

common theme in all the AASET groups we talked to.

If anybody is interested in looking at the AASET project, it's at autistichhealth.org. We're about to engage a second call for purpose of sampling because we didn't get enough people of color responding. We're making a second attempt to expand our sample with the intent of trying to get more of those voices.

Not everybody who is living with autism feels comfortable speaking their truth. Lindsey and my friends have worked so hard. I've worked so hard at working our work so that could say that to you, but know that it is not something that we walk away from without scars emotionally, physically and cognitively. This costs us cognitive capacity. I thank all of you.

this time and time again in our qualitative study of autistic individuals taking it on themselves, bringing packets of information about autism when they would go seek out mental health services so that they could try to educate the clinicians who again very few of them had any sort of autism training.

Even when clinicians have been trained to work with autistic individuals, it's not exactly clear what they had been trained in. Another major barrier is that most mental health evidence-based practices were not designed for autistic people in mind although there are of course exceptions that we've heard about today.

Similarly, most existing evidence-based practices for autistic individuals are complex and multi-faceted and therefore may not be able to be implemented effectively in these community settings. An easy example of

this is perhaps the evidence-based treatment manual has 90-minute sessions, but the community clinic can only bill for 50-minute sessions and the clinicians don't know how to make this match.

Moving on to a system's level barrier, this is a big one. Whenever I present on this, I see a lot of people nodding in the audience because apparently it is a problem across states and even across countries. This problematic disconnect between the mental health and developmental disability systems. This, of course, can result in autistic individuals getting turned away from services.

We've heard people talk about this already today. You can imagine how discouraging and frustrating it would be. You've worked up the courage. Let's say you have really impairing anxiety. You're ready

to get treatment. You call a clinic. You say I really need some anxiety treatment. You're going through the intake process over the phone. Then you mention that you have an autism diagnosis or that your family member who you are calling about has an autism diagnosis and you hear on the line we don't treat autism so you need to call the developmental disabilities clinic. And you call the developmental disabilities clinic and as you are going through that intake process, you mention that the real primary concern right now is anxiety and you are told we don't treat anxiety. You need to call the mental health side. We've heard about this a lot from individuals this going back and forth and how exhausting and discouraging that really is.

The final problem I'd like to highlight is this. Our current mental health care

system is bad for children, but it's even worse for adults. And there are many reasons why this is. One of them, I think, is that most of the research to date on mental health services for autistic individuals has focused on children although this is changing and there is some growing work on adults on the spectrum.

As you saw on my earlier slides, it's more likely that clinicians who work with children have some training in autism compared to clinicians who work with adults. I think this may reflect the historical bias that autism only affects children, which we all know is not true. But in talking with clinicians, it seems like if they were training to be an adult provider, no one thought to mention autism to them in their training.

In addition, we know that many children on the spectrum are receiving mental health services through school so in school-based programs. As others have talked about, when those individuals graduate, they face a services cliff where they lose access to those services and supports including mental health services.

Clearly, there are some major problems in our mental health care system for autistic adults. I know I only covered a few this afternoon. But I'm hoping that we can spend the last few minutes maybe on a slightly more uplifting note, talking about some possible solutions. Of course, I'd love to hear everyone's ideas about this during the discussion period.

The first thing, which we've talked a lot about today and it's a clear area of need is clinician training in order for more

clinicians to be skilled and feel confident treating autistic clients. I think this training needs to happen both at the preservice level, meaning in graduate programs so through course work, through practicum placements, and also in continuing education.

Of course, this training cannot be offered only to child providers or clinicians working with children. We desperately need more adult providers training in autism as well.

You all heard from Judy Reaven earlier today. She and her colleagues are doing very exciting work in this area of training clinicians to deliver cognitive behavioral therapy for anxiety and I am hoping to see more work like this in the future.

And then although clinician training is certainly an important step toward improving

mental health services for autistic people, we know from the implementation science literature that other strategies may be needed to produce sustainable change in clinician behavior. Moving forward, it's essential to examine other implementation strategies in this context as well.

Ideally, we want to choose implementation strategies that directly map on or target the barriers and facilitators that we are talking about here.

Dr. Lauren Brookman-Frazee and Aubyn Stahmer in California are doing this type of tailored implementation strategy work. They are currently conducting a large study, testing the effectiveness of a multi-level implementation strategy for two different autism interventions. They are doing that direct mapping or the tailoring that I'm talking about.

Another big piece that we've been talking about today is community academic partnerships or partnering with stakeholders. When we think about making our treatments accessible and relevant to the community so that clinicians can actually use them and the individuals in the community can actually benefit from them, learning from stakeholders and these partnerships are so key.

And then finally, the coordination between mental health and developmental disability systems. There's a lot of work to do in this area, but I think we can make great progress if we work together and get people from both sides to increase their communication.

The last point I'd like to make is that these difficulties that we've been talking about today of accessing evidence-based mental health treatments in the community are

not exclusive to autism. This research to practice gap extends well beyond autism and is a problem across the board. It makes me think about and wonder how our goal of improving mental health services for autistic people intersects with other initiatives to improve mental health services more generally or globally. Should we joining forces with other groups to maximize our impact?

I will leave you all with that question along with some acknowledgements to our wonderful community partners, the participants in our studies at Penn, along with our funding sources, the NIMH and the FAR Fund. And then I've had the wonderful opportunity to work with a really amazing research team and mentors along the way. I wouldn't be here without them. Thank you all for listening at the end of the day. I

sincerely appreciate it and I look forward to our discussion time.

(Applause)

DR. DANIELS: Thank you, Brenna, for that nice summary that captured some of the themes that we've been discussing throughout the day. We have some time for some questions for Brenna as well as we can kind of segue into our final discussion as well if there are any pressing questions that you had from throughout the day to bring them up. But maybe first if you have any particular ones for Dr. Maddox, we'll go with those. Dena.

MS. GASSNER: Thank you so much. I kind of got a little rattled when you showed the one slide where the provider said that they would not feel competent working with autistic people because she clearly doesn't understand she already is. That lack of realization that autism doesn't always come

with a lot of bells and whistles is just impacting. And then as you described the woman who had to go in with her own literature to train her provider on how to work with her. The cognitive fatigue of that level of intensity just to basically be heard is so extraordinary.

And the last thing I want to say probably for the day is we haven't spoken about the intersectionality with gender fluidity and LGBTQ communities and the high rate of suicide when that intersects with autism. I'm hoping that we just keep that in mind as we go forward. Thank you so much for at least hearing those voices. Another shout out for qualitative research.

DR. MADDOX: Thank you, Dena. I agree. Those are really very powerful quotations from these individuals. I feel really fortunate that I was able to hear them.

I should say - I didn't mention in the presentation, but we are working with several of those individuals who participated in the qualitative study to design a training program for community mental health clinicians who work with adults and I agree with you. They are already working with adults on the spectrum even if they may not realize it. We are really excited to launch that training program.

DR. DANIELS: Thank you. Scott.

DR. ROBERTSON: I was wondering also. Are any of your collaborators by chance autistic people who happen to also be clinicians? I know that's easier said than done because of the fact of stigma, et cetera. It's very hard for autistic people even in clinical practice or law or medicine or whatever to be out about it, but are often working out there on the field. As more and more folks feel more

comfortable I think over time to come out about being autistic in social work, occupational therapy, counseling, psychologists, psychiatrists, et cetera. I have met autistic people in a lot of the different clinical fields. Maybe that would be good in terms of opportunities for direct connections on that.

Because I know that folks who have the perspective of both the clinical world and have the perspective as an autistic person as well like that duality there I think has been helpful in terms on the collaboration end on thinking outside the box, not exclusively, but especially for helping when you're looking at new unique ways for addressing solutions for improving access to autistic adults and getting the trainings and what you are thinking about on the curriculum on what

could work well as far as practices out there in the field.

Outside of my DOL hat, I do some qualitative research on the side in occupational therapy and some other fields. One of my colleagues had met an occupational therapist who has a doctorate in OT and is autistic and I think is the first autistic person with a doctorate in that field. We have presented together. I think he has been helpful. He is not here on the east coast, but he has been helpful on educating a lot of folks in terms of the perspective on the autism side firsthand and how to be thinking differently when they are approaching clinical practice to be making sure they are having better supports for adults and thinking about ways in non-neurotypical ways because this gets back to the hammer and nail kind of -

The only downside, I think, sometimes for non-autistic folks in the clinical space are they are going to keep - I'm not knocking folks. It is what it is. Folks will sometimes be approaching things from normative ways. And sometimes I think it has been helpful for us as autistic people to be did you think of X, Y, and Z, and people are like I completely - it didn't occur to me that maybe when you cross connect, again, the clinical and the perspective - together on that you may get some new ideas. The fresh thinking that was mentioned before.

DR. MADDOX: Thank you for bringing that up. Yes, we do have a few collaborators in Philadelphia with that kind of dual perspective, which I greatly value.

One young woman. She is actually assisting right now Drexel University in Philadelphia has partnered with some other

organizations and they are launching a peer specialist training. If anyone is familiar with the peer specialist model in mental health so individuals with the lived experience are helping other individuals who are going through the mental health system. I think it's a great idea to have that for autistic adults. She has been a collaborator in our study and is also helping lead that effort of training autistic adults to be peer specialists, which I think is really exciting.

And then if anyone is familiar with GRASP, there is a support group outside of Philadelphia that is run by autistic adults. They don't necessarily have the clinician training in terms of being a therapist, but they have been running this really growing and vibrant group and bring that perspective

as well. We are very appreciative of those types of collaborators.

DR. DANIELS: Micah.

DR. MAZUREK: Thanks so much for that presentation. I think that is a really nice ending for our day to bring it all together and think about how we can make things better in the community.

I just wanted to share some thoughts from our ECHO Autism work where we really focused initially on training primary care providers and caring for children with autism. We just wrapped a transition to adulthood ECHO, again focused on primary care. But we did have a self-advocate as an expert member of the hub team as well as a parent of an adult with autism. I think that lived experience to your point, Scott, is just so informative. It just adds such a richness to our abilities to understand

different perspectives and train providers so thinking about ways to train community-based providers, post-professional is really important.

I was also curious about your thoughts about implementation strategies and whether there are modular approaches to treatment or kind of high-yield treatment packages that we could train community-based practitioners that could be cross diagnostic in terms of the co-occurring conditions.

DR. MADDUX: Yes, I think the modular treatment approach is very helpful for that. Jeff Wood and colleagues have a paper from 2015 with Lauren Brookman-Fraze and a couple of others talking about that type of approach. Modular, transdiagnostic if possible because I try to put myself in the shoes of a community mental health clinician. They are seeing so many clients. At least in

Philadelphia, they get these trainings all the time. I think the last thing they want is for someone to come in and say here. I'm going to train you on this very specific treatment that you're going to use for this very specific problem for this very specific group of people. And they would get - I think it was in Carla's slides - more bang for your buck with a transdiagnostic modular type of treatment where it could apply to more people and more problems.

DR. DANIELS: Thank you. Denise.

DR. JULIANO-BULT: Thank you for your presentation. It was great. I wondered if you could give us some of your thoughts on coordination between mental health and developmental disability systems, if you have models or conceptual models to talk about.

DR. MADDIX: Thank you for raising that question. This is something that - I don't

think Julie Taylor is still here, but we presented together at the Gatlinburg conference in April. I caught her afterwards and said can we talk about how to do this because people are bringing it up, but the next steps are somewhat unclear to me.

David Mandell, my mentor at Penn, and I also recently talked about it. And his suggestion, which I will repeat now because it's the best thing I have as an answer, was let's first just spend some time. I have spent a lot of time in the mental health side of things in Philadelphia. I need to spend some time on the developmental disability side and really just be an observer and learn and see what is happening there and start to hypothesize some next steps. If anyone else has ideas, I think we are very open to hearing them.

DR. SIEGEL: I will offer a somewhat heretical comment on that, which is - in the state that I live in Maine, in the child system, there's one agency. It is the Office of Child and Family Services that oversees mental health for everyone including people with autism or intellectual disability or any other developmental disability. There's no distinction. You come in and you get seen in psychiatry or therapy or whatever it is and it works quite well. Their rights are protected and all of those things.

And then the minute they turn I believe it is 19, there are suddenly two agencies: developmental disability services and the mental health. Instantly, there are massive problems including not wanting to pay and pass the buck and all those things.

Perhaps the heretical part or simplistic part is my answer is just blow one of them up

and that's silly. But really the question is why do we have this split and there are lots of historical reasons, but does it really match our current conceptualization of autism or other developmental disabilities? Does it really benefit those individuals to have a separate agency overseeing their services? I'm sure there are cases where that is the case, but it also seems to generate a lot of barriers. That's a global thought.

DR. DANIELS: Dena.

MS. GASSNER: Can I just bring up a point from a colleague on the phone? Our friend, Chloe, who is on the National Board at the AHRQ, who is also learning to manage behaviors said that one of the gaps we see is a lack of support for the family and the individual when medication changes happen because that can be a very tumultuous time.

She's also a big advocate for the ending of the barrier of child life specialists being limited to pediatric centers. She has had to appeal to have further surgeries in a pediatric center because she's over 21. But she needs the support that only child life can provide. That's another barrier to support that's really relevant. I appreciate her texting during the meeting to say can you remind them of this. Thank you, Chloe.

DR. DANIELS: Alice.

DR. KAU: I just want to thank all the speakers, everyone coming to the workshop. I learned a lot. I want to thank especially those self-advocates and the parents who bring your story to share with us and to put meaning all the work we do. Thank you.

DR. DANIELS: Thank you. Scott, do you have another question.

DR. ROBERTSON: I just had a couple of quick comments and a question. I guess it is what it is on logistics. It's too bad - I guess SAMHSA doesn't currently have a rep on IACC.

DR. DANIELS: No, they are not on the IACC.

DR. ROBERTSON: They were previously or no?

DR. DANIELS: They were previously, but they stepped off.

DR. ROBERTSON: Okay. Because of the fact of the cross connection and this focus.

The other quick comment was with the work that we actually have related to autism and neurodiversity at ODEP is that some of my other colleagues were actually encouraged that some of the focuses on autism can actually benefit people with mental health disabilities broadly because there is a lot

of overlap, as we have seen today. And then obviously also with autistic people and mental health specifically in terms of we were looking at the intersectionality on that. There is just on the general mental health population group that there are things that can be learned from autism and vice versa.

The question that I have though was about the federal committee on mental health that was established by the 21st Century Cures Act, which I believe is still going on.

DR. AVENEVOLI: I can't remember the acronym.

DR. ROBERTSON: It's Interdepartmental Serious Mental - ISMICC.

DR. AVENEVOLI: SAMHSA actually runs that, the Assistant Secretary, who happens to also run SAMHSA runs that. It is ongoing. I think the next meeting is July 2. NIMH is not

an official member of that. We attend the meetings out of interest. SAMHSA - federal --

DR. ROBERTSON: My question was going to be about whether anyone - if anyone had presented - we have a rep over there. I haven't asked them recently the goings on of that committee.

DR. AVENEVOLI: They do publish all of the materials and I believe they have videos from at least segments of the meeting. You should be able to retroactively see what has been discussed on the agendas. I think anyone can attend as long as they have sufficient seating.

DR. DANIELS: This is a good discussion reminding us that we can reach out to SAMHSA. And even though they are not a member of the committee, they are welcome to attend or contribute to work that is going on in the

IACC and perhaps we can have them in to talk to us again sometime in the future.

DR. ROBERTSON: Maybe you could share with what came out of this. Maybe they would be interested on hearing in terms of the thoughts and ideas that came out of the workshop if someone comes from SAMHSA.

DR. DANIELS: Yes, I think so. So we can do that. Are there other comments around the table? Lindsey.

MS. NEBEKER: I just wanted to echo what Dena had mentioned earlier. I wanted people to be more aware about this committee that we were involved in as AASET, as Autistic Adults and other Stakeholders Engaged Together.

And what we did is that we were part of a committee that had come together to try and get other input from other autistic adults, specifically about their health care needs, mental health needs so prioritizing what

positive health and health care needs outcomes would be desired, identifying what the evidence-based interventions and best practices for the autism community's perspective.

We had a meeting last fall here in this area. We all got together during this meeting and tried to put together a list of ten priorities which we wanted to have in consideration for research or for federal funded research, I believe. Dena, you might need to correct me on that. I'm not sure.

MS. GASSNER: It was the PCORI funding.

MS. NEBEKER: PCORI funding. Okay. Four of the ten were related to mental health. In this meeting, there was just a lot of mental health that kept being brought up. There is just this real interest. I would just encourage that we continue inviting committees or inviting more autistic adults

into sharing the input of what the mental health needs are of our community.

DR. DANIELS: Thank you. Melinda.

DR. BALDWIN: Thank you again for the presentations. My work centers on child maltreatment and children in foster care. As you talk about there not being mental health treatment that impacts children who are residing in foster care who are on the spectrum. I'm hoping that as some of our work progresses that that will also be able to be translated into some of the child welfare work.

I'm currently involved in some work with treatment in therapeutic foster parents. They often bring up this is great work and it's perfect, but my child has been diagnosed with autism and how do I translate this work in my home to him because they haven't been involved with the kids during their early

developmental years. They've often missed out on how to handle behaviors as they developmentally progress. I hope we don't forget about that population as well as we move forward.

DR. DANIELS: Thank you. More comments around the table? I'm not seeing any. We can move toward wrapping up this meeting. It's been a long and very interesting and very moving, very stimulating and exciting to hear about the possibilities that there are and of course much work that is to be done and many opportunities for further research and improvement of services. We thank you all for being here for this and especially to those who shared from their personal journeys about mental health conditions and how they've affected them. We know that that is deeply personal and we really appreciate people being willing to share about that.

To finish out today's meeting, I wanted to talk with the working group about what's coming up next. As you know, one of our goals for this entire activity is to come up with some kind of a written document for the IACC. And the IACC is ending on September 30 and the last full committee meeting of the IACC is July 24. Our goal will be to get a draft of some kind of written document to them to look at by July 24. I will be working with the chairs on an outline for a written document.

We probably will be doing some of this by email before we are able to have a phone call because that takes doodle polling and it takes time to put together a phone call, but we can take volunteers to work on various sections once we figure out what kinds of sections we might want and we can take any input by email if we need to revise that.

Just keep in mind. We'd love to have some volunteers that are willing to help us write the draft. We'll circulate that and then we'll try to meet again by phone at some point in the future. We'll keep you updated on that.

I would like to say thank you to the OARC staff for the work that they did in putting this meeting together and the work of the working group so all of the staff are recognized here. If OARC staff would like to stand so that people know who you are. I didn't use a photograph on this one.

We'd also like to acknowledge the support that we had from NIH staff here to run the video cast and other AV and the Bizzell Group for their logistical support. We thank all of them and thank you all for being here unless there are any other final comments. Shelly, do you have a comment?

DR. AVENEVOLI: I do. Thank you. This has been a very stimulating meeting. As usual, there are many more ideas than we can possibly do at one time. I think as you think about the document, think about how there is some synergy across many of the ideas presented. Think about how we might prioritize those kinds of things moving forward.

Last but not least, I want to thank Susan for all of her work and planning for today. She would be on that staff list too.

DR. DANIELS: Thank you everyone. It has been a great day and we hope everyone has safe travels home. Thanks.

(Whereupon, the Working Group adjourned at 4:48 p.m.)