and then just come up with subgroups.

The subgroups I guess could have further conference calls to talk about their subsection before things are written. I think it is a little bit – at this point, before we have this second major meeting, we should probably hold off on figuring out what it is going to look like. Julie, what do you think?

DR. TAYLOR: No, I like that, David. I think that makes a lot of sense. Once we sort of have the lay of the land, in terms of having all of the presentations, we can think through what that will look like and then, you know, have people write on sections that they are most knowledgeable about.

DR. DANIELS: Okay. That sounds like a reasonable plan.

So I think then on this call, we have pretty much gotten through the business that we need to. Are there other – any other last comments that people have that they would like to share before we adjourn?

DR. CROEN: This is Lisa Croen. I am just wondering when is the next meeting that you, David and Julie, referred to?

DR. DANIELS: They are talking about the workshop. So we tentatively have identified February 28th as a possibility. And so feel free to mark that on your calendars, but you will hear from OARC about trying to confirm a date. Obviously, we haven't completely nailed down the topics and the speakers yet and we will want to kind of work on that, but we are looking at February 28th or one or two other dates around then for this workshop.

And it would be similar to the September 27th. An all-day workshop in-person. We would fly everybody here who wants to come or you could be on the phone. And it will be webcast.

DR. ROBERTSON: Thanks, Susan. I will make sure to calendar that.

DR. DANIELS: Sure. Great. Well, thank you.

MR. JOYCE: Hi, Susan. This is Joe Joyce from the Autism Society. All I want to say is thank you to everyone that is on this call. I have been just listening and amazed with all of the brilliant dialogue. I just would like to thank everyone for all of your hard work that you are doing. It is wonderful.

DR. AMARAL: Thank you.

DR. DANIELS: Thank you. Thank you to everybody.

DR. AMARAL: This is David again. I just want to make sure that everybody feels that we are taking in all of your comments. This, again, this phone call says to me, again, people are really passionate about the things that they think are most important. We want to – we certainly want in the final document to acknowledge all of these areas. We will have to come up – we are going to work together to try and come up with a document that doesn't give short shrift to any of these issues.

I think there will be some that will be sort of easier to deal with. Some that will be more complicated. Thank you for the education on trauma. I learned a lot about that. You know there will have to be some areas where we will be indicating that a lot more work needs to be done. As people were saying, we need to get other agencies involved in that. But that will be a very valuable document because it will give guidance to not only the NIH, but their other governmental partners about areas that can be improved on.

I really appreciate – again, this was a great phone call. I appreciate everybody's input. I appreciate your taking the time. I hope those folks can make the February 28th meeting if that is the day. I know it is not –

DR. DANIELS: It is not set in stone yet.

DR. AMARAL: It is not set in stone yet, but whatever date, I would encourage people to come and contribute and then get involved in the writing. We will have a really great product.

So, thanks everybody for participating.

DR. TAYLOR: Thank you.

DR. DANIELS: Thank you.

(Whereupon, the teleconference adjourned 5:00 p.m.)