INTERAGENCY AUTISM COORDINATING COMMITTEE
HEALTH OUTCOMES WORKING GROUP
WORKSHOP: ADDRESSING THE MENTAL HEALTH NEEDS OF PEOPLE ON THE AUTISM SPECTRUM

TUESDAY, MAY 21, 2019

The Interagency Autism Coordinating Committee (IACC) Health Outcomes Working Group convened in Rockville, Maryland at the Hilton Washington DC/Rockville Hotel & Executive Meeting Ctr, 1750 Rockville Pike, at 8:30 a.m. Susan Daniels, Ph.D., presiding.

PRESENT:

SUSAN DANIELS, Ph.D., *Executive Secretary,* IACC, Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

DAVID AMARAL, Ph.D., *Co-Chair*, IACC Health Outcomes Working Group, University of California, Davis

JULIE LOUNDS TAYLOR, Ph.D., *Co-Chair*, IACC Health Outcomes Working Group, Vanderbilt University

SHELLI AVENEVOLI, Ph.D., representing NIMH

MELINDA BALDWIN, Ph.D., Administration for Children and Families (ACF)

GREGORY BARNES, M.D., Ph.D., University of Louisville School of Medicine

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

PRESENT: (continued)

DAN COURY, M.D., The Ohio State University College of Medicine

LISA CROEN, Ph.D., Kaiser Permanente Northern California (attended by phone)

DENA GASSNER, M.S.W., Adelphi University

ANTONIO HARDAN, M.D., Stanford University Medical Center (attended by phone)

JOSEPH JOYCE, M.B.A., Autism Society of America

DENISE JULIANO-BULT, M.S.W., (representing Denny Pintello), NIMH

ALICE KAU, Ph.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

CONNOR KERNS, Ph.D., University of British Columbia

CLARISSA KRIPKE, M.D., University of California, San Francisco (attended by phone)

BETH ANN MALOW, M.D., M.S., Vanderbilt University Medical Center (attended by phone)

MICAH MAZUREK, Ph.D., University of Virginia

DONNA MURRAY, Ph.D., University of Cincinnati (attended by phone)

KEVIN PELPHREY, Ph.D., University of Virginia (attended by phone)

PRESENT: (continued)

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

STUART SHAPIRA, M.D., Ph.D., (representing Patricia Dietz, Dr.P.H., M.P.H.) Centers for Disease Control and Prevention (CDC)

MATTHEW SIEGEL, M.D., Maine Medical Center

TABLE OF CONTENTS

PROCEEDINGS

DR. SUSAN DANIELS: Good morning and welcome to this Interagency Autism Coordinating Committee Workshop, Addressing the Mental Health Needs of People on the Autism Spectrum. We welcome our online audience, people in the room, attendees, workshop participants, our speakers, our working group members and members of the IACC. We hope that this is really exciting and interesting day to talk about these very important issues that the IACC has raised interest in and wants to address through their work.

We're going to have a few minutes of introductions so I'm going to allow us to have a few moments of welcome and then we're going to do a roll call and have a few introduction slides and then we'll go around the table and do introductions.

Welcome to all of you. I will be giving you a little bit of background on the reasons we're having this meeting, but first I'd like to turn it over to Dr. Shelli Avenevoli, the Deputy Director of the National Institute of Mental Health.

DR. SHELLI AVENEVOLI: Great. Good morning everyone. Welcome to DC. You actually caught a really great week to come to DC. We've not had so many of those lately. Hopefully at lunch time, you can get out and have a stroll and just enjoy the nice spring weather here.

I want to welcome you on behalf of NIMH and our Director Joshua Gordon, who apologizes that he cannot be here today. He has a competing commitment at the American Psychiatric Association in California.

NIMH is very pleased to host this meeting. This meeting is in conjunction with the prior workgroup meeting, focused on the broader health needs of individuals on the autism spectrum. This one focuses on the mental health needs. This fits very squarely into the NIMH wheelhouse. It is part of our mission.

As all of you probably know, NIMH not just funds autism research, but the research on the full spectrum of mental health disorders, all the way from the basic science, trying to understand the causes of our disorders through translation of that into new, novel, and effective interventions and services for people in need. We are very pleased to host this workshop. There is a number of staff here as well so please make sure you interact with them during the break. And thank you very much for your time and enjoy your time today. Thanks.

DR. DANIELS: Thank you, Shelli. And I'd like to give a couple of minutes to our chairs of this working group, Dr. Julie Taylor and Dr. David Amaral, to say welcome as well.

DR. JULIE TAYLOR: Hello everybody. Welcome. On behalf of the working group, we are really thrilled that you are all able to join us, many of you for the second time for these meetings and some for the first.

As we've been having our discussion in the working group after the first meeting, it became very clear very quickly that issues of mental health - it was a set of issues that we really needed to devote some significant time to. You will see that today we devote significant time to these issues and there's a lot to cover. It's a really packed day, but I think as we were trying to put together the agenda, there are a lot of really important issues that we wanted to at least touch on and have some conversation around. We'll all have to bear down and be ready for kind of a whirlwind day I think of mental health and autism. But I think we'll have some nice conversation and really looking forward to what we hear.

DR. DAVID AMARAL: Thank you, Julie, and thank you all for being here. I really appreciate you taking time out of your busy schedules to join us as well. Beyond what Susan and Julie have said, I just want to also reiterate that the reason we've called you all together is to gather initial testimony, but we do plan to have a document that will come out of these meetings. And that work produced is what really is the goal of both of these sessions. Keep in mind that we are trying to get sort of the tip of the iceberg here. But we'll go into more depth when we do our document.

And the purpose of the document is to disseminate widely beyond academic centers into areas that may not have as much interest or influence in terms of academic medicine on the state of the art of autism research. And we would like to ensure that practitioners all over the country all over the world are aware that these health issues, that these mental health issues are considered to be important aspects of autism that are addressable. Too many times I hear at the MIND Institute, families complaining that their kids who have GI problems or this or that are simply dismissed as saying that's just because they have autism. Well, we want to try and begin changing things and ensure that if a child with autism or an adult with autism has gastrointestinal problems or has sleep disturbances that those can be addressed regardless of whether they have autism or not. This is just one step in that process.

Again, after this meeting, you're not off the hook. We're going to be tapping into your expertise and hopefully try and produce a document. Susan tells me we have a goal of mid-summer. We’re going to get to work on this very quickly. I appreciate all of your help in trying to get that document being as effective as possible. Again, thank you for being here. I look forward to hearing the conversation today.

DR. DANIELS: Thank you, David. For those who are listening online, you may access our materials on the website. So on the meeting link for this, we have a listing of publications. You can access all the public comments and other materials that go with this meeting so you can go there.

I wanted to also let you know. There is a live feedback link open on our webcast for those who are members of the public who may want to comment and that will be open until 10:45 for people who want to make comments and then we'll summarize those during the public comment time in the meeting.

We do have disability accommodations available here in the room. We have CART. We have a quiet room and closed captioning is always on NIH Video Cast so you can access those.

And next, I'm going to do a roll call so that we can know who is in the room and on the phone. Starting with our working group members, David Amaral.

DR. AMARAL: Here.

DR. DANIELS: Julie Taylor.

DR. TAYLOR: Here.

DR. DANIELS: Sarah Cassidy.

DR. SARAH CASSIDY: Here.

DR. DANIELS: Craig Erickson is going to be on the phone. I'm sorry. I'm also doing speakers at the same time. Now, I've moved to speakers. Kate Gotham.

DR. KATHERINE GOTHAM: Here.

DR. DANIELS: Darren Hedley.

DR. DARREN HEDLEY: Here.

DR. DANIELS: Connor Kerns.

DR. CONNOR KERNS: Here.

DR. DANIELS: Anne Kirby.

DR. ANNE KIRBY: Here.

DR. DANIELS: Brenna Maddox.

DR. BRENNA MADDOX: Here.

DR. DANIELS: Dennis Mashue.

MR. DENNIS MASHUE: Here.

DR. DANIELS: Carla Mazefsky.

DR. CARLA MAZEFSKY: Here.

DR. DANIELS: Alison Morantz.

DR. ALISON MORANTZ: Here.

DR. DANIELS: Lindsey Nebeker - might be coming in a little bit, Judy Reaven.

DR. JUDY REAVEN: Here.

DR. DANIELS: Matthew Siegel.

DR. MATTHEW SIEGEL: Here.

DR. DANIELS: So we have almost all of our speakers. And then the working group. Greg Barnes

DR. GREG BARNES: Here.

DR. DANIELS: Tim Buie – are you on the phone. Lisa Croen.

DR. LISA CROEN: Here, on the phone.

DR. DANIELS: Thank you, Lisa. Dan Coury. Orrin Devinsky is not going to be with us today. Sarah Gardner. No. Dena Gassner.

MS. DENA GASSNER: Here. And John Robison sends his regrets. He could not make it today.

DR. DANIELS: Thank you. Antonio Hardan.

DR. ANTONIO HARDAN: Here on the phone.

DR. DANIELS: Thank you. Joe Joyce. Maybe on his way. Bryan King, I believe, couldn't make it. Clarissa Kripke.

DR. CLARISSA KRIPKE: Here on the phone.

DR. DANIELS: Thank you. Beth Ann Malow.

DR. BETH ANN MALOW: Beth is on the phone.

DR. DANIELS: Thank you. Donna Murray.

DR. DONNA MURRAY: Here.

DR. DANIELS: Thanks. Micah Mazurek.

DR. MICAH MAZUREK: Here.

DR DANIELS: Christina Nicolaidis. Denise Juliano-Bult for Denny Pintello.

DR. JULIANO-BULT: Here.

DR. DANIELS: Dora Raymaker. Did I hear something? Dora, are you there? Scott Robertson. Elliott Sherr was not going to be able to make it and Sarah Spence was not going to be able to make it. And from IACC members, Sam Crane is not able to come. Patty Dietz for CDC.

DR. STUART SHAPIRA: I'm the alternate for Patty today. She's not able to be here.

DR. DANIELS: Thank you, Stuart, Stuart Shapira. Jennifer Johnson, I don't see. Kevin Pelphrey is not able to make it today.

DR. KEVIN PELPHREY: I am here on the phone.

DR. DANIELS: You're on the phone. Thanks Kevin. Thanks for speaking up. Marcy Ronyak. I think she had a competing commitment, but might join us by phone for parts of the day. And Alison Singer is not able to be here today.

For IACC members just to check if some folks are on the phone, Jim Ball, Melinda Baldwin, Linda Birnbaum or Cindy Lawler, Judith Cooper. Geri Dawson is not able to make it. Tiffany Farchione, Melissa Harris, Elaine Hubal. Alice Kau is here. Laura Kavanagh or anyone from HRSA. Walter Koroshetz, Nina Schor, anyone from NINDS. David Mandell is not able to be here today. Edlyn Pena, Laura Pincock, Louis Reichardt, Rob Ring, Robyn Schulhof, Larry Wexler, Nicole Williams, and Carrie Wolinetz.

The regular IACC members were not required to be here, but we wanted to just double check to see if any of them were on the phone.

Now, we will have a couple of minutes. I just wanted to share with you some background. I'll try not to repeat everything that David said, but we'll give you some background on the meeting. I did want to put this slide up here and we will flash a slide like this throughout the meeting on suicide and mental health crisis resources. If there's anyone in our listening audience who is struggling and needs help, we do have this in our slide set, several numbers and text lines that you can reach out to for assistance. Certainly feel free also to write to – if you can't see these numbers and you need them, put in a request to IACC public inquiries around the IACC website and we can send you the information.

Some background on the working group. For those who might not be familiar with the IACC since this is not a regular full committee meeting of the IACC, I wanted to introduce you to the Interagency Autism Coordinating Committee, which is a Federal Advisory Committee, established by Congress in 2006 and most recently reauthorized by the Autism CARES Act of 2014 and this committee is composed of both federal officials from various agencies that work on autism and public members who represent different parts of the stakeholder community. This is a recent photo of our committee.

This is a listing of the 13 federal agencies and departments that are on our committee at the moment. And so you can see it's a wide variety of agencies that provide research and services for the community and develop policy that affects people with disabilities and autism in particular.

And this is a listing - I'm not going to go through it, but of the IACC public members. And the public members include parents, legal guardians, autistic adults, representatives of leading ASD research services, and advocacy organizations, and others who are part of the community. And this is all on our website as well.

The IACC's role is to coordinate federal agencies on issues related to autism, to foster collaborative relationships between federal agencies, partner organizations, and the autism community more broadly.

It provides advice to the Secretary of Health and Human Services on issues related to autism. It develops a strategic plan that provides guidance to government agencies on priorities for ASD research, services, and policy. And that document is on our website.

It also serves as a forum for public stakeholders to share their views and concerns on issues related to autism spectrum disorder, which is a really important function of the committee. When we have our workshops, we also leave some time for public comment. We'll be doing that a little bit later.

The committee also allows time to share information and updates from various federal agencies, private organizations, and other community members related to autism that include research advances and updates, services, policies, programs, and initiatives happening around the community so that people can be informed and maybe have opportunities to collaborate.

And the IACC also issues a number of reports on research and other topics related to autism. And these can be found on the IACC website.

With this working group, the IACC, as a Federal Advisory Committee, is able to form working groups to work on particular issues of interest. With this committee that convened after the Autism CARES Act of 2014 was enacted, the committee decided that after it had completed its new strategic plan that it wanted to address some particular issues and health outcomes for individuals on the autism spectrum rose to a high level of interest for the committee. It was an interest of the committee ongoing from the time that the committee started under the Combating Autism Act of 2006, thinking about comorbid conditions that affect people on the autism spectrum and a variety of other issues that affect mortality and general health outcomes.

The committee wanted to address this in more detail so they formed a working group. And this working group is exploring ways to support research to better understand the health conditions that affect individuals on the autism spectrum across the lifespan, to increase community and provider awareness of these conditions and their treatment, which David alluded to as one of the issues that the committee is interested in addressing, and to foster development of practice guidelines, polices, service approaches, and other efforts to improve the health and quality of life for people across the spectrum.

The scope of this working group is health and general wellness for people with ASD, co-occurring physical and mental health conditions and we are focusing on mental health today, premature mortality, which we'll also be talking about today, patient-provider interactions, including medical practitioner training, and parental and family mental health. These are all issues actually that we'll be talking about a little bit today in our workshop.

We just mentioned earlier that we had an earlier workshop in the fall that was focused on physical health. We didn't have the mental health one planned. We didn't put physical health in the title, but it actually was more focused on physical health, co-occurring conditions, and this one is focused on mental health, which is a very important complement to what we talked about in the fall. And there's a listing of some of the topics we discussed.

This is our current workshop. We are going to be producing a written document to provide an update on these issues and perhaps provide recommendations or guidance to the community. And there will be continued discussions of this working group and it will conclude in September 2019 when the committee will be going out of session as the Autism CARES Act of 2014 will be ending at that point. Hopefully, there will be a new law in place by then and we will be in the process of forming a new committee.

The working group members. I'm just listing them here and we're going to go and do introductions, but they are in the slide set for anybody who goes back to look at this and an indication of some of the roles that people have in the community.

We wanted to say a little bit about this effort. I'm going to give David Amaral a couple of minutes to say something about this. But there is a commission on the Future of Healthcare and Healthcare Research in Autism Spectrum Disorders. That's being put together by the Lancet. We wanted this working group to be aware of it and we do intend to be collaborative with them in sharing whatever comes out of our work with them. And of course, we will - as the IACC want to invite them to share with us when they have some conclusions from their work.

David, would you like to say a couple of words about this?

DR. AMARAL: Not too much other than this is a meeting, a commission that's in progress. The first – established a membership of this commission. They are having a meeting in September in Los Angeles. And they are having another meeting next year in London in February. This is a meeting or a commission that's really just getting started. I think we will continue having contact with Cathy and Tony Charman, who is the co-chair of this.

And I think one of the things that it emphasizes is that the document that we produce will want to link to all these other efforts as well. We heard at the last meeting that there really are a lot of resources already out there that have been established. We don't want to reinvent the wheel. We just simply want to point folks to where those resources are available. So we'll certainly keep in contact with these and hopefully they'll reciprocate and whatever we produce will be used as a stepping off point for some of the discussions that they do as well.

But I think it emphasizes that this notion that we have to address the health and welfare of people on the autism spectrum has gotten universal acceptance and understanding and hopefully this will catalyze efforts to get something done now. I'm very glad to see that there are efforts beyond this that are already taking place.

DR. DANIELS: We were excited to hear that there's another effort that is working on some of this. Their effort is international and they are going to be looking at issues in both high resources and low resource countries. With the length of time we had in the IACC, we're not necessarily focusing a lot on low-resource countries. There might be some things that they'll be working on that we won't have time to work on in this iteration of IACC although we could take up different things in the next.

Scott, did you have a question?

DR. ROBERTSON: I just had a quick question. Is this commission going to be looking at health care across the life course in terms of children, youth, adults, even adults as folks age for adulthood in terms of health needs and health barriers?

DR. DANIELS: That's our understanding, but there's not a lot of detail about this. They haven't done an official launch yet so they graciously allowed us to mention it to the working group because we didn't want our working group not to be aware of this effort that's being made. They have a number of countries that are represented. The US, the UK, Argentina, Canada, Germany, India, and South Africa. We actually have an international group here today too to talk about these issues. And they had a very long list of all the disciplines they are covering. We don't have a listing of all the people who are in it. But we certainly hope to be collaborative and share our information with them and hopefully we'll hear from them as well. Excited to hear that many people are converging on this area of research and services that are so important to members of the community. We'll keep you posted on that.

And now we are going to take a few minutes to do some introductions around the table. We'd ask people to keep it very short so that we can continue on with our agenda because we do have a lot of people on the table so just a couple of lines.

I'll start and then we can just go around to my right. I'm Susan Daniels, director of the Office of Autism Research

Coordination at the National Institute of Mental Health. And I manage the Interagency Autism Coordinating Committee. And the team of people from the Office of Autism Research Coordination help put this meeting together and later on in the program, I'll acknowledge them, but you'll see them walking around the room and helping out with everything. I know they've been in touch with you. So we're really pleased to welcome you here.

DR. AVENEVOLI: Thanks. I'm Shelli Avenevoli, the deputy director at National Institute of Mental Health.

DR. BARNES: Hi. My name is Dr. Gregory Barnes. I'm the director of the University of Louisville Autism Center. I'm a pediatric neurologist by training and an epileptologist and I'm also the father of a 25 year old with autism.

DR. CASSIDY: I'm Dr. Sarah Cassidy, an assistant professor at the University of Nottingham and I'm a researcher specializing in mental health difficulties and suicidality in autistic people.

DR. ROBERTSON: I am Dr. Scott Michael Robertson. I'm a policy advisor in the US Department of Labor's Office of Disability Employment Policy, ODEP. I spearhead our work and activities and initiatives around autism and neurodiversity in the work place as well as collaborate on our work around inclusive apprenticeship, autonomous vehicles, driverless cars, and accessible technology, particularly accessible work place technology. Thanks.

DR. MADDOX: Good morning. I'm Brenna Maddox. I'm here from the Penn Center for Mental Health in Philadelphia. I'm a postdoctoral research fellow there. I'm also a clinical psychologist.

DR. MASHUE: Hi. I'm Dennis Mashue. I'm a father and a co-founder of a company called Tuck's Tooques with my autistic son. Today will be tough for me, but I think that our story needs to be heard. So thankful for being here.

DR. GOTHAM: Thank you. My name is Kate Gotham. I am a clinical psychologist by training and an assistant professor in the Department of Psychiatry and Behavioral Sciences at Vanderbilt University Medical Center and I am interested in studying depression in ASD.

DR. KAU: I am Alice Kau. I'm here today representing NICHD. Our director, Dr. Bianchi, is a regular member of IACC. Mental health issues in autism are highly relevant to NICHD's funding. I'm so delighted to see many of our grantees are here today.

DR. MORANTZ: I am Alison Morantz. I'm the mother of a 13-year-old boy with autism and childhood onset schizophrenia. I'm also a professor at Stanford Law School where I'm just on the brink of launching a new initiative called the Stanford Intellectual and Developmental Disabilities Law and Policy Project. We're particularly doing some work around state policy in California, but would love to contribute as well to federal policy issues.

DR. SHAPIRA: Good morning. I'm Stuart Shapira. I'm the associate director for science and chief medical officer in the National Center on Birth Defects and Developmental Disabilities at the CDC and all of the autism work at CDC goes on in our center.

DR. MATTHEW SIEGEL: Hi. I'm Matthew Siegel. I'm associate professor for Tufts University. I'm at Maine Medical Center and I'm a child psychiatrist and pediatrician by training.

MS. GASSNER: I'm Dena Gassner. I'm a national board member for the Arc US. And I am a new adjunct at Towson University in their autism certificate program, training on transition to adulthood. I'm a very old PhD candidate, writing a dissertation on systems navigation with social security. I'm here initially because I'm the parent of a 25-year old who just hired his first job coach last week. Thank you.

DR. JULIANO-BULT: Hi. I'm Denise Juliano-Bult. I'm a program officer in the Services Research and Clinical Epidemiology Branch. I'm here representing Denny Pintello and representing NIMH and our portfolio, which is in services research for people with autism.

DR. KIRBY: Hi. I'm Anne Kirby. I am from the University of Utah. I'm an occupational therapist by training.

DR. REAVEN: Hi. I'm Judy Reaven. I'm a clinical psychologist by training and associate professor at the University of Colorado School of Medicine, also affiliated with JFK Partners, which is the UCEDD in Colorado. And I'm interested in studying anxiety and ASD.

MS. LINDSEY NEBEKER: Hi. I am Lindsey Nebeker. I am a development specialist at the Autism Society of America. I am not part of the work group or the committee, but I was just invited here today to provide some remarks.

DR. MAZEFSKY: Hi. I'm Carla Mazefsky. I'm an associate professor in psychiatry at the University of Pittsburgh, clinical psychologist by training, and I have always pretty much focused on mental health and emotion regulation in autism.

DR. COURY: I'm Daniel Coury. I'm a developmental behavioral pediatrician by training and professor of pediatrics and psychiatry at Ohio State University. I also serve as the medical director for the Autism Treatment Network and for the Autism Intervention Research Network on Physical Health.

DR. KERNS: Hi. I'm Connor Kerns. I'm a clinical psychologist by training and assistant professor at the University of British Columbia in Canada. My clinical practice and research focuses on anxiety and autism.

DR. MAZUREK: Hi. I'm Micah Mazurek. I'm a clinical psychologist and an associate professor at the University of Virginia where I direct the Supporting Transformative Autism Research and I'm interested in co-occurring health and mental health conditions in people with autism and improving access to care.

DR. HEDLEY: Good morning. Darren Hedley, Olga Tennison Autism Research Centre in Melbourne, Australia at La Trobe University. I'm a research fellow there. I have my training in psychology. We have some research programs around transition to adulthood, mental health over there. The programs that – both in employment and we've also looked at suicide over the last few years and focusing on those two mainstreams.

DR. AMARAL: Good morning. I'm David Amaral, a professor in the Department of Psychiatry and at the MIND Institute at UC Davis. And I'm also the director of an Autism Center of Excellence, funded by the NICHD.

I'm happy to see the program officer here as well.

DR. TAYLOR: Hi everyone. I'm Julie Taylor. I'm an associate professor in the Department of Pediatrics at Vanderbilt University Medical Center and a developmental psychologist by training. And my work is focused on the transition to adulthood and adult outcomes for individuals on the autism spectrum.

DR. DANIELS: I'd like to go to the phone. Lisa Croen, would you like to say a couple of words?

DR. CROEN: Sure. Good morning. This is Lisa Croen. I am an epidemiologist by training and the director of the Autism Research Program at the Kaiser Permanente Northern California Division of Research. My research focuses on medical and physical and mental health issues in individuals with autism across the lifespan and access to health care and transition issues.

DR. DANIELS: Thank you. Antonio Hardan.

DR. HARDAN: Good morning everyone. I am a child psychiatrist and I'm the director of the autism program here at Stanford University. I have an active clinical practice in children and adults with autism and also I have a lab that is focused on examining neurobiology of autism and investigating novel interventions in ASD and the development of disorders.

DR. DANIELS: Thanks. Clarissa Kripke.

DR. KRIPKE: Hi. This is Clarissa Kripke. I am a family physician. I direct the Office of Developmental Primary Care at the University of California San Francisco in the Department of Family and Community Medicine. I do a lot of teaching of health professionals about autism and aggression and self-injury and run a multidisciplinary team that includes psychiatry and psychology for taking care of people with transition aged adults and youth with developmental disabilities.

DR. DANIELS: Thank you. Beth Ann Malloy.

DR. MALLOW: Hi. I'm Beth Mallow. I'm at Vanderbilt University Medical Center. I'm a neurologist here. I specialize in sleep. I'm also very interested in the co-occurring conditions of transition age youth and adults, having a 20 year old and a 17 year old on the autism spectrum. I very much appreciate being able to attend by phone as my 17 year old is graduating from high school this week.

DR. DANIELS: Thank you. Donna Murray.

DR. MURRAY: Hi. I'm Donna Murray. I'm vice president of Clinical Programs for Autism Speaks – Autism Treatment Network and we have a focus on research and clinical improvement of co-occurring conditions in autism.

DR. CRANE: Susan, can I just interrupt really quickly?

DR. DANIELS: Who is this?

DR. CRANE: This is Sam Crane. I've actually been on since the roll call, but I couldn't actually call in by phone until now.

DR. DANIELS: That's fine. You can go ahead and introduce yourself.

DR. CRANE: Hi everyone. This is Sam Crane from the Autistic Self-Advocacy Network. I'm also a member of the IACC.

DR. DANIELS: Thank you. And Craig Erickson, are you on the phone? He'll be with us later. Kevin Pelphrey.

DR. PELPHREY: Hi. This is Kevin. I am a father of two children on the spectrum and three other kids as well. I'm a neuroscientist at the University of Virginia. I direct an Autism Center of Excellence Network, focused on adolescent girls transitioning into adulthood. And I'm a member of the Interagency Autism Coordinating Committee.

DR. DANIELS: Thank you. Carrie Wolinetz.

(No response)

DR. DANIELS: Is there anyone I've missed who's on the phone? Okay. It sounds like we have everyone. We got through the introductions actually a little bit early. If we feel comfortable, we can start early. That might mean we have a little extra time for discussion. We made this quite a tight agenda, but that would be a bonus if we have more time for discussion.

With that, I'd like to just briefly introduce Dr. Carla Mazefsky, associate professor of psychiatry and psychology at

University of Pittsburgh. She'll be presenting an overview of mental health issues and people with ASD. There is a longer bio. All of our bios are up on the website so you can access those there. Carla.

DR. MAZEFSKY: Good morning. Thank you for having me. In a nutshell, we are here today because mental health disorders and problems are much more common – are very common in autism spectrum disorder across the lifespan and have a substantial negative impact.

Pinpointing specific rates for specific disorders though is quite the challenge. Our diagnostic manual for psychiatric disorders has changed over time even in terms of whether or not having ASD excluded the possibility of certain disorders such as ADHD.

And then across studies, we see drastically different methods from recruiting from treatment seeking psychiatric clinics to population-based studies, use of wide range of measures, most of which are not validated in ASD. And then on top of that, it's legitimately challenging to identify mental health disorders in the context of ASD particularly for those who are less verbal, but I'd say that is true in general.

One of the things I'm going to do today in attempting to pull literature together is pull from the Oxford Handbook, which we just put together. I'm hoping that it represents the latest synthesis on where we are with mental health in autism and many of the authors of chapters are sitting in this room and will speak later today.

This was probably the most difficult slide in my talk to put together. I tried to pull from the different chapters on specific disorders and co-occurring symptoms that are common in autism. One possible pull what we know from meta-analyses or average rates. Even so, you can see there are huge ranges. It's really tough to say how common specific problems are.

And then for some of these, we have a better sense like anxiety. We at least have a few meta-analyses to pull from and others are literally just a handful of studies and huge ranges. And certainly in the literature, you've seen both lower and higher rates reported. I would say the one take home from this slide is even when we can't pinpoint a very specific number, in virtually every case the rates in autism are substantially higher than we see outside of autism.

The one thing we do have consensus on is that mental health needs to be a major priority area. You see this in terms of what parents of young children with ASD want, what parents of adults with ASD want, and what adults with ASD themselves see as important for research.

And the reason that is is because of the heavy burden that comes with mental health problems. And I'm stealing that phrase from Dr. Joshi because I think it's sort of a perfect way to capture the huge impact that mental health has on those with autism and their loved ones. First and foremost - added impairment, distress, and family stress. We know that mental health problems are the biggest contributors to the very high health care utilization rates in autism, including extremely high rates of hospitalization. Mental health often interferes with the ability to complete treatments for core symptoms of ASD.

We also see uniformly teachers, students with ASD and parents describe mental health and related emotional and behavioral problems as a major barrier in educational and employment settings. And then unfortunately, mental health problems also often land people with ASD in the criminal justice system. And then beyond that, we know there are many physical health implications associated with mental health problems in terms of medical comorbidities, injuries to self and others and even premature death.

As we digest all that heavy information, I think the thing we really need to keep in mind is we should really be able to do something about this. Mental health disorders should be treatable.

I do think we have made progress in this area. We at least have some options that we know are evidence based with the most established being cognitive behavioral therapy and functional behavior assessments. And then there are a number of other areas where there is growing interest such as mindfulness.

In terms of medications, we know we have two FDA-approved medications for irritability, pretty good evidence for a variety of ADHD medications and then we have growing interest in new agents.

The one thing that I think is exciting and important to point out is that perhaps with the exception of functional behavior assessment, most of those advances and particularly evidence-based distinction has really only been in the last 10 to 15 years. We are seeing a major uptick in the number of studies. And that two-slide overview was very cursory and does not fully capture the number of new treatments that people are considering.

I think there is a lot to be excited about, but I think there is even more to be unsatisfied with in terms of the current state of our mental health treatment for autism.

In terms of psychosocial treatment, I don't think there's anything we fully addressed although some disorders such as anxiety have received a bit more attention than others. There are certainly a lot of very common mental health problems in autism that have not been included or studied as an endpoint to any single clinical trial yet.

We are very far from any notion of personalized medicine for mental health in autism. The options for people with co-occurring intellectual disability that are non-medication are extremely limited. And even with our evidence-based treatments. What we typically see is lower effect sizes in autism. And then with every subsequent replication, those effect sizes seem to go down. We need to figure that out.

And there is also a huge gap from research to practice. I think one of the major problems there is we have such a limited number of qualified mental health providers who understand both autism and co-occurring mental health disorders, to the point that sometimes people are turned away from services all together.

And then although we appreciate or beginning to appreciate that this is really a lifespan issue and maybe even adults with autism are suffering even more from mental health problems, we really have a limited number of studies to draw from in terms of adults and full lifespan, understanding of mental health.

In terms of medication, I think our tagline could be we don't know. It hasn't been studied, which I am stealing that quote from Lisa Croen, who has on the phone.

And I think really what we see is by and large we use a lot of medications that are used off label in autism. We know virtually nothing about long-term effects or what happens when you use multiple medications.

And then what we do know from the existing literature is almost for everything that people with autism tend to respond less well and have more adverse side effects. There is much to be done in terms of medication as well.

With that, what should we do? I could spend an entire day on this, but since I was only given 15 minutes, I'm going to talk about just three things I think we should consider. And the first is measurement. I really would like to emphasize. We can't make any valid conclusions without valid measures. In terms of both diagnostic measures and change-sensitive treatment outcome measures, we are likely missing identifying mental health problems in ASD because we don't have good measures. We really struggle to understand across studies because we don't have a lot of consistency in terms of what we use in our measures. And then when treatments fail in a trial or don't work, it's hard to know. Is that because of the treatment or is that because our measures are not valid in autism, are not sensitive in autism?

Second, we can probably get better at developing more effective and targeted treatments if we can better identify the causes for mental health problems in autism.

Here, I'm going to pull from Dr. Carter Leno and Dr. Simonoff's chapter where they raised four overarching things we could consider in terms of what's increasing these rates of mental health disorders in autism.

The first option would be perhaps there is an increased prevalence of what we know is established risk factors outside of autism. For one example, we see a lot of overlap in genes that are implicated in both schizophrenia and autism. Or we know that feeling like you don't belong or is a risk factor or feeling like a burden is a risk factor for depression and suicide and one could imagine that that might be an experience that is more common for people with autism.

Another possibility is that when risk factors are present that people with ASD are more vulnerable to the effects of this.

Perhaps someone with ASD who experiences a trauma might fare worse from that due to poor coping skills or difficulty communicating.

Or there could be a decrease in protective factors. We know that social support is very helpful in terms of resiliency and maybe people with ASD are more at risk for mental health because they lack such protected factors.

And then finally, it's possibly that core features of autism itself increase risk. For the adolescent who really badly wants friends, but has poor social skills and gets neglected, rejected that maybe that leads to the social anxiety or maybe the sensory sensitivities increase risk for aggression or self-injurious behavior.

Next, I think we could maybe make more gains if we can identify some mechanisms or processes that are shared across the mental health problems that we see in ASD. While there is a lot of value, I think, to disorder-specific approaches, in autism, that's especially challenging. I've already mentioned how tough it is to really neatly define diagnostic categories in autism, but another layer on that is most people do present with multiple overlapping types of mental health problems. They have both anxiety and depression.

And then because we have that shortage of providers that I mentioned before, our dissemination efforts are going to be much more limited if we try and develop a specific treatment for every specific disorder within ASD and then expect that the general mental health field is going to be able to learn how to administer those treatments.

I was just going to wrap up with one example of how we are trying to do this in our work, which is focused on emotion dysregulations. So here, I'm talking about impairments and regulating the intensity or duration of emotional responses. With the support of NICHD, we started with very systematic and thorough measure development effort. And we developed the Emotion Dysregulation Inventory or EDI to be a change sensitive, validated measure across all ability levels in autism.

I think there are some important take homes about the demand for the EDI, which I pulled those numbers last week and they are already out of data. I think it shows both that people are paying a lot more attention to mental health in autism across the world and in clinical and research settings and that we really need these better measures. If we can create them, people will use them. And if we can get some gold standards, we might be able to have more consistency across studies and make more progress.

The availability of the EDI also allowed us to more definitely look at the prevalence of emotion dysregulation in autism. EDI reactivity on the left - that captures rapidly escalating, intense, and sustained negative emotional reactions whereas dysphoria captures general unease, distress, low positive affect.

Here on the top two pie charts are a representative US sample so that's a sample matched to the US Census. And what you can see here is even among a community sample with autism so it's not a treatment-seeking sample, the rates of clinically elevated - these are clinical elevations of dysphoria are more than two times that of a general use sample and for reactivity, it's more than four times. And then the inpatient numbers I think speak for themselves.

This also allowed us to show that emotion dysregulation is associated with a host of those negative outcomes and mental health that I noted earlier as well as a wide range of manifestations of mental health problems from aggression to suicide.

That led us to develop EASE or the Emotion Awareness and Skills Enhancement Program where our idea was if we can improve emotion regulation, maybe we can have an impact on a range of psychiatric symptoms. And here, we specifically are looking at depression and anxiety and problem behaviors and improved functioning.

It is too preliminary to say for sure, but I think our open trial, which was with adolescents who are verbal, showed some proof of concept that we could make a dent across a range of mental health problems. We are now with support of DoD funding, doing a more rigorous trial to more definitively look at the efficacy of this approach.

And then I was very excited just last week to get the news that we were rewarded an ATN AIR-P grant to extend EASE to those also with intellectual disability or less verbal ability. So like we developed EASE, we are going to work together with researchers, clinicians, parents of children with ASD and adults with ASD themselves to make the manual modifications and then see if we can make this work. And even if we can also extend the impact to other manifestations including sleep.

I didn't think I would have time for a summary so I thought I would just end with – start the meeting basically with these final thoughts. I'm really honored and excited to be here and I look forward to working with all on our shared mission to improve mental health in autism. Thank you.

(Applause)

DR. DANIELS: Thank you, Carla. We have a few moments now to have some discussion. If anyone around the table would like to discuss some of the concepts that were shared here.

MS. GASSNER: I just wanted to mention that anecdotally among my tribe, my folks who are living with autism, one of the things that we are starting to hear more and more of is the idea of late onset cognitive decline with aging. It is very anecdotal. No one is studying it to my knowledge. But what we are hearing people report through the network of self-advocates is that as they are aging, they are starting to notice that the cumulative effect of a lifetime of trauma, of living in a world that they never received accommodations for, has resulted in them actually having more brain fog, more difficulty focusing. As we are looking at mental health, I think it is important to remember beyond depression and anxiety, but just simple cognitive function as something that we should also be considering.

I, myself, am going to just come – and tell you I started Strattera in December and it was a game changer. But my brain had just exhausted itself and I couldn't focus anymore. I was never diagnosed with ADHD, but the cognitive decline is certainly something I have struggled with. The good news for me is that it's fine. It's working for me and it’s exactly what I need.

I will just put another plug in for microdosing because I am a very low dose, but it's enough to make a difference. As we think about it, I hope we'll just think more broadly toward the whole lifespan, including all of us who are in our graying years. Thank you.

DR. AMARAL: Carla, can I ask a question? This is David. Given the heterogeneity of autism and we I guess could start from assuming that some individuals with autism go on to have mental health challenges and some may have lesser challenges or not any, do you see the EDI as a screener for those who are going to go on to have challenges?

One of the things that would be helpful is to be able to predict who is going to be at greatest risk and then try interventions for that population first. I was just wondering if that's what you see it being useful for.

DR. MAZEFSKY: One of the things that we did or one of the reasons that we collected the general US sample was so that we could make clinical cutoff scores, which I think is useful. When we developed it, we validated that version from ages 6 and up. We tested every item to make sure that there were no psychometric biases based on age so you can use the same measure across childhood. We're hoping to get funding now to make an early childhood version, which I think you do need a different version. You do expect differences in the early childhood 2- to 5-year-old range. But my dream would be that we could get a big sample of young children and follow them over time and begin to understand who is at risk and target before things become a big problem.

DR. ROBERTSON: Thank you, Carla. That's an excellent presentation in terms of an overview on the space and – just a comment that I had is and it kind of fits with my also own experiences as an autistic adult is the - what was mentioned in terms of the different factors that may be experienced. I think it seems to me like we've been more like a combination of some of those maybe. Sometimes maybe there is a heightened because of genetics, et cetera, but also because of the experiences including like trauma, bullying. We already know other literature that bullying even in general in childhood has continuing effects into adult life. We've had a lot of that research, as many of you all know, in the last several years.

For instance, on my case, I was bullied very intensely all the way through childhood and adolescence and even into adult life and had a lot of other things that caused PTSD and complex PTSD and that have really shaped a lot of the adversity.

I'm hopeful in part with which you also mentioned is how that could align with looking at trauma, trauma-informed care around autistic people and trauma-informed approaches and including looking at the diverse childhood experiences that individuals experience.

I know that there was the one published study out there that it was adolescents, I think, but I think we have not had ACE's related papers around autistic adults across the lifespan on the diversity in terms of what that looks like from a trauma standpoint. I think that will be helpful on the mental health to improving approaches is finding out where that comes from in the backdrop and how we can help individuals by meeting them where we are especially on the trauma. I think the literature needs more of that and the resilience sense. Thank you for cross connecting to this in your overview.

DR. DANIELS: Thanks Matt. Did I see a hand? Stuart.

DR. STUART: Just with regard to the previous comment. The CDC is conducting a study currently called SEED team where SEED stands for Study to Explore Early Development. The original initial study is evaluating children who are 3 to 6 years of age with autism spectrum disorder and has an extensive data collection looking at genetic and environmental risk factors for ASD. But the first cohort of children that was evaluated through SEED is now young adolescents aged 13 to 16 and there is a follow-up study with those families to collect additional data including an extensive survey that does include all of the mental health concerns. There will be data forthcoming on this longitudinal, prospective study that should help inform the field with regard to the previous comment that was made.

DR. DANIELS: Thank you. Dennis.

MR. MASHUE: Carla, when you put up your graphic of all the various challenges that are faced by autistic adults, I wanted to yell bingo. I think if you had a roomful of autistic adults that would be a pretty common theme.

DR. DANIELS: Connor.

DR. KERNS: I just wanted to make a quick comment on trauma that I think actually in the last five years or so, there has been a substantial shift towards attention to potentially traumatic events and stressors and actually there are at least three papers that have looked at adverse childhood experiences or increased risk in kids on the spectrum as adverse childhood experiences were previously defined.

And in addition to that, there is – NICHD is actually funded early career investigator need to look at what are definitely potentially traumatic events for people on the spectrum, particularly in adolescents through young adults and doing that, using a mixed methods qualitative approach, which involves talking to adults on the spectrum about their experiences in their lives, caregivers, and also talking to experts in both the autism and trauma world about what do you think are actually signs of a traumatic reaction.

I just wanted to respond to that to let you know that I think that there is research that people are paying attention to this now. It has been an area that was neglected particularly relative to other psychiatric disorders. I also think it's extremely messy so we'll be talking a lot today about how do you even determine if somebody on the spectrum has anxiety or has depression, has PTSD. And I do think we have to be very careful about how we approach this and we need good research, but I do think we are moving in that direction.

And then I had a question for Carla, which is – I think, Carla, one thing we were talking about in our last meeting was what are some kind of essential skills that we might be able to disseminate to mental health providers or providers who work with people on the spectrum to better support the mental health needs. I think emotion regulation and the idea of treating emotion regulation is really interesting because I'm wondering if there are basically core skills about helping people with emotion regulation that we might transmit to providers to help them better serve this population.

I was wondering if you could just speak to that a little bit and also if in your studies you've seen actually broad changes across psychiatric conditions, for example, in both internalizing and externalizing when you treat the emotion dysregulation and what those changes look like. What can we accomplish just treating emotion dysregulation and what do you think is going to need a more specific approach?

DR. MAZEFSKY: That was a loaded question. My thought is that we – well, just to take one step back. I do think that we need to just sort of distill the myth that it is difficult to treat autism if you are not an expert in autism. I think we have to do a better job at helping providers outside of the autism specialty field feel competent when they have someone show up at their office who has autism and a mental health condition.

With Matt Siegel and the autism inpatient collection group, we wrote a paper about how to best treat psychiatric inpatients with autism with some guidelines. I think we can do that same sort of thing for general practice. And I think a lot of what people are doing and even what we are doing, it is not that it is a totally new approach that has never been used in mainstream mental health, if you want to call it that, but we are maybe packaging it a little different. We are delivering the therapy a little bit differently. We are making it more accessible. I think we could certainly work towards getting some of that out there.

And we have focused on emotion regulation in our work because we do think it's related to both internalizing and externalizing problems and we have seen in the people who have come through our studies so far improvement in both of those domains when the emotion dysregulation improves. Just a general, better ability to maintain emotional control and to seek help when they need it from others and to have that increased awareness.

I'm forgetting the second part of your question.

DR. KERNS: I think just are there certain times where you think it is going to be more specific to certain disorders where what can't we get at by just treating just general emotion dysregulation.

DR. MAZEFSKY: That is why I think it would be kind of nice if we could do this sort of blend of something like a skill set that we could disseminate widely like we could have this way. We improve emotion dysregulation. This is how you might best support clients with ASD, but then these are the circumstances when you might need to do a little more with personalized medicine.

We have had some cases if we stick with trauma where people have had a very specific trauma experience or very specific family dynamic that makes the treatment progress more challenging. I do think we need to get – it would be ideal if we could have huge studies that we could better identify what the situations are.

And also I think in terms of anxiety, which I know Judy will talk about more and we see decreases in anxiety, but for kids with really severe phobias. We know that exposure therapy is probably the best treatment. We would probably want to add that on to what we are doing. I do think there is value in some specific targeted treatments in addition to just building your skill set to handle all kinds of adversities.

DR. DANIELS: Julie.

DR. TAYLOR: Carla, you brought up, I think, a lot of things that are worth highlighting. But one thing I think in particular is a topic, an idea that came up in our first working group, which is this myth I think that a lot of providers have that to treat somebody on the autism spectrum, you must be an autism expert. And if you are not an autism expert then there is no way that you could ever possibly effectively treat someone on the spectrum.

And I think this is a topic – I think a theme that can come through in our document that we are writing that I think will be really important to be talking about and thinking about across the different range of health and mental health conditions to try to dispel that myth to whatever extent we can.

DR. DANIELS: Micah. I will come back to Dena. I just want to give a chance to people who haven't spoken yet. Micah.

DR. MAZUREK: Carla, that was just a great overview of our day today and made me think about a lot of different things including what Julie just brought about the need for training providers in the communities to be able to help people where they live. But I was also thinking about in terms of connections to our last session, the need for measuring outcomes across health and mental health. I'm thinking about sleep disorders, in particular. It would be great if we could be measuring both mental health outcomes and sleep outcomes in our sleep studies and vice versa because I think there is a lot of interrelationship among symptoms and conditions across mental health and physical health conditions.

DR. MAZEFSKY: I couldn't agree more. That was why in our latest iteration of our next steps for EASE, we are trying to also look at sleep and target sleep. These are all related to underlying self-regulation and there is so much overlap in the comorbidities. I agree.

DR. DANIELS: Brenna.

DR. MADDOX: Thanks. I really enjoyed that, Carla, and I think echoing what other people are saying, this idea of the clinician training, which I will be talking some about at the end of the day so I'm hoping we don't cover all the points right now that I have in my slides because I don't want to be redundant later. But I completely agree and it is what we are hearing in Philadelphia as well both from clinicians and from adults on the spectrum. I think if clinicians can better understand that they are still treating those mental health conditions that they've already been trained to treat, we are not asking them to target the core traits or symptoms of autism. I think that's a big piece of it.

And then a related point that David Mandell, Lauren Brookman-Frazee and I talk about a lot in terms of clinician training is can we actually get in the door with this training focused on autism and actually improve their practices more across the board or more broadly because I think clinicians are really eager for autism training. For example, if we went in and help them learn how to better target emotion dysregulation in autism, would that also then help them treat emotion dysregulation across the board in all people? I think it really could. So I think it's an exciting area, not just to improve mental health services for individuals on the spectrum, but for all people.

DR. DANIELS: Dena.

MS. GASSNER: I was just going to speak to that more or less and the idea that the first thing we have to do with training clinicians is teaching them that if they specialize in a specific discipline and a person comes to them because they are experiencing domestic violence and that's their practice field that they are also treating autistic people. The silos around this are one of the greatest barriers we face. They don't realize if you're treating veterans, if you're treating homelessness, you're working with our population and that has to become a forefront issue.

And I also wanted to speak to intersectionality with emotional regulation.

We already have a tremendous amount of literature on resilience training like there's actual curriculum on teaching people how to be more resilient. I think the recovery process after an event is so difficult for us, we don't have language for it. We can't communicate effectively about our feelings. And so it's all intersectional with all of these other pieces. It's complex. I'm grateful that you're taking it on.

DR. DANIELS: Joe.

MR. JOE JOYCE: Thank you very much for the presentation. I just have a short question. The EASE program sounds very interesting. How would one go about learning more about it in more depth? Is there literature or a website or something that we could look into this in more detail?

DR. MAZEFSKY: We do have – we published our pilot trial paper although we did make some revisions to the EASE program after that based on the feedback from the open trial. And I think that was listed in the resources today.

And then we are actually working on a paper, more of like a clinical piece about how you would apply at least the mindfulness aspect that we use in autism and the best way to use those skills.

And then we're always happy to talk. We have some information sheets on strategies that we are using. We haven't released the manual yet since we're still testing it. But I can always chat with you later too about what we actually do in the program.

DR. DANIELS: Scott.

DR. ROBERTSON: I appreciate learning more – sorry. I didn't want to come across as – in some cases, I'm only aware of things that are ready, that have already come across in the literature, whatever so thank you, Dr. Kerns, for helping kind of educate on some of the growing things that is happening more on that. That's exciting to hear on the trauma space.

I appreciate also what was mentioned in terms of the connection to what we already have in terms of resilience center and how we can connect that back to autism and that makes me think of also the broader emphasis on positive psychology kind of aspects on autism, optimism, hope, et cetera. We don't really see that a lot in the autism literature I have to be honest. It's kind of very doom and gloom. I wish we could have more of that emphasis in terms of what has come out of Penn and other schools on the positive approaches folks can take, self-compassion, et cetera. There are a lot of teachable strategies, approaches that I think we could be working with autistic youth and adults that could help with dealing things as folks are growing up and then into adult life especially with the fact that autistic adults obviously we grew up with a lot of baggage in terms of barriers, in terms of folks being told we are wrong all the time, et cetera because of difficulties, challenges, and I think just having some of that positive psychology cross connection resources that we already have, connecting them back to autism and making sure the autistic youth and adults can sort of access the resources that they need.

I hope that also maybe across – can connect back to some of the other presentations later in the day to is that positive psychology element and maybe we can see more papers kind of literature that cross connect resilience, et cetera back to autism and helping autistic adults be able to have tool kits of things that can help manage challenges in a productive, positive kind of constructive manner. Thank you.

DR. AMARAL: Carla, I wonder if you could say a little bit more about the EASE program in terms of the candidates. For example, our individuals who have intellectual disability also candidates for the program. Sorry. For my ignorance, I don't know that much about the requirements and what's actually conducted.

DR. MAZEFSKY: That's because I flew through that and I didn't actually say that I don't think.

Our current trial is IQ of 80 and above and verbal, but we are in this process of modifying it for individuals down to a non-verbal IQ of 50 and even with some limited language. That's in process because we are going to work with stakeholders and the revisions. Currently, it's an individual therapy approach with a therapist with a verbal patient, but we are working towards expanding that.

We started with targeting 12 to 25 kind of trying to do that adolescent into young adult period since we see huge struggles in that developmental age range although I see no reason it couldn't be done with adults. But that's just in terms of our older adults. But that's why we started with that age range for our research.

DR. DANIELS: Darren.

DR. HEDLEY: I just want to make a quick comment about the connection and bring up background to the connection into mainstream mental health. I think that focus needs to be both at the practice level or clinician level, but also at the research level.

We tend to -- as autism researchers, we tend not to go to mainstream mental health conferences. We tend to stick with autism conferences and things like that. I think we've got a lot to learn from mainstream mental health as do they us and the implications of autism into mainstream mental health practices.

Last year I went to one of the first mainstream mental health conferences I've ever been to. And there was no one there that knew anything about autism. I think we need to take some responsibility for getting what we know across and vice versa and hopefully that will have flow and effects into practices as well.

Certainly, in the employment area that we work in mental health is one of the major concerns and it's really difficult for people that are in employment to get access to specialists who have some experience in autism. The people who work within EAP programs are the employment assistant program just almost refuses to work with our guys in employment.

The second point was just concerning trauma and PTSD. This seems to be popping up and really only recently. But I know there is some work over in Israel at the moment and particularly with groups that are working within people employed within the IDF, the Israel Defense Force, and specifically looking at PTSD trauma in autism. It's certainly an emerging research area that I think we should keep an eye on.

DR. DANIELS: Thank you. Anne Kirby, did I see your hand up?

DR. DANIELS: Kate.

DR. GOTHAM: I just wanted to go back to Scott Robertson's comment about positive psychology, it really resonated with me as I was putting my presentation together for today about depression in autism that the thing that was missing that I cut for time was prevention because there was nothing about prevention. It doesn't exist yet. And that idea of positive psychology - I think Carla's work is the closest probably targeting the emotion regulation first would be a form of prevention. We are very lucky to have all the amazing work she is doing.

But it makes me think about kind of just broadly the history of our research field that autism is still a relatively young field. I feel so lucky to be at this point in history where we are branching out to look at parenting, temperament, things that before were just kind of luxuries and now they are necessities to look at. I think prevention of these things of mental health issues is one of those areas that we are going to get to and that will be such a good day when you don't have to think – we don't have the treatments we need for acutely ill individuals right now and that has to be the focus, but rather how do we make lives better. How do we enjoy life? How are we positive and preventative?

DR. DANIELS: Connor.

DR. KERNS: I just wanted to third that point. For Dr. Robertson and Dr. Gotham, I was thinking the same thing. Prevention is in my slides on anxiety too. Maybe it will be a theme throughout today.

But I do think that that's so important for us not just to be focusing on intervention, but to see if there's anything we could be doing on the front end to actually prevent this suffering to begin with. In order to do that though, I do think we need to have perspective longitudinal studies and to look at some of the very good ones that we have going on right now to see how we can really use them to better understand the developmental trajectories of different mental health symptoms and also how they are interwoven with autism symptoms and severity in general because I don't think we have a great idea right now of where the predictors of these mental health conditions or even long-term how the mental health conditions influence the developmental trajectory and the developmental health of people on the spectrum.

DR. DANIELS: Any other comments from the group about our introductory talk or issues that you generally want to bring up before we get into the rest of the meeting? It sounds like we've gone around pretty well. We're about nine minutes ahead of schedule. Why don't take our break? Would you like to start the next session five minutes early? I don't want to get us way off schedule so that listeners who are on the webcast might miss it if they were planning to just tune in for particular parts. Why don't we come back at 10:10 and that will give us a little bit of extra time in our break. Thanks.

(Whereupon, the Working Group took a brief break starting at 9:51 a.m. and reconvened at 10:15 a.m.)

DR. DANIELS: So the next session that we are going to have today is hearing some personal perspectives on mental health issues in ASD from three speakers that we have with us today, Lindsey Nebeker, Dennis Mashue, and Alison Morantz. Each of them will go up to the podium and share some personal perspectives and then we're going to have some time for discussion. We really thank all of you for being willing to share from your personal journeys. As we know that this is a public forum and it's sometimes challenging to be able to share these things. But I think it's going to be very helpful to our working group and to the public who is listening and people that maybe struggling with their own issues at the moment. It will be encouraging for them to hear some of the ways that you've navigated through these things and just to know that there are other people out there that have issues as well. That's why this working group is meeting to talk about these issues.

With that, Lindsey, if you would like to step up to the podium. Each of you can introduce yourselves how you'd like as well.

MS. NEBEKER: I want to thank IACC, first of all, for inviting me, Dennis and Alison and those who will be sharing their public comments later on to be here today and sharing a part of our journeys with you.

My name is Lindsey and I have been a development specialist for the Autism Society of America for a little over seven years now. I received my formal diagnosis of autism at around age two and a half in the early 1980s under the DSM version III. I also have a brother who is also autistic and has high support needs.

There are several of you in this room who I know personally, including colleagues from work and there are others I know who either are watching this webcast live or will be listening to a prerecorded version of this webcast later on.

While I have already gone public with what I'm about to share with you, I will admit that retelling it each time makes me nervous and to some extent awkward. It makes me nervous because I know what I will be addressing might be hard for some people to hear, but it needs to be addressed.

In early January 2016, a few days before an Emmy-nominated documentary I was featured in aired on television. I opened up a sponsored Facebook post from PBS that had appeared on my feed. It featured a video interview clip of me. I opened up the post. Four weeks later, I was found by a security guard unresponsive near a hotel lobby shortly after the end of a film screening event. I was rushed to the hospital in an ambulance after attempts to revive me had failed and that entire night into the day my spouse, Dave, who I had only been married to for three months was there shaking and scared that he was going to lose his wife that night.

Twenty-two hours after I was found I woke up in my bed inside our hotel room. I was confused and I asked myself why am I still at the hotel. I learned that I had been in the ER for 13 hours. Then when my vitals went back to normal, they simply released me. They detected the ethanol in prescription drugs in the blood test, but no one had detected that it wasn't an accident. While I had been preparing for the possibility of surviving that event, I was not at all prepared to have to explicitly explain to everyone that what happened that night was not an accident.

The weeks and months that followed while processing it all through medication and therapy evoked a lot of emotions for me, confusing and frustrating emotions about how all the red flags that I had assumed were so clear during my childhood, adolescence, and adulthood had gone undetected. The crying in my bedroom, the morbid poetry, the cutting, the episode of anorexia, the intense isolation, or even that previous suicide attempt, which had occurred four years prior to that one. Was my own mental health simply viewed as part of the autism and swept under the rug, assuming that it was a phase that will only pass? Perhaps I had been far too good at masking. It's a skill set that had been acquired at a fairly young age, self-conscious of what everyone thought of me because I wanted to fit in. A mask that had been used to cover all of that darkness occurring in my life especially that time while in the public eye while I was still trying to handle it privately.

Then in late 2016, a post from MTV appeared on my social media feed. It was a casting call for young adults on the spectrum to audition for a television docu series based on the film I was in. It completely caught me off guard. I was trying to understand why those involved in film who were also at the hotel that night and knew that I had nearly lost my life to suicide would even consider creating a spinoff.

It especially got me concerned when I learned that MTV had not even considered budgeting any autistic consultants, mental health professionals or other representatives to watch over the best interest of those young adults who would be sharing their lives in front of the camera. I realized in order to prevent harm from potentially occurring to other people in my own community, I had to take a risk. I had to break my silence.

On April 2017, I published an open letter to MTV. I expressed my concerns, but I also expressed that if steps were taken to handle it appropriately, the television docu series could potentially be a good thing for a community. As of today, May 21, 2019, that letter is still up and accessible online in case you are interested to read it. Eventually, for a reason that remains unknown, a decision was made that production would be halted and the docu series would no longer be pursued.

In our conversations on autism research, we still need to consider all of the possible contributors of depression, the drugs you might be taking, your genetics, a physical health issue, poor and inadequate nutrition, or a brain chemistry imbalance. We need to keep having these conversations. But before we can dedicate focus on improving research and services, we need to dedicate focuses on the way we treat each other.

In the 37 years I have been alive, the most astounding observation I have noticed is that the most ablest, damaging, and vial words that I have personally received have come from people in the autism community: family members, professionals, organization leaders, and yes, even other autistics.

That PBS Facebook post that I mentioned to you earlier contained slightly over 200 comments, filled with vicious words, similar to the words I had kept coming across throughout that past year when we had been covered by the national media. And nearly all of those words came from people who identified themselves as a part of the autism community. That moment was the breaking point of a vessel that had been swelling and when my suicidal ideation turned into a confirmed decision.

Sometimes I think that we have a tendency to say or write things without really thinking about how our words can impact other people. Even if we are well intentioned, we cannot invalidate a person's feelings when they say they felt attacked by our words. Statements can be argued, but people's feelings cannot. And it seems that in plenty of cases, those words are conveyed under the assumption that it will never be seen by those who they are targeting. Those tweets, those public Facebook posts, those blogs, those podcasts, those YouTube videos criticizing me or criticizing my spouse. I see those and it has a more significant impact on me than you may realize.

I learned a big lesson from that experience. I learned that in order to take better care of myself, I had to stop myself from searching for that ugliness on the Internet.

For those who choose to attack or use hurtful words, even though it devastates me, I can appreciate where your emotions are coming from. You might be angry because you don't feel recognized. You might be struggling to understand why there are some who have received a platform while you are still struggling to receive the supports you need and perhaps a human like me may not be a fair advocate for our community.

Before you make your judgment, you need to know that the main reason I got into this arena in the first place was not about me. It was about my brother. The reason I have stood on a podium a handful of times and testified in front of IACC at previous meetings was because of my brother and other humans like him who had high support needs and needed to be listened to.

If you are planning to speak or write hurtful words to a person who you only know through who you have heard through the media, before you do, please consider that there might be facts about that person you are targeting that you may have no idea about. And before you press send, please think about whether expressing your anger and hurt towards another person with autism will provide you with that comfort, relief, or support that you and your loved ones deserve to have. I want you to receive all those things, but please let us be kind to one another because it has already been proven countless times with school age kids and members of the LGBTQ plus community who have been bullied, words hold power and words can make or break you.

Regardless of whether you embrace autism or hate autism, please be mindful. Please try your best to imagine when you hear messages surrounding you about how your condition has destroyed a family or caused a crisis because of a condition that you did not choose to have, how that would make you feel.

To be completely honest with you, when I hear and see those messages, it has made me wish I was dead. It has made me wish at times consider suicide. It has made me ashamed for having caused ruin to other people's lives and it has made me wish at times that my brother and I were never born. Please be kind to one another.

I don't want to close my testimony under a gloomy and discouraging sentiment. To end it on a positive, I do want to share with you one piece of encouragement. If you ever decide to open up about a difficult experience about your own mental health that has occurred in your life, it is hard to talk about it, but it is important to talk about it. It is hard because you may have been shamed for raising your voice or that you have been told that opening up about your own mental health is an embarrassment perhaps voiced by your community, your colleagues, your friends, maybe members of your own family. All the people in your life who you trusted would love and accept you most.

But the silver lining to all this is that with each downfall that you survive in, you become just a little more stronger and a little more resilient. It will become clearer who you are and who are really there for you. Resilience is a strong force, a lot of us on the autism spectrum that exists in our families as well.

I am so glad we are having a conversation about this now. My sincere hope is that if we can prevent at least one person on the autism spectrum from not having to experience the pain and trauma that I and many of my other colleagues have gone through then we are one step closer to making progress. Thank you.

(Applause)

DR. DANIELS: Thank you so much, Lindsey, for sharing those words with us.

Next, we have Dennis Mashue.

MR. MASHUE: Good morning everyone. Can you hear me okay? My name is Dennis Mashue. I'm a father of - I'm going to go ahead and apologize. There are going to be tears, but I've reached a point in my life where tears, each one, indicate that I'm feeling again. I want to thank you guys, IACC, for having us here today to know that there is this much horse power in a room concerned about the future of people like me, Lindsey, my son Tucker, is immense. So thank you very much.

I'm here to share my experience of being an autistic father raising an autistic child. What I will do here – I'm going to share words with you, but at the same time, I'm going to run a looping slide show just so you can get a flavor of what life is like or was like for my son and me.

The first thing I'd like to do is say hi Tuck. My professional background consists of ten years in military intelligence. I worked for ten years for a Fortune 50 chemical company. Since then I've worked for 15 years as an autism neurodiversity advocate and for over 5 years my son, Tucker, and I have operated a business together, which we call a pro-autism model.

I became a solo parent when Tuck was 11. For the next two years, I struggled with the work life balance and eventually lost my job, lost our home to foreclosure and bankruptcy. At that point, I began to question everything, but my primary driver being to preserve Tuck's spirit and also his autonomy.

During this reflective period, three events transformed my approach to raising my son. The first was Temple Grandin's mother, Ms. Eustacia Cutler, who came to do a presentation in our little town in Michigan. She picked me out of a crowd of a couple of hundred people to sit down and talk about the importance of a father in the life of autistic children, which I've become to understand is pretty rare. A lot of fathers aren't able to fix their children so they want to step out of the pictures. I didn't have that option and I wouldn't have taken it anyway.

Shortly thereafter, I saw John Elder Robison's Ted Talk Organic Education where he basically took me back to a time where children learned a trade or worked in a family business with a parent and we had really gotten away from that model and we need to get back to it.

The third thing that happened was over breakfast with my son Tucker who was then 14. He told me teachers think I'm dumb. As I was trying to process that, he was scrolling on a white board that he uses to communicate. Tucker is largely nonverbal or minimally verbal I had described is as. He had scrolled on his white board and he thrust it out at me and it said I am smart. That day we started to rewrite our life plan. We opted out of all social service supports, which we never received. We opted out of all traditional education programs and we launched a company called Tuck's Tooques with help from a Nepali expedition leader, we connected with artisans in Nepal to import a line of hand-woven winter hats and we launched our company. Interesting date – Lindsey, you'll probably pick up on this. We launched our company in January of 2016.

My primary objective with creating a business was to help develop a sustainable Tuck. We wanted to equip him with job skills. We wanted to also build a company at the same time, which could provide him with a sustainable livelihood as an adult at least until a point where he may choose to do something else, go to college, get a degree, do whatever.

But our launch plan began with yearlong van life trip. We got rid of everything we owned. We loaded our camping equipment in our old minivan and we hit the road for a year. Our mission was to promote his company, his brand, and also to hit as many national parks as we could, hitting 49 national parks in 32 states.

But also Tuck was able to present his story. This nonverbal 17-year-old kid was able to present his story in a PowerPoint format in front of more than 3500 people. Also, one of the successes of our trip that summer was his promotional video wound up being viewed by 200,000 people. We connected with a lot of people around this country. The term positive psychiatry has been mentioned a couple of times today where we were putting this autistic family out there in front of people who when they met us, related to us and went we're not as neurotypical as we think we are because what you guys are doing makes sense to us.

A couple of other successes from that road trip from the first year that we were in business together were Tucker received an endorsement from a director at Michigan Department of Education. It had to be unofficial because we were not supported in any way by any kind of school programming. But the statement was made that this is the most effective transitional model for a young autistic adult that I have ever seen.

He also arranged ambassador relationships with world-class polar explorer, Lonnie Dupre, and also with Her Odyssey, which is a two-woman/person-powered expedition traversing the Americas from Patagonia to the Arctic Ocean. These people are actually using his products and promoting them.

Organizations that have invited Tucker to come in and present what has been described as a socially innovated business model. Pearson education is kind of a big deal in the education world. Central Michigan University, Appalachian State University and the Autism Alliance of Michigan have all had Tucker come in and present his business model as an example of what a nonverbal autistic person is capable of accomplishing with some supports and in this case, supports from his dad. We did not have much as far as outside supports.

With all the success, why am I standing up here talking about mental health? We were on our way. We are doing really good. Tucker based on discussions with our advisory boards who were helping us manage this business, it like we were 12 to 18 months away from him being a sustainable, independent adult at age 18 or 19 with his own company.

I'm standing up here because I spent the first 50 years of my life operating as a neurotypical person. I had no idea why I didn't understand community. I didn't understand education. I didn't understand my peers. But I was smart enough to develop a large file of social scripts in my head and although I didn't understand why I needed these, I knew that in order to be successful in the educational program, I needed to be able to parrot these statements. I did it well enough that I was elected to student council president and to the homecoming court at my high school. I had no idea what to do with those things or why I wanted them, but everybody else wanted to do them so I figured out how to make it happen.

But I couldn't learn in school. School was absolute chaos for me. I could smell shampoo, deodorant, fabric softener, toothpaste of the person sitting next to me. I could hear their pencil lead scratching on their paper. When you multiply that by the other 20 or 25 kids in the classroom, I was learning nothing. Now, as 30 some years later, I see my son experiencing the same difficulties.

Along about that time, I also started to experience what is known as autistic burnout, which is a result of adults not knowing their neurology or possibly knowing it, but having to mask their neurology for decades and constantly observe every word and every gesture from people that they were in interaction with and having to at the same time pull the appropriate file from my brain to respond in a correct manner. It's become also automatic, but it's also the reason why I isolate myself a lot because I don't have the energy to do it anymore.

One thing I hope that you guys will take into account – it sounds like you are already ahead of the game here – is the process -- when I had a good job, my son was ineligible for any kind of direct support or mental health services because the Medicaid criteria is what drives everything. I had a good job. He didn't qualify for anything. When I lost my job as a result of continually fighting for services for my son, he still didn't qualify because I had a house and I had assets. Once we lost our house, he still didn't qualify because I had money in my 401(k) account. Once that was exhausted, suddenly the State of Michigan came in with an offer of direct support care for my son so that I could go get a job.

I went and got a job. Once we had support in place and five weeks into this job, I received my first paycheck, the first one I received in three years, I also received an email from the State of Michigan stating based on you starting this position and your new income, your son is no longer eligible for services. And by the way, we are going to back bill you for the past five weeks of direct support care that he has received based on your income.

I see a lot of people in this room going how can that be or that's not right. It's not right, but it can be because parents like myself don't have the time to raise our children and also earn a master's degree or PhD in social work or social policy to learn how to navigate these systems, which seem to be designed to withhold services from the people they are supposed to be serving.

I came here thinking I hope somebody is going to listen to a little bit of what I have to say and I've already heard a lot of people in this room say what it is that I wanted to communicate and that is we need to take the horsepower in this room and somehow move that horsepower to the ground. From my perspective as a parent, universities appear to be a holding tank or I guess a repository of a tremendous amount of knowledge and support, but it's not making it out into the community.

I'm excited about what I see here today because that seems to be the predominating thought process is how do we get services out to the people who need them.

I'd like to thank you guys all for being here and for mostly engaging autistic adults in how exactly it is that we can serve autistic adults. I think if we look at the

LGBT community or any other marginalized community that true progress starts to happen when we actually engage members of that community. What I really hope that will come from this event today is that parents like me and there are a lot of us out there don't have to live in poverty to, one, avoid the programs out there that are supposed to be helping us, but are in fact far more of a hindrance than they are helpful. Please take that with you today when you leave. As you do your research, keep that in mind. Thank you very much.

(Applause)

DR. DANIELS: Thank you very much for sharing your story, Dennis.

Next, we have Alison Morantz.

DR. MORANTZ: Thanks for inviting me to speak on this panel. My name is Alison Morantz and I'm a professor at Stanford Law

School and a mother a 13-year-old boy named Micah. I'm here to share my thoughts on how we can improve the lives of people who experience autism as well as severely disabling forms of mental illness. But I want to start by sharing Micah's story.

He was a sweet, happy baby and a bright verbal toddler. By age 3, however, his impaired social development and restricted interest led to an autism diagnosis. We threw ourselves into our role as ASD parents. We put him on a special diet. We provided him with nutritional supplements, started ABA therapy, social skills therapy, occupational therapy, speech and language therapy, riding therapy, swim therapy. You name it. We tried it.

But even before he started preschool, Micah started engaging in assaultive and destructive behaviors. This in itself wasn't particularly unusual, but his behaviors didn't seem to resemble those of other autistic kids we knew. He didn't have meltdowns or displace significant anxiety. He didn't get overwhelmed by sensory stimuli or by changes in his routine. Instead the root of his aggression seems to be an overriding compulsion to control other people and prevent them from exerting control over him.

I once asked him, why he hurt other people when he knew this would result in him losing opportunities to do the things he wanted. He said because giving you consequences is a gazillion times more important to me than losing privileges or getting consequences myself.

This response not only showed a remarkable amount of insight for such a young child, but it also summed up why conventional ABA therapy was ineffective.

Within two years, both of the ABA companies we had hired to provide in-home therapy had quit. After an 18-month interval in which we used a home-grown behavioral technique, things became more dangerous than ever. And meanwhile Micah started talking about people lying to him. It started with his nanny, but soon he started accusing all grownups of lying even though he couldn't identify any specific falsehood or explain exactly why grownups couldn't be trusted.

After several terrifying incidents in which we narrowly averted serious injuries, we realized we couldn't continue to roll the dice. But the children's psychiatric hospitals in our area refused to admit children with autism so we admitted him to the University of Utah's Neuropsychiatric Institute. The dedicated clinicians at UNI were stumped by Micah's extreme behaviors and none of the medications they tried and there were many of them helped him.

Seven months later at his next placement at a residential treatment center near Salt Lake City, new problems emerged. He started to obsess about his foods, accusing staff of peeing or spitting on it. Meanwhile his thoughts became highly disorganized and his level of intellectual functioning dramatically declined. And much of his language, which had always been his strength, started to resemble word salad.

By the time Micah was 9, he had been transferred to UCLA's Resnick Psychiatric Hospital. His OCD symptoms had abated, but the paranoid delusions had ripened into full-blown psychosis. He also by then had failed multiple trials of antipsychotic medications. UCLA didn't know what to do with him and the nurses were poorly equipped to handle his behaviors.

But by then there was nowhere else for Micah to go. We applied to and had been turned by every licensed community care facility in the State of California. That is including group homes, residential treatment centers, literally every center.

Although we learned that the National Institute of Mental Health had done a 20-year inpatient study of childhood onset schizophrenia. When we reached out to them, we learned that that study was in the process of winding down. Since we had no in-state options, we spent the next two years continuing to follow Micah around the country. He spent five months at Eagleton Academy, a residential treatment center in Western Massachusetts that was shut down soon after Micah left because of abuse, four weeks at Monarch Academy in Cleveland, whose wonderful staff tried valiantly to halt Micah's downward spiral as his OCD symptoms flared up again and culminated in a hunger strike, and several months at the University of Pittsburgh Western Psychiatric Hospital where he was eventually locked in his room 24/7 because of his refusal to wear clothing or use the toilet.

In 2016, we persuaded Stanford Children's Hospital to admit him as an inpatient for last ditch trials of clozapine, the one antipsychotic medication we had been unable to do a full trial of because by then he was no longer taking oral medication and an experimental anti-inflammatory treatment. But neither of those trials turned out to be successful.

Michael's odyssey around the country, which included seven different placements in three years, was punctuated by instances of reported staff abuse. In one case, the staff member in question was immediately fired. But in the other cases, the allegations were followed by cursory investigations or simply ignored all together.

There was a common pattern to these incidents. In each case, a staff member had reacted to Micah's disruptive or assaulted behavior by losing their temper and physically retaliating against him.

It's been two and a half years now since Micah was discharged from Stanford Children's Hospital. I'm not quite sure if it meets Hollywood ending standards, but I'm happy to tell you that the most recent chapter of his story provides significant grounds for optimism.

In the summer of 2016, we appealed directly to the State of California for help and eventually formed an unprecedented partnership to keep Micah safe, in state, and close to home. Here's how it works. We bought a new house near our home that we carefully retrofitted to keep him safe. Meanwhile the state provides intensive around the clock staffing and the school district provides 90 minutes a day of in-home instruction.

Micah's mental illness still scares off most ABA providers. The Means(?)Institute, the only local vendor of in-home ABA that agreed to provide Micah with a home-based program, dropped him like a hot potato as soon as the higher ups realized the severity of his condition. This was the third time we had been abandoned by an ABA agency and the second time we had to create our own program.

Fortunately, along the way, we found a board-certified behavioral analyst who was excited rather than scared off by the challenge of using behavioral principles to help an autistic child with severe co-occurring mental illness. She has overseen his program since its inception.

Micah has made remarkable progress in the last two years. His aggression in property destruction although still quite significant is much lower than they've been for years. In recent months, he has even begun making trips into the community and to visit us at our home in Palo Alto. He's learned and can often follow the three big rules for community outings. Wear clothes, use the toilet and don't do things that are unsafe.

This is a picture of Micah at Stanford Children's Hospital. You can barely see him. He is sort of naked under a blanket inside a fully enclosed tent bed, which is sort of an open cage sort of in 2016 where he was often confined for a good part of the day and occasionally put into four-point physical restraint.

This is a picture of the first big milestone after we created this new program, which came in November 1, 2018. What happened was we went trick or treating at the homes of several hand-picked neighbors on the night after Halloween. This is the four of us wearing our costumes.

And this is a picture of Micah just this past January on his 13th birthday party at Chuck E. Cheese where we went during sensory hour and ordered pizza and even played several of the games.

Don’t get me wrong. Barring a medical breakthrough, Micah will probably never again be able to live at home, organize his thoughts, or regain the intelligence and insight that he lost with the onset of his psychotic illness. His symptoms sometimes prevent him from doing things he wants like the other day when T-nice, the personified entity that Micah says lives inside his brain and talks to him, told him he couldn't enter a movie theater. It can also create medical complications such as just five days ago when T-nice told him he could no longer take the medication that he takes to control his seizures.

Nevertheless, his quality of life and subjective well-being are much higher than we could've imagined two years or even ten months ago.

I'd like to switch gears a little bit. I noticed when we were giving introductions, I'm the only person in the room I think at least around the table with either a JD or a PhD in economics. I want to say at the onset that as I switch gears, I bring both of those perspectives to bear in my remaining remarks.

My goal is in my nascent policy work to think about how to bring state and federal resources to bear to provide people with autism across the whole lifespan with the resources, the services and supports they need to maximize their subjective well-being, whatever that looks like.

Here are several thoughts on how we can further those goals. First, we need to expand treatment options for people with autism and co-occurring mental illness. Micah's story illustrates that even an autistic person with the most severe form of mental illness who does not respond to any medication can make progress with a dedicated provider who is not scared off and is willing to think outside the box and can live safely in his own home with appropriately individualized supports.

If the vast majority of ABA providers treat ABA therapy like a hammer and autistic children like nails, in my experience, they shun children with dual diagnoses especially those diagnosed with more severe forms of mental illness like Micah. The rigid and narrow application of the behavioral techniques can do a profound disservice to many people with autism, but especially those with co-occurring mental illness.

Meanwhile many parts of the country face a shortage of inpatient psychiatric treatment or residential living options for children and adults with any form of severe mental illness. But for those who are also autistic, the problem is compounded because here again many programs turn them away.

Somebody earlier used the phrase dispel the myths. I'm speaking about the myths about autism among mental health care providers.

But I want to mention the flip side of that coin is that ABA providers and those who specialize in autism often are just as likely to shun individuals who have severe co-occurring mental illness like Micah. I think we need to dispel the myth on both sides.

What all of this means in practice is that people of autism and mental illness are at great risk of living in highly restrictive and often traumatic settings or being moved from placement to placement as Micah was with no stability for them or their families. Nobody can make progress in these circumstances.

Although Micah was dealt a pretty terrible hand in life, we realize how fortunate he was to be born to parents who had the education and financial means to fly around the country, keeping him safe, buying his own house and fight a series of legal battles to enforce his rights. If he had been born into less privileged circumstances, his parents would almost certainly have been forced to relinquish custody and by now he would probably be either dead or award of the state living in an institution for mental disease or comparably restrictive environment. If his schizophrenia has onset a few years later, he would likely be in prison.

The bottom line is the mental health and ABA fields urgently need to expand the continuum treatment options so that all people with autism and co-occurring mental illness can get the care they need, not just those who happened to be born into highly educated middle class families who engage in consistent vigorous advocacy.

Secondly, NIMH should again take the lead on investigating childhood onset schizophrenia, COS. Roughly 28 percent of participants in the initial study met criteria for autism, raising fascinating questions about the etiology of autism and severe mental illness or at least psychotic illness.

NIMH's intramural research program is the only place in the country and probably the only place in the world with the capacity to investigate these questions in a serious and sustained way. It should make all of the data from the original study available to the public, a step, which is long overdue, and launch a new study with a particular focus on the connection between childhood onset schizophrenia and autism.

Third, we need to do more to keep autistic people with mental illness safe from abuse especially those who engage in significant aggression. Micah's story, which again involved multiple instances of abuse at three different institutions, is a case in point. Changing the status quo will require improved training and oversight of staff who provide direct care especially in inpatient and residential settings.

I have to believe that the nurses and other direct care staff and most of the hospitals and residential treatment centers Micah was treated at are supposed to be trained in safe knit physical management techniques such as QBS safety care. But I can tell you from experience that these techniques are rarely applied properly if at all in response to aggression. As a result, some people with autism are being put in harm's way in the very facilities that are supposed to be keeping them safe. This will also require more training of family members in cases where individuals are living at home.

Finally, we need to collect more and better data on the quality of care provided to people with autism and mental illness. Our current surveillance system is not up to the job of protecting their safety and enforcing their rights. The data available on medicated funded long-term care facilities is a case in point.

The Center for Medicare and Medicaid Services, CMS, collects very detailed data on nursing homes, including a minimum data set on the outcomes of each resident and a rating system to compare quality across facilities. No comparable surveillance system exists for intermediary care facilities, the nursing home like facilities also funded by Medicaid that serve individuals with intellectual disabilities. The data that CMS collects on

ICF is much less detailed, poor in quality, and includes no information at all on individual long-term outcome. This two-tiered system of regulatory surveillance is unjustifiable.

Similar surveillance gaps exist in community-based settings funded through Medicaid waivers. To my knowledge, there's no federal data at all on the quality of care provided in such settings and the patchwork of state data resources is riddled with holes.

In short, until we can start collecting and analyzing data on the quantity and quality of care being provided to people with autism and severe mental illness, we will lack the ability to promote their safety and welfare in highly restrictive or community-based settings.

I want to close my remarks by sharing some thoughts about street lights. I assume that many of you are familiar with the old joke about the drunkard who chose to look for his lost keys that he lost somewhere in the neighborhood right under the street light because he said that's where the light is the strongest. This story reminds me of the challenges we face in understanding individuals with autism and co-occurring mental illness.

For decades now, the fields of psychiatry and ABA have examined the neurocognitive and behavioral characteristics of autism in relative isolation, presumably because they assume that's where the light was the strongest. But the more we learn about the autism spectrum, the more we understand that autistic ways of thinking and being and behaving are just one facet of a far more complex continuum of neurodevelopmental phenomena.

I think it's time to stop looking for our keys under the same street light we've been looking at for decades and to build more street lights by prioritizing the study of individuals with autism and co-occurring mental illness for two different reasons. First and foremost, it's the only way to know how many more Micah's are lurking in the shadows imprisoned either literally in prisons or in other highly restrictive environments. Until we find these individuals, we can't give them the support they need to live safely in the community and exert control over their lives.

The second reason is that building more street lights may advance the science of autism in unexpected ways. NIMH's originally study in COS underscores this point. The originator of the study was quite surprised to discover that 28 percent of the children in her 20-year cohort met criteria for autism. We don't yet understand the significance of that correlation. But at the very least, it suggests that autism or at least certain forms of autism likely share common developmental pathways with schizophrenia and possibly other kinds of mental illness.

In other words, focusing more on people with dual diagnoses could point the way not only towards the lost set of keys we think we are looking for but also to other cross cutting neurocognitive mechanisms and developmental pathways that transcend our current diagnostic categories.

(Applause)

DR. DANIELS: Thank you, Alison, for sharing those comments. Since we are over time, we're going to go right into public comment and we're going to come back for discussion at the end of the public comment session.

I'd like to call up Dr. Eileen Nicole Simon to share her comments.

DR. EILEEN SIMON: I decided to attend this workshop because providing for the lifelong needs of developmentally disabled autistic people is such a serious issue. Best will be when autism can be prevented. But in light of the epidemic that began in the 1990s, solutions must be found and immediately for providing appropriate life-long care.

Discussion of mental health services should be the focus of this meeting. Many more psychiatric afflictions beyond anxiety, depression, suicide and aggressive behavior need to be addressed. More inpatient or residential units are badly needed to provide the care and services needed.

I submitted a comment to the IACC a few years ago about a possible way to hire and house autistic adults. Marriott has a chain of Residence Inn hotels with a full kitchen, dining space, and living room area in each unit. I asked for discussion of developing a possible plan for housing autistic adults in a few units of each Residence Inn hotel, and employing them to also work in the hotel.

I recently took a grant-writing course at UMass Boston. Looking for private foundations that seek to provide grants for worthy causes, I noticed that Marriott has several philanthropic organizations, including the Marriott Hotel Philanthropy. The online link to the Marriott Foundation is marriottfoundation.org.

I want to contact Marriott with my plan. I would like to find collaborators for this effort. I hope I can have more interactive involvement in this workshop, beyond making this brief presentation.

I would appreciate discussion of this idea by members of this IACC workshop committee.

Thank you.

DR. DANIELS: Thank you.

Next, I would like to call up James Williams.

MR. JAMES WILLIAMS: Thank you. It is very nice to be back here at an IACC event after three years. I am an adult self-advocate with autism and I've experienced many mental health issues throughout my life. My comment today is about those issues.

On an abstract level, it's very easy to feel sorry for people with autism who are experiencing mental health issues. Depression, anxiety, suicide, aggressive behaviors, and self-injurious behaviors. They are very real and they are very serious issues and they affect many people with autism. But what I'm here to tell you today is this. These issues are not just symptoms on a sheet of paper or on a diagnostic evaluation. And people don't live with these symptoms in a vacuum. They are caused by the genuine stressors and struggles that people with autism experience in their daily lives.

Now, I'm aware that many of these symptoms are direct symptoms of mental health conditions and we will probably figure out later on some time that they could be bona fide symptoms of autism. I also have come to conclude based on my experiences, they are the byproducts of the struggles that people with autism live with every day.

I have never experienced a mental health issue just for the sake of experiencing that issue. Every bout of depression, every bout of anxiety, every bout of aggressive or self-injurious behavior I ever had was a consequence of another symptom of autism, a consequence of living with other symptoms of autism. I shall give you an overview of those indirect consequences.

I do not experience depression in a vacuum. My depression is the consequence of living a lifetime of existing in a world where just being myself is offensive to other people. Living in a world where my brain is instinctively telling me behave in a certain way while the world is saying that way your brain is telling you behave is inherently wrong and inappropriate.

I don't just experience anxiety in a vacuum. It's the product of living in a world where I've been shunned and rejected by so many people even people who are formally my close friends, people I thought would always be there for me.

It's the product of living in a world where every social move I make brings with it a risk of being shunned or having an unpleasant social response from people around me. And although I have not engaged in aggressive behavior for many years, back when I did, it wasn't because I was a bad or a violent person. In fact, my family would always call me even when I was going through growth spurts in adolescence, the gentle giant. It was living in a world where there would be times when I'd be so angry and so frustrated about not being understood and not being listened to. But sometimes I'd have episodes of aggression and violence as a result.

And the self-injurious behavior that sometimes emerged was also a response to that as well. Just living in a world where people weren't listening and I desperately needed them to.

In one unconventional situation, I was in high school. It was science class. I was in a group project where my partners refused to listen to anything and the teacher wasn't paying attention. The only way that teacher would pay attention is if I fell off a stool. It made such a loud noise. He had to stop what he was doing and pay attention to how these kids that he partnered me to work with were shunning me.

What does this mean? Mental health issues aren't just symptoms that are directly a part of autism. They are also the consequences of the reality that people with autism live with. They are the consequences of the symptoms of autism that we have already established whether or not it's in the DSM or whatever. Symptoms of mental health aren't just direct symptoms. They are the indirect byproducts of the other issues people with autism live with.

Looking ahead, what does this also mean? It means that we also have to look at the consequences of so many interventions and treatments that want to – that try to tell people with autism the way you are is wrong. Just the way you are is inappropriate and intolerated. Don't get me wrong. Social skills instruction and other interventions have helped people with autism like me, but they also come with a message. Your way is wrong while the way of neurotypicals is right. What makes you you is interolable and unforgivable.

I will close with this. If we want to take a look at mental health issues and autism, we can't just think abstractly anymore. We have to think ourselves what are the social realities. What are the social realities of daily life that are causing these issues to occur? And also, are we really prepared to challenge some of the sacred social norms that we might not have questioned on a daily basis throughout our lives to pay attention to how those issues are hurting other people?

I'm going to close with an anecdotal example. When I was in high school, I was traumatized by mandatory fire drills because the loud noise and the commotion during those drills. I met a disability advocate who spoke eloquently on an abstract level about how regulations by many lawmakers were hurting people with disabilities. When I went up to that advocate and talked about how mandatory fire drills in so many settings have hurt so many people with autism, this person's mentality immediately changed. No more did they talk about an abstract about needing to change laws. Immediately that person got defensive and worshipped just how important fire drills were, refusing to acknowledge the pain I had gone through due to those requirements.

We can't be abstracts anymore. We've got to realize we're going to have to get uncomfortable and pay attention to the social realities that our society enforces and how they can cause so many mental health issues that people with autism face on a daily basis. With that, thank you very much.

(Applause)

DR. DANIELS: Thank you, James, for sharing those comments and to all of you that were here in person to share your comments. We really appreciate hearing all these really important points.

We're now going to have Dr. Oni Celestin from the Office of Autism Research Coordination share some brief overviews of the public comments we received in writing from people around the country who wanted to share on mental health issues. We did not receive any live feedback comments so there won't be any of those. But Dr. Celestin, you can go ahead and share those comments.

DR. ONI CELESTIN: Good morning. The IACC health outcomes working group has received written public comments from seven commenters. The working group has been provided the comments in full, but they will be summarized briefly here.

Ms. Stacey Hoaglund described her work coordinating mental health resources in the aftermath of the shooting at Marjory Stoneman Douglas High School in 2018. She detailed the different types of trauma that students with ASD experience, including the everyday trauma of navigating a neurotypical society. She believes that students with autism need to be taught how to overcome trauma. In addition, she believes that parents, teachers, and those in the general public need to be better educated about autism and ways that they can help make a difference.

Dr. Eileen Nicole Simon described the experiences of her two adult autistic sons. She feels that the state mental health resources and services were inadequate and that the staff and the group homes where they lived were not properly trained or compensated. She would like to retain a personal care companion or PCC for her son and she would like the working group to discuss the availability of grants for PCC assistance.

Mr. Alex Graves expressed concern about current discussions in the autism community. He feels that the medical model of autism should be protected. As an autistic adult with significant disability, he does not feel that he can relate to the experiences of less impaired autistics who advocate for neurodiversity-based models of autism. He believes that more money should go towards funding research and finding cures for autistic impairments. He also believes that diagnoses such as Asperger's and class autism should be recognized instead of the autism spectrum terminology.

Dr. Rita Honan wrote about the importance of including autistic students in social events both in and outside of school. She believes that staff should be trained on how to support autistic students as well as support and coaching the peers of autistic students.

Once in high school, she believes that neurotypical students should coach their autistic peers on social nuances. She also advocates for ASD consultants in the work place to teach best practices for engaging with autistic coworkers.

Finally, she feels that engaging in day programs will help prevent mental health concerns in young adults with ASD.

Ms. Sandy Krause believes that living in a neurotypical world likely causes anxiety in autistic individuals. She believes that mental health services for autistic individuals should be more accessible.

Ms. Lisa Wiederlight submitted a comment on behalf of SafeMinds, advocating for more biomedical research into the causes of co-occurring mental health conditions in autism.

She also wrote about the need for appropriate treatments for these conditions in autistic individuals and the need for mental health professionals to be properly trained to recognize mental health issues in autistic individuals and their caregivers.

Finally, she expressed concern about the long waiting lists for mental health services that exist in many areas.

Mr. Matthew Doll would like the working group to discuss the availability of Medicaid Comprehensive Community Service and other benefits to individuals with ASD.

Specifically, he is concerned that the presence of an autism diagnosis unnecessarily excluded individuals from these services in favor of autism-specific services that may not be as relevant in every instance.

This concludes the summary. Thank you again to everyone who submitted public comments.

(Applause)

DR. DANIELS: Thank you, Dr. Celestin. Now we have a little bit of time for discussion. Our next session starts at 11:45. We'll take this time to talk about the personal perspectives that were shared as well as any of the public comments. We can open this up to the working group to discuss.

Dena.

MS. GASSNER: I just wanted to bring to everyone's attention a program that I think calls to or speaks to the self-advocates who were talking about living in a world that's not adapted for our needs. The Marshall University's College Autism Program this fall will train their first freshman class in their welcome week on how to be an ally to neurodiverse people, the entire freshman class. They have trained the community that the university is located in. They've trained every teacher, every service provider on campus. At some point, autistic people are begging you. We're begging you to not make us the only people trying to be inclusive. We can't keep being asked to change. That is what is destroying the mental wellness of autistic people.

That being said, I think my dear friend Dennis who was struggling to maintain his composure failed to update you on the most important message he came to bring you today. And I think he's ready to do that now.

I want you to be able to capture the difference in your experience as you've acknowledged your privilege and how you've been able to use your financial status to achieve things. Dennis represents the other side of that coin as a single parent who, as you have heard, lost everything in the effort to try to help his son. I want you to know where Tucker is now.

MR. MASHUE: Thank you, Dena. I just recognized up there that I wouldn't be able to get through the description. You saw the images of the life that Tucker and I had together. And I got to tell you to see your minimally verbal 17-year-old child get up and deliver a Power Point presentation in front of graduate students in a lecture hall of 100 to 150 people, to see him light up - I'll be honest. A lot of these graduate students are 23, 24-year-old young ladies and they all want to get a picture taken with Tucker. After he did his presentations, you never saw an autistic kid swagger out of a venue like he did. We had a lot of successes.

But the long and short of it was that when we lost services because of my error in calculating exactly how much salary I could make in order to maintain my son's services, we filed a lawsuit against the State of Michigan. Community mental health is the gatekeeper for mental health services in the State of Michigan. We won that lawsuit basically stating you can't just drop people off your rolls for arbitrary reasons and then bill them back for services. The lawsuit took over a year to play out before, yes, we won and the result is nothing because as the lawsuit was going on, Tucker's eligibility for Medicaid expired. He was required to go through the reevaluation process again.

And oddly enough, after we had won a lawsuit against the State of Michigan in an attempt to hold on to the full-time care support budget that we had, low and behold, he is reevaluated and now rather than qualifying for 60 hours per week of direct support services, now he qualifies for 20 hours per week. Nothing retaliatory at all in that scenario I'm sure. I try to look at everything with a sense of humor. I look at that situation and I go wow. All I had to do is follow a lawsuit against the State of Michigan and I cured 66 percent of my child's autism. I am available on a consulting basis if anybody would like to –

Tucker's current situation. When we were on the road, we were in discussions with Appalachian State University, which has a really wonderful two-year program for students with developmental disabilities. They do a wonderful job of integrated their developmentally disabled students, not just autistic students, into the community, into the university with a solid support network of their peers.

Tucker has been working toward attending that program since he was 15 years old. We've made visits to the campus. I was also in discussion with them because they are interested in our approach to transition where we developed a business model that was kind of a hybrid, vocational and educational, and it was working. It was working wonderfully. They were interested in ways that maybe we could take that model and embed an entrepreneurial track within their program for developmental students or developmentally disabled students.

When the wheels fell off in 2017, I experienced a breakdown. And what happened within the next months was that Tucker was immediately stripped of his civil rights. He was stripped of his autonomy. He was placed into guardianship with the State of Michigan.

His friendships were severed. His father and my family, which had been the only family involved in his life for over a period of five years have been completely carved out of his life. He used to love to hike, kayak, and mountain bike. He has access to none of those activities anymore.

We had established a mentorship program with our local university's bowling team. Bowling was a big thing for him. That was terminated.

He was pulled out of an education program with guidance from Appalachian State University's program. They help identify an effective assessment tool to determine where Tucker was academically as we were trying to prepare him for university life.

When they asked me with Tucker sitting in the room, they said where is Tucker academically. We need to know this information so that we can – when application time comes around, we know what we are dealing with. I said his public school program has perennially assessed him at a second and third grade level with regard to math and reading comprehension. And the people in the room just looked at me and they looked at Tucker and said that's not true. I said yes. You know it's not true. I know it's not true. But every time I challenged our school district when they come back with this finding year in and year out, the response is that we know our assessment tool doesn't really fit Tucker's learning style, but it's the only one that we've got. So they continue teaching him at a second and third grade level year in and year out.

When we finally pulled him out of the traditional public school, we enrolled him in an online program and the school that we enrolled him in knew that his dream was to attend App State. And they wanted to help us prepare to get him there. I said we need to identify an assessment tool that will work with Tucker's learning style if there's any hope that he's ever going to learn at an appropriate level. They did a little bit of research and came back and recommended an assessment tool. They recommended it to the school that he was attending. He participated in both math and reading comprehension. In reading comprehension, he scored superior for an 11th grader. He was 18 years old. And he scored as average 11th grade in math comprehension.

When I was carved out of his life because of my mental health status, he was immediately pulled from the education program that was teaching him at an 11th grade level, reassessed back into the same old public school district this time at least at a sixth grade level. He had been receiving instruction three hours a day at an 11th grade level. He is currently receiving instruction one hour per day at a sixth grade level.

He's no longer allowed to have any involvement with the business with his name on it. This is the current model of mental health delivery in the State of Michigan for developmentally disabled people transitioning into adulthood.

There's a lot more to our story and that is going to be coming out shortly. But for the time being, I think it is very important to understand that this young guy was a year and a half probably from being an independent human being and now he's warehoused in what I can only describe as an institutional setting. Yes, he's in a two-bedroom home out in the community, but on the rare occasion that I've been able to go and visit him, I've observed that he spends 16 to 20 hours per day in his bed. He's morbidly obese. He is incredibly lethargic and he has totally resigned to the life that he's been placed into.

I hope you all will consider – I represent a lot of parents here, especially single parents who have to make the decision do I honor my child or do I throw him into this broken system so that I can go to work and make a living. We chose to opt out of that situation and create our own way and we did it in a very convincing fashion.

I miss my son. But even more, I miss him having the opportunity to reach his potential. Thank you, Dena, for bringing us back to that.

DR. DANIELS: Thank you very much, Dennis. We have a few more minutes for discussion. Scott.

DR. SCOTT ROBERTSON: I think all these personal perspectives are very powerful and I hope that everybody takes them to heart both the personal experiences and the issues and barriers that have been raised.

Dennis, I wanted to focus just for right now on what you've been sharing especially since in my case conveying a lot of the employment perspectives and a lot of the work related barriers, employment-related supports, economic and income kind of aspects to this that I hope we don't lose sight of that. I hope we don't lose sight of the fact of the cross connection unemployment and the social determinants of health that is has related to that and folks not being able to access services and supports or being booted off them because of income levels or because of private insurance not covering the same things as maybe Medicaid. Those come up in a lot of discussions among my colleagues at DOL and ODEP. I hope folks know that this is being discussed across the board on a lot of what we're looking at in terms of policies and practices. I find it really important to keep learning and keep hearing about all these specific barriers and challenges, as I say in our case, on the employment and work end just to make sure that folks don't lose sight of that and that folks that are just struggling to get by or are not being able to achieve their full potential in terms of opportunities that they could in terms of – because of not receiving the right supports and services or not having family supports or a full range in terms of coverage there. I hope that that comes up also later on the discussion is the work side that people are real people trying to live their lives at times.

And the economic aspect – like work is what supports that. But the work life balance on being able to say be a person with disabilities and be an autistic person raise another autistic person. We need more support on that like that can look like in the work place. Thank you for particularly spotlighting this and also for all the other personal perspectives on this. Hearing the stories has really been strong and as I say powerful on shedding light on a lot of these issues.

DR. DANIELS: David.

DR. AMARAL: I wanted to ask a question of Dr. Morantz. Could you say a little bit more about the organization at Stanford that you lead? I think it is called SIDDLAPP. You had a lot of acronyms in your presentation. And maybe more generally speak to the issue of whether there are developing consortium of lawyers who could be addressed, start dealing - a lot of the issues that we have heard this morning are actually legal issues that research may not be able to address.

One of the hallmarks of the autism community is that a lot of solutions are actually brought to the community by parents who are affected to it. I was wondering if there was a group of lawyers who are coming together to try and help out.

DR. MORANTZ: Okay. So first of all, yes, I struggle with an acronym and the best I could come up with. I'm probably a month or so away from launching the website. The Stanford Intellectual and Developmental

Disabilities Law and Policy Project. You got it right. It's the best that I could do.

I think there is a real scarcity of – I come at it from the perspective of law and economics. I think there's a real scarcity of advocates with the specialized expertise to address some of these really profound and highly variable resource constraints that have been mentioned just again most incredibly, powerfully and movingly just now in Tucker and Steven's story.

In the State of California, we know that there are extreme inequalities, which are highly correlated with race and ethnicity. None of this should be surprising because it is a system in which it is the individuals with strong advocates like our son, whose needs get taken care of and those who do not have access to strong advocacy as we just heard so powerfully don't get those resources. It's a highly unequal system.

In terms of mustering the advocate resources to sort of foreground those issues and try to address them, I think that we are at the most beginning stages. That's part of the reason why I felt it was important to try to start this initiative. We are starting right now by just focusing on some of these issues specifically in California because it seemed like a logical place to start. And so much of this is driven by state policy.

Another difference may be worth highlighting is the importance of state law and the fact that state laws are so variable in this regard. Your experience in Michigan and the experience in California - part of what drove the differences in these outcomes in addition to the ones I've already mentioned is the fact that California is the only state in the country that has something called the Lanterman Act, which essentially guarantees on paper. I'm not saying it actually happens in practice. But at least in theory, as you know, guarantees individuals with IDD and increasingly large fraction of who have autism, the right to remain in their community with supports they need to live their best possible lives. California is the only state that has a Lanterman Act.

The gap between the theory of the Lanterman Act, what it does and the practice, is quite large and something that various advocates are trying to address. But I think the important role of state policy is critical.

Also, forming collaborations between people with legal expertise and again I might be the only one here. I'm one of very few. And people had the medical expertise as well.

I think those collaborations are critical. We're trying to start that at Stanford, but I would love to work with others to try to increase that group because it's a very small group in answer to your question to my knowledge.

DR. DANIELS: For the last comment here, Joe Joyce, and then we will have to move on to the next session.

MR. JOYCE: Thank you. I would just like to thank the presenters for your personal perspectives. I know there's nothing more powerful than to hear firsthand your experiences. My son, David, is nonverbal and has severe self-injurious behaviors. He actually accompanied me last year at the IACC meeting to provide a public testimony. I firmly believe that your personal stories are very powerful.

Also, being with the Autism Society of America, I would like to thank Lindsey, our very own Lindsey of the Autism Society, for your perspective, which was extremely inspirational. I think your words that people need to be kind to each other. In today's social media age, words can be so hurtful and can lead to such unintended consequences. I think that was a very powerful message.

Finally, I would like to thank Dr. Simon for your idea on the Residence Inn. I think that's what we need are people to be creative and look for new ideas for employment and housing as the autism community transitions more and more into adulthood. Thank you for that idea.

DR. DANIELS: Wonderful. Thank you. Actually, it's a perfect moment. We have a few people that joined us a little bit later or that we managed to miss earlier. Joe, would you like to introduce yourself?

MR. JOYCE: Thank you. My name is Joe Joyce and I am the board chair of the Autism Society of America. I was a little bit late due to the traffic. Thank you very much for having me.

DR. DANIELS: Thank you for being here. And Melinda Baldwin.

DR. MELINDA BALDWIN: Melinda Baldwin. I'm the representative here from the Administration for Children and Families, particularly from the Children's Bureau and work with child maltreatment and trauma and behavioral health issues at the Children's Bureau.

DR. DANIELS: Anyone on the phone who has been missed? And then I just wanted to take a moment to acknowledge also Dr. Ann Wagner, from the NIMH is here and she's the National

Autism Coordinator for HHS. She's listening to our discussion here today. Thank you all for being here.

We are going to move on to the next session, which is going to be on anxiety and OCD in ASD. Right now, we'd like to welcome Dr. Connor Kerns, who is a member of the working group, to give our first presentation in this section.

DR. KERNS: Hello everybody. Before I start, I just want to say I do feel quite affected by everything that has been said over the last hour and a half. This is not a criticism, but I think I have a tough place in the line up to go after all of that.

I'm going to go through my presentation, but I do have a pit in my stomach. I just want to acknowledge everything that has been said today.

I do want talk about the co-occurrence of anxiety and OCD in individuals on the spectrum and where we've kind of gone with the research. And I did want to acknowledge funding sources and disclosures and particularly to thank NICHD for supporting me in early career awards so pretty critical support early on in my research.

I do want to start with basically underscoring the point that anxiety and anxiety disorder are not synonymous. It's important to think for us to think about that anxiety is an emotional tool. Anxiety is something that helps us survives life, stay physically safe, socially safe, make good social decisions, basically intended to adaptively guide us through our lives.

If we are talking about what's the prevalence of anxiety in individuals on the spectrum and in the general population, it should be 100 percent.

When we are talking about anxiety disorders is when we're talking about that adaptive mechanism actually become dysregulated. And it is no longer protective, but actually standing in the way of the individual, becoming harmful as opposed to helpful.

I think this is an important distinction for us to keep in mind when we're talking about anxiety and OCD and people on the spectrum because there are many adversities that people on the spectrum will face as we've discussed today and there is certainly much more individuals on the spectrum to be anxious about. And sometimes that anxiety is going to be adaptive and appropriate and potentially help them stay socially safe.

But what we need to focus on is when it becomes excessive, all-encompassing and is actually inhibiting their lives as opposed to helping them live it.

There's also this tension, which I think we've heard a lot today whenever we are talking about comorbidity. And by the way, I'm going to be talking specifically about anxiety, but I think a lot of these issues apply to mental health concerns in general.

There is a natural tension between not wanting to over pathologize individuals and give people five or six diagnoses when maybe one diagnosis would be more appropriate. We want to be parsimonious in how we approach diagnosis.

At the same time, we have to be concerned about diagnostic overshadowing, which is this problem where if you have a diagnosis of autism or developmental delay that nothing else gets diagnosed and everything is attributed to the autism itself.

I do think at this point in terms of the research, we have a lot of good converging data that suggests that we should not allow anxiety disorders to be over shadowed or overlooked in individuals on the spectrum, true anxiety disorders. We have to be careful about how we assess and diagnose these, but they are absolutely there and they are associated with significant incremental functional impairments. Things like debilitating profile in terms of depression, self-injurious behavior, sleep problems, gastrointestinal issues, more family stress, and poor quality of life.

There is a message of anxiety disorders as they co-occur with autism or associated with a more severe, but actually a specific more severe impairment. It is more specific than just saying two disorders are worse than one. A good way to look at this is if you look at social deficits that are associated with anxiety and autism. We do see that some types of social skills appear to be worse so making social initiations. If you have anxiety that's particular hard. Certain types of repetitive behavior are more associated with anxiety, but not all autism symptoms are associated with anxiety. We have to be careful. There are specific additional impairments.

And there are reasons for us to think that we need to measure this carefully because it's potentially adding a lot of noise to research data and it is potentially if we don't recognize it, we're missing treatments that could be implemented or invalidating a person for something that they are actually experiencing. I do think research has helped in this regard.

In addition to everything that anxiety is associated with and what it adds, I also want to make the point that anxiety can be pernicious in its own right. For this, I always like to use this image from the 1930s, the little engine that could. This is an old, old story. But for those of you who don't know it, this is a little engine that is tasked with carrying an entire circus train up a giant mountain. He's a very little engine. And he wills himself over the mountain with the huge burden by saying I think I can, I think I can, I think I can, I think I can, I think I can.

And the reason that I include this slide is because you have to understand that part of what anxiety is is it's the things that tell kids, it tells every single one of us that we can't. It makes you think that you can't. And that is important particularly if you're a kid who's facing a lot of adversities, who is facing legitimate challenges to think you don't have a shot in the world of actually overcoming them is extremely problematic. And it works against what we actually try and target in therapy, which is teaching resilience and mastery. I think I can, getting over the mountain.

There's also a distinction here to be aware of between pain and suffering. And to me, anxiety and depression really tap into this suffering definition, which is that we all have pain and challenge in our lives. Suffering can be conceptualized in what we actually add to that emotionally, the emotional struggle, the internal blame that we put on ourselves for experiencing that pain.

When we think about targeting anxiety, we're actually talking about trying to relieve suffering for people, which is important in its own right.

Finally, there is a research emerging that suggests that if anxiety is present, it's potentially moderating outcomes for other autism symptoms or early intervention or even the treatment of problematic behavior or disruptive behaviors in individuals on the spectrum. If these kids have co-occurring anxiety disorders, they're actually responding less well to some critical treatments. All of these are reasons why we need to pay attention, but there are also tensions around determining what is anxiety, what is the anxiety disorder truly in somebody on the spectrum.

I want to talk to you a little bit about that and tell you as best I can what we know about prevalence. One of the, I think, most robust methodologically studies that we have is that done by Emily Simonoff in the UK in 2008. She actually used semi-structured interviews and had a population-derived sample so a sample that is likely to be representative of the population and looked at the three-month prevalence of different anxiety disorders in 10 to 14 year olds on the spectrum. And what you see is we have a number of a little over 40 percent had some kind of anxiety disorder with generalized anxiety and social anxiety disorder being most common followed by panic, specific phobia, OCD and separation. This is a pretty good methods-wise study. It's more tightly controlled.

However, you have to consider it against this backdrop that if we actually look at all of the studies that have looked at rates of anxiety disorders in people on the spectrum, the range has actually been estimated between 11 and 84 percent, which is not a great range. It's like saying 0 to 100.

Now, some of that variability has to do with the samples, how they were recruited, if you put the word anxiety in your recruitment flier, if you're looking at a clinical sample versus community. But there's also an issue here of how is anxiety disorder actually being defined and measured that factors in.

And something else you'll notice here in Simonoff's paper is that we're really just looking at DSM and in this case, it was DSM-IV anxiety diagnoses so things that met the full criteria based on these pre-existing research measures.

Because that particular sample was from the UK over ten years ago, I wanted to also present a little bit of newer data. This is unpublished data. It's under review at a journal right now. But I just wanted to give it to you to give you another data point.

This is the point prevalence of parent-reported anxiety conditions in the 2016 National Survey of Children's Health, which is a population-based survey of parents of children in the US, but it's different than what Simonoff did and that we didn't do semi-structured interviews. The researchers here just asked parents has a doctor told you that your child has an anxiety problem.

Interestingly, we see that about 40 percent of kids, parents of kids on the spectrum are saying that their child was identified with an anxiety problem. That's substantially more than we saw in children without ASD, 6 percent. You see a little bit of a different in terms of there are about 35 percent in 6 to 11 year-old range and 54 percent in adolescents.

And just to provide a data point for adults as well, this data was presented at our prior meeting, but I did want to note Lisa Croen's work and found 30 percent anxiety disorders in adults on the spectrum when examining medical records in California. Actually, we are seeing some convergence around a 40 percent range.

But clearly, there are issues with this data as well. In order for parents to be able to tell us my kid has been identified with an anxiety problem, first of all, anxiety problem is not the same thing as diagnosis. First of all, a parent being able to tell you that that means that a provider actually assessed for anxiety disorder and conveyed that to the parent. There are huge disparities in access to care to even get something like this. We have to understand that this data is problematic as well. I just wanted to give you a couple.

I also want to point out a study done by Carla Mazefsky in 2012 that actually looked at the children who were coming through the research study, what their community diagnoses were, how many had been identified with anxiety disorders before the research eval and how often the research evaluation agreed with that. And only 53 percent of those who had a community diagnosis of anxiety disorder actually also met criteria on the research assessment, 0 percent of those with OCD.

This is, again, just illustrating these two tensions we have that we could both be missing anxiety disorders in this population, but also potentially over pathologizing and looking at a symptom of autism and saying that's an anxiety disorder when maybe it is, maybe it's not.

And just to provide an overview of some of the challenges, there are overlapping symptoms. A classic example of this is social avoidance. Someone could be avoiding social situations because they are afraid of what other people think if they are going to make fun of them or maybe they don't want to be in that social situation. It's not that they are terrified or afraid of it, it's just not their inclination. They prefer to be doing something else. Not all social avoidance of people on the spectrum may be due to social anxiety. At the same time for some people, it absolutely is.

There are communication barriers. A lot of how we assess anxiety disorders is when people talk about their worries when children identify things that they're afraid of. Of course, many individuals on the spectrum are not able to communicate verbally, which would interfere with our ability to assess anxiety and many highly verbal people still have trouble communicating about their emotions. Just because the individual has a lot of verbal ability does not actually mean it's always going to be easy for us to assess the presence of anxiety disorder there.

And then I also want to bring up this point of that we also have converging evidence now, I think, growing evidence to suggest that there may be distinct manifestations of anxiety in individuals on the spectrum. Things that don't fit these existing categories that we have in the DSM, which are based on research with neurotypical populations about what an anxiety disorder is.

And keeping that all in mind, we have to know that all of our research until very recently has been reliant on measures that were designed for neurotypical populations and then applied to this group, which we absolutely had to do in order to begin research in this area. But because of these issues, it's an inherent limitation to some of the work.

And just to illustrate this for you a little bit, I wanted to bring out these quotations from Leo Kanner's article in 1943 where he described autism and also a more recent quote. Kanner described Donald. We brought him to a playground slide. When other children were sliding on it, he would not get on it. He seemed horrorstruck. When we're looking at Donald, we have to think is this truly social anxiety disorder. Is Donald afraid that the other kids are going to make fun of him, that they won't like him, that they're going to laugh at him? Is he afraid that he doesn't know what they're going to do so he does not care what they think about him? Maybe that's not quite on his radar, but he has trouble predicting the children and that is inherently anxiety provoking. That doesn't actually quite meet the definition for social anxiety disorder if it's currently run, but it's certainly a fear. Or maybe Donald just wants his own space and he's annoyed that the other kids are there. These are some of the complexities that we deal with when trying to assess anxiety in kids on the spectrum.

Alfred does a good deal of worrying. This might cue us up to think about generalized anxiety. But what is he worrying about? He frets when the bread is put in the oven to be made into toast. He's afraid it will be burned and be hurt. He's upset because the moon does not always appear in the sky at night. This does not fit easily into our categories of how we often think about generalized anxiety disorder and yet he is clearly worrying. This is what I mean. A slightly distinct presentation.

I also want to include this quote from Audrey, an adult, on the spectrum, who was featured in this qualitative study. I get anxious in social situations as I don't see emotions in people until they get to a 10 and then it's an explosion, and I don't know when it's going to happen. This is a fear not necessarily people are going to think badly of me or reject me. It's just I have trouble understanding what people are going to do and that's inherently anxiety provoking for me.

In research, when we try and expand our definitions of anxiety a little bit and measure both traditional DSM-defined anxiety disorders and also these more distinct broad manifestations, we've had some interesting results. This is data from 59 youth on the spectrum, 7 to 18 originally recruited at Children's Hospital Philadelphia, IQ range of 67 to 158. This was not a study about anxiety. This was an imaging study. These are not participants who were recruited for anxiety, just for their ASD diagnosis.

And importantly, 37 percent did not meet criteria for an anxiety disorder both traditional DSM and this more broad distinct presentation. 17 percent had the classic DSM anxiety disorders. 31 percent had that DSM traditional diagnosis and also a more distinct manifestation. These things often seem to go together. And 15 percent had only a distinct presentation.

That slice of the pie is particularly meaningful to because it tells us that depending on what we want to call those distinct manifestations if we want to call them anxiety disorders or not, it changes our estimate of the rate of anxiety in the sample by 15 percent.

It's also important to note that the things associated with traditional versus distinct anxiety presentations were slightly different. Verbal ability was particularly associated with the presence of classic DSM anxiety disorders like social anxiety, generalized anxiety. It was not associated with distinct presentations. You would see a fear of change, a fear of unusual stimuli like glasses, men with bears, and the flush of a toilet bowl. A child I worked with had a fear of gloves. You would see that in a child with a lower IQ and an extremely high one.

They're not as differentiated by the IQ score of the verbal ability.

I also want to point out that in a follow up when we look at the sample and we looked at brief measures, parent report measures or self-report measures, which clinicians often use as a quick way to try and understand if a kid is at risk for anxiety or not. The sensitivity of those tools to detect even traditional anxiety disorders in this sample was very low. They're actually missing the majority of children on the spectrum who we felt clinically after a comprehensive diagnosis met criteria for anxiety disorder even a classic one. It's even worse for the distinct presentations. This is important to keep in mind because that's not necessarily true in treatment-seeking samples. In kids who are referred for anxiety treatment, I think the measures actually seem to be performing better. But when you are trying to use these measures to actually screen for anxiety disorders, we have some converging evidence that there are some problems. There are some significant limitations here. And this is just one study. There are a series of other studies that are pointing out some of these limitations.

I also wanted to present a little bit more data on this that is quite consistent what was seen at Children's Hospital Philadelphia in 2014. This is new data coming out of the MIND Institute, the Autism Phenome Project. Again, a longitudinal study of autism where the children are now 9 to 13 and we're looking at what's the presentation of anxiety in this sample.

Here, again, hopefully this pie chart looks familiar. This is very exciting to me.

We don't often get consistency in research. But what we see again is that 32 percent do not meet criteria for an anxiety disorder even when we're looking at carefully. Keep that in mind. This is prevalent. It is not universal in the population.

Twenty percent met criteria for traditional anxiety disorders, 32 had both traditional and a more distinct presentation and, again, there is a particular slice of 17 percent. Distinct is the only thing that we see.

One more thing. When we look at brief measures again, they are not detecting anxiety disorders in a lot of kids in this sample. If you look at the kids who have an IQ below 70 so one difference between this autism phenome - APP study and our prior study is the IQ range is much broader. When we actually look at kids with an IQ below 70, the measures are pretty terrible. They're just not detecting the anxiety disorders in that sample.

And this might have something to do with why. This is a breakdown of basically the different types of anxiety above and below an IQ of 70 in the sample. The black is kids who did not make criteria for an anxiety disorder. As you can see, that's quite similar. This is telling you it's not necessarily that anxiety is more common in higher or lower IQ individuals. It is actually equally common. But what is different is the presentation or the quality of the anxiety.

What you can see in these red circles that I have, these are the circles that are showing us traditional anxiety. But you can see in IQ below 70 that there's this big blue bar and the light blue bar is a lot smaller.

This is showing you that the vast majority of traditional anxiety is a phobia for individuals with a lower IQ. A lot of our measures don't ask about phobic responses. They ask about more generalized worries, social anxiety. This might be part of why we are really missing the anxiety in this more cognitively disabled group.

This is looking at the distinct anxiety again. You can see the circles are quite similar. The rates of distinct anxiety are quite similar regardless of IQ presentation.

MS. GASSNER: Can you define that?

DR. KERNS: Distinct anxiety? Yes. It's a broad term for presentations of anxiety that do not fit into existing DSM categories. What the types of anxiety that we're particularly measuring are social fears that have nothing to do with fear of negative evaluation so being afraid of what people might do, but not necessarily that they will reject you.

Idiosyncratic phobias. The way that we've been talking about it, which is a fear of glasses, certain stimuli, lights, specific sounds, the Qmart, are just some things that come to example. Other researchers have talked about as unusual fears. It's something that has been talked about in autism for a long time. Fears of change, worry associated with a perseverative interest. You are really focused on something and you have a lot of excessive worry about if you're going to get access to that thing. It's not generalized worry, but it's worry that's happening all the time around the circumscribed area. Those are just some examples. And they are things that seem to be somewhat related to the presentation of autism itself.

As a summary, I just want to reiterate that anxiety has been talked about within the context of autism for a long time. In the last two decades, we finally started to research it. And we've made huge progress using the tools that we had to try and understand. I think that's why I'm able to present research to you today. That there are a lot of things we understand now. But certainly using those measures is not going to be sufficient for us moving forward to truly understand this phenomenon.

What we've also learned is that we actually have to understand what is the phenomenology of anxiety in autism. And what I mean by that to put it in layman's terms is we need to take a moment to talk to people on the spectrum, the families that we work with, to really understand what is it that people on the spectrum are worried about. That is my summing phenomenology down to a very important point.

We need to think about what are they worried about. Are we measuring that? Again, do we see that as adaptive in helping them, guiding them through their lives or actually is it hindering them in some way? Because if it's helping, if it is adaptive, it's not disorder. We are really looking for that part that is dysregulated, that is turned up too high.

Another way of thinking about this is the fire alarm. Fire alarms are very important for telling you to get out of the building when the building is on fire. But if your fire alarm is going off constantly, you can't live in your house anymore. That's what we're looking for for anxiety disorder.

And I think we've learned too that how we choose to define anxiety disorders in this regard will have substantial ramifications for research and practice.

In terms of future directions, there has been progress on this measurement issue. I've been doing some work in terms of diagnosis, but also Jacqui Rodgers in the UK and Larry Scahill have developed continuous measures of anxiety that are more tailored for individuals on the spectrum. I think we have potential to move forward and learn even more at this point.

We also need to think about better understanding now that we can assess anxiety a little bit. The biological underpinnings of anxiety, both to understand its etiology, but also to give us more tools to assess anxiety in individuals who can't self-report or who don't the language. There are limitations to behavioral observation and self-report measures.

As we've talked about today, longitudinal and prospective studies are going to be incredibly important. Everything that I was presenting before is predominantly cross sectional, which means we don't have a good understanding of what contributes to anxiety, what's a predictor or also how anxiety is going to influence the development health of the individual over time.

Finally, effective and accessible prevention and treatment. And the prevention is where I think we're a bit behind and we need these longitudinal studies to try and move in that direction because wouldn't it be great to prevent this suffering before it occurs.

I want to thank all the individuals on the spectrum and their families who clearly we could not have done any of this research without them and also all the incredible research collaborators that I've been able to work with, mentors and support staff. Autism research is a team science so thanks everybody.

(Applause)

DR. DANIELS: Thank you, Connor.

Next, we have a talk by Judy Reaven, who is associate professor in the departments of psychiatry and pediatrics at the University of Colorado.

DR. DANIELS: Thank you, Connor. Next we have

DR. REAVEN: Hi everybody. I want to thank you for inviting me to be here. It has been a very wonderful morning so far. I've really been moved by a lot of the personal stories and other information and certainly have appreciated the complexity of mental health, co-occurring and individuals with ASD. I'm going to be talking about anxiety, which is really kind of a piece of it. And thank you, Connor, for a really wonderful lead in.

I think anxiety might be a little bit of a bright light in a lot of this conversation because the most research has been on anxiety intervention.

Connor did a wonderful job of talking about diagnosis, but I'm going to just start with thinking about the real-world impact of these symptoms. When folks might be afraid or worried about using a bathroom that can really impact your life. You might have trouble for all kinds of reasons. It could be the toilets. It could be germs. It could be other people in there. But it's a problem if you and your family have to go to a funeral and the only way to get there is to go through an airport and you have to fly and use a public bathroom.

It's also a problem if you want to go someplace fun, if you want to go to do Magic: The Gathering, or Anime or Comic Con and you still have to use a public bathroom to get there. That's a way that it can interfere.

Fear of being late. We've worked with plenty of kids who can't walk into a classroom because they are a couple of minutes late and they just won't do it so missed opportunities. You can go through this list and you can really see the real world impact.

And what I want to highlight is something Connor actually also said too, which is that if you have some of these worries, you then become a person who says to yourself I'm the kind of person who can't. I'm the kind of person who can't use a bathroom. I'm the kind of person who can't walk into a place late. I'm the kind of person who can't leave my parents or make mistakes. And I think what we want to do is be thinking about how that kind of thinking affects our lives and to really help our folks be more resilient.

Another way to think about it is – at least this is how I think about it is anxiety is this big obstacle and a big barrier. And that part of intervention is to move it out of the way so that people can go along on their roads. I get that it's complicated and that sometimes anxiety is not the only issue and there are other factors, but it is something that we want to pay attention to and get that boulder out of our path.

CBT. I'm going to talk a little bit about CBT, cognitive behavior therapy. It's the treatment of choice in the general population. We've shown very good results and decreases in anxiety symptoms across a number of trials for individuals without ASD and also the evidence so far has also shown the same thing in CBT that has been modified for kids on the spectrum.

Core components for people who may not be familiar are comprised of some of these basic steps here. Psycho-education refers to talking with folks about what anxiety might do to your body, but also what the core components of the CBT approach might be.

Somatic management refers to managing all those physical feelings that you have in your body when you might feel anxious. Cognitive restructuring refers to what people might be telling themselves so some of that negative thinking that we referred to earlier.

Problem solving might be where people are given a couple of choices and they really walk through the process of trying to make some good, informed choice between maybe choice A or choice B.

Graded exposure is bolded here because graded exposure is thought to be the key component in anxiety intervention. It means facing your fears a little at a time so doing the thing that you are afraid of. You have to do anyway.

Relapse prevention is a natural phenomenon of really a lot of psychotherapy, which is that symptoms do come back. Anxiety comes back once people leave intervention. And what we want to do is work with them around - it's going to come back. Don't freak out. But here are some things you might want to think about in terms of reminding yourself what strategies used the first time.

By way of illustration, this is a common problem that certainly I've worked with young folks about, which is not wanting to talk in public and not wanting to order in a restaurant. That's the scenario. There might be a series of physical feelings that might result so sweaty palms, rapid heart rate and headache. And then you might have some thoughts. There are a whole bunch of thoughts you could have, but some might be I'm going to sound stupid. They're not going to have the food that I want. What if they don't understand what I say? If you have that combination of thoughts and feelings, it's going to lead some behavior and most likely avoidant behavior, which would be avoiding a restaurant, asking somebody else to talk for you and just refusing to talk.

If we are going to intervene, what we want to do is intervene on all those parts. We need to intervene around the physical parts, helping kids be able to - and adults too for that matter, helping all of us is a human experience, helping all of us figure out how to manage our physical feelings. Sometimes it's deep breathing. Sometimes it's taking breaks. Sometimes it's walks. It's all sorts of things for folks. And sometimes it's just going through it.

The other thing we want to pay attention to is how do we manage our thoughts. It could be I'll give it a try. If they don't understand, I'll just repeat myself, and I'm hungry so kind of the positive pieces that folks were mentioning earlier.

But then again most importantly, you can manage your thoughts and you can manage your body, but you have to face fears at the end of the day in small steps. For this example, what might that look like? Well, it might look like a very first beginning step. Maybe you tell your mom or your dad what food you want rather than having to talk for yourself.

Maybe a second step might be you're pointing to the food on the menu when the waiter comes by. You can see this gets progressively more challenging.

Then you have to start talking one to two words when asked by the waiter, responding with a full sentence. You get to the final point where you're going up to a counter and you're independently ordering.

This can be very empowering. I really want to be thinking about the empowering nature of what this does for folks when it's like no, I'm the kind of person who can't talk in a restaurant to I'm the kind of person who can order my own lunch and that becomes a big deal.

There's a lot of global interest really in ASD and anxiety. As I said, I think this is the probably the most researched area with regard to intervention around mental health.

Starting in Australia, doing Tony Attwood's expressing feelings program, and then to Jeff Wood doing BACA(?) at UCLA and then some of our own work in doing Facing Your Fears Program in Colorado and then the UK has done some really good work as well, some around intolerance of uncertainty.

A lot of these interventions can be in one of two camps, a lot of conceptualized as individual treatments where folks come by themselves with perhaps family members depending on the age and group interventions where people come in multi-group families.

Most of the research so far, not all of it, but a lot of it has been focused on school-aged kids, fewer with adolescents, even fewer with adults, and primarily in clinic settings.

A lot of the work initially has been around thinking about how do we modify CBT for individuals on the spectrum and we want to keep CBT the same so we want to keep the core components there because we know that's what has been effective.

But what we want to do is think about how do we modify the approach to make it accessible to people who might have more learning challenges, who might think more visually, who might be more concrete learners in some areas as opposed to abstract learners and have potentially some verbal limitations. We want to pay attention to using a lot of visual structure, predictability to routine, pace the sessions well, have it be fun. And I really think this can be a roadmap for how to think about other modifications for other interventions, these kinds of approaches.

We pay attention to what's required from a prerequisite perspective, maybe making sure everybody knows what we're talking about with regard to emotions, using multiple choice lists. Instead of open-ended questions like what makes you anxious, it's much more look at this list and now identify what makes you anxious or worried or gets in your way.

And then of course, parent involvement has been critical in most of these interventions. Why are parents important? Because parents can help generalize skills from one setting to the other.

One of the things that we do at least in our work is encourage parents to model their own brave behavior, to try to ignore what might seem excessive in terms of displays of anxiety, to help identify what kids need to face, what targets and use coping strategies, and then of course rewarding brave behavior because that is what this is all about is helping people, helping all of us really be brave.

Just a brief word about treatment for OCD. I've talked a lot about anxiety interventions, mostly around social and GAD and separation. There has been a little less work focused directly on OCD, but there's been some. There have been some case studies. There's also been a recent study by Russell and colleagues that did some adaptations to what would be a standard treatment for OCD. You can see the modifications are similar to what I've already talked about. We want to modify using visual supports, helping people make the connection between thoughts, feelings, and behavior and perhaps even doing some prereq work around differentiating emotions.

But then a core component for OCD intervention is exposure/response prevention, which is similar to kind of what we talked about with regard to facing fears. But if you, for example, had a fear around germs, a common fear around OCD, folks who have OCD where you're afraid that if you touched a doorknob, there's going to be germs on it. And then you might have accidentally touched your face. If you accidentally touch your face, the germs might somehow enter your body and you would become quite ill and even die.

If that's the scenario, part of what we want to – and then what you have to do to neutralize that is to wash your hands, get hand sanitizer in a frequent kind of way. What we want to do with an intervention is encourage people to trigger the anxious feelings and to block the compulsive behavior so to block hand washing and to block use of the hand sanitizer.

There's been a third wave of CBT. Carla, I think, mentioned it a little bit. We're thinking about mindfulness and acceptance-based interventions. Essentially mindfulness is really helping people be aware of being in the present moment and when there are negative thoughts or uncomfortable cognitions to recognize them, but not do anything about them and to kind of accept them without judgment. And a lot of these kinds of mindfulness-based approaches have been adapted for older adolescents and adults. And I think it's a really encouraging field and I think exciting to see where we are going to go with it in the future.

A super brief word about medications. In some ways, I think Carla actually already mentioned this too. We don't know a lot. The reason I wanted to say just two words about anxiety and medicine and our folks are because in the general literature, when we've looked at CBT and medication use that medications in addition to CBT have been superior to CBT alone or meds alone. There hasn't been an equivalent study that I know of in the world of ASD. And I think it's something that we need to be thinking about. Certainly anecdotally the folks that I work with, many folks are on medications. But there still continues to be a whole number of anxious symptoms that aren't completely covered by the use of medication. I get the feel that we need at least some research that's going to help us look at both.

But SSRIs have been ones that people have been interested in paying attention to, especially around the psychopharm of anxiety and ASD.

And although it might be approved for treating anxiety in adults, it continues to be medicine that is prescribed quite a bit for our population, but we need more research to really help us understand if it's the best drug of choice and for whom.

What's on the horizon? A couple of things. One is implementation science. This is a topic that's near and dear to my own heart and I think people were actually referring to it earlier, which is how do we get evidence-based practice from clinic settings or university settings into the real world. We need to do that. There are all kinds of reasons for that to really increase access for folks who just can't get to clinic settings for various reasons.

Some of our own work you can see. We've done a little bit of work in moving from our own lab into other programs where people might not have expertise in mental health, but might have expertise in autism. Playing around with some tele-health to really try to reach underserved communities.

And then our current work right now, which is funded by HRSA, is doing an implementation of Facing Your Fears in public schools, and teaching school providers, some of which are mental health people and some of which are not so interdisciplinary folks to deliver CBT for the reasons that everybody was talking about earlier.

Technology, I think, is also on the horizon. Smartphone applications. Some of our early work was using an iPod touch, I think that's what they were called, to do some software work around CBT. There's also a new application out of the UK called Molehill Mountain application. And I think that can be really useful for young autistic people as well as virtual reality. Again, a recent study out of the UK looked at using VR for specific phobias with good encouraging results.

I think another piece that is going to be kind of on the horizon is really understanding mechanisms so what's really underlying the development of anxious symptoms. Alexithymia or the ability to identify and recognize your own emotions. Emotional acceptance, which is this idea that we all have a lot of negative emotions we might experience through the course of a day or a week and how to manage those and encourage distressed tolerance.

And then intolerance of uncertainty, which is being able to tolerate not knowing and that the idea of not reacting so negatively when we just don't know something. And perhaps mindfulness might be a good way to try to address some of those underlying mechanisms.

Who's been left out of interventions and treatment so far? I think we all know.

Adolescents and adults. We've talked about that. Far less studied than young people.

Individuals with ASD and ID out of this intervention have also been left out. It's really encouraging that we are starting to do more work in this area.

And then low income and traditionally underserved minority communities have also been left out.

With regard to individuals with ASD and ID, what do we know? We know that these folks also have significant mental health needs, but receive less mental health care. We know that there are a lot of barriers in part because there has not been a lot of research in the population and lack of interventions for folks.

There have been some really good encouraging case studies that use graded exposure and positive rewards. But some of the researchers said maybe we should be using some cognitive approaches, even folks with ID. Some of our initial work spearheaded by my colleague Audrey Blakeley-Smith, who has been to modify our Facing Your Fears Program for teens with ASD and ID.

We were also curious about who's participating in CBT research and we wanted to look at the demographics honestly. We took a peak at all the studies that have been done in the US of folks over the last five to seven years and got over 473 participants and really just compared the demographics to the US Census.

As you might imagine, we found significantly more white participants relative to what would be expected given the US Census. Same thing with maternal education. A more highly educated maternal sample compared to what we'd expect again for the US Census.

You can see who's participating in research and this has implications in terms of how we design interventions and who we are reaching. We, as a field, including our own work, have to do a better job of trying to reach folks that haven't had access.

Finally, what is the real world success look like? This is what it looks like. It's being able to change the I'm the kind of person who can't thinking to I'm the person who can. I'm the person who can use the public bathroom on my way to Comic Con. I'm the kind of person who can walk into a classroom. I was five minutes late. Kids looked at me, but I walked in and sat down anyway. Those sorts of things. This is what, I think, we're really trying to go for. At least the initial research so far has been really encouraging and I think we just need to continue on with it. That's what I've got. Thank you very much.

(Applause)

DR. DANIELS: Thank you. We have about five minutes for discussion. We can have two to three questions or comments, I think, and fit it in because I don't want to keep people from lunch.

DR. KIRBY: Thank you to both of the speakers. I was wondering if one or both of you could speak a little bit about the possible role of sensory responses and how that interplays with anxiety and the impact that that might have on what we know about treatment.

DR. REAVEN: I can talk about from a treatment perspective first. We thought a lot about that because a lot of the fears and issues that some folks have come to us have been sensory based, have seemed to be sensory based. Toilet flushing, loud noises, car alarms, all kinds of things.

For us, what we've really tried to do is think in a careful way about how do we proceed. And usually what we do is take the lead from – and this is mostly with kids, take the lead from the child and/or their parents about this is an issue that we want to address because it's getting in the way of their lives and they might have tried other kinds of interventions. They've gotten a little bit of progress, but have not been able to get as much as progress as they would like.

We talk with them really directly about the psycho-education and we talk a little bit about what an intervention like this might look like including great exposure. Honestly, I can't tell you everybody gets better because that's not fair to say. But I can tell you a lot of people have responded well to great exposure strategies even around sensory-based fears.

DR. KERNS: I can just comment on relationship between the two things. It's certainly a measurement difficulty in that a lot of – for example, having a difficulty with loud sounds might be very difficult to differentiate from a fear of loud sounds. That's something we have to deal with in a lot of, again, our questionnaires. Sensory profile, being associated with a brief anxiety measure, potentially are double counting the same symptom. When we see correlations between sensory and anxiety, we have to be very careful about that.

That being said, they are associated in many of the research studies that I've reviewed and I am aware of at least one study that showed over time that sensory difficulties were predictive of more anxiety symptoms several years later, but not vice versa. I think it's something we definitely want to be attending to in terms of potential precursors of anxiety and vulnerabilities.

In terms of how we try and handle it when we're being as careful as possible about measurement diagnostically. When I'm thinking about am I diagnosing a specific phobia of loud sounds in a kid who has a sensitivity to loud sounds, I don't just want the kid who when they walk in the school and the fire alarm goes off covers their ears and is screaming and crying and needs to leave. That is a sensitivity. I would not necessarily equate that with anxiety disorder.

The children that I would go forward and make a diagnosis of specific phobia of loud sounds are the children who are unable to enter the school building because they're afraid there might be a fire alarm that day, who spend their entire day checking with the principal to get reassurance that there is not going to be a fire alarm or that they will be notified and removed from the building so they can't actually pay attention in school anymore even though they are quite bright because they are just so worried about when the fire alarm is going to go off.

Another example would be a family I worked with. Whenever they went to a new place like a hotel, their child had to case the joint to locate all of the fire alarms in the building because he wanted to know where they were. This is an example where it's not just the sound going off that is causing enormous stress, but it's the fear of the possibility that it's going off that is actually functionally impairing the child and preventing him from being able to go to school, potentially going to stores for the family's mobility is impacted. That's where we can see actually anxiety disorder layered on top of a sensitivity. You do see both things, but they're not the same thing. Does that make sense? That's how we are trying to approach it more carefully.

DR. DANIELS: Thank you. Scott.

DR. ROBERTSON: I like also how the presentations were starting to get into the implementation science. As we expand the research that we're taking and bringing out into the field, is the research also getting into or could it be more getting into also looking into coping and compensatory strategies and use of tools and technologies that autistic adults and others are using in terms of stemming aids and things like that. Unless this has been changing, I know historically often the literature hasn't really looked first hand at especially what autistic adults are already using as far as strategies that could be helping other autistic people in terms of coping with anxiety, other challenges or what folks have done especially in terms of other strategies or approaches in a detailed manner.

Sometimes I feel like when I read the literature at times, it's a bunch of numbers and it's always hearing the same story playing, but things that can actually enhance practices out there in the field and then generalize across. I feel like sometimes we're lacking on that in the literature base at times. We don't have the larger tapestry or at least a tapestry that can feed into and ignite more on enhancing practices, enhancing national policy around this. Is there anything you can speak to of maybe things that are changing in the research field as far as looking as coping, compensatory, use of technology and tools individuals may be using or have used previously that we can look at and say these are positive ways they are doing it that are helpful? This could be applied to other autistic people or maybe even outside of autism. Maybe there are from other disabilities, other health conditions that folks have been using certain strategies and tools and techniques. In a detailed manner, we could be like this would work really great for autistic adults, adolescents, and children.

DR. REAVEN: I think that is a really great idea. I don't really know of any systematic research so far that has really looked at it in a careful way that you're describing.

I will say that when we work with folks, we ask them what they're doing. You want to know what people are doing already. You don't want to try to introduce something that feels really foreign. You really want to say what is it that you're already doing. What works for you? And with the hope that it is an adaptive strategy. I think that is why technology really needs to be entertained in many many ways because of an affinity for using technology for all kinds of reasons for many of us. But I don't have any knowledge around anything systematic.

DR. KERNS: I don’t know anything systematic either. I think there have been – I'm aware of at least one study by Spiker that looked at an association between intense interest and anxiety and that actually kind of putting yourself in that world and thinking about your interest was associated with anxiety, but not other aspects of the intense interest. Again, kind of specific relationship that maybe we should be paying attention to.

I think also if we are thinking more about these more distinct presentations of anxiety that might be a particular area where we might want some fresh ideas about what are all the different ways that we could approach kind of helping people cope with this.

That being said, I also agree with what Judy is saying. With any coping mechanism, we need to be careful that it's still helping us cope and it's adaptive as opposed to becoming maladaptive. For example, exercise can be a really good coping strategy for people. If you exercise too much and you start compulsively exercising and it takes over your life, it is no longer adaptive. That's actually true for a lot of coping strategies that we teach. Whatever ideas we get, keep that in mind as well.

DR. DANIELS: Brenna, last question and then we're going to lunch.

DR. MADDOX: I was just going to make a quick comment related to these points going along with what you were just asking about, Scott. I agree with Judy. I think that's a great idea. We are just wrapping up a study at the University of Pennsylvania where we were asking autistic adults specifically about their positive experiences with mental health therapy to ask them what were those clinicians doing that made that a positive experience for you and hearing you ask that question. I wish we had asked questions about and in your own time, what types of coping techniques or strategies were you using. We'll have to do another study about that. But I do think we got some really practical tips about what mental health clinicians could be doing to better serve autistic adults.

MS. GASSNER: There's another plug for autistic consultants in research.

DR. MADDOX: Absolutely.

DR. DANIELS: Wonderful. Thank you so much for those presentations and for all the presentations this morning in the morning session. We're now ready for lunch. There is a restaurant here in the hotel called Olives and they only have a buffet at lunch time. There also is a group of fast casual restaurants just across the street, not directly across, but to the side to the left if you're heading outside. They have a Smashburger, which is one of the faster ones and some other things.

But we are scheduled to be back here by 1:35 to start our session on suicide. I'd like to start that on time. Just be judicious of your time with getting your lunch and then we'll meet back here. You're also welcome to bring your lunch back here if you'd like. Thanks.

(Whereupon, the Work Group participants recessed for lunch at 12:39 p.m. and reconvened at 1:35 p.m.)

DR. DANIELS: Let's get seated again so that we can get started on this afternoon's session. We are going to be talking about depression and suicide this afternoon. We have four different presentations and then we'll have time for discussion on this important topic.

To keep us on time, I'm going to go right ahead and introduce Kate Gotham from the Department of Psychiatry and Behavioral Sciences at Vanderbilt University Medical

Center, who is going to be talking to us about depression in ASD. Thank you, Kate.

DR. GOTHAM: I know it is the post-lunch slump, but I have to say it was just so inspiring and moving to be here this morning, the science, and the testimonials and that I feel like will get me through the lunch slump. I'm really excited for this afternoon so thank you for having me. It's really an honor to be here.

I didn't get the memo that we could have fancy titles. I'm just talking about depression in autism spectrum disorder. I am interested in studying how and why autistic people become depressed so that we can develop better treatments that address those pathways in particular.

I have lofty goals for getting through this information in 15 minutes. Everything is just at a bird's eye. Obviously, very few details.

But I want to present what we know about how common depression is in ASD, why it's bad, what it looks like in autistic people, what are some challenges for assessing it, what maybe some pathways or mechanisms by which it develops, how people think we should treat it and if we have time, some new science about those mechanisms and an example of why depression has very broad impact on autism research in general even if we don't always realize that.

In a recent meta-analysis in the Journal of Abnormal Psychology, people with ASD were found to be about four times more likely to experience depression compared to the general population when pulled across age ranges.

These were the things that were associated with higher lifetime depression rates. Being an adult, higher measured IQ, structured interviews versus less in-depth methods of asking people about their depressive symptoms, self-report versus other reports.

I know it's small font, but if you can look at these ranges or these rates, 40 percent, 52.8 percent. Unless you think that those are high on their own, several independent studies, and independent teams actually, have found 50 to 75 percent lifetime depression rates in studies of more cognitively able adults who are assessed with structured interviews. This is a shocking problem.

It seems as though there is a sharp increase in rates of depression in girls with ASD around adolescence, similar to the general population. Interestingly, there is some small longitudinal data to suggest that boys with ASD tend to have high depressive symptoms in childhood compared to same-aged neurotypical peers and that those symptoms persist into adulthood.

Depression is bad. Outside of the context of autism, depression is one of the greatest global contributors to lost person days of functioning and within the autism community, depressions associated with impairment in several areas and add significantly beyond existing functional impairments, similar to what Connor Kerns was talking about with anxiety. It's also associated with greater service use and medication use, greater risk of serious health complications. I'm not going to talk about suicidality at all in this talk, given the speakers that are following me.

And finally, there is some data to suggest that autism interventions and supports work less well when people are depressed.

Not surprisingly given this prevalence and this impact, depression is repeatedly identified by the autism community as a high need, high priority for more services and more research.

Does depression look different in people with autism? We don't really know. Initial reviews of depression in ASD summarized or perhaps just speculated, the depression was marked by more somatic symptoms in ASD so trouble sleeping or eating, fatigue, restlessness, headaches, stomach aches, et cetera.

At this point, we have a lot of anecdotal evidence and some quantitative evidence that suggest that autistic people have high cognitive symptoms of depression as well so sense of failure, pessimism, self-criticism, hopelessness, et cetera. At the end of the day, both kinds of symptoms, bodily symptoms and thoughts, feelings occur in ASD. This may differ by age of the person with depression.

In addition to traditional DSM symptoms of depression like tearfulness, sadness, losing pleasure in things they ordinarily liked, people with ASD maybe more likely to experience some atypical symptoms of depression like changes to the quality or intensity of their interests or increased aggression or self-injury.

It can be really hard to assess for depression in ASD. This is pretty similar to things we heard this morning. Health care professionals may not even notice it or just attribute all symptoms to autism.

And also depression is known as an internalizing disorder and it tends to be more challenging for people on the spectrum to identify and communicate about these internal experiences particularly if they are emotional in nature, not for all people obviously, but for many. And that intersects with high rates of alexithymia in ASD or that difficulty in recognizing and labeling emotions. Finally, we don't have a good sense of what signs of depression to even look for in minimally verbal people.

You don't really think of autism and depression being similar disorders or having similar presentations, do you? Well, I know you can't read this font so I will read you this overlap in the Venn diagram.

Imagine someone who is irritable, has poor or flat eye contact, flat facial expressions, poor eye contact, social withdrawal, low motivation, difficulties with attention and concentration, problems with eating and sleeping, and repetitive thinking. Am I describing a person with autism or with depression? It could be either.

And that's empirically supported too. People with depression as a group score high on tools to measure autism symptoms. And people with autism as a group score high on depression measures.

I accidentally left in a redundant bullet point here, but assessment becomes harder when there's mixed reliability of self-report on internal states within the autistic community. That's one other aspect, a challenge to assessment measurement.

And Sarah Cassidy's group attempted to review how well-known depression instruments worked in people with ASD. And I hope I am summarizing this correctly, Sarah. But there were hardly any studies that met the rigorous review criteria for inclusion in the first place. And then what was included didn't show evidence of working particularly well to identify depression in ASD so measurement is a big problem for us in this area.

In terms of vulnerability factors for depression, we already touched on age. Higher cognitive ability. That's associated with greater ascertainment of depression. But we don't know if that's just because we don't diagnose depression in intellectually disabled or minimally verbal people. Or it could be actually because of increased insight where self-awareness that is actually pushing those rates up in more abled individuals on the spectrum.

There may be some characteristics associated with autism that make depression more likely and I'll talk about those next. Also, we're coming to realize how not rare it is to experience trauma and adverse events if you are on the spectrum. This, too, has been associated with depression as well as family history of depression.

For this slide, we're talking about contributing or causal mechanisms to developing depression. Here, I'm just going to say only that there are several correlates and contributors to depression as identified in the general scientific literature on depression that have also been noted in autistic samples.

But my takeaway point here is that trying to intervene on any one of these bullet points from any one of these domains first of all would be very welcome movement. We're happy to have any and all help, but probably won't do the job without at least recognizing that there are contributors at play from all of these other domains as well. I think it might have been Dr. Robertson or someone this morning kind of made a similar point.

If I'm honest, I think changing the social and environment context will be the most bang for the buck. I say that even though my own interests lie in the overlap between the other two domains I identified, the psychological and neurobiological domains.

These are the two things we study most in our lab. The first is social motivation and loneliness. If you have social needs that are not being met, you are likely at greater risk for developing depression. And social reward or the capacity to experience pleasure in social things and want more of them. That's variable across human beings. And in a recent study, we found that for adults who reported having more of this capability to experience social pleasure, those adults had greater loneliness if they also had more autism symptoms. And they had less loneliness if they had fewer autism symptoms in the context of being able to experience or reporting themselves as experiencing social pleasure.

And in turn, loneliness was our strongest statistical predictor of depression. All of that can be a little bit hard to unpack when I'm going so quickly, but it has really simplistic implications, which are getting your social needs met is important and autism can get in the way of that in our current world.

We're also interested in repetitive thinking as a contributor to depression in ASD. And the evidence is building that when cognitive perseveration that marks ASD settles on negative topics so here's kind of this inherent cognitive perseveration. When applied to negative topics or events, that's probably a specific vulnerability for developing depression.

We're also interested in studying the mental health effects of cognitive perseveration in general. Is it benign or even protective if it's focused on non-negative stimuli usually in the form of these strong special interests in people with autism? Or is there something taxing about that cognitive perseveration that affects mental health as it affects physical health? For that, I would refer you to Jos Brosschot's work, B-R-O-S-S-C-H-O-T, about the physical health tolls of cognitive perseveration. And we don't know the answer to that. If it's awash, if it's protective, if it's negative or associated with negative outcomes, but we're working on it.

Treatment. I'm just going to blow through this quickly because it is very similar to what we heard from the anxiety group earlier. CBT is a highly effective treatment for depression in the general population when it is delivered way and that's key.

We have several randomized controlled trials that suggest CBT works to treat anxiety in ASD though not much data at all for depression as an outcome.

Behavioral activation stems from CBT science. It focuses on treating anhedonia or the loss of interest or pleasure within depressed mood. Treating that by reinforcing - promoting reinforcing activities. To my knowledge, behavioral activation has been largely overlooked in the ASD population as a standalone treatment. But I think it's a really promising lead for us because first, it can be applied to less verbal populations and second because we have data from Julie Lounds Taylor's work and other's work to indicate that minimally structured lifestyles, for example, those with few set obligations or activities are associated with poorer emotional health outcomes and people with ASD and BA focuses on increasing engagement, not just an easier pleasurable activities, but also in more challenging and meaningful activities like building adaptive behavior.

There are few small pilot trials of mindfulness-based therapy that have reported to decrease depression and anxiety in adults with ASD. By the way, when I have very busy slides, most of the references at least for this slide you can find in our chapter in the Oxford Handbook that Carla Mazefsky referred to this morning.

And finally, SSRIs as a medication are very commonly used in ASD, but to my knowledge, there's no RCT of efficacy for using them to treat depression specifically in ASD.

We also need more data on how to best tailor treatment type to individual differences in cognition, insight, ability to generalize across contexts, how to tailor treatments to needs, interests, and values of the recipient of that intervention, and to individual mechanisms that might contribute to depression for a certain person.

With that in mind, I have two more slides on some recent work from our lab. We're interested in how people with ASD process emotional material and whether that holds any clue for why they might become depressed or how to treat that depression.

In one task, we show emotional faces to adults with ASD and adults with depression and adults who have never had either autism or depression. And then we measure their pupil diameter for eight seconds as a proxy for neural responsivity to those emotional faces. This is a non-invasive eye tracker. It just sits there under the computer monitor.

And in our study, people with ASD responded to these faces just as we would have predicted from previous studies of psychophysiology in autism whereas the neurotypical – I don't know if they are neurotypical, but the non-ASD depressed people here in blue – they had a high and sustained response to these emotional faces and the non-ASD, non-depressed people in green had a low response, no big deal. ASD was right in the middle sort of slower growing, but ultimately a similar response to these emotional faces as the depressed group by trial end. That's a pattern that has been noted before in ASD literature.

But when we split our ASD group into three subgroups by low, medium, and high depression scores then our depressed participants with autism responded just like all the other depressed participants. And our non-depressed participants with autism in green responded to the face stimuli just like the typical controls or very close. We might conclude that the response to our task had more to do with mood than with autism.

There are two important takeaways here. One, if depressed people with autism have a similar neuroresponse to emotion as depressed people without autism then maybe some of the active ingredients in known depression interventions are likely to be effectively or we would think they may be effective for autistic people versus the need for autism-specific depression treatments.

Second, measuring and analyzing mood, anxiety, and attention, those kinds of other co-occurring issues, that might help us to interpret autism research findings more accurately because obviously not everything we observe in ASD stems from autism. But it's easy to mistakenly think that if you're only looking here at this aggregate level. It looks like diagnostic mean effects, but it's actually – here, diagnostic mean effects are actually masking these effects of mood.

We saw the same two takeaways in a different paradigm, this time using eye tracking. When presented with payers of the same actor space, making a neutral or an emotional expression, people with ASD oriented faster to sad faces, what we would call a negative attention bias. And that was even stronger for participants with greater depression symptoms and greater rumination or repetitive thinking.

We see depression-like phenomena in ASD and that might hint at treatment targets or at least starting blocks for treating trials. And, again, some things that we think we see as primary autism findings actually just mask differing levels of depression within autistic people.

To sum it up, depression is concerningly common in autistic people. It has a negative impact on all kinds of markers of health and outcome. And people want help with this. This is high priority, urgent.

And assessment is tricky because of symptom overlap, difficulty communicating about internal states, lack of validated measurement tools. Some treatments for depression show promise, but we need research in this area.

And some preliminary psychophysiological data indicate that there may be key similarities in depression on and off the spectrum. We hope that similar work will inform that treatment research that we need.

I think that is everything. Thank you.

(Applause)

DR. DANIELS: Thank you, Kate.

Next, we have Anne Kirby, assistant professor in the occupational and recreation therapies areas at the University of Utah, to talk about suicide and autism.

DR. KIRBY: Great. Thank you so much. I will be the first of three speakers talking about suicide today. I don't have any conflicts of interest.

I want to start the conversation just talking a moment about terminology. I would just like to advocate for the use of consistent and clear terminology when we are talking about suicide and autism. Suicide is generally used to talk specifically about suicide death so death caused by self-directed injurious behavior with intent to die as a result of the behavior.

I will also talk about suicide attempts as well as suicidal ideation, which includes thinking about considering or planning suicide.

Suicide is currently the top ten cause of death in the United States across all age ranges. And it's the number two cause of death among people 10 to 34 years of age. About 13 per 100,000 individuals die by suicide every year in this country.

We know that there are sex differences in both suicide and suicide attempts. Males are about three and a half times more likely to die from suicide. And females are about one and a half to two times more likely to attempt suicide.

We also know that there are racial differences in rates of suicide and suicide attempts with the group that is known to be at highest group being the Native American and Alaskan Native populations.

What we know about autism in suicide is a lot less clear. The studies that exist, which seems to be a pattern today, are that we see pretty broad ranges of reports. Clinical and convenient sample research has shown attempt rates between one and almost half of samples. And suicidal ideation. Again, those thoughts have been reported in up to 72 percent of samples.

And one study done by Sarah Cassidy, who will speak in a few talks, found that compared with a population control, the autistic sample was over nine times higher to experience suicidal ideation.

But there is little population-based research and population-based research is really needed for us to understand more of the true rate rather than a rate in a group that goes to one particular clinic or a group that volunteers to participate in a study. And there are three studies to our knowledge that look at population-based samples. One from Taiwan that looks at suicide attempts and two that have looked at suicide deaths, one in Sweden and one that we did in Utah. I will talk about those now.

The study from Taiwan led by Chen found that an autism group was about six times more likely than age and sex matched controls to attempt suicide and that's even after controlling for relevant demographic factors as well as co-occurring psychiatric conditions like depression.

The Swedish study led by Hirvikoski looked at causes of mortality in autism and he found that those with autism were almost eight times more likely than matched controls to die from suicide. And they were able to look at those with and without intellectual disability. Those without intellectual disability were found to be over nine times more likely to die from suicide than controls while those with intellectual disability were over two times more likely. Both groups at more risk than the non-autism population though much more pronounced in those without an intellectual disability.

What we were able to do in Utah is use administrative data to look across a 20-year period to see about suicide death. We found 49 individuals who had died from suicide between 1998 and 2017 who had a documented autism diagnosis in their medical record.

We compared rates in autism to the whole population, which is distinct from what those prior studies had done using matched control approaches.

We saw ages at death between 14 and 70 years. Fourteen is relatively young adolescence and all the way through what might be considered older adults with an average age of about 32.

We looked across this 20-year period in 5-year intervals. In the first 15 years, we did not see a significant difference between the autism and non-autism populations though we saw gradually increasing incidence during that time. But I have the 2013 to 2017 time period bolded in red here to point out that in the most recent time period, we did see a significant difference between the autism and non-autism groups with the autism group about one and a half times more likely to die from suicide than those without autism. But this difference was really strongly driven by females. With females being at over three times greater risk dying from suicide than their non-autistic female counterparts.

What we see in Utah is a similar pattern to what was seen in the Swedish study. We are seeing some repeated evidence that females with autism are at significantly greater risk than females without autism to die from suicide.

Again, we saw about a three times greater risk and in Sweden, they saw a 13 times greater risk. But I want to be very clear because I think this often gets misinterpreted. We do not have evidence that females are at greater risk than males. Females with autism are not necessarily at greater risk than males with autism. And when you look specifically at what we found in both Utah and what was found in Sweden, the actual incidence rates are really similar. But what we are seeing is that females with autism are at much greater risk than females without autism and again in the general population, women are much less likely to die from suicide. But in autism, that may not be the case.

We also had the opportunity to look at suicide specifically among young people. When doing that, we saw over two times greater risk in autism than in non-autism populations in Utah. And the females were over five times greater risk with males about one and a half times greater risk.

The reason we did this is not particularly because we think young people are at greater risk, but because we have better diagnostic clarity among young people than we do among the older adults. I think everyone in this room knows that our diagnosis has changed over time and our ascertainment of older adults with autism is likely not complete. Looking at this young group was a good opportunity to really focus on a group that we think there's more diagnostic clarity among. But it doesn't mean necessarily that older adults are not at risk and I think we need more research in that area.

I do want to point out though that suicide death is still rare. We heard this morning about high rates of other co-occurring conditions in autism. I don't want the idea of suicide to overshadow that though it is certainly concerning and important to study further.

When looking at time at risk approach, we saw about 6.4 suicides per 10,000 person-years. That is 10,000 years in total that each person was alive. It's a relatively low number. I think just part of this broader conversation of this is one important consideration, but there are a lot of mental health and quality of life issues that are also important and then also which we've spoken about earlier, other causes of premature mortality that are important to consider.

I'll take a moment just to talk about the methodological challenges of this body of work. Again, we've seen the autism diagnostic criteria change over time. That affects our ability to look at changes over time in suicide rates.

There are also likely missed diagnoses, especially among certain groups like women, older adults and those without intellectual disability.

Suicide is also not a completely straightforward thing to measure. And suicide and suicide attempts require a clear indication or documentation of intent to die or else they are not labeled as such. That's important to think about and it can be very difficult to make those determinations. We may be under estimating true rates of suicide or suicide attempts.

And then finally, it's important to talk about how this is a relatively rare occurrence, suicide, and we're talking about a subset of the population, people with autism. Those small sample sizes inherently come with more risk of error in our understanding. And this challenge can become even more profound when we are looking at subgroups of the autism population, including females, people with or without intellectual disability, and also racial and ethnic minority groups.

It's also important to think about what we can glean from this information to inform prevention efforts. I'll point out that one of our results found differences in suicide methods between autism and non-autism groups that lead us to believe that means restriction approach, which is very popular in suicide prevention literature may not be enough in this population.

We also have talked about some protective factors today. Our study did not find employment to be a particularly prominent protective factor. Again, addressing protective factors may not be sufficient. We may need to target suicidality more specifically.

And it's also really important to think about co-occurring conditions and the role that they may be playing in these experiences of suicide and suicidality.

I'm really interested and have started to look at co-occurring conditions among those that we found in Utah who had died from suicide. And a number of them are sort of popping up as looking interesting in our preliminary work including depression, anxiety, bipolar, psychosis, ADHD, sleep disorders, personality disorders, and substance use disorders. We'll be looking more at that.

Just to give you a sense of the planned future work that I'm hoping to do. Disentangling autism and co-occurring conditions in risk determinations, I think, is an important step, again, using population-based approaches.

I'm really interested in conducting qualitative and community-engaged research on this topic to really partner with community members who can contribute their lived experience to our understanding.

And then developing tailored strategies to support the autistic community and their loved ones is really obviously an important direction for this work.

I'll just end there and thank my funding source for the work that I talked about as well as I have a host of mentors and advisors that have been really supportive of my development in this area. I also have the opportunity to start to work with some autistic women who are really passionate about this topic and have been consultants and are moving forward working with them. Thank you to Sara Luterman and Whitney Geertsen. Thank you all.

(Applause)

DR. DANIELS: Thank you, Anne.

Next, we have a talk on mechanisms underlying suicide risk in autism by Darren Hedley, who is at the Olga Tennison Autism Research Centre, School of Psychology and Public Health at La Trobe University in Australia. Welcome.

DR. HEDLEY: Thank you. There will probably be some overlap with some of Katherine Gotham's work as well obviously, around depression and we're certainly looking at some of the same things.

I'll start by talking about some of the assumptions that drive our research. First, we see suicide as a transdiagnostic phenomenon that cuts across different psychiatric conditions and subclinical presentations, which is consistent with ADOC here at NIMH.

And in terms of autism, we see it as an umbrella term that is applied to a range of neurodevelopmental conditions. It has a reliable behavioral presentation. I want to focus on the social communication and interaction, which will feature through the talk. And also issue that autistic traits often measured with the autism spectrum quotient. The studies I'll talk about today have used that as a measure of autistic traits, extend into typical and other non-ASD populations.

We also assume that both autism and suicide have complex biological, neurobiological, genetic, epigenetic, and environmental origins.

Some of the research questions that drive our lab are firstly, could there be a relationship between autistic traits and suicide risk and behavior in both autistic and non-autistic populations?

Secondly, could there be a common and/or interacting mechanisms that underlie suicide risk and autism?

As you've heard before with the previous talk that there seems to be evidence of an increased risk of suicide amongst autistic population and particularly this is the case in those who do not have a co-occurring intellectual disability where the risk may be significantly higher than the general population.

This is a brief summary of Chen's paper, evidence that a diagnosis of autism independently predicts risk over and above other psychiatric conditions and typical demographic variables.

And also a suggestion that high autistic traits is a risk factor for suicide in non-autistic populations.

In terms of risk factors, Sarah Cassidy's group probably had one of the high profile papers in this area from 2014 and identified depression as a risk factor, but also potentially age of diagnosis. The group in this study, the participants in this study were all adults who were diagnosed with Asperger's syndrome as adults.

From this research, consider the potential impact of untreated or unrecognized autism that may be leading to a lack of appropriate supports through life and until that point where the diagnosis occurs.

And this paper also highlights particularly the importance of providing appropriate post-diagnostic support in late diagnosed adults.

And interestingly, in Sarah's study, amongst the group, those who had a history of plans or attempts of suicide, had higher AQ scores than those who did not.

In a second study by Sarah's group, the study involved two large samples of adults with autism and also a control sample. It was one of the first studies to use a good measure of suicide behavior, the SBQ-R.

Amongst the usual suspects, employment, satisfaction with living arrangements, having one or more developmental conditions, depression, and anxiety together accounted for around 13 to 21 percent of variance and SBQ-R scores and this is just in the autistic sample here at these rates.

But then in addition into that – sorry, I should point out. Satisfaction with living arrangements and depression were both independent predictors of scores on the SBQ-

R. But then in addition to that, non-suicide self-injury, camouflaging or masking as was discussed this morning, and unmet support needs, each provided around an additional 3 to 4 percent variance on the SBQ-R.

Interestingly with this study in the autistic sample, the AQ or autistic traits were not related. There wasn't a significant correlation with the SBQ-R. However, in the control sample, there was a significant relationship between the AQ score and the SBQ-R accounting for around about 3 percent variance.

However, while it's important to identify the risk and protective factors, it's equally important to develop and test theories of why suicide occurs and understanding what factors are involved, how they interact, is essential for developing effective and targeted interventions, and I think individualized interventions as well.

Certainly, there is an urgent need to identify the underlying processes and mechanisms that underpin suicide behavior in autistic and non-autistic populations. That's what the second half of this talk will focus on.

In terms of theoretical frameworks, there is a really nice review paper that just came out fairly recently by O'Connor and Portzky. This was a review paper with a talk to around 32 experts around the world who contributed to a book on suicide. They are asked to discuss current challenges, future around suicide research and this is from the general population, not targeting autistic populations at all.

But one of the main frameworks that they discuss here is the ideation-to-action framework. This framework assumes that effect is associated with suicidal ideation are distinct from those associated with suicide attempt or suicide itself.

There are three theories that they identified that fit within that framework. Probably most people are familiar with Joiner's interpersonal-psychological theory of suicide. There are also a couple more models that are similar.

What you can see here is that there is a set of factors. For example, in Joiner's model, thwarted belongingness and burdensomeness lead to ideation, but then it requires an additional factor for that to turn into suicide attempt or behavior. In the case of Joiner's theory, it's having the capability for actually completing suicide.

But the important point here that I wanted to make is that all three theories emphasize the social context. This includes isolation, disconnection, loneliness, and social disadvantage leading O'Connor and Portzky to suggest that suicide is the end product of complex interplay of neurobiological, psychological and social processes. For us, this sort of suggests that there is a role for ASD traits in theories concerning risk and behavior.

Turning to mechanisms, again, quite a nice paper from Cassidy's group, Sarah's group. This study they looked at autistic Joiner's model in a group of young adults without autism. The model there I think you can see it. It's an example of Joiner's model. You see thwarted belonging, perceived burdensomeness, and capability for suicide.

This is the nice part here. They included the autism spectrum quotient of the AQ and suggested that autism traits may lead to an increased risk of social isolation; therefore, impacted belonging.

Similarly, maybe a higher rate of burden or unemployment and things like that in autism, impacting therefore perceived belongingness. The study results supported that idea. Burdensomeness and thwarted belonging both mediated relationship between autistic traits and lifetime suicidality. The highlighted blue path there was significant pathways, the indirect pathway from autistic traits to suicidality and the direct effects in both of those models were not significant. Recall that this is a non-autistic sample.

We conducted a similar study in a group of adults, a fairly small group of adults on the spectrum. And, again, we found in this case a mediating role for depression between social support. In this case, it was tangible support. We looked at a couple of different types of supports, but it was actually tangible supports. Support for getting something that you actually want was the most important one. It came out as being significant. The pathway there through to suicidal ideation.

And then, again, this was a similar sample from the same people. But we looked at loneliness here. Again, we see a similar pathway with depression mediating the relationship between loneliness and suicidal ideation. But the interesting thing with both of these studies is that the AQ wasn't correlated with suicidal ideation in either of these two groups.

However, we conducted a third study and this is with an Australian population study. It's more of a complex model obviously. And it incorporated both social supports and loneliness. ASD severity was measured again with the AQ. This was a larger population. I think it was about 185 in this study here of younger and old adults with autism. Again, a cross-sectional study. All of these studies are cross sectional. These need to be expanded into longitudinal research.

However, what you can see in this model is again mediation of loneliness and social support from autistic traits through depression. And then depression relating, mediating the relationship with suicidal ideation. This model here is something that we're building and there are other factors that need to go into this. However, it highlights the role of social isolation and the potential pathways from autistic traits, which we suggested affect social relationships.

In terms of a summary, social factors are certainly likely to be important in understanding suicide ideation and behavior in autism. The specific role of autistic traits in suicide models is unclear. But there are certainly some research findings that suggest an interaction between autistic traits and social constructs that feature in contemporary suicide theories.

The prevailing mainstream theories are likely to be useful in understanding suicide risk and behavior in autism particularly those that examine social factors or constructs.

There's limited evidence of a direct pathway from autistic traits to suicide ideation and behavior from the research I presented here. However, there is support for indirect paths from autistic traits measured with the AQ particularly to suicidal ideation or behavior in both autistic and non-autistic samples.

I would like to summarize by suggesting that understanding the contribution of autistic traits to theories and models concerning suicide risk is likely to have important implications for research in both autistic and non-autistic populations and therefore to clinical practice more broadly.

Just acknowledge all the people at OTARC and around the place that have helped us with this research, particularly Dr. Mirko Uljarevic, currently at University of Melbourne. Also, our funding sources. Thank you.

(Applause)

DR. DANIELS: Thank you, Darren.

Next, we have Dr. Sarah Cassidy, assistant professor at the School of Psychology, University of Nottingham from the UK. Thank you for being here.

DR. CASSIDY: Thank you so much for inviting me today. It has been really moving, been really honored to hear all the personal accounts today. Thank you for sharing those.

I think what I'm going to be talking about in my presentation is more about where do we go from here and the role of working in partnership with autistic adults and those who support them to really set the research agenda to make sure that the research that we do on life and death issues is actually really important to those affected by research. And some of the topics that I'm going to be talking about really touch on key themes that we've been discussing today and it isn't just relevant to reducing suicide or suicide prevention, but mental health more generally.

We know from excellent research in the UK conducted by Elizabeth Pellicano and Sue

Fletcher-Watson and colleagues that research in autistic people because of the very different perspectives and experiences that we bring to the table can actually have very different priorities for research and different views on what should get researched.

We know from research – A Future Made Together report in the UK that what gets funded in research and the research actually gets done and carried out by researchers can actually be very different to what autistic people, their families, clinicians, those on the ground think would actually benefit the most. The priorities are actually very different.

What we've been trying to do over the past three years because suicidality and suicide in autism is so under-researched, we just thought it was so important given the previous results about the different kind of priorities that researchers and autistic community can have that we really have to identify shared priorities with autistic people and their allies to make sure that research that we do is actually important to these groups. It grew kind of organically over three years. A lot of people joined us. It kind of had a snowball effect and we've kind of ended up with something really special, a kind of starting point for where we should go from here.

It started in 2016 where I was fortunate enough to get an early career grant from the Economic and Social Research Council in the UK and funding from the National Institutes of Health Research in the UK as well. We ran two national open workshops where we just invited researchers, clinicians, autistic people, their families, those who support them just to talk about suicide and autism and what they think should be the future priorities, what we needed to look at because we knew from our 2014 paper that this was a really tragic and really important issue to look at further, but we just didn't know where to go next.

We had 60 attendees and we managed to generate buy in from that and we identified some very broad topic areas, wanted to look at risk and protective factors, measurement, et cetera.

From that, generating that buy in, we then could go to the International Society for Autism Research and we got support for three special interest groups at the INSAR annual meeting. And we reapplied every year, but we were successful and over three years, we ran these international SIGs, which were an amazing opportunity to talk about issues relevant to suicide and autism research and practice with autistic people, the allies, researchers, clinicians, charities and funders of research from all around the world.

In year one, we had 40 attendees. But in year three, there was standing room only and we had more than 100. A lot of people really came and joined us on our journey. We demonstrated growth.

And from that, we got further funding from Autistica, a leading autism research charity in the UK, in association with the James Lind Alliance Priority Setting Partnership and this is a wonderful organization in the UK that was specifically set up to link researchers with those affected by research and patient groups. We call it patient and public involvement or PPI. But it was really to put those affected by research really at the center of the agenda of making research priorities and putting that link between researchers and those affected by research. They joined us as well.

And we took our priorities that we developed over the past two years at INSAR and these workshops and we had 40 attendees. They really changed those broad kinds of priority areas into 48, a really long list of 48 more specific research questions.

And then we got further support from the International Society for Autism Research to write an INSAR policy brief in 2019, which is this year. We very recently held our final meeting, identifying our top ten priorities. But lots of work went into this. We got those 48 research questions. We had a really large online survey. We got 788 stakeholders to rank those 48 research questions to identify the top 20. And then we had a meeting of 30 stakeholders that ranked that top 20 to identify the top 10. That's how we narrowed it down. It's three years of work with workshops, online survey, meetings. It's a lot of work that has gone into this.

And this just gives you a snapshot of what actually happened at our meeting where we get together in small groups and we rank these 20 questions. Then we end up with this final top ten here.

What have we done? We've worked with over a thousand stakeholders worldwide to identify these top ten priorities with equal representation of autistic people at every stage.

We've done the systematic review of the available evidence, which shows that none of these questions or priority areas has been extensively studied.

It doesn't stop here. We're going to do further community engagement to help develop the final report end of 2019/early 2020, which will be published on the INSAR website. It is also really important to note that all of those 48 research questions were really important. These top ten aren't the end. They are just the beginning. They will have to be updated quite regularly and this is just the start. It's just where should we look first, not the be all and end all.

I'm going to move from priority 10 to priority 1. I'm going to move from the bottom to the top. I'm just trying to get you to give you a flavor of what each question could mean, trying to put it in context of autistic people's experiences and previous research.

Priority 10. What is the impact of poor sleep on suicide risk in autistic people and how can this be measured? As an autistic adult put it, I feel it's never one thing but accumulative then add lack of sleep to trauma or PTSD and life may become unsustainable.

We know now that sleep difficulties, staying asleep, sleeping too much, frequent awakenings because of nightmares and these kinds of difficulties could be really prevalent in autism. But this is an incredibly understudied area, sleep in autistic people. It's really understudied and it's only just starting to take off.

What is the impact of poor sleep on suicide risk? We know that poor sleep in the general population is associated with increased risk of suicidal thoughts and behaviors, but what about in autism? This could be a shared risk marker that we just don't know a lot about even how to measure it in autistic people.

Priority 9. How well do existing models of understanding suicide actually apply to autistic people? In Darren's excellent presentation, we saw a number of different models that could really resonate to the experiences of autistic people and provide us some clues for where to look next. What can we learn from the general population regarding suicide and autism and vice versa? What can general population models learn from models of autistic people and autistic traits?

We heard a lot about social difficulties, loneliness and the role of those kinds of factors that aren't really given prominence in general population theories, but maybe we should revisit that.

Emerging evidence that autism and autistic traits increase risk of known risk markers for suicidal thoughts and behaviors as Darren went through, but there's also evidence for new risk markers like camouflaging. These might also apply to the general population because there's recent work showing that like autistic traits, camouflaging also exists in the general population along the spectrum.

Priority 8. How do autistic people seek help when they are in a crisis? As another autistic adult said, there is nothing more disheartening than being told you are not trying enough, hard enough to find support. And also I can't always communicate if I'm in a crisis.

We know from previous research not only in the UK, but the US and other countries, the unmet support needs and satisfaction with your support predicts suicidality in autistic people.

And we know that support is hard to obtain, but it's life-saving. This is really a worldwide issue and it's something that we've really discussed today and has been really pertinent in the testimonies that we've heard from autistic people and their families. This is a really important worldwide life and death issue.

Priority 7. What is the experience of suicidality in autistic people? Is this experience different to the general population? As an autistic adult said, I felt like I was having a breakdown inside, but I just didn't know how to make the inside feelings show to other people.

Are there different pathways to suicide in autistic people which need adapted assessment, treatment and prevention strategies? That is something that has been a bit missing from the presentations that we have so far because it's such a chasm in our understanding.

Priority 6. How should interventions be adapted for autistic people and individual presentations? Again, that has been touched upon in relation to talks earlier this morning with regard to depression and anxiety and other mental health conditions, but it also applies to suicide as well.

I really love this quote, which I really think captures some of the things that we've been talking about today about busting myths. We should look at what works, not what's on offer because it's just always been done that way.

We know that there are a shortage of professionals trained in autism and mental health and lack of appropriate treatments available, assessments, but there is real potential of adapting suicide prevention strategies, things like suicide safety plans that I write about in a chapter in the Oxford Handbook that has been mentioned earlier today.

It's really important to see the opportunity here, not just to make things better for autistic people, but for everybody who has a slightly more complex presentation with maybe one more diagnosis. We should be looking at individualized medicine for everyone. It can't just help autistic people. It could help everybody, this approach. It's not a niche issue. It's something that could be make things better for everyone.

Priority 5. How can we best identify and assess suicidal thoughts and suicidal behaviors in autistic people in research and clinical practice? That's something that has come up in every presentation today from depression, anxiety, OCD, and it's the same for suicidality. How do we actually measure and identify risk and behaviors in research in clinical practice?

As somebody said in one of our studies, an autistic person, it's a future question and you don't know what's going to happen to you in the future. This is in relation to a question on the suicide behaviors questionnaire revised that asks are you likely to attempt suicide someday. It's a future question. How do I answer that?

And somebody else said, whose risk are they for these questions? Are they for my risk or are they for the clinician's risk?

We know that there aren't any validated suicidality assessment tools available for autistic adults in our recent systematic review. And in the general population, it's really important to know that suicide risk assessment tools such as checklists or self-report measures – they do not accurately predict future suicide attempts and they are also not cost effective in clinical practice. There are a number of studies that have shown that. In our discussions at our summit, we really discussed the need for something new and trying to think outside of the box.

Priority 4. How can we further understand suicide where mental health is not a factor across the lifespan? This was a really strong experience of a lot of autistic people that came through all of our workshops and the way that they described their experience of suicidality in the online survey.

I'll give you a quote because we're still trying to wrap our heads around this and there's going to be more research to try and define what's meant here, perhaps through qualitative research. But this quote captures it. It's more the autistic people without dementia being placed in dementia care due to nowhere else for them to go.

A lot of the participants in our work talked about their concerns about aging, aging in autism, which is really an understudied area. There were concerns from the autism community regarding that and increase risk of mental health problems and suicidality, being stuck in a home with lots and lots of other people, not having a lot of control about their environment, et cetera. We know that this is a really key issue of concern for the autistic community.

Priority 3. To what extent are autistic people not believed about the severity of their distress? For example, I just don't show emotion the way other people do so no one believed there was anything wrong with me or that I needed help. Who knows me best? Our narrative is often misunderstood, dismissed, and over written. There are so many examples of autistic people coming into contact with services, attempting to tell clinicians that they are feeling suicidal only to be turned away. Why is that?

In our study, there were factors such as lack of understanding and knowledge on the part of professionals about autism. Maybe it's alexythmia, difficulties in successfully articulating one's own internal emotional experience. Some people described being so used to camouflaging that when they actually came to disclose, they did it with a smile on their face because they are so used to doing that and they just didn't - the level of distress just didn't come across.

Maybe it's a double empathy problem. Damian Milton's really interesting new theory about social understanding in autism. It being two way. Basically two people being on completely different wavelengths and finding it difficult to understand each other.

Priority 2. What are the risk and protective factors for suicide in autism across the lifespan? There is a lack of research, we know, into why autistic people are at risk of suicide, but it's really necessary for understanding and prevention, which Darren already covered in his amazing talk.

Some progress has been made, but there's much further to go. Looking at things like gender as Anne was discussing, camouflaging, which we uncovered in our research, loneliness, which Darren has covered in his research, sleep, nobody has looked at that, support, employment, mental health, many others.

The top priority and what really resonated with me is that as soon as I arrived here, David came up to me and basically said this to me about why this meeting was happening here and why it was so important to write this report. What barriers do autistic people experience when seeking help which may put them at greater risk of suicide? But it could also be greater risk of mental health problems.

People like me don't get support was the title of our qualitative paper in relation to this question. Attitudes towards me, attitudes about me, the current system, being dismissed, and no specific autistic pathway for autistic people to receive mental health support.

Worryingly in the UK, a recent report from Autistica had to look at what kind of research has actually been funded between

2013 and 2016 and they found no funded service delivery research in the UK despite it being a community priority. This is such an underexplored area and it's something that we all agree from our discussions today that we need to tackle.

Where should we go from here? I would argue as would all of our partners, over a thousand people who have joined us on this journey, that co-production is not optional. We need to work with autistic people and those that support them throughout the research process to make sure that our research is appropriate and useful to those affected by research. We're much more likely to successfully prevent suicide in partnership with autistic people than trying to do it on our own.

We need to close the gap between community priorities for research and what is actually funded and researched. What will make a positive difference on the ground? I think there's a really big learning opportunity between autism research and suicidology research, which have been traditionally very separate. There's an opportunity to make things better for everybody and do that learning between autism and suicidality research both ways. It's not a niche issue. What we learn about autism in relation to suicide could also help the general population.

I would just like to thank all of my collaborators and particularly autism community partners and all those who participated in our events and research over the past three years. I'm really looking forward and I think it's really important that we continue this journey.

(Applause)

DR. DANIELS: Thank you to all the speakers on this panel. We have some time now for questions and answers and comments so open it up to the working group. Dena.

MS. GASSNER: I just wanted to say – reads like my autobiography. I experienced repeated sexual assault first of a family member and then through clergy in my local church, multiple pastors crossing boundaries because I kept trying to find a father figure because the father I had had certainly not treated me right. Although I had processed the sexual assault at the time I presented for my first treatment, because I had been sexually assaulted, they assigned all of my hardships to that prior trauma. As a result of that, they did not treat the underlying issue, which was the developmental disability.

I bring this to the table to say that the number one first major trauma that set me back was someone not understanding autism when they saw it, denying me that diagnosis, which would in turn have given me my framework of identity upon which I could build supports and strategies and scales. But without that as the foundation, we're left floundering with nothing.

And the second was the misdiagnosis I received of bipolar disorder, which resulted in 16 psychiatric drugs, medical maltreatment, and just this continuance and exacerbation of the anxiety and the depression.

The only thing that kept me from considering suicide before I could love myself enough was loving my children and believing that there was a better purpose for me on this planet than to just continue floundering as the way I did.

The other issue that presented me with depression was sleep. I had two kids under 4, one with autism, one with ADHD, a husband that worked midnights. Nobody at my house slept. The combination of those intersections resulted in my only real cognitive deterioration through my life with autism.

But then after I got my diagnosis, I found my tribe. I found my family. And those people taught me what it meant to live a complete life with autism. I didn't outgrow my autism. I grew into it. I grew into understanding how I experienced the world differently and how the world experienced me differently and from that information, I could then adapt, accommodate, support myself.

As I'm coming into my own wholeness, I then start to experience secondary trauma as a parent of an autism child abused by all the systems that were charged to support him. It doesn't surprise me how high the rates of suicide are.

I wanted to speak to the speakers. I wanted to say to Darren, as you keep talking about loneliness and isolation, I'm part of a PCORI-funded grant looking at health care access. We interviewed many, many adults with autism to ask this information and the number one resource they needed to overcome the barriers to health care that Stoddart and Burke and King have written about and others, is a systems navigator. And even if it isn't an interpersonal relationship, having a navigator to hold your hand to help speak when your words fail you, to help elucidate what your symptomology is, seemed to be the common theme in all the AASET groups we talked to.

If anybody is interested in looking at the AASET project, it's at autistichealth.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.

Sarah, I've been a groupie for five years now of your research. I think it's also time for us to look at how people are surviving this. What's on the other side of this? How are people resilient in the face of all of these abuses? How can we that use information to inform interventions to help other people become healthier, living well with autism, not in spite of? Thank you. Sorry. That was my moment of the day.

DR. DANIELS: Thank you. David.

DR. AMARAL: I was wondering if all of the speakers could address the issue for maybe family members who are listening to this or will listen to this in the future. What are the danger signs that they should be on the lookout for for their individual with autism and their family? Do we know yet whether the danger signs, the risk factors are different for somebody on the spectrum than somebody who is neurotypical? Sarah first maybe.

DR. CASSIDY: That work is in progress. We are just coming to the end of a psychological autopsy that has been interviewing friends and family of people who died, who either didn't have a diagnosis of autism, who did have a diagnosis or maybe were on the diagnostic pathway or self-identified as autistic or suspected that they might have been autistic. We are going to be looking at that to see if there are any kinds of unique signs between the groups, anything specific that we need to look out for, any specific barriers that may have contributed those deaths, but we don't know for certain if there is any kind of really unique factors yet.

DR. HEDLEY: I think, maybe from my work – looking for more common risk factors and protective mechanisms and then testing those in autistic samples. Although one thing that we have found with my other hat on with employment, we've been conducting work in the employment arena over the last four years. Our initial hypothesis, I guess, was that employment particularly for those who had been unemployed or had poorly matched employment that providing meaningful jobs and some job security, et cetera, would have a positive impact on mental health. We didn't find that. We didn't see a really significant effect on mental health through employment. Most people didn't really change.

There was a small group who when we looked at individuals who did get better and who seemed to be doing fairly well. And their qualitative work showed that people seemed to be quite satisfied with their work and doing well. But there is certainly a handful whose mental health got worse. It was a very small group from the group that we looked at.

I think that's something to be aware of. In the general population, employment is a protective factor. But for at least some individuals, I think employment certainly brings additional stresses and suicidal ideation and concerns for suicide is something that pops up in a bit in employment work and something to be aware of.

DR. KIRBY: I will add to that. I agree that we do not have any knowledge of specific risk factors, but I would advocate for really listening to autistic people when they express that they are struggling even if they are not putting suicidal ideation to words.

I think for too long providers have thought autistic people wouldn't be interested in attempting suicide. Interested is not the right word. Sorry - wouldn't consider suicide and don't have enough understanding of the world around them to really be experiencing suicidality. I've had providers tell me no. I don't think that could be an issue.

I think it's really important for us to listen to people and for those who are nonverbal just to look for at least what are known to be kind of conventional signs such as sleeping a lot and disengaging from things that are normally enjoyed and things like that. Really paying attention to what they are telling us either for verbally or nonverbally.

DR. DANIELS: Thank you. Scott.

DR. ROBERTSON: A couple of comments. One is I think it's important also to keep in mind – significant portion of autistic people who are able to communicate about in terms of the experience on it and maybe introspectively think about potential consequences of sharing. I've known lots of autistic folks who may have fear about talking about it because of past – poor experiences with mental health system, which is not well educated on autism and a fear of ending up in inpatient settings. There are some good settings of mental – but there are also a lot of settings that have not been helpful for folks and have felt more like prison for a lot of folks that have had trauma – some of their mental health inpatient experiences so that leads to a lot of folks often not wanting to report it because it's a consequence like if this – so often we'll just – we wind up struggling throughout life because – it's not alone with just depression, et cetera. There are other reasons. Autistic adults also may not report from other traumatic experiences, other settings, but just to keep that in mind at times is that folks may walk around and not report things.

And then the other thing on related to employment is I'm wondering - I think we need more studies specifically focusing on cross connection on employment and health and mental health and autism is I'm wondering if it's - because it's not just about getting a job. It's about the quality and the supports you have to maintain and even some of those autism-focused hiring initiatives are only now in the last few years, focusing more on mental health aspects. Mental health doesn't go away that autistic adults can have that long term. I know it has been coming up on discussions at times on the employment space. I wonder if it would be interesting to explore that in later research on the cross connection on employment.

We did find sleep quality – I know that I did see a study out there that sleep quality had a more a direct – at least one study had a more direct connection. Maybe the employment status of autistic people. I'm wondering if that relates to the increased stressors on the job with performing the job or the social interaction with people – jobs have positives in terms of economic well-being. It can be additive social experience. But it could also have – there could be a lot of difficulties, pressures, challenges that can exacerbate difficulties with mental health and physical health.

I can say for myself there have been positives and negatives in my own employment experiences. I love the work that I've been engaged in the last several years, but the stresses have really exacerbated and put a lot of pressure on me health status wise. I know I'm not alone with a lot of other autistic friends and colleagues and other folks I've known out there.

I think that's something to keep in mind and all the more reason why employment, independent living, et cetera, we have to get more focused on the cross connection of mental health in the community and quality of life outcomes and get really – have the more narrow connection of how mental health relates to these certain niche areas to find out just whether – having employment, but having good supports does help with mental health. I think we have to tease that out.

DR. DANIELS: I will take one last question before the break. Connor.

DR. KERNS: I was wondering if the speakers could talk to the relationship between ideation and actual risk of self-injury and death. As a clinician, this is something that I worry about a lot. Often clinically, the option I have if I'm concerned about suicidal ideation, depending on the community you're in, is to walk somebody to the emergency room where then they will get a psychiatric evaluation and potentially be put in a psychiatric inpatient unit that's not familiar with people on the spectrum. I think this is something that's really pressing for clinicians working in the community. What is the relationship between having these thoughts and extreme distress and the actual risk of self-harm and death given that we often don't have good options for actual suicide risk management? We might have some concerns about where our client might actually be going.

DR. CASSIDY: It's really an excellent question and really important. I think what stops us or has stopped us in addressing that question is the lack of validated tools because you kind of need those first before doing those kinds of studies. A lot of studies like that have been done in the general population, but to my knowledge nothing like that exists in autism at the moment.

The kind of prevalent studies are very broad brush in our systematic review. A vast majority of them up to 2018 had not actually used any suicidality kind of assessment tool that had been developed for any of the clinical group. They have mostly been kind of opportunistic samples in clinical. Like say, for instance, our 2014 paper is quite like that. It was an opportunistic sample out of a particular clinic, using a question that had been developed by the clinic. We don't know how these questions kind of operate in terms of clinical kind of risk prediction or anything like that yet to my knowledge.

DR. KIRBY: And I will say, again, I am still looking at co-occurring condition data for the individuals that we looked at who died from suicide. But I will say preliminarily only a small portion of them had a documented suicide attempt or suicidal ideation in their medical record.

I think there may be people experiencing suicidal ideation who do not go on to attempt or die from suicide. But then on the flip side, there are people who we may have not seen any of those warning signs ahead of time who do go on to die. I think we need to know a lot more about both sides of that.

DR. DANIELS: Thank you. We have time now for a short break and then we are going to return at 3:10 for our next session.

(Whereupon, the Working Group took a brief break starting at 2:58 p.m. and reconvened at 3:15 p.m.)

DR. DANIELS: In an effort to try to stay on time, let's go ahead and start the next session. We're going to be talking about self-injurious behaviors and aggression. We have two speakers for this session. Dr. Matthew Siegel from Maine Medical Research Institute and Maine Behavioral Healthcare and we have Dr. Craig Erickson, who is going to be online with us from the University of Cincinnati College of Medicine and Cincinnati Children's Hospital Medical Center.

We will start with Dr. Siegel.

DR. SIEGEL: Good afternoon. Thank you. I have a very technically unsophisticated presentation yet. Of course, I'm the one where it was the wrong presentation. Anyway, very honored, pleased to be here and just really struck by both the stories we've heard, but also I just really want to recognize some of the researchers in the room who are really examining these issues with great rigor, really taking apart depression, anxiety, et cetera in this population. I think that's just remarkable and it's wonderful to be here.

I'm going to talk about aggression and self-injury in people with autism and try to highlight some of the research gaps and opportunities. These are my disclosures.

As we've heard today and is now familiar in this room, but I think still is not necessarily greatly appreciated in the wider community or in the autism community or in autism research necessarily is that aggression and self-injury are very significant issues for the population. This gives you some sense of that.

To unpack this, for the first line, aggression and the first line of self-injury, those rates of 5 and 11 percent come from a community survey of kids in school who are identified with autism on their IEP. In other words, not a clinically referred sample. This is a community sample of kids and this is the report of whether they were experiencing either of these things from the parent. And aggression is physical aggression. This is not words. This is physical acts and self-injury. I think in a non-clinically referred sample, the fact that 5 and 11 percent is quite high actually. Certainly, it's hard to think of any other population where that would be the prevalence in just a community sample.

Outpatient clinics so people who are coming for mental health services, the rates are higher, but the estimates vary widely.

And then not surprisingly, when we look at specialty psychiatric hospital units that are for people with autism and intellectual disability of which there are about 12 to 14 in the country currently, the aggression is present in 80 to 90 percent of those individuals and self-injurious behavior present in 20 to 25 percent.

Here we have a day where we're talking about mental health in people with autism. Why are we talking about aggression and self-injury? I think that's a fair question. I just wanted to give a moment to that because I think it's important to recognize that aggression and self-injury are not disorders. We heard about anxiety disorders, depressive disorders, and other things. They are not disorders and it's important for us not to think of them as that. They are symptoms, but they are symptoms often of an underlying mental health issue or other issues. I won't go through all of these items, but these are some of the many things that can lead to what I see as a final and problematic symptom being aggression or self-injury.

At the top of the list is psychiatric comorbidity and then there's lots of other reasons that can lead to these problems, including functional communication deficits and you can see the rest of the list. I think that that is – as clinicians and hopefully as clinical researchers, that's how we try to approach this.

In terms of the epidemiology and course of aggression and self-injury in autism, there is actually a real dearth of prospective, reliable information across the lifespan. We all know that longitudinal studies that characterize disorders are not – or symptoms in this case are not – they are not exciting necessarily studies. They are expensive and by definition take a long time; however, they are very important and we have a real lack of them in this area.

In other words, when someone comes and their child – maybe a 4 year old is having aggression or self-injurious or something, we really can't say based on literature what the likely course will be. Will this be a problem for three years? Will this be happening when they are 30? We don't really have information on that.

Unlike if someone, for example, shows up Tourette's syndrome and you can say there are two peaks. There is this early peak and then there is a later peak. We often see a defervesce after adolescence though not always and at least we can give them some sense of the course of what may come and we really can't do that with these significant problems.

There was one paper I saw that did do a three-year longitudinal study of self-injurious behavior in autism and this was with a group of kids that averaged – median age was 10 years old, followed them for three years and concerningly self-injurious behavior in that study in that sample persisted in almost 80 percent of the kids. There wasn't information on what concurrent treatment they were receiving or not. But I think at least from that study and we know this I think clinically, time does not heal. Time does not typically make these things go away or time alone.

What are the impacts of aggression and self-injury? Why are we talking about this? Families report and I find this quite striking. They fairly consistently report that when these things are occurring and in this instance aggression specifically that is a bigger problem and of greater concern to them than the autism itself. It's having bigger impacts on the family than the autism itself. I find that quite remarkable. It's because of these various factors including stress, isolation, financial burden and decreasing support options.

While I said we really don't know much about the natural history or course, here's a little bit of broad brush information that a few studies have shown that problem behaviors broadly defined, which means broader than just aggression and self-injury, do remain heightened in autism compared to typically developing and intellectually disabled non-autism intellectually disabled samples. And that there may even be subgroups where this increases into adulthood. But again, I think we have very limited information or reliable information.

I do think that it can be said that this is particularly a problem for individuals who are minimally verbal and that term covers a wide scope from truly non-verbal to probably phrase speech, but in the minimally verbal, which is 30 to 40 percent of the autism population.

I think something that we can say is that the inability or the challenges in reporting one's distress efficiently even with assisted communication in some cases can create an environment where these behaviors seem to come out of the blue.

This is, I think, one of the core problems and I'll go into this more with these behaviors is if it seems to come out of the blue then that results in increasingly restrictive settings for people, inability to access the community, more utilization of various interventions. It minimizes the ability of people to anticipate obviously an outburst and really limits the opportunity also to address the distress and the behavior in the moment.

I think what we've learned from the families we work with over time where this is going on quite a bit is that the most problematic element of this is not – they have taught us, I think, that the aggression self-injury is more impairing than the autism itself and what's most impairing about the aggression and self-injury or the worst effect is that it bends the person's developmental trajectory downward. And of course, that's my framing and phrasing of what we've heard.

What do I mean by that? Hopefully, I can illustrate this. On the left Y-axis, we have development. On the X-axis, increasing age as move to the right. Here is an individual. Here is their developmentally trajectory. And they are reaching their potential, let's say. As they get older, their developmental increases. Their functionality increases.

Let's take another individual and this is a person with autism. Let's take another person with autism and they are going along this line here in blue and they are developing along their developmental trajectory, whatever it is. But then at this point where this red arrow is, let's say they are 4 years old and they are in preschool and they start to have self-injury. And the preschool, which is a good kind of basic developmental preschool, kid diagnosed with autism let's say at 2 years old can't handle it. It's too distressing for the other kids and the staff. They say this child needs to be in a different setting. The child is effectively kicked out of the developmental preschool and spends – no one's intention, but spends six to nine months finding a new preschool, six to nine months at 4 years old, which of course a critical developmental window that they spend at home. This is not an uncommon story whatsoever.

Their trajectory of what their potential whatever it would have been is bent downward by that missing six to nine months of therapeutic intervention.

They are going along now on this trajectory and let's say at 7 years old, they are now in a public school. They are in a pretty good self-containing classroom. They are getting intervention. But then at 7 years old, they develop aggression towards others and this child aggresses toward another child and now they get kicked out of their local public school, this good self-containing classroom and gets sent to an out-of-district specialized school placement.

In that process, they lose time, but they also access more able peers. They lose some social interactions. And so perhaps their developmental trajectory bends further downward.

And then finally, they develop either persistent aggression or it's too intense at one moment. They end up in the emergency room, get hospitalized, and are out of school for quite a long time. That school ends up saying we can't take them anymore or we could frame it as lots of other reasons including they become very aggressive so they can no longer access primary care or dental appointments. That further bends the trajectory downward. And really I think one of the most insidious effects is that they are not accessing their community anymore because this is what keeps them these behaviors from being able to go to the grocery store, go to a restaurant, and go out to dinner with their family. They and the family's world shrinks and shrinks. We end up with this gap between where this person is developmentally and whatever their potential was. I think that is the most insidious and problematic effect of these behaviors besides the obvious immediate danger.

We might say then where are we in respect to our understanding scientifically for these two problems: aggression and self-injury. And the reason I put this up is because I've had program officers say to me well we did that. We did some drug trials. We did that in the 2000s. And what I would say respectfully is I think we did do that with very broad brush measures, but more importantly with no understanding of mechanism, tried some drugs, a couple were somewhat helpful, most are not.

Just to display this, the classical approach to a disorder or a set of symptoms in this case is you want to identify these things on the left side. You want to know the epidemiology, natural history, et cetera.

To illustrate this let's say for a sore throat, do we know these things? I would say yes. We generally know these things. We know the epidemiology of sore throats. In an adolescent, 90 percent are viral, 10 percent are bacterial although we always are worried about strep throat. We know the natural history. We know the etiology is a virus or bacteria, et cetera. We can check off all these boxes for sore throats.

Where are we in terms of aggression and self-injury in autism? I would propose that we have a bare grasp on epidemiology, as I showed in my first couple of slides. We really don't know the natural history. We don't have a good grasp on the etiology or the mechanism at a biological level. We don’t have biomarkers for its occurrence or onset or risk. Our treatment, I would say, is plus/minus and I'll talk about it a little more. We really don't have treatment beyond the basic approaches for refractory cases. We really, I think, have a lot of work to do in this area particularly at the mechanism and biological level.

In terms of treatment, what are our options? Currently, this is a list of many, not a total list, but these are many of the more common options we have for treating challenging behaviors in autism. We have applied behavioral analysis, which is incredibly important and strong evidence base. We have psychotropic medication, which is important, but with less of an evidence base and some of these other strategies.

With these top tow, applied behavioral analysis, I think it is important to note that it's incredibly important. We use it in all of the programs that I oversee. However, it is not the end-all/be-all. Thirty percent of functional behavioral assessments do not determine a function or inconclusive about those behaviors.

And I think also importantly, how scalable really is ABA particularly for problem behaviors in older kids or adults? It is incredibly time-intensive. It takes a high level of skill and staff. There are settings where we can do that and there are many settings, I think, where we can't. I think we have to be realistic about that.

Psychotropic medications, as we all know, have significant side effects and very inconsistent success primarily because I think the heterogeneity in the autism samples was not really evaluated in any way in those medication trials. These are our current approaches.

I want just to give you a sense of what is a different way we could come at this. I want to tell you a little bit about one of our patients who has given us permission to do this picture and story and an approach we are taking as not this is the best approach, but rather this is just an illustration of trying to back up and come at this from a different perspective.

This is Ryan. He is a 23-year-old man with autism. I've known him for a long time. And his mother Wendi. And this is what Wendy says about Ryan and their situation. Due to his inability to manage his emotions and communicate, he attacks us when he becomes agitated or stressed. This behavior is very unpredictable. It often occurs with little to no warning signs. It has happened in our home, his school, in the community and sometimes while driving a car. It is so bad that we can no longer safely live in our home with Ryan. This is despite having the best psychiatric care – despite having hopefully competent psychiatric care and lots of other resources applied to this problem. This is still the situation.

A couple of things that I thought were quite notable that Wendi really articulates is the key problem here is that it's very unpredictable. This is a family in a system that can handle an unbelievable amount of challenge, as many of our families can. Yet what takes it over the top for them is that it is very unpredictable and thus occurs with little to no warning signs. That's the key piece for them. They can handle the aggression if they know it's coming.

For the sake of time, I'll move along quickly. But we are trying to come at this problem of aggression in this instance and you could apply this to other problem behaviors from a different viewpoint. And the viewpoint is we're not looking at the function of the behavior, which I know is unusual to say and we're not looking at trying to dampen it down with various medications, but rather we're looking at it as what's the mechanism. One way to look at it is someone’s (inaudible word) equilibrium in terms of their physiology. They have a triggering stimulus, whatever it is. They experience distress. They have physiological arousal and then engage in aggression or another problem behavior in part to try to regulate that physiologic arousal. And then that can lead to a feedback loop of more arousal and aggression or perhaps they are able to regulate their emotions and thus their arousal and perhaps not engage in aggression. It's a very simple model, but that's what we're looking at.

We do know that there is a relationship between physiology and aggression as well as other behaviors. In this figure from Matthew Goodwin from Northeastern University who is a key co-investigator on this, we have a person who is a baseline with their right heart in the 70s. We see this rise in heart rate and then we observe an aggressive episode here.

The key part – and then you see a decrease in arousal after the episode ends and then back to baseline. The key part for us is before the behavior happens, the observable behavior happens, there is a rise in heart rate in this example. In other words, it is not out of the blue. We just don't have the x-ray vision to see this rise before we see the actual behavior happen. We need to get the x-ray vision or in this case, the – I don't even know what the metaphor is. I don't have a metaphor. How do we get this x-ray vision?

This is a complicated slide, but we did a pilot study, which is in press with Autism Research, where we measured the physiology of kids with autism and what we measured was heart rate and electrodermal activity, which is a measure of arousal of the sympathetic nervous system and motion, and a couple of other things.

We coded their behavior by a research assistant, set up in time. Then ran all that data through machine learning classifiers to try to see if we could predict in retrospect when a challenging behavior was going to happen. We were able to do that with fairly good accuracy of around 80 percent just on the pilot study. Now, we are replicating and expanding and hopefully improving on that with a much larger study.

In terms of unmet research needs in aggression and self-injury. I went through that example very quickly of using physiology in our example, again, not because that is the end-all/be-all, but just a very different way to approach this where we're not looking at function, we're not inferring anything. We're trying to use objective measures to get ahead of these behaviors.

Some needs are I think we do have a real need to understand better the natural history and life course of aggression and self-injury, including into adulthood. There is I would say a methodology that people kind of mellow or temper in adulthood. I don't know that to be true. I think we don't know. That's important.

We need validated tools as we've heard today for psychiatric comorbidity broadly in autism as well as specifically in different disorders such as anxiety, depression, et cetera.

Judy Reaven mentioned that there were basically almost no pharmacologic studies of anxiety in autism. That is because until about a week ago or a couple of weeks ago, we have no validated measure of anxiety in autism. You can't run a clinical trial if you don't have a measure of what you are studying.

I personally think that we have put almost very little money into studying functional communication, which is very important in relation to behaviors. And I keep waiting to see the RFA on that or hoping.

As I said, I think we need novel approaches to aggression and self-injury that are grounded in biological mechanisms and use objective measurement. I think also those could be combined with ABA approaches and might be very powerful in doing that, but first we have to develop them.

As we heard, emotion regulation and measurement and treatment are very important in and of itself and in relation to aggression and self-injury.

I think a real theme that we heard today in multiple talks and discussion was the importance of sleep and sleep disturbance, which we know is common in autism, but we actually know very little about that, the biology, the natural history, et cetera of sleep. Extremely important and we definitely see a relationship to challenging behaviors, but we don't understand that relationship at all. It really has not been studied.

And finally, I would say a research need in this area is many of the individuals who engage in these behaviors end up in what I would call complex, real-world treatment programs whether that is a residential treatment program, an inpatient treatment program, a specialty school treatment program. Those settings where we spend hundreds of millions of dollars a year as a country are virtually unstudied. There are almost no studies of residential treatment. How do we know it's helpful? What is more or less helpful? I think that is really important. It's not easy to study those complicated packages, but I think there are ways to do it including comparative effectiveness studies.

In summary, individuals with autism can develop these very serious behavioral challenges and it's not rare I would say. It's somewhere between uncommon and common.

Parents report it is the unpredictability and lack of warning that is perhaps most impairing. I think these items are under researched and their underlying mechanisms are not well understood.

I mentioned our pilot study. I think there is a real need for novel research in this area. It's time for a second pass, I think, at aggression and self-injury.

Finally, just some resources for parents or individuals or clinicians who are working on this. Two resources on the left are what's called a parent's medication guide that is on the website of AACAP, the American Academy of

Child and Adolescent Psychiatry. The reason I point to this is not because I'm particularly focused on medication, but rather the people who develop this and I was part of the work group. Most of this document is all about how not to do medication. It's all the things you should be looking at and assessing before you get to medication if you have the time and safety to do that. I think that it's actually that part of it that is most interesting. It's available for free download.

And then on a right is a similar kind of pathway of how do you assess these behaviors and look at all the factors that could be contributing, which I showed very briefly on one slide before you get ideally to medication.

Just acknowledge – I have many collaborators, co-investigators, but I want to acknowledge Dr. Mazefsky and Dr. Goodwin, who have been key people in our work as well as the funding sources on the right.

Thank you very much.

(Applause)

DR. DANIELS: Thank you Dr. Siegel.

Next, we're going to move on to Craig Erickson, who is joining us virtually. We're just going to take a moment to switch over to him.

DR. CRAIG ERICKSON: This is Craig Erickson.

DR. DANIELS: You are on. Welcome.

DR. ERICKSON: Can you see my screen?

DR. DANIELS: Yes, we can see it.

DR. ERICKSON: If folks can see my screen, I will get started.

DR. DANIELS: Yes, go ahead. We can see you.

DR. ERICKSON: Great. Sorry I can't be there in person. I have to coach fourth grade boys' baseball in about 90 minutes. I apologize. It sounds like it has been a great meeting and I appreciate the opportunity. I know we're a little bit behind on schedule so I'll be brief and to the point. I think Dr. Siegel did an excellent job covering the ins and outs of aggression and self-injury in the context of autism.

I'm going to speak about medication management and I think really the key is that the caveat is medication is definitely a secondary option following evidence-based behavioral interventions. It's best done in combination with such interventions. The goal of medication is the least amount of medication at the lowest effective dose is really to boost safety and enhance ability to participate in various daily living opportunities, educational and therapy opportunities. We will never claim a magic pill. And really this needs to be part of an interdisciplinary treatment team and not just single prescriber by themselves to have the best approach.

First, there are two FDA-approved medications targeting irritability, which the FDA and the United States defines as aggression, self-injury, and severe tantrums. This is the only indication specific to autism for any drug at least here in the United States and really essentially all over the world.

These medications that are approved are newer generation anti-psychotic drugs is their classification. They FDA approved in youth with autism exhibiting aggression, self-injury and/or severe tantrums. But they are really equally utilized in adults despite the FDA approval being in really kind of the age 5 or 6 to under 18 age range.

There are drugs that have classically been recognized for use in schizophrenia and bipolar disorder and then were brought into autism work really over a decade ago, following multiple placebo-controlled well-designed studies that showed marked reduction in irritability as defined by the FDA based upon both caregiver and clinician measures.

These are really options 1A and 1B that we use when needed to treat aggression, self-injury and severe tantrums. I'm going to speak about some of the tolerability issues with these medications because response rates are probably about 70 to 75 plus percent. We can reduce these behaviors. But the tolerability issues become a significant concern.

Other medications that have been studied and used that little evidence supporting their use. Valproic acid or Depakote is a seizure medicine in an FDA-approved mood stabilizer in bipolar disorder. It's had negative placebo-controlled study.

Naltrexone is FDA approved to treat opiate and alcohol use disorders. It has limited evidence. Older medication can cause some GI upset and liver function test concerns. We don't use that very often.

Lurasidone is a newer generation antipsychotic. It had a large, negative placebo-controlled study. It was not helpful.

And then I mentioned the SSRIs or the selective serotonin reuptake inhibitors because we see about a third of individuals with autism may get disinhibited and more agitated on these medicines. This is tricky and why medication management by someone with expertise in autism is ideal because you could be treating a perceived anxiety or mood issue and sometimes unearth aggression and agitation. We see this on our inpatient services where maybe overuse of SSRIs for unclear indications or sometimes trying to treat aggression can make that situation worse.

Another option I want to mention quickly and we reported on this when I was at Indiana University and we used more and more of it is Paliperidone, which is the active ingredient in Risperidone in a time released formulation. It has to be swallowed. It's not liver metabolized. There are no drug-drug interactions. We've been increasingly utilizing this for folks that have tolerability issues sometimes related to sedation or having to take drugs multiple times of the day with Risperidone. Increasingly were Paliperidone prescribers in this area.

Tolerability concerns. Weight gain is number one and probably number two - significant risk. Dr. Siegel mentioned it. It really limits the use of these otherwise efficacious medicines. I'm going to speak to that specifically. And then abnormal movements associated with extrapyramidal symptoms and akathisia, which is a constant need to be in motion.

Risperidone elevates prolactin, which in males sometimes can cause gynecomastia or rare breast tissue development. Interestingly, you can blunt or block this risk adding low dose aripiprazole to risperidone. I'll speak about multiple anti-psychotic use in a few minutes.

Weight gain. It's a big issue. We have studied it over long-term treatment and we have not seen any differences of aripiprazole versus risperidone. Originally, we thought aripiprazole had less of a concern, but in this paper where we followed large cohorts of individuals, BMI z-score is kind of a standard deviation, age-adjusted body mass index. That increase there of .53 or .56 per year is really over a half standard deviation of body mass increase per year of treatment, which is really significant and very similar between the drugs. We can't differentiate them based on weight gain and the weight gain is significant for both.

We have studied differences in this drug class with other agents that are used off label to treat aggression, self-injury and severe tantrums. And what we've found is that ziprasidone or Geodon is really consistently weight neutral, which is known in the field, but in the context of autism, it's not causing weight gain. In quetiapine or Seroquel, it causes significantly less weight gain in individuals with autism compared to risperidone and aripiprazole, which are FDA approved and compared to olanzapine or Zyprexa, which is really considered to be the worst weight gaining of the commonly used newer generation antipsychotic medicines.

What do we do about the weight gain? What if the behaviors are significantly improved when medication is indicated? Metformin use has been subjected to a long-term report about over two years of treatment in a large cohort of youth with autism that we reported on and it has been the topic of a short-term placebo-controlled study, both reported weight loss or weight plateau with treatment. Metformin is FDA approved to treat type 2 diabetes, but we use it for these weight gain issues.

This graph – the key points are the third and fourth dots. What we see is this increasing arc of BMI z-score going up, up and away and then from initial dose to final dose, that's where metformin is initiated. And then when we did our final look at each individual patient's data, we see a plateauing in a directional overall loss from really a rapid increase. You hate to add a medication to treat a problem, but metformin we see generally good tolerability with some concerns of gastrointestinal upset and loosening of bowel movements. But a large number of individuals with autism that we've treated have tolerated it okay and they've been able to stay on otherwise effective aripiprazole or risperidone in other medication use and have been able to get rid or at least maintain a steady weight when they prior had significant weight gain.

Other option is ziprasidone, which I mentioned or Geodon. We've reported on 42 individuals that we systematically treated with ziprasidone about 50 percent response rate for those that weren't tolerating FDA-approved treatments. We tell families in clinic it's a coin flip, but it's not going to cause weight gain generally at least in the vast majority of cases. I think Dr. Dominick in our group worked this up a few years ago and it is a go-to option if metformin is not tolerated or not desired.

What do we do when first-line treatment fails? In tertiary care center when I was at Indiana University, almost 40 percent of referred patients presenting with severe irritability were drug refractory, meaning they had failed aripiprazole and risperidone either due to lack of effect or tolerability problems or they failed one of those drugs and multiple other medications. At least in a tertiary care setting, this is a real concern. We really started to do some work up. What do we do when FDA-approved agents fail?

One thing that we've done – it's a small percentage, but for those that it affects, it's a major concern. Over 6 percent of 1100 patients we were treating took multiple antipsychotic drugs. That may be aripiprazole and risperidone or other combinations. We noted good tolerability. It may be safer to be on multiple newer antipsychotic agents versus older drugs or even different drug classes. This is an option that we go to at times with some positive response and those that are refractory to first line treatment.

Clozapine is a medication for very severe aggression, self-injury and irritability. We published on a small cohort treated in an inpatient autism unit that's part of Dr. Siegel's research consortium of inpatient programs. We're now up to 52 persons with autism across youth and young adulthood who have taken clozapine, who have exhausted many other medication options.

The risks here are weight gain, sedation, and drooling. But this medication requires blood count monitoring because agranulocytosis is a medical term for your white blood cell count can drop essentially to zero, which can be life threatening. You have to do complete blood counts weekly for six months, every other week for six months and then monthly for the life that you're on the medicine. That's a major concern and a problem and kind of limits use. But the medication can be very helpful and we've even had folks, for example, have avoided residential placement being on clozapine when other efforts have failed including great behavioral efforts, FDA-approved medication, and other off-label medication. But it's a big step to clozapine because of the safety risks and the monitoring required, but we're up to over 50 individuals and the majority of whom have had real success with this approach.

And then electroconvulsive therapy or ECT and a nice review paper from Lee Wachtel, Max Fink and the folks at Kennedy Krieger at Johns Hopkins in their autism severe behavior program are really some of the leaders in this work. We've increasingly used more ECT or electroconvulsive therapy over time in folks that have been significantly drug and behavioral intervention refractory.

Dr. Wachtel speaks about a concept of agitated catatonia and self-injury in the context of catatonia. It's really a lot of purposeless severe self-injury and aggression with intermittent periods of more of a catatonic withdrawn-like state. And we have had some patients that have been completely drugged, not fully responsive and have had intensive behavioral intervention, intensive inpatient care who have responded to ECT. But obviously, that's a big step. It's not for everyone. It's kind of a last treatment in our armamentarium, but it's something that we increasingly think about to utilize in the most significant cases.

I said I would keep it brisk and I know Dr. Siegel and I now have some time for questions and try to get us back on track. I really appreciate the invite to participate and again sorry I'm not there in person and glad we could remotely connect about drug treatment of irritability and autism. Thank you.

DR. DANIELS: Thank you, Dr. Erickson. Now, we have a little bit of time for discussion. I'm going to steal a little bit of time from the end of our meeting and give us – how about three questions or comments and then we can move on to the next?

MS. GASSNER: I just wanted to help us remember that in distress the hippocampal region of the neurology starts to shut down. Regardless of your highest capacity under the right set of circumstances, we all know that language doesn't work even in the most articulate people.

Similarly, as Lindsey was willing to share with us today, self-injurious behavior again is not limited to people who have ongoing, consistent, severely intensive behavior. It can happen to people who know enough to hide it. Those people are at a different kind of risk, not better or worse, but different.

And then I also wanted to layer into that the cumulative effect of traumas. It could be that just one little domino falls here and then another one and it may not be one big FDA measurable event and then you have the behavior. I appreciate the work that both of you are doing on this and especially other research on non-suicidal self-injurious behavior as a gateway to suicide.

DR. DANIELS: Thank you.

DR. MORANTZ: Just a quick comment and then a question. The first comment is I'm so pleased to hear that ECT is being used in this context. I didn't mention as part of my narrative. But we were sufficiently persuaded by some of the growing evidence base sort of in similar context of those that were mentioned that we did do a trial of ECT with Micah. Unfortunately, again, it wasn't successful.

But I feel very strongly that there is still a lot of stigma and bias for good reasons because of the really atrocious history of the use and abuse of ECT so we all know why. But particularly in California and California is not alone, it's enormously stigmatized in a way that increasingly I'm persuaded based not on Micah's experience, but those of other treatment-resistant people of all ages that we really need to overcome that stigma. I hope that others in this room feel the same way and maybe we can work on that particularly in the state in which I reside. That's the comment.

The question is I was actually curious on the weight gain issue. I've actually heard different answers to the question of what is the mechanism. Is it something independent of an increase in appetite? Is the increased appetite the mediating factor? I was just curious to hear the speakers' thoughts on that because I've never gotten a straight answer to that question. Thank you.

DR. ERICKSON: I think you haven’t gotten a straight answer because I don't think medical science knows. We have individuals that consume a large amount. They have an increased appetite. Clinically, I see that as the majority. We also have cases of individuals that really don't report eating more and gain weight where there is likely a change in metabolism. I think our field has not sufficiently profiled who may be a weight gainer or not biologically. We've not sufficiently evaluated those questions. I think those are things we can figure out and we can predict ahead of time, but we've not had the opportunity, the funding or the emphasis to do so.

The truth is I've treated thousands of individuals with autism and irritability and I don't have a perfect answer and I think that's to be established.

DR. DANIELS: Lindsey.

MS. NEBEKER: I was just going to kind of give a quick comment. You had mentioned about parents reporting about it being the unpredictability that is one of the greatest impairments. It actually kind of rang home for me because my brother has had aggression issues. I remembered how unpredictable it was for us to not know when he was about to have a meltdown or attack.

Our dog actually became our informal predictor. It was fascinating. We had a golden retriever while we were growing up. I think he got to some sense and I'm not sure how, but usually around 15 minutes or so before my brother would start engaging in aggressive behavior, our dog would get very quiet and hide under our grand piano and he would just kind of lay and stay there. I think that's really interesting because we hear about animals who respond before earthquakes. I'm not sure how that connection that animals might have with humans as well. I just thought that was really interesting.

DR. SIEGEL: Just to add to that or go off that and also Dena's comment about the hippocampus going blank when you're at a high emotional or agitation state. One thing that was unsaid in my rapid, but not rapid enough talk was that some people said so what. So what if you get a two-minute warning before one of these episodes or three minutes? That's nothing. Our response typically is actually that's an ocean of time compared to having no warning and the types of interventions. It opens up a whole new window potentially for intervention, which all needs to be studied and that's if we get the system to work reliably.

But typically, the interventions we do now are with your comment and mine, Dena, that typically the interventions to help someone de-escalate are very concrete and basic. They are taking deep breaths, take a seat on the floor, bounce on a ball, go into a quiet space, just very basic interventions that I think don't require processing. We don't start talking about consequences with the behavior and what's going on. In fact, we talk as little as possible in that moment. Just adding to that.

I don't know anything about pet therapy, but there are seizure dogs, I believe, that help predict seizures. I wonder if that might relate to the phenomena you picked up on in your own home.

MS. GASSNER: Sadly, too many teachers and parents don't know to stop talking. It goes back to parent training and school-based training and helping people to know that everything intuitively they would do, which is try to talk someone down escalates them.

DR. DANIELS: Related to that question, are wearable sensors being used at all in experimentation with this?

DR. SIEGEL: I will answer that. Dr. Erickson might have more to add. As I went through very rapidly, that study where we are looking at physiology, which is all wearable sensors. We have a ways certainly to go with that until we reach a place where we think it's reliable and hopefully predictive. But wearable sensors are definitely I think a promising avenue. But then we'll have to be paired with behavioral intervention and others.

DR. DANIELS: Thank you. And last question for Joe Joyce.

MR. JOYCE: Thank you. I would just like to comment if I could about our experience with ECT. Our son spent 22 months in Kennedy Krieger working with Dr. Wachtel from age 7 to 9. They attempted every med trial and behavioral strategy, ABA, all the behavioral interventions, tried every med that was discussed he tried. Nothing worked. And then they came to us and suggested ECT. This is after two years in the neurobehavioral unit at Kennedy Krieger. He was still only 8 years old. As a parent, I was very fearful of attempting that. Fortunately, my wife was the courageous one.

They put us in touch with Max Fink, Dr. Fink, who is called the godfather of ECT. I spoke to him directly. He told me that all of the meds that our son had tried are far more hazardous and dangerous than ECT ever will be. If you were willing to attempt the med trials, you should have no qualms about attempting ECT. We did.

And I can tell you that he was a totally changed boy. It's remarkable. His self-injurious behaviors were 8000 a day and after ECT, they went down to single digits, less than 10. It was just remarkable the effect.

I just want to say that that stigma that's out there needs to be put to bed. It's a valid treatment that I think of all the things that have been discussed, it's the one that works at least from our experience.

The hard part though was when he was finally discharged from the inpatient unit. We could not find any outpatient services that would provide ECT especially at his age at only 9 years of age. He was the youngest person I believe in the history of the United

States to have ECT treatment for autism. I had to drive him seven hours round trip once a week to Newark, New Jersey. They were the only ones that would provide it on outpatient. I think that's a problem that I think needs to be addressed. More outpatient services for ECT. But I just wanted to share. Dr. Siegel, I didn't know if you wanted to comment on that.

DR. SIEGEL: Thank you. I also want to let Dr. Erickson who is involved in this as well, but just to say that since we're sitting here at the IACC and part of the goal here is to identify research gaps and perhaps help direct research funding. Though it will be very difficult and I think will take great bravery, the way to pursue this is like everything else. We need a quality clinical trial. We have case series of kids with autism using ECT for various indications, catatonia, severe self-injury, aggression, bipolar, but we need a quality-controlled clinical trial of which there has been none yet. And it will be very difficult and it will take bravery on everyone's part. But I think if we are going to understand this better and see how it's helpful for and who it is not that that is the path.

I do just want to comment also that it is an important option, but I just want to be clear at least from my perspective and I think from a lot of my colleagues that it is very much right now partly because of the lack of clear controlled evidence, very much a last resort for the most severe cases.

In fact, if you don't mind, I also want to just change - you said ECT for autism. It's not how people generally think about it. It's ECT for severe self-injury or aggression or a clear psychiatric disorder. I'm not picking on you, but I've heard other people say that and that worries me greatly. We do not do ECT – people do not generally do ECT for autism.

MR. JOYCE: I misspoke on that. It was definitely for the SIB.

DR. SIEGEL: That's okay. As usual, calling for more research.

DR. DANIELS: Anything from Dr. Erickson before we move on?

DR. ERICKSON: I think research in the initially treatment resistant population with different medication strategies, ECT and predictors of response and tolerability is really the key. Like everything with autism, we can't have a pigeonhole approach and we can do a lot more to profile initially who may best respond, who may best tolerate a treatment and that's a huge area of research need across medications and in ECT. Great conversation. I appreciate this topic.

DR. DANIELS: Thank you so much to our panelists for that panel.

We are now going to move to our last talk of the day. We're going to be talking about mental health services issues for people on the autism spectrum and this is Brenna Burns Maddox from Penn Center for Mental Health at University of Pennsylvania.

DR. MADDOX: Thank you so much for having me here today. I'm honored to follow such an impressive lineup of speakers. I do recognize that I'm the last talk of a very full day. If you feel like you need to stand up at any point to stay awake or do some jumping jacks, I will not be offended. Please. I do recognize. It has been a very full day.

Part of that full day has already set the background for this talk on the barriers to mental health services for autistic individuals. I have very little to say here. We've been hearing all day that many individuals on the spectrum have high rates of psychiatric conditions. However, many of them do not get effective mental health treatment in their community.

And the research continues to show us that untreated psychiatric conditions are associated with a host of negative outcomes, including things like adaptive functioning impairment, loss of employment, hopelessness, social isolation, and overall poor quality of life. This is, of course, very concerning and it leads us to the question. What are the barriers to effective mental health care for autistic individuals? What's getting in the way? We've been talking about that throughout the day. As I said earlier, I think some of this will be a little redundant, but important to drive home the point.

To address this question, I'm going to briefly present on five main problems or barriers. There are certainly more than five of these, as you all know, but five seems like a good number for 15 minutes. I'll end with some possible solutions that I'm hoping we can talk about together as a group during the discussion period. During the presentation, I will be pulling from the published literature as well as from our own work at Penn.

The first barrier is that many clinicians do not feel confident about working with autistic individuals. When I say clinicians throughout this presentation, I'm referring specifically to mental health clinicians although this fact actually applies to physical health clinicians as well.

We know that clinicians in the community are treating conditions such as anxiety and depression. They are intervening for suicide risk all the time. And they do this well. They do this pretty confidently. But when someone comes into the clinic with anxiety or depression and autism, many clinicians basically throw up their hands and say we don't know what to do here. They feel anxious. The clinicians feel anxious. And they feel uncertain about treating autistic individuals.

This is a quotation from Dr. Lauren Brookman-Frazee and her colleagues work in California from a community mental health clinician, working with autistic children. She said we're probably somewhat all out of scope of practice when we're dealing with these kids. We heard very similar themes from our qualitative study in Philadelphia talking with community mental health clinicians who work with adults.

As one clinician told me, I've worked with a lot of diverse populations of all ages, but this is the one area that I would not feel competent to work with. This really strikes me because again these clinicians are working in complex clinical settings with complex patients. They are treating things like psychosis and substance use, bipolar disorder. But as this clinician said, it's really autism that's making them feel uncertain and anxious.

These two quotations highlight a lack of confidence in general about treating autistic individuals broadly. We also have data showing limited confidence or comfort in treating specific targets, specific mental health targets.

For example, these data come from 100 community mental health clinicians where they told us that they are significantly less confident treating anxiety and depression in adults on the spectrum showed in the green bars compared to adults not on the spectrum. We see similar results when we're asking clinicians about their confidence and intervening with a suicidal client or patient. This comes from our ongoing study at Penn, looking at how we can best adapt the safety planning intervention for adolescents and adults on the spectrum. And clinicians told us that by and large they do not feel very confident in intervening when someone on the autism spectrum comes in with suicidality.

We know that clinicians that are not very confident. This isn't surprising when we think about how few clinicians are actually trained to work with individuals on the spectrum. As I talked with a few people about today during the breaks, the clinicians who are trained oftentimes are private pay providers and charge quite a bit of money for that expertise. If you think about how are the majority of individuals on the spectrum going to access treatment, we do need to think about these clinicians in the community.

Again, pulling from Dr. Brookman-Frazee and colleagues' work, this is specifically looking at clinicians who work with children in publicly funded community mental health centers. And about half of the providers said that they had some training in autism during their graduate training, but this training was not extensive or intensive in any way. Only about 5 percent of them would call themselves autism experts.

We can compare those findings with our data from clinicians who are working with adults in the community. In this sample, 84 percent said that they had never received any training, any mention actually of adults on the spectrum in their graduate course work or in any sort of continuing education workshop.

And of course, this lack of training has downstream effects when it comes to individuals on the spectrum seeking mental health services. This is a quotation from an autistic woman who said I can't even find therapists who know very much about autism spectrum disorders. So I have to continually be trying to tell them that my needs are not the same and it is a real challenge to sometimes work with these folks. We heard 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. MADDOX: Yes, I think the modular treatment approach is very helpful for that. Jeff Wood and colleagues have a paper from 2015 with Lauren Brookman-Frazee 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. MADDOX: 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.)