# U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

# INTERAGENCY AUTISM COORDINATING COMMITTEE

# FULL COMMITTEE MEETING

TUESDAY, JULY 9, 2013

The Interagency Autism Coordinating Committee (IACC) met in Room 10, Sixth Floor, C Wing, Building 31, 31 Center Drive, Bethesda, Maryland, from 9:09 a.m. until 5:28 p.m., Thomas Insel, Chair, presiding.

PRESENT:

THOMAS INSEL, M.D., *Chair*, IACC, National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary*, IACC, NIMH

IDIL ABDULL, Somali American Autism Foundation

JAMES BALL, Ed.D., BCBA-D, JB Autism Consulting and Autism Society of America (attended by phone)

ANSHU BATRA, M.D., Our Special Kids

JAMES BATTEY, M.D., Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD)

PRESENT (continued):

LINDA BIRNBAUM, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (attended by phone)

COLEEN BOYLE, Ph.D., M.S.Hyg., U.S. Centers for Disease Control and Prevention (CDC)

JOSEPHINE BRIGGS, M.D., National Center for Complementary and Alternative Medicine (NCCAM)

SALLY BURTON-HOYLE, Ed.D., Eastern Michigan University

MATTHEW CAREY, Ph.D., Left Brain Right Brain (attended by phone)

JAN CRANDY, Nevada State Autism Treatment Assistance Program and Nevada Commission on Autism Spectrum Disorders

GERALDINE DAWSON, Ph.D., Duke University

DENISE DOUGHERTY, Ph.D., Agency for Healthcare Research and Quality (AHRQ)

TIFFANY FARCHIONE, M.D., U.S. Food and Drug Administration (FDA)

ALAN GUTTMACHER, M.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

LAURA KAVANAGH, M.P.P., Health Resources and Services Administration (HRSA)

DONNA KIMBARK, Ph.D., U.S. Department of Defense (DoD)

WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS)

PRESENT (continued):

SHARON LEWIS, Administration for Intellectual and Developmental Disabilities, Administration for Community Living (ACL) (attended by phone)

DAVID MANDELL, Sc.D., University of Pennsylvania

JOHN O'BRIEN, M.A., Centers for Medicare & Medicaid Services (CMS) (attended by phone)

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds

SCOTT ROBERTSON, M.H.C.I., Autistic Self Advocacy Network (ASAN)

JOHN ROBISON, Self-Advocate, Parent, and Author

ALISON SINGER, M.B.A., Autism Science Foundation (ASF)

LARRY WEXLER, Ed.D., U.S. Department of Education (ED)

ALSO PRESENT:

TIMOTHY BUIE, M.D., Massachusetts General Hospital for Children

JILL ESCHER, Escher Fund for Autism

WENDY FOURNIER, National Autism Association

RICHARD FRYE, M.D., Ph.D., University of Arkansas for Medical Sciences

ALYCIA HALLADAY, Ph.D., Autism Speaks

PORTIA IVERSEN, Parent and Advocate

ALSO PRESENT:

ROBERT LOWERY, National Center for Missing and Exploited Children

SHANTEL MEEK, M.S., Administration for Children and Families (ACF)

JAMES PERRIN, M.D., Massachusetts General Hospital

JEFF SLOWIKOWSKI, U.S. Department of Justice (DoJ)

LEE WACHTEL, M.D., Kennedy Krieger Institute

TABLE OF CONTENTS:

TABLE OF CONTENTS (continued):

PANEL ON WANDERING:

# PROCEEDINGS:

Dr. Susan Daniels: Thanks. I just wanted to check to make sure we have a quorum so we can start our meeting.

I'd like to welcome everyone to this meeting of the IACC today, July 9th, 2013. We're really looking forward to a great meeting. We have a packed agenda as usual.

Today, Dr. Insel is going to be joining us a little bit late, because he had a new grandbaby last night and has some grandfatherly duties to do this morning and will be here as soon as possible. But in the meantime, Dr. Alan Guttmacher from NICHD will be sitting in for him as chair.

So, we are really looking forward to a number of panels and presentations today that will really help to inform our Committee and the listening public. And we want to welcome all those that are listening online and to our webcast and to the phone line.

Dr. Guttmacher, do you have any comments that you'd like to make, welcoming folks?

Dr. Alan Guttmacher: Just that I was delighted – Tom sensibly asked late last night if I would sit in chairing for him.

I'm delighted to do it anyway, but of course as the Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, it's important to us that children get off to a good start. And having grandfatherly attention is part of that. So, I'm very happy that Tom will be joining us a little bit later and taking over the reins when he's here.

I think, rather than going all the way around and reintroducing ourselves to each other because the faces are fairly much the same, there have been a couple of changes we thought we might mention in terms of the makeup of the Committee.

One is that Dennis Choi has stepped down from the Committee. And the second, we're very glad to see that Geri Dawson is still around the table, but she's wearing a slightly different hat than she has in the past. So, we thought we might have Geri tell us a little bit about that.

Dr. Geraldine Dawson: Thank you, Alan.

Well, as you know, I've had a wonderful five and a half years at Autism Speaks, but I am eager to return to my roots as a scientist and also as a clinician working directly with families.

And I'm going to be joining the faculty in the Departments of Psychiatry, Pediatrics, and Psychology at Duke University, where I'll be establishing a new Center for Autism Diagnosis and Treatment and codirecting the Developmental Neuroscience Research Program there.

Dr. Guttmacher: Thanks, Geri, and we all congratulate you on that and look forward to you continuing to do great things for the autism world in your role.

Our first speaker today, James Perrin – you have full biographies for all of the speakers in front of you but just to briefly introduce Dr. Perrin, it's tempting to say he has done everything in pediatrics in his career, but that actually would be a lie.

He has not been the president of the American Academy of Pediatrics, but he is the President Elect. So, as of January 1st, we can say he will have done just about everything in terms of leadership in American pediatrics in general.

But, specifically, he's long been interested in issues around autism and both in terms of research and clinical care has had a real role in that through his life at MassGeneral, at Massachusetts General Hospital.

And, again, read the full biography to get the full note, but he's certainly an expert to speak to us about – you'll see we have him double-billed – but the first of his two tasks is to talk to us a bit about racial and ethnic differences in subspecialty service use for children with autism. Jim.

Dr. Daniels: Alan, can I step back just for a second to do roll call and –

Dr. Guttmacher: Oh, absolutely. Excuse me.

Dr. Daniels: Sorry about that.

Dr. Guttmacher: We have to approve the minutes, too.

Dr. Daniels: And we need to approve the minutes. We have a couple of housekeeping items, but we are really looking forward to hearing from Dr. Perrin. So, we will get to that as soon as possible.

I'd like to quickly go through the roll call. I know that Dr. Tom Insel is not here, but will be joining us.

(Roll call)

Dr. Daniels: All right. So, we have a quorum for the meeting. I'd also like to turn your attention to the minutes, the draft minutes that I sent around to the Committee from the last meeting on April 9th.

I did have a couple of comments come to me by email. Does anyone else have any comments that they want to have us add or delete or change anything in the draft minutes?

(No response)

Dr. Daniels: Seeing no comments on the minutes, do we have a motion on the floor to accept the minutes?

Mr. John Robison: So moved.

Dr. Daniels: Second?

Dr. Denise Dougherty: Second.

Dr. Daniels: All in favor?

(Chorus of ayes)

Dr. Daniels: Any opposed? Any abstaining? The motion carries to accept the minutes with the changes that were sent to me online, and they will be posted on the Internet very soon on the IACC Website.

I'd also like to bring to your attention that we posted all of the meeting materials for this meeting up on the Website.

So, if you go to the IACC Website and go to “Meetings and Events,” the first item there you'll see a link to materials, and there's an extensive list of materials.

We didn't expect everyone to read it all, but we wanted that information to be available both to our Committee members and to the public.

We've put together quite a list of publications on comorbidities with autism that we thought might be helpful, as well as some guidelines.

And this time around we also put together the list of all the publications that went with the science update that we'll have this afternoon from Dr. Insel, because I know that the public and the Committee are very interested in that science update each time. And so, we thought that would be an additional help to have a ready link to many of those publications, but please feel free to access all that information.

And if you have a laptop or an iPad or other tablet here, you might be able to access it right here in the room.

So, are there any other housekeeping questions before we move into the agenda?

Dr. Linda Birnbaum: Susan, this is just Linda. Should I be able to see you all now on the videocast?

Dr. Daniels: To see what? The materials?

Dr. Birnbaum: Yes.

Dr. Daniels: The materials are on the Website. So, if you're watching the videocast, if you have a second screen or an iPad or something, you can go to the IACC Website and access the materials there. But on the webcast, you'll be able to see what's up on the screen, which will be the slides and video of our faces smiling as we talk about all the exciting progress that's going on.

Dr. Birnbaum: All right. I'll go get

someone to help me get that up. Thanks.

Dr. Daniels: Anyway, I will turn things back over to the Chair.

Dr. Guttmacher: And just to prove that even though I tried to skip the minutes and the roll call, that I'm not completely against procedure, I would remind folks in the room to please use your microphones so that those on the phone can hear us. But at the same time, remember to turn your microphone off because this room is limited as to how many mics can be on at once. So, just try to remember to do that so people on the phone can fully participate.

Dr. James Battey: And you have to push the button to activate the mic.

Dr. Guttmacher: Good point. You'll see the red light come on, and then remember to turn it off.

So, Dr. Perrin, the floor is yours.

Dr. James Perrin: Thank you, Dr. Guttmacher, and thank you very much to the members of the IACC. It's a real privilege and honor to be here and to present a variety of pieces of work.

The agenda has changed a few times under Susan's direction, and we had a recent paper in *Pediatrics* that Susan asked if we might start out by discussing, which is a paper looking at racial and ethnic differences in the use of subspecialty care by children with autism.

My colleague on this work is Sarabeth Broder-Fingert, who is a fellow with us in pediatric health services research and doing a lot of work in this area.

So, the background, of course, for this issue is that a number of people have shown that there are substantial racial and ethnic differences in different aspects of care.

David Mandell and colleagues have shown that African American children receive the diagnosis of autism later than do white children. And along with that, they have later access to early intervention and other services.

Some of the reports coming out of the CDC and the Federal Maternal and Child Health Bureau by Michael Kogan and others have shown, among other things, that African American children with autism, or their parents, more accurately, report more delayed or foregone care; they're less likely to have a usual source of care; they have difficulties getting needed care.

And I found of particular interest in the, I believe, 2007 data, that among the relatively large number of children who were reported as losing their diagnosis of autism, that's not quite a fair statement.

This is really children whose parents said that at one point they had a diagnosis made of autism, but they no longer had it at the present time. That was the category we're talking about.

There is a very, very high

overrepresentation of African American children in that population of children who lost their diagnosis.

We can't tell from the database why, what's the rationale for this change. It's of interest that these were young children, as well as older children. We thought it might be more older children that had been classified in some different way, but in fact that doesn't seem to be what's going on here either.

So, this is again an interesting finding from the work that's been done here, I think, and requires some more exploration. And there are higher rates, we believe, of comorbid conditions among children and youth with autism.

So, our specific study that was reported in *Pediatrics* recently came from the large Partners Healthcare programs. Partners Healthcare is a large integrated health delivery system in eastern Massachusetts. It includes the Massachusetts General Hospital, the Brigham and Women's Hospital, and a number of other hospitals, as well as a series of community providers of one sort or another.

So, it's a very large integrated delivery system, and it has a research patient data registry, which we explore together to understand more about the use of subspecialty care within this population.

So, I need to be very clear in saying I have no idea really whether Partners is generalizable to the rest of the country. But, nonetheless, what we looked at were children and youth who had the diagnosis of autism spectrum disorder in our database, and this is more than just claims data.

I don't want to get too far into the differences between claims data and clinical data, but this is actually a fairly rich database, which gives a lot of information about the diagnoses that children have, as well as the ability to go back to medical records to confirm those diagnoses and to look at other services that children received.

We looked at children ages 2 to 21 years with visits from the years 2000 to 2011, and we examined rates of visits with three major groups of providers: gastroenterology and nutrition, neurology, and psychiatry/psychology.

We also looked – along with visits – at laboratory and other procedures done, including some gastrointestinal procedures – endoscopies primarily – EEG and neuroimaging, sleep studies, and neuropsychiatric testing.

Let me tell you what we found. We had about 3,600 children and youth in this study. So, it's a pretty sizable population.

This population was predominantly white. We had in that group about 188 African American children and 240 or so Latino children. It was, as you'd expect, predominantly a male population.

So, this is one of our examples now of

the findings with respect to the visit rates by children with autism to these three groups.

So, we considered the white children as sort of our reference group here and are now comparing, in the third column, African American children with white children.

And these numbers are – just to explain them – if you have a 0.32, so if you had a number of 1 there, that would be equivalent rates/visits to GI/nutrition.

0.32 basically means that African American children were about one-third as likely to have a GI/nutrition visit as were white children. Latino children were approximately the same, 0.32.

If you look at neurology, the story is somewhat the same. About half as likely for African American children to have seen a neurologist at any point in their experience with our system of care. And for Latino children, about 0.40. And then again, similarly for psychiatry and psychology, i.e., consistently across these three major groups of subspecialists beyond autism care providers, a substantially lower rate of use of these subspecialists by African American, Latino and, to a degree, other nonwhite children.

I'm sorry, I'm going backward. This is now looking at structured procedures rather than visits, and the story is somewhat the same here.

We don't actually have a pointer; is that right? It's not that important. I think I can go through these. If you'll forgive me, I'll try to explain them.

So, let's look primarily at column 3, which is the African American children. And if you look, then, the first group of GI/nutrition studies, stool studies – colonoscopy is one of the types of investigations done by gastroenterologists. Endoscopy, another kind of study done.

And basically what you see here is that

for these children, the rates of these studies were between half to a third to almost a fifth of the rates of white children. So, that's really what you see here.

For Latino children with the exception of stool studies, endoscopy, the actual procedures were done at about a quarter of the rate of white kids in the study.

Neurology, this is now looking at EEGs. I put this in parentheses, because this is not statistically significantly different here because the rates of EEG in the total population were actually relatively low, somewhat to our surprise.

But nonetheless, you can see here again that there are lower rates of these particular studies for African American and Latino children.

And then if you look finally at some of the psychiatric testing, neuropsych testing and developmental testing, you can see that again there's some differences here of interest.

Latino children were far more likely to have developmental testing than were white children. That's one of the areas where there was somewhat of a change from what we had happen in the earlier kinds of studies here.

These are really most of our results. So, in summary for the results here, we certainly see major differences by race and ethnicity in subspecialty service use.

I do want to go back, for those of you who are more interested in some of the scientific aspects of this, to really say that we controlled in all of these analyses for age, for gender, for insurance type, which is our best evidence of social class that we had. We didn't have other income information on these families. So, all these are controlled for those variables here as well.

So, again, we do find major differences by race and ethnicity in subspecialty service use in our population.

What are some of the potential explanations? There really may be substantial differences in presentation or severity. That is to say, children who are African American may present substantially later, they may present with more severe evidence of autism, or they may present with less severe evidence of autism. We don't actually have good information to answer that kind of a question.

And those differences in presentation might explain the likelihood by which people are looking for comorbid conditions in that population.

There may be differences in physician or parent referrals. A number of the referrals to subspecialists actually occur through parents rather than directly through autism specialists or primary care physicians. So, there may be differences that way, too, that parents may themselves refer at different rates in different race and ethnicity populations.

And there may be differences in followup referrals. We've done some other studies with our population looking at likelihood of succeeding in getting your referral done if a referral has been made and found major differences there, major barriers, really, to getting yourself to the referral physician or referral health program there.

So, those are some of the potential explanations for what we have here. We don't have good reasons to know the real answers at this point.

So, that's the first presentation, and I would love to have questions.

Dr. Guttmacher: Yes, let's pause before we go into the second presentation. Any questions, thoughts folks have about this one?

Tim.

Dr. Timothy Buie: Jim, did you have control data of patients without autism to see if there were differences in referral there, or is there a way to compare that outside the autism population or other subspecialties?

Dr. Perrin: So, we actually have not looked at that, Tim. It could be done with the database, certainly.

So, I would assume that we would find some similar results if we were to look at the use of, for example, endoscopy by race. Within our total population, I would expect some differences.

I think it might be interesting to look at the inflammatory bowel disease population and just see if in that population there are real differences in rates of endoscopy.

My guess is that all kids with IBD do get endoscopy at some point, but I wonder if there are real differences there by race and ethnicity in the sense of use of services over time.

Dr. Larry Wexler: Thank you, Dr. Perrin. What were the proportions in terms of the public insurance versus private insurance by race?

Dr. Perrin: They are dramatically different, certainly. So, African American kids have a much higher rate of public insurance than do white children.

As I said, we controlled for that difference in all of our analyses. So, we have done the best we can to eradicate the differences in insurance in presenting the results that we have.

And when we did that, I might say that the differences actually expanded rather than contracted.

Dr. Wexler: Was there any consideration to look at kids' ZIP Codes?

Dr. Perrin: There was consideration to look at kids' ZIP Codes, and we may actually go ahead and do that, because I think that's a really interesting issue about whether geographic access makes a real difference here.

I think it does, but we have not looked at that. It's a wonderful question.

Dr. Wexler: The work that we've done with that would indicate it's not geographic access, it's socioeconomic access.

Dr. Perrin: Well –

Dr. Wexler: Anyway, that's something maybe for the future. Thank you.

Dr. Guttmacher: David.

Dr. David Mandell: Are there enough differences in the odds ratios for the different procedures that might allow you to use that to explore potential reasons for other disparities?

So, for example, are – so, some of these procedures are tests that are much more evasive than others. Some may be more likely to be covered or to require prior authorization or not require prior authorization.

And I wonder if by looking at the differences among those procedures you might be able to tease out some other reason for the disparity.

Dr. Perrin: That's a great idea. I think we'll take that back, and I think we can do that.

I think we probably do have sample sizes large enough to look at that. So, that's a wonderful idea. Thanks, David.

Mr. Scott Robertson: So, it seemed one of the most surprising findings to me anyway was the fact that there was a higher use of some of the services.

Was that surprising also to you in the investigation? I mean, did you expect to encounter that at all?

Dr. Perrin: So, if you look, the only one for which there were significant differences – in sense of higher – was the use of developmental testing.

And we did not, you know, we do have some measures of severity which we've included in the analysis, but I actually do not believe that we included IQ or developmental status as a control variable.

We certainly could go back and look at that, and that's probably worth doing. My guess is that plays a real role here.

Mr. Robison: Do you know in a general sense what the ratio is of services provided in the Partner system for black versus white kids as a whole, excluding autism?

Dr. Perrin: So, I think we do know a number of things. The answer is basically yes.

We know a number of things about variations in care and it – the major variation that we have found really has been in the use of subspecialty care.

And in general, what we have found is that and this may get back to the geographic or social class differences as well – that it's not easy to get to see our subspecialists. That's the simple way of saying it.

For those of you who know the geography of Boston, for example, we serve a lot of communities up in the North Shore, and you have to come across some rather unpleasant bridges to get into downtown Boston and to see our subspecialists.

So, we've learned from doing some focus groups with parents that that's a huge barrier to really coming to see our subspecialists.

So, indeed, we do think there are some problems that a number of communities face with respect to the utilization of subspecialty services not specifically relating to autism.

Mr. Robison: So, you're saying that general services are similarly provided for black or white kids, and it's only specialty services like autism where there's a significant disparity?

Dr. Perrin: No.

Mr. Robison: Is that right?

Dr. Perrin: No, no, no. You know, I think that as an institution we provide very similar services across the spectrum regardless of race, ethnicity, and insurance status and so forth.

On the other hand, you know, thinking about the chronic illnesses of children, which are obesity, asthma, mental health, and neurodevelopmental disabilities including autism, those are all conditions that are really, we think, worse in poorer communities.

And we know that we're providing high-quality care, but we also know that to really solve the problems, for example, of obesity in Chelsea, Massachusetts, it's more than providing high-quality medical care.

Mr. Robison: Right, yes. I didn't mean to suggest that you weren't providing high-quality care.

I guess what I was trying to understand is where does the system break down for those communities? And it sounded to me like you're saying that in the case of black families in this study, that they seem to get GP-level care, as it were, at a similar level to anyone, but the specialist care they do not get. And I hear you suggesting that perhaps transportation is a barrier, and perhaps there are other barriers.

And I also heard you suggest that, in fact, some of these groups might have worse problems with these subspecialties, and yet they are underrepresented, which would make the shortfall actually even worse than their statistics would show.

Dr. Perrin: I actually agree with that. Right.

Mr. Robison: Okay.

Dr. Perrin: And I think that the, again, from our working with families and listening to their stories, what they really tell us are several things.

One is that there are real barriers to getting to see the specialists. That there are language barriers that occur in our subspecialty units. There are just the physical barriers of getting there.

Families who are poor, obviously, as we

know well, it's difficult to take the time off from your marginal employment to be able to take your child in to be seen.

And families may not agree that this is really a valuable referral. They may not see that this is something they want to do. So, we hear all of those things from our focus groups with families.

Mr. Robison: If we were to say that MassGeneral represented kind of the best standard of care in the Boston area and there are many providers that are maybe a step down from you in capabilities and so forth, is there any study that looked at whether some of the shortfall that you show in your data is picked up by other providers, maybe community providers who don't have the resources that you do, but may happen to be closer to the people who need the services?

Dr. Perrin: So, I think – I wouldn't say that we provide the best care in the Boston area, but we certainly provide high-quality care in the Boston area. And I think actually, in general, children get high-quality care in Boston. Although, we did some studies years ago that might imply you get better care in New Haven or Rochester than in Boston.

I don't want to go back into those old studies of ours, but to really respond to your question more directly, I do think that we have a problem more generally in this country of getting adequate specialized services to children who need them in many of our communities.

I think this is just one example of that, frankly. But if you look across the country given the difficulties of really recruiting high-quality young people into many of our pediatric subspecialties, it's a big issue for us at this point that we don't have a good distribution of pediatric subspecialties.

So, I think there are some real areas that we're not providing high-quality care. We need to improve that. I think that's absolutely critical that we do that.

Dr. Guttmacher: We have time for one more, and that's Idil.

Ms. Idil Abdull: First, thank you very much, Dr. Perrin, for coming here, for doing this.

I was just wondering if you were able to differentiate parent – you said there is a parent referral and a physician referral.

And I grew up in Boston. So, I figured whether you lived in Roxbury, Dorchester or whether you lived in Newton or Brookline, if you were a family who was aware of what your child needed and you were educated about it, I think you would walk needles on fire to get it.

I think the problem might be, and I wanted to know what you thought and what your study said, but I think the problem might be the parent education.

In communities of color, there isn't a lot of – there is autism awareness per se, but there isn't autism awareness in what interventions are available, what services you should get, how important it is to get the subspecialty.

And then the other area is a lot of low-income kids have Medicaid, and Medicaid has a long waiting list. A lot of specialists don't even take or they take a certain percentage and they cut off. And so, that could be another barrier.

And I know John is here, but that's a CMS problem. I think when we say your child has a medical condition, we should be able to get it because it's medically necessary whether you have, you know, private insurance or public insurance.

And I thought, you know, I'd like to know what you think about that and if it's patient referral versus parent referral.

Dr. Perrin: So, not in the area of autism, but in other more general and looking at about a dozen subspecialty areas, we actually are trying to understand more about how some of our communities understand referrals, and it's sort of half and half.

That is to say, part of it really is that the physicians aren't necessarily following up adequately to make sure the referral took place. And we have tried actually to put in better systems in our unit so that there are staff whose job is just basically to monitor the referrals at that level, but a large part of it is the parents.

And it's a complicated issue. I mean, it's not so simple as knowledge, frankly, because parents have many things on their plate. A lot of things to worry about.

They're worried about getting food on the table and clothing for their children and shoes on and so forth. So, they have to set some priorities as to how they're going to spend their energy and their time.

And we hear that from parents, that I'm not sure this referral, frankly, is that valuable to me. They don't quite say it in those terms, that's my term there, but we do hear that as well as one of the other pieces of that. So, there are many barriers that we have put into place with that.

Our specialists all take Medicaid, but there was a study that you may have seen in Chicago 2 or 3 years ago which looked at really what happened when people called for appointments to pediatric subspecialists – I don't remember which institution – and indeed if they said they had Medicaid insurance, their appointments were 4 months off. And if they had private insurance, they were seen within 2 weeks, things like that.

So, there are many more subtle discrimination that occurs at that level, too. And, you know, I can't say we don't have evidence that occurs in our system.

By the way, we did look at that. We couldn't document that in our system, but I think that is happening, too. So, there are many barriers for referral to take place.

Ms. Abdull: Just to follow up then, were you able to ask those families, and were they able to say that they were – they had parent education or they had advocates advocating and telling them that, you know, it's important to get this or this is what autism – it affects the whole body.

I just find that it's parents who are well informed are most likely if they are told it's important, they are most likely to get the services rather than patients who are just told by the doctor. Because the doctor, you see them 10 minutes.

But if you see advocates and parent support groups and if you have access to the Internet, and low-income families probably don't have access to the internet, don't own a computer, it just makes it that much harder.

Dr. Perrin: So, you're on to something terribly important. And in my own career, we have involved parents from the beginning in essentially all the research and all the other work that I've done, and it's tremendously valuable to do that.

I think it's really very much worth saying that in poor communities, parent advocacy programs are far less well developed than they are in middle-class communities. We all know that.

And you are right on target that if you had someone in your community whom you trusted who said this is a valuable thing to be doing, you're more likely to do it. So, I couldn't agree with you more.

And it certainly is true in the poor communities that I work in; parent advocacy is developing. We're working on that, actually, but it's not nearly so rich as it is in our middle-class communities.

I think it's a critical issue. Thank you for raising that.

Dr. Guttmacher: I know there are more questions, but we better move on so we can have questions about your next talk.

This is one of real interest to the Committee as well, and that's speaking about parent-physician efforts to address wandering.

Dr. Perrin: So, I did not put together any slides for this. And I know you have a panel this afternoon on this issue, and it's a tremendously important issue, of course, that really does need some attention.

I think I just wanted to make a few comments in this area. That's why we labeled this a "commentary" rather than really a presentation.

First of all, I think all of us – clinicians, parents, advocates – know how painfully common wandering and bad outcomes of wandering are.

We were all very surprised and humbled by the IAN study that came out a year or 2 ago that just looked at the IAN sample and really showed that half the children in that sample had a history of wandering. A quarter of them were wandering enough that it was really dangerous, worrisome to their health. So, this is clearly an issue for us.

And I'll wear my pediatric hat in a moment and say that it's an area that if you look back to the 2007 Academy of Pediatrics' work on guidelines and recommendations for the diagnosis and treatment of autism, wandering is not even mentioned. I mean, it just is not there in the 2007 report.

I'm sorry about that. I think that's unfortunate. It has certainly developed in the consciousness of families and certainly developed in the consciousness of practicing physicians.

We are very much interested in increasing physician attention to that. The new toolkit that is out has some information both for physicians and that physicians can give to parents about wandering. And we're really encouraging that this be used as actively as possible.

I know that this group has done some really valiant work to develop a V code for wandering. 40.1 I believe it is, or something like that.

And then I asked our staff to see if we have any evidence from any of the databases that we have access to, to figure out whether it's being used. And the simple answer is no.

We don't have, you know, first of all, most of the databases we have are not recent enough to show that there's been any use of this V code. And then the little data that we do have, the few data that we do have would suggest it's really not being used.

I want to be somewhat honest in saying I'm not surprised, because I believe that the use of V codes, and I'm getting a little bit into arcane knowledge here, but the use of V codes by clinicians is pretty marginal.

And the reasons for the lack of use of V codes is almost no public or private payer will reimburse physicians for a V code listed as a service. So, there's very little incentive for doing so.

The primary incentive would be if you're in a place that really wants to focus on wandering and understand something about the rates of wandering, then I think we could probably provide some incentives, but I'm not optimistic that this will be a strategy to really substantially increase attention to wandering.

I do think that there are some really exciting things happening in the area of developing electronic methods for monitoring young people.

I think what we'd like to do is get the pediatric community and family-practice community to become increasingly knowledgeable about that so that we can really provide information to families as they're addressing this problem and, frankly, preventing this problem.

Shouldn't be addressing this problem.

Should be a preventive side given the high prevalence of wandering among young people. So, that's really the main comment I wanted to make.

I know you're going to have a much more robust discussion this afternoon. I'm sorry I can't be here for that discussion, but I hope my colleagues here will tell me what comes out of it because we're really very much interested in that.

Dr. Guttmacher: And since we will be having that robust discussion this afternoon, let's not launch into it now because that would probably take the rest of the morning, but specific questions for Dr. Perrin about what he's had to say?

Ms. Alison Singer: So, thank you, Dr. Perrin, for being here today and for talking about this really important topic.

I think you are correct in saying that pediatricians are part of the prevention side of wandering.

And our goal as advocates who are focused on wandering, is to prevent wandering. Then, the other side is to focus on first responders and recovery after the kids wander.

One piece of data that was not included in the study published in *Pediatrics* – do you have that chart that I sent? Can we put that chart up?

Okay. Well, I can just tell you that one of the pieces of data showed that over 51 percent of the families who participated in the study said that they had not received any anticipatory guidance about wandering from any health care practitioner.

Only 14 percent said that they had heard about the potential for wandering from a pediatrician. Far more are hearing about it from the advocacy community.

So, I understand that the AAP created this factsheet, and that's great. I know it's part of the autism toolkit. But it's my understanding also that physicians are required to pay for the autism toolkit, and so the uptake of that product has been pretty low.

What can we do as an advocacy community to encourage physicians, pediatricians particularly, to include wandering as part of the anticipatory guidance, to talk about resources that families can access, and make referrals for families whose children have already exhibited the potential for wandering?

Dr. Perrin: So, I think there are a number of things that we can work together on in this area.

As I said, I think the pediatric community did not really, frankly, was not very aware of this in the mid-2000s. And I think this has become something we've certainly, as a community, have become substantially more aware of.

And we certainly would like to see it as part of the kind of anticipatory guidance that we provide to families raising children with neurodevelopmental disorders that are children likely to have wandering.

You know, our strategies for advising pediatricians in what to do obviously include things like toolkits, but we do a tremendous amount of different kinds of continuing education nationally and locally as well.

Autism is an area that's extremely interesting to pediatricians at this point. So, if we put on a conference that relates to autism, we usually have a lot of people in the pediatric community who come, because they're desperate for more information about how to do this better.

We have involved parents a lot in a number of those continuing medical education activities as well, and they are very articulate about the kinds of issues that they are dealing with.

So, you know, I think we have some work to do to make pediatricians more and more aware of that, but I can assure you we're really committed to making that happen.

Ms. Singer: So, would it be possible for us to have a panel at the next AAP conference focused on autism and wandering?

Dr. Perrin: I can't promise you that, but I can certainly say we can put that on the table. We can put in those proposals.

I am embarrassed to say that the next NCE has already been planned about a year in advance. So, we're talking about a year from now, but let's work on it. I'd be happy to try to make it happen. I can't make any promises.

Ms. Singer: Or if anyone drops out, I'm sure we would be happy to –

Dr. Perrin: Sounds great. Sounds great.

Dr. Guttmacher: Thank you.

Dr. Perrin: But we should put that on the table. That's a great one.

Dr. Guttmacher: Walter.

Dr. Walter Koroshetz: So, just a question. A lot of the journals will have, you know, editorial pages where, you know, important topics can be broached in a short fashion.

Would IACC be, you know, welcome to submit something like that to *Pediatrics*?

Dr. Perrin: Sure. Absolutely.

Dr. Koroshetz: Because that would

Dr. Perrin: Absolutely. And we can help advocate for that. We can't, again, make promises of publication, but we can certainly advocate for that. It's a great idea.

Dr. Coleen Boyle: Jim, on one thought, too, I know I shared this with you offline, but maybe to take that guidance that's available for parents and actually turn it into guidance for practitioners and get it out of the toolkit and maybe available and, you know, more focused. So, that might be one way of just bringing more attention to it.

Dr. Perrin: You know, I think that's really worth exploring. There's a lot of guidance to parents in the toolkit, and what I have been wondering about is how much of that could go up on our parent Website, which is healthychildren.org.

And that might be really worth our trying to make happen. I, again, need to explore what our opportunities are there.

Ms. Abdull: I was wondering if – first, I wanted to – I don't know if everybody knows, but just last night I sent it to you, Dr. Daniels, there was a child right here in D.C., Northeast, that wandered. A 7-year-old autistic kid that wandered off and died. The police found him dead.

And I think what Alison said is good, but I was just also wondering if it's possible for the AAP to send out just even a little paragraph to their chapters, statewide chapters, something about autism and wandering and because each, you know, chapter has a listserv.

And if they can repeatedly just every few months send that listserv out and say please talk to your families that have children with autism about wandering and just even to be aware – a lot of parents are not even aware that their children can take off, have no fear of safety, and will wander into danger.

I think waiting for another year or for another AAP meeting, that's a day too late and more lives to be lost.

I think we can do something at least with your chapters and just – because you have – in Minnesota we have – the AAP has their meetings, and it couldn't hurt to give them 5 minutes to talk about autism and wandering.

Dr. Perrin: Yeah, I think so; it's a broad issue here, and I'd say I think we do a pretty good job at the Academy in communicating both with families and with the pediatric community.

We also think we can do an even better job, and we're actually in the midst of redoing our communication structure so that we are getting the messages out to both of those constituencies, parents and pediatricians.

I hate to say it, but I've learned how to tweet. I'm an old person, but I've been able to do that, and this is exactly the kind of thing that I tweet, that kind of notion. So, we're trying to get the message out in a whole bunch of different ways.

So, any more you can think of, let us know. We'll try them, I promise.

Ms. Abdull: So, will you tweet today –

Dr. Perrin: Yes.

Ms. Abdull: – after the meeting about us?

Dr. Perrin: I will tweet today, absolutely, about this issue.

Ms. Abdull: We'll look forward to that.

Dr. Perrin: I can assure you I will tweet about this issue. Absolutely right.

Ms. Lyn Redwood: Thank you so much, Dr. Perrin. The National Autism Association, as you know from riding the bus this morning, also has a toolkit that's wonderful, that has a lot of resources for families.

And if it would be possible for the AAP

to look over that toolkit, there might be some information in there that you could get out to your membership.

I know it's very complicated, in terms of what type of devices are available, and there are strengths and weaknesses for each of those.

It's really sort of a multifactoral approach to also include training for first responders. So, there's a lot that really needs to go into this initiative training the parents, training first responders.

So, if AAP could possibly look at some of the products that are available now and utilize those to get out to their pediatricians, that would be a nice way to not have to replicate the wheel when another organization has done a lot of work in this area already. Thank you.

Dr. Perrin: That's exactly the kind of collaboration we'd like to do. Perfect. We'll recommend, for sure.

Dr. Guttmacher: So, let me ask we're going to now move to our panel on comorbid conditions in people with autism.

I'm going to ask Dr. Perrin to put on yet another one of his hats, and that's his hat as head of the Clinical Coordinating Center for the Autism Treatment Network, to really give this introduction to the panel in terms of the sort of overview of comorbidities among patients who are served by the Autism Treatment Network. Jim.

Dr. Perrin: Thank you very much, Alan. If I can have the next – do I do the next slide, or do I just – well, there we go. Great.

So, yes, I hope you will forgive me for wearing a few different hats, but I'm happy to put on this hat for a while.

But I would also say that some of you know that my career has been really based in understanding the issues that families face raising children with a variety of chronic health conditions.

And I am not an autism specialist. I really came into this because of Tim Buie and some other people who corralled me one day and said, “You know, I got something to work on and would you help out?” But you will see my interest has really informed a lot of the work of what we've done with the Network over time.

So, the Autism Speaks Autism Treatment Network currently has 17 sites in North America, 2 in Canada, 15 south of the border.

We are dedicated to improving care for children with autism and their families, and the Network began with an emphasis on medical conditions among children with autism.

Tim will be far more articulate than I am later on about some of the gastrointestinal issues in children with autism, but it was that kind of thinking that really led to the formation of the Autism Treatment Network.

We also serve as the Autism Intervention Research Network on Physical Health, the AIR-P, which is funded through the Health

Resources and Services Administration, Maternal and Child Health Bureau, and has allowed us to expand the work of the Network to do a substantial amount of clinical research.

We have 16 or 17 studies either finished or ongoing within the Network, and it has also allowed us to put a good deal of energy into improving our efforts to improve care and to disseminate the findings in our new care models much more broadly.

I am going to talk almost entirely about one piece of the ATN work, our registry, which we began the really beginning of the Network.

Much of what I'm going to talk about was reported in the November 2012 supplement to *Pediatrics*. I want to stress that supplement is open access. So, anyone can get copies of any of the papers in this supplement by going to the *Pediatrics* Website. You don't need a password or anything else to get to these papers.

The registry that we have within the Autism Speaks Autism Treatment Network currently has over 6,300 children with data. It's a really large and robust repository of information.

The supplement that we published also includes clinical practice guidelines and Network research reports of a variety of kinds.

I'm not going to spend time today talking very much about those parts, but I'm going to limit it mainly to registry data.

So, what are some of the coexisting symptoms and conditions among children with autism?

Obviously, gastrointestinal nutrition symptoms and disorders are very much discussed, talked about, and increasingly studied.

There are large variations in diet preferences and diet supplements that children with autism are involved with. There are questions about gut motility. Does it vary in important ways among children with autism?

And obviously, one can think about the fact that there are neurotransmitters in the gastrointestinal system. And, therefore, if there are neurotransmitter problems that are part of the larger syndrome of autism, are those also affecting neurotransmitters in the GI system? We need more information in this area.

There's a lot of interesting information recently about the immunology of the GI symptoms – GI system, excuse me – and whether that variation in immunology and how we understand that may also influence how children with autism respond to things being placed in their intestines.

And finally, there's a lot of interesting work in the areas of the microbiome. There was a recent paper that I think many of us saw in, how do you say it, *PLOS*, which looked at variations in the microbiome among children with autism.

I think these are all areas where we are in desperate need of more information. These are very, very important areas to be working on.

And certainly in the Network, we would love to have the advice of the IACC on the kinds of areas that you would prioritize that you think ought to really be studied in this relatively large population that we're working on.

Seizure disorders are common among children with autism. Sleep disorders are common among children with autism. A variety of other mental health conditions are common as well.

I haven't put down metabolic and mitochondrial and other disorders. I haven't put down endocrinologic disorders. Those are also ones that are really worth addressing and understanding more among young people with autism than we currently do.

I think what's changed dramatically is that, a decade ago, people basically said, “Well, you know, children with autism just always had gastrointestinal problems; they just don't sleep well; it's just part of the autism.”

I believe that as a community of parents, advocates and clinicians, we've really changed that.

I think we've come to the point to recognize that these comorbid conditions really do exist. We have a lot to understand about what they are.

As a clinician, I've been teaching for 30 or 40 years that we don't refer to children as "cystics" or "leukemics," but we refer to them as "children" first who have leukemia.

And the same thing is true with autism, that children first really does mean that we need to think about the whole child and all the aspects of her development, her physiognomy, et cetera, that may be relevant to trying to make a child healthier, happier, and more functional over time. So, I think this is part of that broader effort here.

Let me now present some of the data that we have from our registry. This is first some data on the prevalence of gastrointestinal disorders.

And the first numbered column here is asking parents, did your child have any of these in the past 3 months at all? And the last column is, were these problems actually chronic, i.e., did they persist through the 3 months and really before that time as well?

So, needless to say, the chronic column is a little bit lower rates than the – any in the last 3 months rates are.

It's important to note that half of the children in our sample have had GI problems in the previous 3 months of one sort or another, and you can see the rates. Constipation is consistently in every study the most common one, but diarrhea, pain, nausea, and bloating are also really quite common in our population and in most populations of children with autism.

I forgot to mention a little bit about the demography of our population that we're examining here. This is a predominantly younger population of children with autism.

About 55 percent of the children are preschoolers; 45 percent are ages 6 and up. So, you will see evidence here that is more is somewhat skewed to younger populations of children with autism. And I believe that may be true for GI disorders, or it will be more true when we get to some of the other conditions.

This is just a table which shows you a number of studies relating to the prevalence of GI disorders in children with autism.

It's striking – the range varies from 9 to 91 percent in these studies. So, a tremendous variation among them shows how difficult it has been to do really high-quality research in this area.

I think it's worth noting that many of these studies do not have comparison groups here.

So, if you have a red tube, you have a comparison group here. And with the exception of the one study on the far left there, the one by black here, all the other studies that have comparison groups have substantially higher rates of GI disorders among children with autism than in the comparison population. So, we will continue to have debates, I think, over the next year or 2 or 3 as to whether there are higher rates of gastrointestinal disorders among children with autism.

I don't think there's any debate about the fact that they're pretty common among children with autism. They need to be attended to, they need to be treated, and they need to be managed.

Let me move on to the notion of seizure disorders, epilepsy in children with autism.

This is now looking at about 2,500 children in our sample.

In this population, about 16 percent had a history of seizures. We found no difference by autism diagnosis or by gender. We did find higher rates of seizure disorders among white and Latino populations here.

We also found IQ differences. That is to say that children who had had seizures had somewhat lower IQs on average than children who had not had seizures.

And we also found that parents reported higher levels of skill loss among children with seizure than children without seizures. So, this is clearly an important problem in autism.

There are a lot of really very important issues to understand here, which include some of the issues of interictal discharges, basically children who have seizure-like foci on their electroencephalograms but do not have frank seizures.

At this point, we still don't know enough about this population to know whether this is a clinically important difference or not and one that really merits some treatment. It's just one of a whole series of questions for which we need to have better answers.

There are also, by the way, among our population of children with seizures, higher rates of gastrointestinal problems and higher rates of sleep problems. And no great surprise, there are lower Vineland adaptive scores among the children with seizures and also less good performance on a number of child behavior checklist scales in this population, too.

Moving on to sleep disorders, previous reports had basically said that about a half to two-thirds – I'm sorry – half to three-quarters of children with autism have sleep disorders, whereas it's only about one-third of children without autism. These are a lot of variations again among these reports.

In the paper that we have in the supplement, we looked at about 1,200 children, this time limited to ages 4 to 10 years partly because of the available measures on sleep disorders that are available.

And we categorize these children as "good sleepers," no evidence of sleep problems; children with mild sleep problems, which is about half the population; and children with moderate to severe sleep problems, which is about 18 percent of the population.

Again, these are younger children, I'll remind you, and we did find somewhat lower rates in the older population. Children over seven or eight had lower rates of sleep problems than did the 4- to 5-year-olds in this population.

Again, we have several studies that we've published, as well as ones reviewing the data from the registry which show a very strong association of sleep problems with problems in daytime behaviors.

Again, not a surprise. The children who don't sleep well at night are much less likely to be able to perform well in their following daytime tasks, to really work well in their educational programs.

And their parents also typically haven't slept very well the night before, either, and they're also not so good in their jobs – whether they're in the office or whether they're parenting at home if they haven't slept well.

So, this is really, frankly, a critical area where we can and are doing better than we used to.

I'm going to move on a little bit to psychiatric symptoms. Again, previous reports suggest that about a half to three-quarters of children with autism have attention deficit hyperactivity disorder.

Of course, one of the problems here is that *DSM-IV* basically discouraged you from making a diagnosis of ADHD if you already had a child with a diagnosis of autism.

That has changed with *DSM-5*. I think that's one of the steps forward in *DSM-5*, by the way, but it does mean that I think any analysis of claims data or any analysis of even clinical data is likely to underestimate the prevalence of things like attention deficit hyperactivity disorder among young people with autism.

For our work using here the Child Behavior Checklist, we do find high rates of high scores on the attention subscale, and about one in five children have high rates on the hyperactivity subscale as well.

So, even using those kinds of measures, we find moderate to high rates of disorder here.

This is another study using the National Survey of Children's Health. That's another Perrin. That is not me down there on the bottom. So, I'm happy to show this other Perrin's work in this context, but it's really worth noting the high intersection of a variety of these conditions.

So, this is now the National Survey of Children's Health 2007. You can see at this level the prevalence of these conditions within the study sample. About 7 percent with ADHD, 5 percent behavior conduct, 4 percent depression/anxiety, half a percent with autism, but the comorbid behavioral conditions with any of these primary conditions is very high.

Look at autism. Almost 77 percent. Comorbid physical health conditions also very high 39 percent among children with autism. Fairly dramatic findings, we believe, about how frequent these conditions are.

And the top figure is an attempt to show you the overlap among all of these conditions. A really quite dramatic overlap, and we need to understand more about those connections.

We looked to psychotropic medication use within our population, and here it's worth noting that only 10 percent of our population of children under the age of 6 actually used any medication. By the time you're an adolescent, it's about two-thirds of the population are on some medication.

The medications that were used in our population are predominantly stimulants. So, even though a child may not have a formal diagnosis of ADHD, it's not at all uncommon for the child to be on stimulant medication.

The next major group are SSRIs, atypical antipsychotics and then alpha-agonists. Those are the four major groups of medications in the children in our population.

Of interest, the coexisting reported psychiatric diagnoses in our sample are actually quite low; about 19 percent have a coexisting condition of ADHD, about 8 percent anxiety.

And I think what this means, quite simply again as what I said a few moments ago, which is that many children are treated without having a formal diagnosis of these coexisting psychiatric disorders. And I think that's an area, again, where we need to be more sophisticated as we move forward in trying to understand the co-occurring conditions here.

And there's a lot of work to be done about whether medications are equally effective in children with autism who are exhibiting ADHD symptoms, as an example, or anxiety.

Do the treatments we have for anxiety really work just as well for a child with ASD as they do for children without ASD, or not?

We have some evidence that suggests maybe yes, but we also have some evidence that suggests perhaps not.

Let me end with a couple of slides showing you some studies of quality of life. And I don't want to go into too much detail here, except to stress here we're looking at a particular measure called the Pediatric Quality of Life measure. And these are basically, in many cases, parent reports of their understanding of the child's quality of life.

These are often known as proxy indicators of quality of life, but the important thing here is to really stress that children with autism compared to children with other chronic health conditions have with very few exceptions, a far less good quality of life.

So, this is a fairly dramatic impact on quality of life, more so in certain areas than others. So, less so, for example, in physical health quality of life, but look at social functioning here and compare that to children with other chronic conditions in general. It's a very, very dramatic difference here.

And by age, I just wanted to stress that the quality of life – this is now entirely within the population of children with autism – goes down substantially as you age with almost no exception. Pretty consistent that quality of life diminishes for young people.

It's an area where we ought to be measuring better and understanding what are the ways that this happens and what we can do to make some differences there.

Let me just end with a couple of quick things about what we're trying to do within the Autism Treatment Network and our related Autism Intervention Research Network on Physical Health.

We do provide an initial evaluation for all children in our Network, and this is not only children going into our registry – an assessment of medical, including psychiatric coexisting conditions, gathered from parent report, parent concerns, clinician reviews, and some screening measures. We can do better than we're doing, but we're doing a good job already.

An area that we're focusing on right now within the Network is a substantial expanding involvement of primary care physicians in the ongoing care of children with autism and really collaborating, and it gets back to our wandering discussion.

And we are also doing a lot of quality-improvement activities in the Network, which is really trying to improve constipation, sleep, and wait time.

Currently, we're moving on to some other areas, because we really had some very exciting success in those areas, but I wanted to stress how the network is really dealing with some of these issues of coexisting conditions.

We also provide a lot of practice support in the family toolkits. I've listed just a few here, but we have published practice guidelines for constipation, for insomnia, for medication use for ADHD symptoms.

So, we're really trying to change how we think about these conditions in clinical practice.

We've produced a lot of toolkits, and I've just looked at the numbers. We've actually had about 55,000 downloads of toolkits from the ATN through the Autism Speaks Website over the last couple of years' time. So, we're delighted those toolkits are getting some use.

What's some of the needed research that we must have at this point? I have listed a few of my favorites, but let me tell you, we would love to have your favorites here, because it will help us to inform what we're doing with them.

Certainly there's a need for surveillance and identification of conditions, these comorbid conditions in both community and hospital settings.

We need to move from the fact that the child has autism as their primary diagnosis to recognizing that there are many other aspects of the child that need to be attended.

We do need to understand how to involve primary care providers much more actively in medical conditions.

The average pediatrician in practice spends a lot of her time dealing with constipation. We believe that they can do that with constipation in children with autism as well.

We need to understand that these variations, variations in rates of psychiatric comorbidity, for example, may reflect major differences in the phenotype and the underlying disorder.

We could become a good deal more sophisticated over time if we understood how to categorize children better using some of these characteristics of comorbid conditions.

We need basic studies in these conditions, and we desperately need some really careful clinical trials and novel treatments. Thank you very much.

Dr. Guttmacher: We'll give Tom a little time to recover his sleep deprivation. We thought we would hold the discussion until the end of the panel.

So, we'll move on next to Tim Buie, who besides being one of the founders of ATN, is a true expert in terms of GI disorders in people with autism.

He directs the gastrointestinal and nutritional services at the Lurie Center for Autism at MGH. Tim, welcome.

Dr. Buie: Thank you. I'm so grateful to be invited to this August group of people, and I don't know who to express my gratitude to. So, I will say "thank you" to all of you for having me, and I'm certainly very happy to be here.

This is certainly a cause that's very dear to my heart. I don't have financial interests to disclose to you today.

I'm going to start by showing you two children that I take care of. And I have permission to show you these videos from their families.

This is Joanna. And Joanna is a pretty typical girl who comes to my clinic as a gastroenterologist. Although I'm not so sure you'll see it, she's a girl who has episodes.

And her parents described her as having multiple episodes a day, usually more than 30 times a day, where her process would be disrupted.

And this is what you see happening with her. She has this episode where she stops her work, she turns away, she changes her body position, she postures, she tilts her head.

And she, I think, had a wonderful pair of parents who said this is not something that we think is behavioral; we want her to have a medical evaluation.

They went to see a neurologist. And the neurologist suggested that this might be a seizure. She had an EEG. And during these episodes, she had no electrical abnormalities.

They thought about the possibility of a tic disorder. Nothing really seemed to fit her story.

So, they saw Margaret Bowman, who is the neurologist who directed our program. And she said, “I'm not sure that this is neurological. I think that you should go see a gastroenterologist.”

You know, I think it's hard when you watch this video to understand why that might fit, but she was really correct, and she, I think, had the idea that after having dealt with many of the patients that we have seen, but here's a girl who never touches herself on the stomach, she doesn't throw up, she doesn't pass gas, and it's not evident that she has stool problems. Why should we think about this behavior as a gastrointestinal issue?

The next girl is similar. And I'm interested that I'm giving you videos of two girls here when we have so many boys.

I'll tell you the boys have these behaviors and often are much more aggressive and much more violent.

This is Becky, and she has kicked a hole in the wall that's had to be repatched. This is her typical bedtime at this point.

She really can't lie flat. She's very uncomfortable when she is asked to go to bed. And that's a good hint for us that there might be a problem, but she also has a variety of other issues.

She's quite aggressive. She will kick and bite. She will also be quite self-injurious, and so she'll bite herself. She's got chronic wounds on her arms that I'll show you in a moment, chronic picking disorder.

And so, she also was taken to her local doctor, and the local doctor said, “I don't know what this is.”

The parents felt that she was in pain. The GI doctor in her area was not willing to do a workup because they felt that she was too unsafe to put through endoscopy or other testing.

However, they tried placing her on an anti-acid medicine considering acid reflux, and she didn't do better.

And so, I think my big lesson from her is that here's a girl that they actually thought about the problem, and they tried to treat the problem, but she didn't improve. Yet, she still had the problem, and I think this is an important step to go forward with in terms of all of these medical issues. Well, I tried to treat this, and it didn't get better.

Joanna has a classic condition called Sandifer syndrome. It's a posturing event that relates to acid reflux. It's described in children under age 5. It's not described in 19-year-olds, but you've seen one.

This is her esophagitis. She has very severe esophagitis with frank bleeding, chronic scarring. She's in a good deal of pain.

And we proved that her episodes were acid reflux related by doing a Bravo pH Probe study where we looked at acid coming back up into the esophagus during the time that we were watching her. And over three-quarters of her episodes were associated with times that she was actively refluxing at the time, which I think is a tool that's been really quite helpful for us in evaluating some of these kids who have unusual behaviors or episodes as we sort them out.

This is Becky, our girl flailing herself on the bed. And you can see that she has areas on her face where she's constantly picking. That wound never healed for more than a year. And these bite marks on her arms that never healed. She's got lymphedema, which is poor lymph flow back because she's had chronic scarring in those areas because they've been so chronically injured.

And this is her esophagitis. She's got really quite sore-looking areas and evidence of chronic scarring. And this is after she has been on standard anti-acid treatment to try to treat acid reflux.

This is her when she's been maximized on her acid treatment. She really gets healing of the wounds. Her self-injury went away completely. And interestingly, she's now in a residential program in New Hampshire.

When she has something go wrong, her behavior goes wrong. And they know that medically she's out of whack when she starts developing this self-injury, because it's under control entirely when her medical issues are managed adequately.

So, gratefully, Dr. Perrin has already covered some of the topics in terms of how often these problems happen, and I just want to highlight a couple of them because, as he said, the frequency that's reported in a lot of the literature is as low as 9 percent and as high as over 70 percent.

But most of the studies that show low prevalence of gastrointestinal issues are retrospective studies where the chart review may not have captured the historical information.

The majority of the more recent studies

that have shown high frequencies of gastrointestinal issues in autism have been studies where they were trying to capture the information and asking more questions about gastrointestinal problems.

Perhaps the best study that Dr. Perrin referenced is Dr. Valicenti-McDermott's paper, where she had that comparison group of patients who had other developmental disorders and children with typical development to compare to. And what she found was certainly that in the children with autism, there was a much higher frequency of gastrointestinal issues compared to those other populations that she evaluated.

We looked at this in a database, the AGRE database with the Vanderbilt Group. And in that study, with a very poor questionnaire seeking gastrointestinal complaints, we found about 43 percent of the kids with autism had issues compared to their unaffected siblings.

More recently, Nancy Minshew's group in

Pittsburgh reported 61 percent. You saw the ATN data that reports about well at least, over 50 percent of the children with issues.

And so, there are very few negative papers that suggest that the issues in gastrointestinal issues are less frequent than kids who are not on the spectrum, and they usually have a critical problem with how their analysis was done.

One of the important papers, I think, that came out in the last couple of years was a paper from USC by Phil Gorrindo and his group. And one of the things that I think is really an important highlight for them is that they found that GI problems were common.

They also found that the parental observations or concerns were usually very, very good – that when the parent was concerned there was a problem, the provider found a problem. And that was, I think, extremely helpful, but what he said was that his questionnaire missed 25 percent of kids with chronic gastrointestinal symptoms.

So, you can't simply rely on a questionnaire. You have to have good providers who are thinking about the problem really and looking at the problems that we think about, or we will continue to miss children because we're not putting their issues and their presentation, which may be different, into the proper perspective.

Do you know anything about particular conditions which are gastrointestinally based? Well, I think we still have a lot to learn here. And, partly, these are very small studies that are done.

Lucarelli reported a food allergy prevalence of about a third of the children that they tested. They did not have preceding symptoms that suggested they should have allergy testing.

Dr. Horvath, here in the Baltimore area, found that there was a family report that about 50 percent of kids had symptoms that were suggestive of food sensitivity or allergy. That was parental report.

And we know that the extension of that is that parents then will look to diets and look to solutions to see if there are improvements.

And some of the studies say that about 40 percent of children on the autism spectrum will be tried on some type of a dietary restriction. Casein-free, gluten-free diets with milk and wheat restriction are the most common, but there are many others.

There has been a paucity of information in the last several years to sort of confirm this idea that food sensitivities might be a problem.

However, Trajkovski, who is in Macedonia, has actually a larger number of patients that he's looked at than the Lucarelli study, and he still supports that about a third of the kids that he tested had evidence of food allergy by IgE testing.

So, by what we call good, standardized

testing, there still is a pretty high frequency of food allergy, especially when we think about the frequency of food allergy in the general pediatric community to be somewhere around 5 percent. So, it's remarkably higher in this population as we can test for it.

And sensitivity is hard to identify. So, there may be kids who have other problems with foods that aren't allergy based or celiac based but that are very real effects of those foods.

One hot topic in adult literature right now is the idea of nonceliac gluten sensitivity because we can't digest gluten in a normal way or other issues.

And so, I think we're learning that we don't have a big enough window to open up and look at these possibilities or test for them in a proper way.

Dietary studies haven't necessarily borne out that a dietary intervention will work globally for children with autism.

A couple of studies done by Knivsberg in Norway did show benefit of a gluten restriction.

In fact, he almost completely replicated his experience with 8 of 10 children getting better when they put them on dietary restriction, but notably those were children who had markers for gluten sensitivity.

And so, he had a good candidate population who might respond to diet based on his markers, and they seemed to get better. They were both open studies. So, all providers knew that they were put on a diet.

When the studies have been more observational, there are often reports of improvement.

But when you take the observational capability or the knowledge of what's being exposed out, the studies aren't quite so good.

So, when Dr. Elder did her study, she did a double-blind study where the providers and the caregivers did not know whether those children were receiving casein and gluten; she could not show that there was a benefit in a dietary restriction.

Notably in her study, and same for Susan Hyman's group that's been reported, an abstract group, they weren't trying to select a group of kids who might be good candidates for dietary restriction either. They were trying to apply it to children with autism and see if those kids would do better for the diet.

So, one of the big questions for us remains: Could there be a subgroup of patients who might respond to a dietary restriction? And I would contend there might be.

We're actively doing a study at MGH right now where we're looking at casein-free, gluten-free diet in children who present with chronic gastrointestinal symptoms.

So, we think that subgroup of kids who present with issues may be better candidates to respond – that's still actively enrolling – but we think that there may be an explanation for why the studies so far haven't shown a benefit so far.

There are certainly issues beyond dietary allergy that might account for why kids do better with certain food restrictions or changes.

Rafail Kushak is our Ph.D. enzymologist, and he has shown in several papers now that lactose intolerance is extremely common in the patients that we evaluate.

His most recent paper was in *Autism* in 2010. And what it showed was that the frequency of lactose intolerance in children who were undergoing endoscopy, so they had significant GI symptoms; the frequency of lactose intolerance was over 60 percent, which is outrageously high, but it was quite high in nonaffected children as well.

And I think that represents the group of kids who are bad enough to undergo endoscopy, but it's something that we know could be a cause of symptoms; and it's an easy, treatable impact in many of the children who are on milk-containing products to try to at least alter what we do for them; and some of them will be symptomatically better if we do.

I think part of the reason that the GI issues have been in sort of question is there was controversy from the beginning.

And when Andy Wakefield talked about the idea that vaccine injury might be a cause of the GI symptoms and autism, it really almost set back the GI community to some extent.

They were afraid to get involved in looking at causation and the like, but we have needed to go back to some of that original work that he did and others in the time to say many of the patients that he evaluated did have inflammatory change in the bowel, they had colitis, they had other issues that might be responsive to treatment.

And if we take out the idea that there is some other cause, we'd still need to look at this community of individuals that he saw and treated and that there may be a group of patients who got inflammatory issues in the bowel.

More recently, in following up on that idea, Walker published an idea that there are certainly differences in gene expression of some children who have autism and inflammation compared to other noninflamed individuals who undergo endoscopy.

So, there's a lot of ongoing work at the gut immunology level and gut gene-expression level and even trying to characterize how many of the children have inflammation in the gut that may need treatment, and I don't want to lose that for getting tangled in debates.

One of the reasons we tried to leave that debate was we wanted to try to get as best information out as we could based on the pooled data.

And so, we did a consensus gathering of

both gastroenterologists and neurologists, other involved experts in the field, and we were able to put together two consensus papers.

One was written by the GI members of that consensus group, and the other was written by the entire group, and it really tried to vet the literature at the time of gastrointestinal problems in autism. And we were able to come to some consensus about what we should do going forward as pediatricians with the community.

And so, I want to just touch on two or three of the key statements that we've put out in this statement.

One was that children with autism who present with GI issues deserve to be worked up. I know that sounds pretty simple, but it doesn't happen in a lot of communities. And it's because of this perception that kids with autism have these problems, we're not going to pursue that.

This is their Bill of Rights, and they really need to take this paper to their doctors to say, “Look, here's the advice; you deserve a workup.”

And I think that's of value. And I think the idea that at least gastrointestinal conditions reported to be common in pediatrics will also be seen in individuals with ASD.

I don't need to tell you that these problems are more common in ASD, because they're common in pediatrics.

And as Dr. Perrin talked about, the pediatrician is taking care of constipation quite frequently in the general offices. He needs to expect that he's going to be taking care of individuals with autism with those same problems. So, really we need to be looking.

We don't think that we have data yet to support a specific entity in autism that is GI related.

I think the most important statement that

I want to highlight is our Statement 6, which is that individuals with ASDs and GI symptoms are at risk for problem behaviors. Because I think the biggest miss that happens in the pediatric office is that, if the child doesn't come in and say, “I have constipation, Doctor,” or “I have heartburn, Doctor,” then they may not think about that as an underlying medical condition.

Many of these children will present specifically with behaviors. Some of them give me good fortune. They'll walk into the freezer, pick up an ice cube and put it on their chest, or they'll tap on their chest as if they are saying, help me here, but I don't always get that help.

And so, I need to look at these problem behaviors as additional symptoms that could impact how I do a workup.

I'm almost done. I think there are some interesting unsettled questions. Could gastrointestinal issues actually have a contribution to the causation of autism?

I think that's a very interesting topic right now. And where a lot of the research is going is looking at whether environmental factors or nutritional factors will affect the intestinal microbiome and that these byproducts of the biome might be actually having their own transmission effects and affecting how the brain works.

This is really where our work as gastroenterologists is going to go in the next 5 or 10 years, I think.

And the idea that inflammation might be a trigger for brain effect may be that inflammation anywhere in the body could be a trigger for brain effects.

These don't have to be brain-based issues certainly as germane to gastrointestinal problems.

I touched on bacterial flora disruptions may alter behavior. There's some amazing information in the last month or 2 about this in unaffected patients that we need to really look to. And that's another conference that I'd love to come and give you sometime if you'd welcome us back.

There are certainly some gene links. I think that the idea that there may be biomarkers such as the MET gene polymorphism, that was strongly associated with gastrointestinal symptoms in the children who had autism, meaning that there is an underpinning of gene issues that then may be triggered.

I think that still remains an important question, but there are probably combination issues of both gene risk and environmental factors.

We found that digestion issues were beyond lactose intolerance. And this is a paper by Brent Williams in *PLOS* where he went on to talk about the disruption of the bowel flora as well, but we found a variety of carbohydrate digesters that were not normal in our intestinal biopsies when we looked at them. Certainly that could be an underpinning that could cause bowel flora disruption.

And I can mention two papers that have talked about the disruption of the bowel flora to specific bugs. And the idea that these are bad-guy bugs and we must kill them is not necessarily the next step that we need to pursue.

We need to understand why bowel flora disruptions cause some of these changes and really address those underlying issues before we pull out another tool to attack.

I think gastrointestinal issues are common, and we need to consider them to be potentially more common in certain settings.

That it's important that we need to look at problem behaviors and really need to think about referring those children on to specialists who see children and have some comfort with that.

And lastly, I think that the behavioral

component in particular needs to be considered by the pediatrician -- that those behaviors probably have a medical underpinning.

There are times when we can't manage patients because they are aggressive or because they are a danger to themselves. And under that setting, I think it's totally reasonable that they may require psychopharmacological treatment or hospitalization to control those behaviors.

However, as we think about these patients, we can't leave the idea that something triggered those things off that may have a medical underpinning.

And if I can ask you to keep that in mind and spread that word to other providers, it's the best thing that I can do as a caregiver. That's one of the messages that we did say in our consensus paper.

Part of the issue is that we who do this a lot, I think are pretty good at what we do. And we know what we think and we're good; but there are a few of us, and the best way we can do better is to educate other providers to do as well as we do.

And so, I think that we are interested in the cause, we're interested in sort of getting to that, but one of the major supports that needs to come going forward is how do we educate other communities how to manage these patients.

We just gave a talk for the adult GI nurses about how to do endoscopy on difficult patients.

These things need to happen so that patients can be taken care of safely, because then they'll be taken care of.

I thank you for your time.

(Applause)

Dr. Guttmacher: We thank you for yours. I know Lee Wachtel is not at her seat. Is she someplace else in – there you are. Good. Welcome.

And she is the medical director for the

Neurobehavioral Unit at the Krieger Institute in Baltimore and will be speaking with us about catatonia in autism spectrum disorder, an area that she has particular expertise, including self-injurious behaviors.

Dr. Daniels: Just a housekeeping note. We didn't schedule in a break, because we had so many presentations.

So, if anyone feels the need, just slip out really quick and come back.

(Unintelligible conversation)

Dr. Lee Wachtel: So, I'm going to be a little bit different and stand up here. I actually didn't realize there was a seat for me at the big table, but this works out a little bit better because I have some videos at the end that I need to be able to close this program for and then scroll through to find. So, hopefully it's okay that I'm up here at the front of the room.

So, I'm very thankful for having been invited today to speak with you about catatonia in autism, which is a topic that I have been intimately involved with over the past several years and I think is of great importance to the autism community given the relatively large number of patients afflicted with this condition and the severe impact that catatonia can have on our patients with autism and their families.

Similar to the previous presenters, I don't have any conflicts of interest or financial disclosures to relate to you.

And the objectives of this presentation are four. And initially I'd like to discuss the concomitance of catatonia and autism spectrum disorders specifically and then take a step back and explain what is catatonia. Because I actually think that for many people that's somewhat of an esoteric term that isn't commonly recognized.

Then, I'm going to go through a range of symptoms and talk a lot about the different faces of catatonia, including what I call the two sides to the catatonia coin, both psychomotor-retarded and psychomotor-agitated symptoms that we see very frequently in this patient population.

One of the additional goals of the presentation today is to gain further support for ongoing research in this topic of study.

Okay. So, catatonia in autism. Why is catatonia in autism spectrum disorders really of any importance or interest?

Well, interestingly, in the past 13 years, there has been a growing number of case reports of individuals, both children – the people in the back can't hear? Is that better? Is this better? Awesome. Okay. All right. So, let's start again.

Why bother talking about catatonia in autism spectrum disorders? In the past 13 or so years, there has been a growing number of case reports of individuals – both children, adolescents, and adults – who have been diagnosed with catatonia in the context of autism spectrum disorder.

And in addition to that, there have been three large international population-based studies looking at the incidence of catatonia in individuals with autism spectrum disorders.

The first one was from the UK by Lorna Wing and Amitta Shah looking at over 500 children and adults with autism, finding that a large percentage of those patients, 17 percent, actually met criteria for catatonia using classic catatonia rating scales.

Wing and Shah also developed kind of their own additional catatonia criteria that we're going to talk about a little bit later, which are also very relevant for individuals with autism.

Five years later, there's another study out of Sweden placing the incidence of catatonia at 12 percent, a little bit less.

Interestingly, you'll pay attention to the numbers in the parentheses as some of the concomitant issues that these patients had, including half of them with self-injurious behavior, nearly 20 percent with extremely aggressive and violent behaviors, and nearly a quarter with tics. So, notice the behavioral and motor concomitances in these patients.

And then very recently just last year from the United States from the University of Michigan is a study of 101 patients under the age of 18 with the range of diagnoses listed there with nearly 18 percent of those patients meeting criteria for catatonia.

And the paper from U Mich actually comments that only two of those patients actually had been previously diagnosed prior to enrollment in the study.

And that really emphasizes one of the most important elements of catatonia in autism, and that is the underrecognition and, therefore, delayed treatment of these patients.

So as much as we think that catatonia in autism is kind of a new thing, like of the last decade, actually if you look back into the history of medicine, which I always find very informative because it often gives us a lot of lessons that we otherwise wouldn't have become aware of, you can find that catatonic symptoms and autistic symptoms in pediatric populations were actually noted as early as the 1920s.

This is a quote from actually the 1960s, but among pediatric neurologists in Russia symptoms of catatonia in autistic patients were noted well before the recent interest in this topic.

And you can see in orange some of the symptoms that I just highlighted: posturing, freezing, food refusal as a symptom of negativism, being inaccessive, negativistic, agitated and a tendency to self-injury, beating their head against the wall or on the bedstead, and other self-injurious behaviors.

This will be very important as we get to the end of the talk and talk about agitated self-injury along the spectrum of catatonic behaviors.

Okay. So, lots of times when I talk about catatonia, people are like, “cata-what?” Like, “What is that? We haven't heard about that.”

So, I think I'd like to step back and give a little bit of the history of catatonia and some of the basic symptoms from kind of our general psychiatric and neurologic literature.

So, there are references to catatonia, or what was initially known as “congealing,” as far back as the British literature in the 1500s, but catatonia was actually given its name, that term was coined in 1874, by a German psychiatrist, Karl Kahlbaum, whose contribution was to take discreet motor, vocal, and affective symptoms and put them together in one disease entity.

And I highlighted those three groups of the motor, vocal, and affective symptoms, because that's what we're looking at today with our patients.

Okay. So, common catatonic symptoms – there are a lot of catatonia rating scales that you can find in the literature.

I think that just going over the most common symptoms is probably a little bit more useful than reviewing some of the unusual German terms that are not readily accessible, but these are some of the common symptoms that we see.

So, patients who are immobile or rigid, who do not move, who assume unusual postures – posturing like a tree, twisted, upside down, limbs askew when you try and move them their body feels like lead, and they cannot be moved. Patients who are stuporous, mute or who have a marked decrease in previously acquired communicative skills; patients who engage in echophenomena, echolalia, or echopraxia, with the latter being repetition of motor pantomimes as compared to words or phrases.

Grimacing, grunting, physical excitement, and combativeness – interestingly, the agitated element of catatonia is often overlooked.

Many people, when they think of catatonia and if you think of how it might be portrayed, for example, in the media, think of the patient who's sitting like a bump on a log. And you kind of get that image even from one of these classic textbooks.

The catatonia textbook here of Max Fink and Mickey Taylor has a Rodin sculpture where, well, there's not a lot of movement going on there.

Both of those textbooks, by the way, are excellent resources. The General Catatonia textbook, and the *Catatonia in Autism Spectrum Disorders* edited by my colleague Dirk Dhossche, University of Mississippi. The top textbook is actually downloadable on the Internet.

But anyway, so we usually think of the patient who is catatonic as not moving, stuporous, and stuck in position, but what's really important to recognize is there's a whole other flipside to catatonia – patients who are highly physically agitated, who are engaging in repetitive, stereotypic behaviors for no apparent operant reason, and often can get themselves in very hot water from those repetitive behaviors as we'll see in some of the pictures.

Negativism – so we've talked a little bit today about GI issues. And one thing that we often see in patients with catatonia in terms of negativism is food refusal, which many times is chalked up and worked up as a GI issue.

There must be some reason GI wise that they are not eating, but it's very important to recognize that patients who are catatonic oftentimes do not eat, do not drink.

They also become so negativistic that they also cannot void without medical assistance.

And then less rare, but we've certainly seen this, is autonomic instability. Catatonia can turn malignant or lethal where you have both thermoregulatory and cardiovascular instability. And that condition untreated has anywhere from a 10- to 20-percent fatality rate.

So, catatonia actually has a very challenging history. And I think it's just sort of now coming back with the *DSM-5*, which is the first venue where catatonia has actually been given its own diagnosis and recognized and where you can diagnose it as a separate syndrome independent of a mood disorder, schizophrenia, or a general medical condition.

Unfortunately, shortly after Karl Kahlbaum, Kraepelin came onto the scene, and catatonia was pretty much kind of stolen or subsumed into the schizophrenia diagnosis, leading to decades of error where basically it was assumed that if you had catatonic symptoms, you must be schizophrenic. If you're not schizophrenic, you cannot have catatonia.

So, many of these patients were not appropriately recognized, and that's an issue that continues today but is gradually getting a little bit better, as we now know that catatonia can be found with kind of four general rubrics of etiologies: medical concerns, neurological etiologies, psychiatric, and drug related.

So, catatonia has been extensively documented. And I took out a lot of historical photos because initially when I learned that this would be podcasted, I wasn't sure if the families would consent that their images be used.

Actually, everybody consented. So, it was not overly necessary, but I kept the historical images just to show you this is a range of historical images largely from France, Germany, and the United States showing a range of catatonic presentations preserved as sketches or old types of photos.

And I just draw your attention to these images, because we see the same in our patients with autism today presenting with catatonia: the posturing, the unusual mannerisms, stupor, unresponsiveness, funny mouth movements, grimacing, and then the severe self-injurious behaviors.

You note the gentleman up at the top corner engaging in repetitive head banging and then the little guy down at the bottom, whose self-injury has progressed so severely that he's effectively mutilated his entire face.

Okay. So, history today – history returns in today's autism. Actually, the very first patient that I worked with who was autistic and presented as profoundly catatonic was this young lady at the top.

And I think it was very serendipitous, or maybe it was just to make it very clear to me what was going on, that she literally presented and was deposited onto my unit in that condition as a clear mirror image of this catatonic patient from early 1900s Germany.

So, you see the posturing of the limbs, the arms – the legs askew. If you tried to move them, you would not be able to. It would be like trying to move a steel bar.

You see the posturing of the hands. You see this patient with a pillow under his neck, which demonstrates a classic catatonic symptom of psychological pillow where patients keep their upper body and head up as if there was a pillow, kind of like as if you were doing an ab exercise, but usually you can't maintain that for more than a couple of seconds.

So, my patient has the same, although, she's also wearing a helmet because she had detached both of her retinas from repetitive self-injury.

And then you see the famous op du cirque and a patient from 1907 Germany and from one of our youngsters in 2011.

Okay. So, why am I bothering to talk

about this, and why am I hoping to kind of gather support and spread this knowledge?

Basically, because of the direct, severe impact that this condition has on many individuals with autism where the symptoms really strike at the core of the patient's functioning.

And so, you'll see several pictures at the bottom. First, I just want to go over some of the basic things that we see in these patients and why this condition can be so severe.

Patients with autism who present as catatonic may not be able to move at all. They may not be able to walk or go anywhere. They may be like my patient who was lifted and deposited onto my unit.

These patients stop eating and become dehydrated and significantly malnourished. Some of them are unable to void. They develop autonomic and thermoregulatory instability. And we've seen many who have developed severe tissue damage from repetitive self-injury.

So, this is really crucial, especially when you're kind of in the trenches admitting these patients and working with them, because these types of symptoms are going to land you in a lot of hot water and oftentimes transferred off of my behavioral unit into a more critical medical-care setting.

And you see a range of patients that we've worked with and a range of symptoms, patients who you see posturing. This man you can't see the bruising that well because the picture is not so clear.

You see two gentlemen with severe self-injurious behavior – actually three – but two of them whose faces are so swollen from repetitive hand-to-head self-injury that their eyes are swollen shut.

And then one of my other patients posturing, and the bowl of cereal under his head would be significant in that he was not eating it.

Additional vexing symptoms – before I talk about the Wing-Shah autistic catatonia criteria, I just point out I added another group of photos just to demonstrate some of the severe sequelae that we see in these patients.

So, again, you see the extreme – the agitation, the self-injury. This young man, not only is he in mechanical restraints, but he's self-restraining, and somebody else is holding him down as well.

We've seen a growing number of patients who have actually detached retinas and needed to have emergency eye surgery to maintain their vision.

And also had a very severe patient who was so self-injurious repetitively to all parts of his body that he actually developed blood in the urine.

So, all right – additional vexing symptoms and some of the symptoms that you see initially that often come to light in an office visit before things look really bad.

A lot of them are from the Wing-Shah autistic catatonia criteria, where it is emphasized that many of these patients become slow. They have difficulty initiating and completing tasks. You ask them to go get their shoes and their backpack and meet you by the door, and a half hour later you find them stuck in the middle of the stairwell.

They require excessive prompt dependence. Previously, a child might be able to get himself dressed, put on his pants and shoes and all that, and now you find yourself having to prompt him through every single step with every single step taking an excessively long period of time.

Many of the patients also become very passive and seemingly amotivated. Unfortunately, this initial presentation oftentimes is chalked up to, kind of, behavior – like, oh, well, okay, the behavioral protocol is not working anymore or the reinforcers aren't meaningful anymore. So, we have to go back to the drawing board and do like another preference assessment, or it's just the patient is being willful.

Many times we see this in adolescents. And so, I often hear that, “Oh, isn't it just an adolescent phase?” They don't want to do things, so they're resisting things and resisting demands.

Many patients will also get worked up for having a neurodegenerative disorder, which, unfortunately – we have not come across any of our patients with white matter disease – but the degree of impairment that the patients show can often lead the neurologist to go down that avenue.

And this is an artistic example of a young man who developed catatonia. And you see that prior to the catatonia he was actually a pretty good artist. I think he was about 10 at that age when he did that drawing. Certainly a lot better than I could draw.

Two years later you see the major regression in his artistic skills. And then you also see – now, that of course is when he was not posturing on the floor unresponsive. Which it wasn't a 24-hour event, but you do see one example of that at the bottom.

This is another example that a speech and language pathologist prepared for me related to a 20-year-old who experienced a significant catatonic regression. And before we got to a point where he was unresponsive lying in the bed voiding on himself and needing to be spoon fed, they noticed these types of deteriorations: So, in April, the patient is able to read in 23 seconds this little paragraph – no problem. Two months later, it takes him 15 minutes to read a single word.

You also notice that he has difficulty forming the word with his mouth. Making the motor activity to get the word out requires a lot of prompting and cues in order to read the single word better.

Similarly, they looked at writing. And I think that probably most of us in the room, it would take us somewhere around 26 seconds to write a sentence of that length, which this patient was capable of doing before catatonia.

After catatonia, it took him 17 minutes to write a single word with 50 cues and extensive hand-over-hand prompting.

Okay. So, let's jump a little bit to self-injury as a symptom of catatonia. This is one of my favorite topics given that we've worked with many patients who have presented with self-injurious behaviors of no operant function.

So, I work in a unit where we deal with many patients who do have challenging behaviors for operant reasons because they want to escape from demands, they want access to attention, tangibles, interruption, function, what have you.

Some patients engage in high-rate repetitive, high-intensity, self-injurious behavior that has no operant function whatsoever.

You can work on an FA until the cows come home, and you're not going to find one.

These are the types of patients who, when you take them out of restraint and ask the attendants to go away, usually can hit themselves more times in the head than you probably could bring your hand to your face.

I have a child on the unit now like this who will engage in self-injurious behavior when he's removed from all of his restraint, with all four limbs alternating.

And we can only observe him for maybe 5 to 7 seconds at a time, because probably after about 5 or 10 minutes, he would succeed in knocking himself unconscious.

So, interestingly, self-injury as a symptom of catatonia is a concept that can be found as early as 1849 in Bell's first description of delirious mania. Delirious mania is kind of along the lines of agitated catatonia.

Unfortunately, I think that self-injury within catatonia was something that was largely ignored because of we talked about Kraepelin's error where -

Dr. Guttmacher: Lee, I apologize for interrupting, but we're running over. Can you try to finish up fairly rapidly?

Dr. Wachtel: Yes, I will.

Dr. Guttmacher: Thank you.

Dr. Wachtel: I mean, everyone went over some.

Dr. Guttmacher: Yes, but we're trying we need to get on schedule. Thanks.

Dr. Wachtel: Okay. I'm actually close to the end. I just need to show my videos.

Right. So, Kraepelin's error and then later absorption of self-injurious behavior within the theories of applied behavioral analysis, but not all self-injury has an operant function to it.

This is a theory that we initially

hypothesized in 2010 and have published on. There's actually an expanding international literature on this with colleagues publishing around the world.

And self-injury as an alternate symptom of catatonia was actually included in the update to the Fink and Taylor book that you saw the cover of before that just came out in January.

So, this all sounds kind of bad and disturbing. But what's really nice and what's really cool about catatonia and working with these patients is that treatment is actually incredibly simple.

There are catatonia treatment paradigms that have been well known and have been published since the 1990s. Basically, those paradigms include benzodiazepines in increasing dosages. Lorazepam is probably used most frequently, because it's most readily available, cheapest, and available in multiple forms.

It's not uncommon for patients to require very high dosages of lorazepam – 12 to 18 milligrams a day of lorazepam would not be unusual.

Although, if any one of us took that type of dosage, we probably would sleep until the next year.

Avoidance of offending agents, namely antipsychotics – I think that's a problem because many times in autism when you have problem behaviors, the knee-jerk reaction is to give the patient Risperdal or Abilify, in which case you actually may make this condition a lot worse.

Patients who don't respond to benzodiazepines usually will respond to electroconvulsive therapy or ETC.

Okay. Now, I am almost done, but I'm going to show my video because I think that the video is worth a million words.

Dr. Wachtel: Okay. So these are just two before-and-after videos. One of the patients you will recognize as the patient who was deposited on the unit. Sorry, there's no sound.

(Video playing)

Dr. Wachtel: So, I think you probably all from working in autism are pretty aware that what she's doing there is setting up the schedule and going over reinforcers and what she's going to be able to earn.

And we talked about ABA not being a treatment for catatonia. But of course when patients with autism are cured of their catatonia and still have other issues, ABA can be an extremely efficacious modality.

I'm going to show you one other video. This one is a little disturbing. This is probably the worst example of repetitive self-injury.

Notice that the patient is engaging in ongoing repetitive self-injury. She's actually already blinded herself in both eyes before she came to treatment.

(Video playing)

Dr. Wachtel: And there you see her after treatment. And the water bottle is significant because in comparison to needing to be spoon fed before, now she's able to feed herself.

And I'm just going to go back to my last slide if I can find it. It's this one. All right. So, we saw the video, and I included a couple of quotes from parents just to really emphasize the impact of this illness on families, as well as the parental perspective on treatment.

So, you'll see in the first quote a family commenting on how they felt that they lost their son twice – once to autism and again to catatonia. And commenting on the way that catatonia took over their son's life and functioning completely and how treatment finally gave them their child back.

The second quote is from a father who was dealing with ongoing repetitive self-injurious behaviors in his son for years. Basically, his son had to live in kind of like a “Michelin Man” type of restraint equipment with multiple attendants just to keep him safe.

And comments on being able to see his real child for the first time and being able to see his child experience periods of joy and happiness. And not even imagining how his child might feel inside after this type of treatment, since his child wasn't able to share for them, but commenting on what an improvement and what a change this was for the family.

Okay. So, take-home message. Catatonia afflicts many people with autism. Unfortunately, catatonic symptoms can wreak havoc on patients who suffer from catatonia whether they have autism or not.

The good news is that catatonia is readily and easily diagnosed. It's also readily and easily treated. Ongoing research is imperative.

Sometimes these types of situations seem somewhat impossible. But when you think that something is impossible, you should always remember the words of the White Queen who told Alice that she believed in six impossible things before breakfast each day.

And, well, if you prefer a dead French philosopher, this is the Marquis de Condorcet, who similarly noticed that we would probably do more things if we believed fewer things to be impossible.

Okay. Well, thank you so much for your attention.

(Applause)

Dr. Guttmacher: Thank you, Lee. Our final panelist for this panel is Richard Frye, who comes to us from Arkansas Children's Hospital Research Institute, where he is a pediatric neurologist and Director of Autism Research, and he's going to talk about immune and metabolic conditions.

Dr. Richard Frye: Well, thank you so much. I want to thank you for the invitation to speak to you today.

Today, I will provide a brief overview of immune and metabolic conditions related to children with autism.

Although I will not be able to do this very broad topic justice in 15 minutes, I will highlight some of the major findings.

What's really exciting about this topic is that many of us believe that a better understanding of immune and metabolic conditions will guide us to developing targeted treatments that will allow children with autism to achieve optimal outcomes, potentially complete recovery.

A lot of weight has been put on genetic causes of autism. As shown in this slide, a recent review demonstrated that only approximately 21 to 29 percent of the cases of children with autism have true identifiable genetic causes.

Thus, 71 to 79 percent of autism cases do not have a clear identifiable genetic abnormality.

As shown at the bottom of the table, there are many inherited metabolic conditions associated with autism.

However, the majority of these disorders have only been reported in isolated cases and are not found in a wide number of children with autism.

For example, of the 112 cases of mitochondrial disease that have been reported in the literature, only about 25 percent of them are related to known genetic abnormalities.

On the top of this slide, I have listed several of the metabolic and immune conditions that are prevalent in children with autism.

These conditions do not appear to be inherited, yet they may have a genetic component.

However, it's clear if there's any genetic component, that it is very complex and likely involves environmental triggers. What's interesting is what's shown on the bottom.

And that is that many of these metabolic abnormalities are found in certain genetic disorders that are associated with autism, even though the genes that are disrupted in these pathways do not directly influence these metabolic pathways.

This suggests that these metabolic abnormalities that are shown on the top may be the final common pathway that causes disease in some children with autism.

In our recent systematic review and meta-analysis, we found that the estimated prevalence of mitochondrial disease in autism is 5 percent, when considering the only three studies in the world that have examined prevalence.

These studies use what's called the “modified Walker's criteria” to define mitochondrial disease.

These criteria rely heavily on identifying genetic abnormalities or severe depression of electron transport chain function to diagnose mitochondrial disease.

However, many children with autism and mitochondrial disease do not have identifiable genetic abnormalities, and some have electron transport chain overactivity rather than underactivity.

Thus, the use of these criteria most likely significantly underestimates the true prevalence of mitochondrial disease in children with autism.

And this is given as an example in our meta-analysis when we looked at the percentage of children with autism that have abnormal biomarkers of mitochondrial disease.

You can see that the percentages are much higher for the abnormal biomarkers in mitochondrial disease and autism than the prevalence of mitochondrial disease that was estimated by the studies I just mentioned.

For example, 31 percent of children with autism have elevated lactate in the blood as estimated by six studies.

Other studies have used carefully selected control children to confirm that several biomarkers of mitochondrial disease were abnormal in children with autism as a group. And those are shown on the bottom.

Another criticism is that sometimes these biomarkers may be falsely positive.

In one of our studies, we found that the biomarker abnormalities could be verified at least half of the time for several biomarkers when these blood tests were repeated and that children with verified abnormalities also demonstrated other biomarkers for mitochondrial disease.

Overall, we found that three biomarkers demonstrated a high prevalence of being abnormal in children with autism even after replication.

In another study that's shown on the bottom, electron transport chain complex abnormalities were found in 8 of 10 children with autism as compared to age and gender match controls.

This study also showed that mitochondrial abnormalities could only be attributed to genetic causes in a small percentage of these children.

In our meta-analysis, we found that children with autism and mitochondrial disease had especially high rates of seizures, motor delays, gastrointestinal abnormalities, and cardiomyopathy, suggesting that these children are sicker than children of the general autism population.

This should demonstrate the urgency to identify these children early on and treat them, as they are at high risk for adverse outcomes.

In a recent study, we demonstrated that children with autism and mitochondrial disease had significantly lower scores on communication and daily living skills on the Vineland Adaptive Behavior Scale as compared to children with autism without mitochondrial disease, again indicating that children with autism and mitochondrial disease are more developmentally compromised than other children with autism and probably sicker.

Many studies have suggested that children with autism have abnormalities in redox, methylation, and folate pathways. The diagram on the top of this slide demonstrates that these pathways are highly interconnected.

Abnormalities in these pathways found in autism are indicated in red, and these are abnormalities that have been verified in a recent meta-analysis.

Other important studies demonstrate that the dihydrofolate reductase gene is associated with autism.

This finding is significant, as it suggests that specific active forms of folate should be used to treat these abnormalities in children with autism.

Other studies support the notion of redox abnormalities in autism. In several independent studies, Dr. Jill James and her group have verified glutathione abnormalities in multiple tissue types, including postmortem brain from children with autism.

Several studies have demonstrated oxidative damage to proteins, lipids, and DNA in children with autism.

Dr. James' group has also shown that redox abnormalities can result in epigenetic changes in children with autism and has specifically demonstrated hypomethylation of DNA in children with autism.

Such epigenetic changes can alter the expression of genes regardless of whether genetic code is normal or abnormal.

Perhaps most importantly, Dr. James' group has demonstrated that glutathione redox abnormalities can be easily treated with a safe and generally well-tolerated combination of Vitamin B12 and folinic acid.

Many studies have shown abnormalities in various parts of the immune system in autism.

Several studies have verified that some children with autism have increased prevalence of autoimmune diseases in their family.

Many studies have reported humoral abnormalities in children with autism. Studies have identified various autoantibodies in children with autism, including autoantibodies directed to brain tissue and to the folate's receptor alpha, just to name a few.

Some children with autism also have reduced immunoglobulins. This appears to be significant, as lower levels of immunoglobulin G correlate with more significant autistic behaviors in two studies.

Treatment with intravenous immunoglobulin has been reported in several small, open-label studies.

The results of these studies are mixed, but at least three have reported improvements in some children with autism with this treatment.

Several studies have reported proinflammatory cytokines in the blood, brain tissue, and cerebral spinal fluid in children with autism.

Most notably, Vargas, et al., demonstrated that proinflammatory cytokines were produced by reactive astrocytes that were associated with activated microglial cells.

There is other emerging evidence that brain microglial cell activation is important in autism.

Most notably, one study has reported that the microglia appear to be key in the development of disease in a Rett mouse model.

We believe that understanding abnormalities in the immune, mitochondrial, and redox systems is crucial to understanding the path of physiology involved in autism for several reasons.

First, these three systems are interconnected such that dysfunction in one system can cause dysfunction in another.

Second, recent studies have suggested that autism is caused by genetic and environmental interactions, and all of these systems are strongly influenced by both the environment and genetics.

Third, emerging evidence suggests that changes in gene expression by epigenetics are significant in autism and all of these systems are known to modulate gene expression through epigenetic mechanisms.

Fourth, and most importantly, these systems are amenable to treatment. So understanding these abnormalities and applying targeted treatments will allow many children with autism to achieve optimal outcomes.

Interactions between these systems are important to understand, and I will provide two examples.

We have recently demonstrated that the mitochondria in a subset of individuals with autism are sensitive to oxidative stress.

When we challenged lymphoblastoid cell

lines derived from children with autism with an agent called DMNQ that increases oxidative stress inside the cell, approximately 45 percent of the cell lines demonstrated an atypical mitochondrial response with a precipitous drop in reserve capacity.

Since reserve capacity is tightly related to cell viability, these data suggest that certain children with autism have mitochondria that are very sensitive to oxidative stress.

The cell lines with atypical mitochondrial responses are highlighted as red lines and red symbols in the graph.

In addition, we found that pretreatment of these cell lines with abnormal mitochondrial responses with a potent antioxidant, N-acetylcysteine, eliminated the atypical response of the mitochondria to oxidative stress, indicating a potential treatment.

To confirm this pattern of mitochondrial abnormalities, we measured mitochondrial function in fresh immune cells derived from 35 children with autism. We found the same pattern of abnormalities in 34 percent of the children.

Children with atypical mitochondrial response had more severe developmental problems, including poor communication, daily living, and socialization skills as measured by the Vineland Adaptive Behavior Scale, indicating that these children with abnormal mitochondrial responses were more developmentally compromised.

Another example of where these systems interact is central folate abnormalities.

The main root for folate to enter the brain involves the folate receptor alpha. This transportation mechanism can become dysfunctional due to autoantibodies to the folate receptor alpha and/or mitochondrial dysfunction, two abnormalities that have been shown to affect children with autism.

Recently, we demonstrated a high

prevalence of these autoantibodies in children with autism. This high prevalence has been confirmed by an independent group in Belgium.

An important aspect of dysfunction of the folate receptor alpha is that many children with autism are amenable to treatment with high-dose active folates such as folinic acid, which are generally very well tolerated and safe.

In two studies, for example, 11 to 20 percent of children completely recovered from severe autism with folinic acid treatment.

Large improvements in autism symptoms have also been documented in several case series, including a large controlled case series we recently published.

We are currently investigating the efficacy of folinic acid for autism in a large, multicenter, double-blind, placebo-controlled trial.

This study will also examine whether key biomarkers such as the folate receptor alpha autoantibodies can predict which children will respond to this treatment.

To summarize, we strongly believe that these immune and metabolic disorders are extremely important to investigate further.

There are many key questions that still need to be addressed. Most importantly, we must understand how we can best treat these disorders in order to achieve optimal outcomes for children with autism.

In our recent review of research trends in autism, we demonstrated that these areas of research are on the rise, but the number of studies are still about 10 times fewer compared to more traditional areas of research in autism such as genetics.

Thus, there is an immediate need to substantially increase funding for these important areas of research so we can better understand the underlying pathophysiology that affects children with autism, develop more effective treatments, and even prevent autism from developing in some children.

In this way, the IACC can help move research forward by making strong recommendations in order to achieve optimal outcomes for the estimated 1.5 million children in the United States with autism.

If you remember one thing from my talk, it's that at least a subset of children with autism can completely recover or at least greatly improve with targeted treatments of these underlying immune and metabolic conditions.

If just 10 percent of children with autism recover with safe and inexpensive treatments such as high-dose folinic acid, this would translate to 150,000 children in the United States.

I thank you for the opportunity to present today, and I'm always available for questions and to help out any way I can. Thank you again for taking the time to listen to my presentation.

(Applause)

Dr. Thomas Insel: Okay. I'm going to take over from Alan. We're almost an hour past where we should be on the schedule, but I wanted to make sure you all had a chance to hear each of these presentations because we've got four extraordinary experts at the table.

And this is a discussion we haven't had before. Much of what we've just heard has actually not been talked about at the IACC in the past. So, I thought it's worth taking the extra time.

I'm going to suggest that since we have a lunch break coming up that was scheduled for an hour, that we just compress that and that we take a little time for discussion now.

I know that there will be some talk about what we need to do about what we've just heard. I'm going to suggest we leave that until the end of the day for the business of the Committee and we use the time – maybe 10, 15 minutes now – to just take advantage of the experts we have at the table for further questions, clarifying questions, questions about what you've heard without impinging any or much further on the subsequent speakers, because we have lots of other things to hear today.

So, let's take if it's okay with the Committee, about 15 minutes now to discuss. And then I'll cut this short at that point, and we'll move on with the rest of the agenda knowing that we'll pick up some time during the lunch break. John.

Mr. Robison: I'd like to preface my comment by saying that I really appreciate the presentations all of you have brought us. They were all insightful and good.

It troubles me greatly, though, that I heard time and again children with autism this, children with autism that.

We know that autism is a lifelong condition. We know that childhood is only one-fourth of the lifespan, and logic tells us that talking about children with autism is talking about one-quarter of the autistic population.

I heard in one of your presentations, for example, how there was a precipitous drop in quality of life. The quality of life went from 70 percent at age 5 to 50 some percent at age 12.

And so, I extrapolate from that, does it mean we're at 10 percent at 50 and we're dead at 65, or does it mean it bottoms out and rises? I mean, it sounds like a joke, but it's a valid question.

I hear from you about this immune dysfunction and that it can mean bad things for children. And I look at my own life and my son's mother who has autism is 55 years old at Mass General Hospital right now with immune dysfunction that she could die of. And I have to ask, is that an autism-related immune dysfunction?

As much as I value the work that you

folks have brought here and as important as it is to study the issues relating to autism in children, hearing the focus on children makes it so clear to me that we have to shift our priorities and we have to put more resources into ascertaining how adults will live with autism. And we need to be asking all the questions that you have asked from a human population as a whole, not just children.

So, I thank you, as I say, for what you have brought us, but we've got to go for the rest of the population.

Dr. Insel: Geri.

Dr. Dawson: Well, I think that's a very good setup for the question I had for the clinicians, and we've talked about a range of conditions here, immune and GI and so forth.

So, how often do you see these typically as something that presents early and is a pretty stable part of the phenotype versus something that emerges maybe in adolescence or adulthood? And, yes, so I'd just like to have more of a developmental perspective, and do we see these worsening over time?

So, any kind of developmental perspective would be helpful.

Dr. Frye: I really think that this is a really important question. And one of the main problems in studying these disorders is we're finding them after the child is diagnosed with autism, you know.

We don't know if these are actually part of the pathophysiology that causes autism.

And that's a really key question, because if we know we have some insight into the pathophysiology and we develop biomarkers, we can start looking before the autism develops and prevent it. And that's kind of the whole golden type of thing, but your point about the developmental course is very important.

A lot of times people are trained that, well, if you don't do things very early on, you know, it's tough for kids to recover.

And I must say that in some of these

disorders, cerebral folate deficiency, particularly if it's identified at any point, that you can see some very substantial recovery.

And actually in our paper it was, you know, a large case series, it wasn't a double-blind, placebo-controlled trial or anything, but we did see that there is some – that actually individuals that were a little bit older – 8, 10, 12 – seemed to respond a little bit better to the treatments.

So, I think it's an open question. I think that personally I don't I think we talk about children, but I think we have to almost take children out of it in the sense that we have to look at autism as this lifelong disease and see the individual as their needs any time that we see them instead of talking about age, because we know they change very differently as they age.

And it may be to account – these disorders may account for some of that, but I think it's really an important point.

Dr. Insel: Could we just get a clarification on something? Lee, you talked in your presentation at the beginning about something related to puberty and the onset of catatonia, and the examples you gave were mostly of adolescents or older people.

Is that the case? Is this something that's tied to a particular developmental stage?

Dr. Wachtel: So, typically the literature points to catatonia occurring most prominently in adolescence and young adulthood, that most of the patients tend to present around that time.

Although, some researchers have even taken a step back and said that symptoms of with such an overlap between symptoms of autism and catatonia – could even autism just be like a form of catatonia, but the types of symptoms that I've described, usually you're seeing patients present as teenagers, young adults. One of the patients in the presentation was 25.

Now, the fact that I've worked with patients in that age group may also be a function of the fact that I work in a pediatric hospital, but typically in the literature the patients cluster around that age.

And talking about kind of the developmental and long-term perspective, what's important about catatonia related to autism as compared to catatonia as part of major depression, a psychotic illness, or a medical illness where you oftentimes can get really good control of the symptoms if you keep good control – for example, of the mood disorder – we don't currently have any way to change the underlying substrate of the autism.

So, for most of these patients the treatments are more – they're of that – they're treatments rather than cure. And these become situations that continue and require ongoing attention and without attention can lead to more and more difficulties and incurring morbidity.

Dr. Insel: Alison.

Ms. Singer: Dr. Wachtel, I was hoping that you could speak a little bit more about the evidence base for ECT in this population of extremely challenged individuals, because I think sometimes people confuse ECT with other types of electronic interventions for behavior management, which we know to be nonevidence-based.

Dr. Wachtel: Right. Okay. Sure. Well, that's a big question. First, I can start by clarifying – I think one of the biggest troubles that place ECT in this population is the fact that a lot of people erroneously associate that with CES or contingent electric shock, like what was used at the Judge Rotenberg Center as a punishment procedure.

So, I mean, if you look back into like the literature of like the 1950s with Lovaas et al., there was a development in the ABA world of – well, they call them “response reduction procedures,” but they're punishment procedures.

I mean, back in the `50s they would slap the patients or shake them, and then they developed adversives.

And so, electric adversives were used pretty regularly, and actually they did use things such as Sears and Roebuck cattle prods. Other adversives included like bad taste or spraying of like a mist in somebody's face.

So, the use of contingent electric shock as a punishment procedure has really nothing to do with electroconvulsive therapy. They don't even use the same type of electricity.

And it is important to keep in mind that contingent electric shock may work through conditioning, but you could probably take a child with ADHD and get them to stay in their seat if they knew every time they were going to get up you were going to shock them with a painful stimulus.

I've actually talked to some parents who had visited the Judge Rotenberg Center and had tried – had CES tried on them and they report it to be extremely painful.

So, CES really has nothing to do with ECT, or electroconvulsive therapy, which basically the benefit of ECT is not related to the electricity, but to the initiation of a seizure deep bilaterally within the cortex.

It happens to be that most convulsive therapy or all convulsive therapy now is done with electricity. Initially, though, it was done with an injection. You can also use a gas.

So, the electricity is just really a means to induce a therapeutic seizure in a highly medicalized setting where basically patients are monitored similarly to the way they would be like in a surgery suite under full anesthesia and muscular blockade to target discrete symptoms.

So, ECT is indicated for has FDA indication for catatonia, major depression, bipolar depression, psychotic illness and is also used in some other movement disturbances, particularly like in Parkinson's, and you'll see some case reports of patients with stranger movement disorders who have had relief from ECT.

In terms of children, the usage of ECT in children dates back to the `40s. There were some studies from New York and also from Paris that certainly wouldn't meet like our standards of modern studies, but significantly they reported benefit to the children.

Many of whom, if you read the descriptions, probably would have been diagnosed as autistic today, you know, without any evidence of long-term damage.

There is not a lot of literature on children who have received ECT until you jump to the `80s. And in the `80s and `90s, there is a growing number, there are a growing number of mostly case reports of children – typically developing children with mood disorders, psychotic disorders.

Many of whom, if you read the cases, also had self-injurious behavior who were safely and efficaciously treated with electroconvulsive therapy.

And then starting in the `90s, with I guess kind of the floodgates opening in the past decade, there has been a huge influx of literature on patients with mental retardation without autism, and then patients with autism spectrum disorder, who have been treated safely, efficaciously with electroconvulsive therapy for catatonia itself, for mood disorders with catatonia, and also for self-injurious behaviors.

It's an area that requires a lot more research, a lot more ongoing research and patient followup.

We have some patient followup on two of our cases in terms of longitudinal neuropsych followup, since the question that always comes up with ECT is, Are you doing damage?

There is no evidence of that in the literature on MedLine. Although, if you get onto the Internet and Google ECT, you'll get a lot of evidence of damage, but that's not science or backed by the research.

And in two of our patients where we were able to do serial neuropsychological testing, we found that there was absolutely no difference in their profiles over the course of ongoing ECT treatment for their underlying condition.

Dr. Insel: Okay, thank you. Scott.

Mr. Robertson: So, I wanted to just concur with what John had said previously about I did notice with the catatonia, it was referring more to across lifespan, referring a little bit more to adults and adolescents, but a lot of the other discussions on co-occurring conditions did not really touch on lifespan.

And I think it affects the fact

ultimately that we're not going to get data, because it becomes this cycle of we're only looking at kids and that's what we have the discussions on. And then we don't get data on adults, which impacts ultimately supports and services and quality of life across the lifespan.

So, you know, I just wanted to concur on that, that I think it's something that needs to be moved forward.

And maybe when we have discussions in the future around co-occurring conditions, that we could also make sure to particularly have an emphasis at some point on adults and adolescents since it's been left out.

So, consistently not just here, but many discussions across the board in the research and practice, and it's, you know, it's a major hole in the science and practice activities. And I think it needs to be addressed for the sake of all the autistic adults and adolescents in the – out there in the world and in our families. Thank you.

Dr. Insel: Lyn.

Ms. Redwood: I personally want to thank all of the presenters here today for coming and also Tom and Susan for organizing this today.

You know, over the years we've heard from families, you know, in our public comment period about the underlying medical conditions that their children have that are often overlooked.

And, gosh, it was back like in 2009 that we added into the Strategic Plan a crosscutting theme of comorbidities – and I'll get back to that in a minute – but I just am so impressed with how this has changed just in the last 4 to 5 years.

Because when the issue was first brought up to the IACC, the recognition of comorbidities really wasn't there. And it wasn't until Geri came and presented some of the ATN data about GI and sleep that it's really gotten on our radar screen.

And there is just so much more we can do, because this is low-hanging fruit where we can improve the lives of children now.

Dr. Perrin, I wrote down one of your comments where you said you'd like to have advice from the IACC on what issues are important.

A lot of families wrote in this time, and over the years I've made copies of those for you and hand-delivered those. I hope you'll have an opportunity to read through them, because they're very rich in terms of the comorbidities that they see most often in their children, and many of those parents are frustrated because they are being overlooked.

I know there are wonderful things happening within the ATN Network, but we need to make sure that that gets out to the general pediatricians, family practitioners, mid-level providers. That's essential.

I would love to see the American Academy of Pediatrics include maybe even an entire day on autism at one of their conferences, have Dr. Buie come and speak about gastrointestinal disorders in autism.

I think that would be hugely important in terms of raising awareness, but we need to take it a step further.

In our Strategic Plan when we did this update, we also said that it was important for the development of multidisciplinary health assessments and effective treatment guidelines that can immediately improve the quality of life for individuals with ASD in their families.

That's something we don't have yet. We have a lot of science coming in. I'm just amazed every day when I go and look at my mail – the new articles that are coming in – and I can't keep up with them anymore.

And I feel like we need some group to be cataloging in that information and say, you know, this is the 10th study that has come out that has documented, let's say, abnormalities in glutathione or in mitochondrial.

What do we need to do to translate that information either into a screening tool or treatment guidelines?

Is the literature not robust enough yet? We need more studies? If that's the case, then it needs to feed into our Strategic Plan so we can say that's an important area that needs to be studied.

So, some type of liaison with the American Academy of Pediatrics and the IACC, possibly a task force, and also with ATN, because those are the networks that can do these types of studies for us. And then we need to work on disseminating that information out to our health care providers and our families.

So, I want to know what we can do as a next step, and I'd like to propose a task force or either a subcommittee to work on these comorbidities, because it is low-hanging fruit where we can improve the lives of individuals with autism today.

You know, one of the comments, Dr. Buie, that you made is that sometimes your patients come in and they put an ice cube on their chest and they tell you that their esophagus is hurting by that behavior.

In the videos I watch, the children were repeatedly hitting their heads, and I just wonder with what we know about a neuroinflammatory process going on in the brains of these children, if we can look at that, because I think that's a clue.

And I personally have assisted with ECT therapy in nursing school back in the `70s, and I found it incredibly difficult to participate in. And I was so glad to see that that fell out of vogue for treatment for depression.

My reading of the literature was that there were a lot of long-term neurological impairments associated with repeated ECT therapy.

And so, I think if we can get to what the core underlying problem is that some of these behaviors – we had one parent – this was not submitted to the Committee – whose child had cerebral folate receptor, very low levels of cerebral folate in the spinal fluid, was treated very effectively with leucovorin. And the child today is on a maintenance dose and is doing absolutely wonderful.

Tom and Susan and I think several others in the Committee were cc'd on these emails that did not get in in time for public comment. So, I think we need to exhaust all of the other potential etiologies for self-injurious behavior before we move forward with electroconvulsive therapy.

Dr. Insel: So, we're going to need to move on because of the time, and I know there are other people who have questions.

What I'd like to ask is if there are questions for our experts, we can convey those after the meeting and make sure you get a response.

Lyn, you put one thing on the table that we probably should just ask Dr. Perrin about, because he won't be around later when we take up next steps and what the business would be.

If we were looking for a way to interact more closely with AAP, what would that be?

Dr. Perrin: I think there are several ways to interact more closely with the Academy, but we do have a task force on autism within the Academy. And that's a natural, easy source, but we have a number of areas within the Academy that are really working on trying to improve understanding, to improve care, and to improve training.

So, I think we would start with that level, but I would assure you that there's a good deal of high-level interest in trying to build a connection with the IACC.

And just to momentarily change my hat, at the level of the ATN we are very much interested in the thoughts of the IACC as to what would be the best priorities and the best strategies for us to implement those priorities. Both would be really helpful to us.

Dr. Insel: So, we can circle back to those issues later. Okay, thanks for being here.

Dr. Wachtel: Dr. Insel –

Dr. Insel: I really –

Dr. Wachtel: – can I just make one comment? I can't let –

Dr. Insel: Okay, 10 seconds.

Dr. Wachtel: Ten seconds. So, just in relationship to what you said about electroconvulsive therapy, I'll just try and tell you something very quickly in 10 seconds.

I think that the procedure as it's performed in 2013 is vastly different from what was performed in the 1970s.

Anyone who thinks that ECT looks in any way bad or harmful or punishing should watch a procedure as it is done now in this country. And there are video links, and I could show you some now.

In terms of ECT causing damage, if you do a medical search of the peer-reviewed literature, there is no evidence of that.

There are histopathological studies, imaging studies, and long-term cognitive studies, including two cognitive studies from the French on adolescents showing no evidence of brain damage from ETC.
However, that's what the media would like you to believe.

Dr. Insel: So, we're going to have to I don't think we really need to spend a lot of time discussing ETC. That's probably a little off topic for the Committee.

There are lots of other questions that will come up. And, as I say, rather than taking time now, let's filter those through Susan, and we'll get back to the experts.

Given where we are with our time and

knowing that there are lots of other people that have traveled a long way to talk to us, I want to make sure we move on and give them their opportunity to meet with the Committee.

So, we're going to move to the next part of the agenda, which has to do with a report from a meeting that was held late in March of this year on environmental epigenetics.

So, I'll introduce Alycia Halladay from Autism Speaks and Jill Escher, who supported this through the Escher Fund for Autism.

Dr. Alycia Halladay: Yes. So, thank you, Tom, and thank you, Susan, for allowing us to come and present.

This particular presentation isn't meant to be an instructional guide or any sort of research review of the role of the environment or epigenetics in autism.

What we really want to do is kind of describe this meeting, the scientific symposium that was held on March 22nd and 23rd of this year.

I know many people in this room were actually planning on attending, and the sequester hit, literally, I think, a week before the meeting was held. And so, there were many people who, some in this room, that were planning on attending, but, in fact, couldn't be there in person.

So, Jill and I are going to split our 30-minute timepoint, and we're going to try and end early so that we can have some time for questions and answers, but we're going to split our time, and I'm going to focus more on the meeting itself.

So, just to give a little bit of historical context here, and I know Andy Feinberg and Cindy Lawler have talked about the role of epigenetics in autism and the role of environmental epigenetics in autism, but just to give some historical context, these are two genetically identical mice.

They are the agouti mice. They have differences in their methylation patterns. The yellow mouse obviously is obese, and it's yellow. And the brown mouse is not obese. It also has different levels of methylation patterns where the yellow mouse has lower levels of methylation.

Interestingly, these phenotypes can be induced or prevented through environmental exposures.

For example, BPA are – the endocrine disruptor BPA can induce the yellow phenotype, and that can be reversed through supplementation with folic acid.

From an epidemiological perspective, we've been able to look at epigenetics and disease through – this came from a recent *Time* magazine story looking at multigenerational effects of the Dutch potato famine.

And so, not only looking at the, you know, the first generation, but the second generation as well.

So, we already know that there've been well-established links between the environment and epigenetic expression. There has not been, until recently, a meeting that focused in on autism.

The Keystone Symposium focused on environmental epigenetics and disease. And of course, the – this meeting that the CEHN held in 2012 and as well as the books, have all shown a strong link between environment, epigenetics, and then disease.

And so, really when we think about epigenetics as the way in which genes and environment interact, there are some kinds of key points to mention here.

One, the first thing is DNA methylation has mostly been considered as the mechanism. And I'll get to that in a few seconds.

More and more we see that looking at the environment and epidemiology studies has allowed researchers to both assess exposures and outcome, as well as exposures, epigenetics, and then outcome.

So, most of them have looked at, say, the first generation – so, the child – so, prenatal or postnatal exposures in the child, but then really – and Jill will talk more about this – we really need to look more into multigenerational exposures.

And so, when you think about multigenerational, that goes down to the grandchild, whereas there have been animal models that have been able to look at great-grandchildren and great-great-grandchildren.

So, there are a few disorders or diseases that have really shown this strong link between the intersection, between using epigenetics as the intersection. And mostly those are in cancer, asthma, and neurodevelopmental disorders, but until recently, autism really hadn't been addressed.

So, one of the strongest ways to look at epigenetics in autism is the use of twin designs.

And this was, unfortunately, a relatively, you know, really kind of uncommented paper in *Molecular Psychology* last year by Robert Plomin and Jonathan Mill's group looking at the twins cohort in the UK.

They looked at monozygotic twins that were discordant for autism and autism-specific traits.

And what they found was there were actually more than 50 differentially methylated regions between the two identical twins and that they correlated between different particular symptoms of autism.

So, they used the CASS. So, they were able to look at social interaction systems, repetitive symptoms, and then social reciprocity symptoms.

And so, this has been the strongest paper to date to really show the role of epigenetics in the etiology of autism.

So, the goal of the Environmental Epigenetics in Autism Scientific Conference, which was held on March 22nd and 23rd earlier this year, was to not only be a forward-thinking meeting, so thinking about where are the gaps, what can research be doing to identify the gaps, what do we know, what do we need to know to move forward, what are some of the tools that need to be developed or utilized in this field, but also we wanted to create a way to have kind of a video library from the presentations that were given so that they could be referenced and seen by, of course, people that couldn't attend the meeting, and we did that.

In fact, there is a meeting Website, which I know that was circulated prior in the list of materials on the IACC Website, autismepigenetics.org. And not only does it have all the, you know, a vast set of information around environmental epigenetics in autism, but also it has video archives of all the presentations.

So, on the Planning Committee were of course Jill and myself. And then, since the meeting was hosted at the MIND Institute –

and, by the way, if anyone has ever had a meeting at the MIND Institute, I highly recommend it, they were great – was David Amaral.

And then also Janine LaSalle from UC Davis, who studies – who uses animal models and molecular mechanisms to study gene-environment interactions in epigenetics.

Dani Fallin, who works with Andy Feinberg, who of course spoke last year on this topic.

And then also David Crews, who is an evolutionary biologist at University of Texas.

So, essentially, here are some pictures from the meeting. We really wanted to talk about the background in mechanisms.

The role of the germline which has really been unaddressed, you know, in autism, but has of course been addressed in other disorders, we had a session on neurodevelopment and the roles of epigenetics in neurodevelopment, and then some examples from the field of particular exposures of interest. And a lot of those pointed to endocrine disruptors.

And we also wanted to put some time aside for ethical considerations. And then of course we had, at the end of the meeting, we had some time for some more focused topics. And those include the use of epidemiology studies, the use of existing biosamples and materials, molecular biology techniques, and animal model studies and how they can contribute.

So, there were more than these emerging themes from the presentation, but I tried to condense them into a short, you know, kind of a short presentation here.

So, the first one was we need more emphasis on genes and the environment, not genes versus the environment.

And I hear – I hear this over and over again – about the lack of under, you know, the lack of the strong data supporting a single gene for autism or multiple single genes for autism or a single environmental factor.

And I think scientists have come to a point now where we all agree that there is a complex interaction between genes and the environment and that needs to be really kind of better considered in research rather than thinking about only environmental factors or only genetic factors.

We need multiple time points on these studies. And of course prospective longitudinal studies are kind of an ideal way to look at them.

Different tissues. Obviously, people thought about the use of, you know, all sorts of different things that could be done with brain tissue.

That's really not feasible. So, we need to, you know, think about the use of other surrogate markers.

We also need to think about a diversity of exposures. If you think about maybe isolating a particular exposure itself, that can be quite daunting because you may, you know, be seeing the trees through the forest.

We need to be thinking about a diversity of exposures and those that look at kind of a broad array of mechanisms.

And that we can really learn a lot from disorders or other diseases that have established or have been able to really show a mechanistic link between epigenetics, the environment, and their disease of interest.

The second point was, you know, really kind of inspired from a paper that was published by the – well, the senior author was the Johns Hopkins group, but it involved a Swedish cohort of rheumatoid arthritis patients – is that epigenetics may be the moderator of gene-environment interactions.

And so, instead of thinking about environments and instead of – this goes along with the first point – instead of thinking about environment coming in separately as genetics, in fact epigenetics can be the moderator of how environment affects genetic expression.

And so, this study was able to use some specific algorithms to show that in fact there's, you know, a few differentiated methylation points, and those are the kind of the top circles, that affect the expression of genes, MHC genes on chromosome 6.

The third point, which Jill will really get to, is that when we think about the life course, we definitely want to think about adults with autism and their needs.

But when we think about the life course from an etiological perspective, we should really be going back to think about the germline.

And this is a figure that I actually stole from one of Frederica Perera's publications, where she looked at the effects of diesel fuel on epigenetics and pointed out that, in fact, you think about mother exposure, fetus exposure, but you rarely think about the germline exposure or the reproductive cells which are actually, you know, part of that exposure during gestation.

So, you know, many multigenerational studies are finding effects in other diseases, and we probably need to incorporate assays to look past just pregnancy.

And the other thing is that there are maybe two types of environmental epigenetics. One that's context dependent that's dependent on, you know, the exposure itself, or one that is dependent on germline dependent. In real life, you're probably looking at both.

And so, in an animal model, you may be able to pull apart the two. But in real life, you're probably looking at both.

And given the recent interest in ART and the publication that came out, you know, we really may need to be thinking about whether or not we're looking at the right place.

If we're looking at ART as the link to autism, in fact, shouldn't we actually be backing that up a little bit and thinking about things like subfertility, reproductive health, and the things that may disrupt that? And those are things like endocrine disruptors, which has been shown to produce changes – germline-mediated changes in development.

And then finally, which probably isn't any, you know, surprise to anyone, is that we really need – we can't just be doing this in epidemiology. We need to incorporate animal models, molecular approaches, genetics, and toxicology.

And another thing that was quite striking is the role of environmental epigenetics on sex differences. I'm not here to advocate or say, but I do know that it's an understudied field across autism. But I do know that there are many researchers who are looking at sex differences and thinking about the role of epigenetics in the, you know, both the difference in the rate and then also the symptoms that are presented.

So, I do want to thank everyone who attended the meeting. Especially thank the members – I'm sorry. Jill, of course, but then also David – both Davids, David Amaral and David Crews. Dani Fallin and Janine LaSalle, who are on the Steering Committee for the meeting. And here are some of the other people that were at the meeting.

We definitely tried to make sure that there were people within the field of autism who could speak specifically about, you know, the uniqueness of autism, but then were outside the field as well.

And then I want to turn it over to Jill, who is really going to talk about how this, you know, how this all impacts families with autism and thinking about – in addition to intervention – a model of potentially, you know, prevention. So, go ahead, Jill.

Ms. Jill Escher: Thank you so much, Alycia. I'm very grateful to have this opportunity to be speaking with you about our symposium and share with you some information that I think is highly relevant to autism and may, in fact, shed some light on the increasing rates of ASD and other neurodevelopmental abnormalities we're seeing today.

The idea that comes from epigenetics that may be very relevant to autism – actually, there are several ideas for epigenetics – but this is the one we'll be focusing on here is that, you know, epigenetics is like this fine-tuning of our genetic code, but what happens when that fine-tuning process goes awry when the instruction book is damaged in some way?

It could be that novel exposures from our recent past have impaired the development of our germline, which is of course our sperm and egg, contributing to the rising incidence of pathologies that we're seeing in our children.

It's a really simple idea, actually, and it dovetails pretty well with what we've been seeing from ASD research.

We see a lot of evidence for heritability of autism, but we don't see a lot of evidence for this Mendelian genetic kind of inheritance coming from previous generations.

We see a crazy quilt, kind of de novo mutations and changes in gene expression in children that's really perplexing and mysterious. And so, that part really isn't new.

But the part that is kind of new is that exposures that don't go back very far in history may have something to do with some of these changes that we're seeing in the subset of autism.

Obviously, I'm one of these people who believes that autism has many, many causes. We're just talking here about one potential subset.

So, I'd like to talk about these environmental exposures. When we think about environmental exposures, we often think about smog, you know, pollution, water pollution, endocrine disruptors like pesticides, BPA, other toxic chemicals, but there's a whole other class of exposures that I think has been wholly overlooked not only in autism research but in many other fields of research, and that is this – what I call the prenatal pharmaceutical craze of the postwar era.

From the `50s and even through to today, but mostly kind of peaking in the `60s, there was an incredible enthusiasm for the use of synthetic chemicals marketed as pharmaceuticals for the prenatal market. And this is just an example of four categories of these kinds of drugs – the synthetic hormone drugs, sedatives/hypnotics, antinausea drugs, weight-loss drugs.

There were many others, and none of these were benign. And some of them were, in fact, quite catastrophic.

You can see thalidomide is one of them. I obviously don't have to tell you that story.

DES was another. Many millions of fetuses exposed to DES causing, and now we now know multigenerationally, pathologies in the affected offspring and even the grand-offspring.

These were novel exposures with no biological precedent in millions of years of mammalian or human history. And I think even today, we haven't really come to grips with what these have done.

So, let's look at a quick snapshot of drug use from this era. This is from a very large cohort called the Collaborative Perinatal Project – more than 50,000 pregnancies.

And the point of this is to draw your attention to the fact that a substantial percentage of pregnancies involved use of drugs – most of them synthetic, some of them natural. And this study showed that about half of the pregnant women in this time period were found to have taken at least two to four drugs during early pregnancy.

That said, drug use varied widely by geography, by demographic, by socioeconomic status, and even by medical practice.

So, why does this history matter? This was a long time ago. I'm talking about like the `50s and the `60s and `70s. And like here we are in 2013, and that stuff happened a long time ago. Why would all this old news matter to us today?

I think it matters, because the science is now raising some really strong red flags about the multigenerational effects of exposures.

This is just three examples. I could have had 10 slides on this, but we now know that endocrine-disrupting chemicals and other chemicals can induce molecular epigenetic changes such as the DNA methylation and histone modification.

There are many layers of epigenetic changes that could happen, but those are two that are best studied.

We know that the epigenome is most vulnerable during early development. Now, when, I mean, I'm sorry to get graphic here, but like when did our eggs develop?

We were born, all of us ladies in the room, we were born with all of our eggs, right? Our eggs developed basically in the first half of gestation when we were, you know, this big, when we were tiny.

And for males, very similar. Different process of reproductive cell development, but you're born with all of your spermatogonial stem cells, which then go on to become your mature sperm later in life after puberty, but the most vulnerable period is that period when we're this small and our germ cells are developing.

We also know here at the bottom that endocrine disruptors have been shown to exhibit transgenerational effects that are relevant to ASD. And that's from animal models. So, we're seeing a lot of hints about why this stuff may be very important.

Now, we just talked about the second point, that the fetal germ cells are very vulnerable, but that's not the only period of vulnerability.

Preconception, fertilization, the early embryo – there's epigenetic vulnerability and also spermatogenesis through the male's lifetime, and there are others.

Another point is that the exposure need not coincide with the window of susceptibility. There are some chemicals that stay in our fatty tissues forever.

So, you might have an exposure when you're 10. And then you might have a kid when you're 30, but that exposure might still be relevant. It's pretty complex.

So, as Alycia mentioned and as I just talked about, the pregnancy exposures can affect three generations at once.

And this is really a paradigm-shifting idea, because now we know that exposures that happened a while ago can have downstream effects affecting grandchildren or even later generations.

We also know that somatic cells, all of our body cells, are affected a little differently than our germ cells and that you may see – in fact, we do see – this in animal models, different effects of exposures in different generations.

There's also this idea of this latency period that if you're exposed to something in utero, you may have this latent birth defect of, you know, in your germ cells, but that doesn't manifest until your kids are born.

All right. So, what does this mean? Does this have any relevance for autism?

I definitely think so, which is why I'm here. And I'm going to offer myself and my children as Case Study Number 1 in this multigenerational hypothesis.

I was born in 1965 in Los Angeles. I still have the same haircut. And I developed, I would say, pretty normally. Some people might dispute that, but went on to graduate from college and law school and pretty successful in my career. So, I'm kind of normal.

There's no autism or developmental or psychological conditions in my ancestor extended family or in my husband's.

We have three kids, and everything was normal – normal conceptions, normal pregnancies, normal deliveries, no unusual exposures, no genetic anomalies. And we even did microarrays looking for like copy-number variations, deletions – nothing. They're physically gorgeous. They're very robustly healthy, wonderful kids, but two of them have highly incapacitating abnormal neurodevelopment, which has been labeled idiopathic autism – basically saying we don't know why, you know, why they're so impaired.

But as much as I love them, they are by any reasonable measure catastrophically neurodevelopmentally disabled, and they're going to need lifelong 24/7 care.

So, why did this happen, and why might this be happening to a subset of kids kind of like them?

Well, here's an idea. Very recently, through a succession of complete miracles that I really don't have time to relate at the moment, I stumbled upon some very shocking information.

And that very shocking information was very detailed records of my prenatal exposures from 1965 from when I was that big.

To say that obtaining these kind of records is rare is an understatement. I always ask, and I'm going to ask it now, has anybody in this room ever seen their prenatal records?

No. I mean, I still haven't found anybody else. I don't know why me. I don't know, but these kind of landed on my lap.

And it took a while, but with the help of a lot of researchers and physicians, I was able to decipher them.

What do these records say? It said that I had been exposed to a veritable barrage of synthetic steroid hormone drugs from the very beginning of pregnancy through at least the second trimester.

Why was I exposed to all of these fake progesterones, corticosteroids, fake estrogens, and maybe a couple of other things? Why? Why? This was 1965. What happened then that maybe isn't happening now or maybe happening differently now?

What happened back then is a couple of things. First of all, this category of drugs was used very, very heavily in pregnancies that were considered at risk or where, you know, the doctor considered the woman to be a “habitual aborter.” That was the term that was prevalent in the medical community at the time. A habitual aborter was any woman who had two or more previous miscarriages.

I hope everybody knows about DES, which

is one of these, quote/unquote, antimiscarriage drugs that didn't really work.

I was not exposed to DES. The drug that was actually more prevalent were these progestins, these fake progesterone drugs, and I was exposed to two of those in addition to these estrogens and corticosteroids. It was a prednisone kind of drug that I was exposed to.

So, why should we care? And also, well, some people say, “Well, Jill, is that a lot? You were exposed to about, you know, 5,000, 6,000 milligrams of these synthetic hormones. Was that a lot?”

Well, I'd like to compare that to birth control pills today. A birth control pill has about 0.18 milligram of synthetic hormones in it.

If you were to add up a year's worth of birth control pills, it would hardly register a blip on this graph. So, I was very heavily exposed.

In fact, the researchers at the time

remarked on – okay – small tangent. I had been researched, I didn't know this, when I was 8-years-old, because I had been so heavily exposed to these drugs, which is part of the reason that I found these records.

So, I just found out very recently that I had been the subject matter of a research study, but, no, this was a massive amount of exposure.

I mean, really it's amazing that I'm kind of quasi sort of normal, I think, but whatever. We won't talk about that.

So, yes, did these drugs affect me? I think they did. There's reason to believe they did. But moreover, did they affect my eggs?

And given that millions of people were exposed to these drugs and tens of millions were exposed to many other kinds of endocrine-disrupting drugs, these are overt endocrine disruptors, but other drugs were, you know, had endocrine-disrupting effects as well. Did it affect our germline, or is the germline impenetrable? Was it impermeable? Did it not change, or was the effect negligible?

Well, the answer is we need to know more. I don't pretend to have all the answers today. Clearly, I think that this is an interesting and intriguing idea, but we need to know more.

We need to consider the possibility that some environmental factors may have wreaked havoc on our germ cells. And I think that the prenatal pharmaceuticals are of course just the tip of the iceberg, you know.

This is “Mad Men” era, right? The `50s and `60s and `70s. We had DDT; we had dioxin, flame retardants, PCBs. Talk about persistent pollutants and many other candidates. Maternal smoking was at its apogee in this era. Recreational drugs, air pollution, nuclear testing even, Superfund sites. And I would even throw in birth control pills since those are also endocrine disruptors in and of themselves.

So, there's a lot to think about in terms of exposures that could be having multigenerational effects.

We run a little philanthropy, an autism philanthropy. We've already kickstarted some projects just to try to get this hypothesis examined and try to get it off the ground.

We've picked some low-hanging fruit, so to speak, and have, with Autism Speaks, funded the first epidemiological study in Denmark looking at three-generation effects of smoking and prenatal pharmaceutical use from the `60s.

We are interested in prevention. And one thing that's very near and dear to me is the idea that we know there's really quite a bit of consensus that prenatal pharmaceutical use can affect human germline but never has been – never has that been on the radar of the FDA.

There's no testing protocol. There's no warning. It's not part of any, you know, way to assess systematically risks of exposure.

So, we're trying to get the germline – our germ cells are the most important cells in our body – on the radar of the FDA.

We have the symposium. We're sponsoring some research into this history, which is really a very hidden history. We want to make medical records much more available to all Americans so we can all know. I don't want to be the only person in America who knows her own prenatal exposures. I want everyone to be able to know – and some laboratory studies as well.

Alycia and I, you know, working with the symposium, came up with some recommendations, more broad recommendations for research.

She already touched on it. I'm not going to go into it in detail, but we do need kind of a multifaceted approach to look at these ideas about how the environment may have affected our genes and may be having these downstream impacts.

Thank you so much.

(Applause)

Dr. Insel: Well, thanks to both of you.

You mentioned at the beginning that the webcast is available online. So, people who are interested can go back to the originals.

Will there be a report out from that meeting that we can get access to?

Ms. Escher: Okay. We submitted to the IACC just a PDF file, which was a summary of the major themes of the conference.

It's not a scientific report, not a lengthy, detailed scientific report, but it's a summary.

So, I would really recommend at this time looking at the summary and then going through the videos on their Website.

Dr. Insel: Great. Okay. And, again, in the interest of time, I'm sorry, but I think we should move on. I want to make sure you hear this next presentation before we break, and we will be able to recover some time over our lunch break, I'm sure.

Let me introduce Portia Iversen who's going to talk to us about nonverbal autism.

I think most of you know Portia. But for those of you who don't, she was the cofounder of Cure Autism Now, one of the original founders of IMFAR as an international meeting.

She has been in the last few years a major proponent of the idea that we should be studying nonverbal autism. Some of this comes up in her book *Strange Son*, about her own son Dov, and some through the Descartes Institute, which she's founded, which is an online community for people who are interested in this topic.

Portia, it's a delight to have you here. I'm sorry we're getting you started so late, and I promise we'll give you the time you need, and we'll break around one o'clock.

Ms. Portia Iversen: Hello. Thank you for having me here today. I'm here, as Tom said – I think he may have said quite a few of the things that are in the first part of my talk, so, I might skip over them – but I'm very interested in nonverbal autism.

I have a son who is now 21 – can you hear me okay? – who has nonverbal autism. He's very severely affected by autism. He has a lot of motor problems and a lot of challenging behaviors and giant mood swings.

So, just to tell you a little bit about me and my life and my involvement, this – what you're seeing here is my son Dov when he was 9 – he's on the left, and a friend of ours, Tito Mukhopadhyay, who at the time was in his early teens.

And I'm going to talk today in a very general way, but I also really hope that the things that I'm saying will make some sort of an impression in terms of research dollars, because we've now – we've had a total of three meetings so far involving nonverbal autism.

The first two were sponsored by Autism Speaks, and they were very useful in getting a fairly good-size group of people interested in the subject and kind of up to speed so they weren't coming in for the first time ever.

And then The Communications Institute here, along with NIMH, sponsored a meeting in spring of 2010, a 2-day meeting, I think it was, on nonverbal autism and put out an RFA. So, that's kind of what's happened so far.

In so many ways, nonverbal autism reminds me of where autism was when our son was diagnosed, you know, almost 20 years ago, and we, you know, really couldn't even find out what was going on with autism.

There was so little going on. It was so mixed in different institutes, what little there was.

I remember Ed Cook had – is a long-term autism researcher – had an adult brother with autism. And he said that the funding was so bad during that time that the only reason he was even in the field was because, you know, I probably shouldn't say this, but he was sort of, you know, taking a little here and there from other disorders to put together something, because he really couldn't get any funding.

This is my husband John and my son Dov. And so, I'm going to go through a really quick timeline here, because – although, Tom kind of covered it – but we started Cure Autism Now around the same time as NAAR started. And it was one of those things, spontaneous things that happened.

There was almost no autism research going on at the time. I think the whole budget when we put it together was a little over $5 million, and we did that by asking, you know, accountants at every institute about what they thought might be considered autism research.

Interestingly, I find myself doing the very same thing now when I am trying to discover for you what is going on in nonverbal autism research. I have a very difficult time telling you, and you'll see as we go along.

We also started the Autism Genetic Resource Exchange, which, in my opinion, was one of the most important things that Cure

Autism Now did, because it allowed researchers from all kinds of related fields to come into the field of autism and not have to worry about spending a ton of money on collecting patients, you know. And they could just use their expertise or knowledge in very relevant other, you know, fields and move right into doing autism research.

I also had the idea of the International Meeting for Autism Research. It's hard for us to believe now that there wasn't a single professional meeting until this one was started in 2000 that was just about autism.

So, you'd have parents putting on conferences, you'd have universities putting on conferences, and there was no place sort of like Society for Neuroscience where everybody would go every year and everybody would talk to each other. So, I figured that this meeting sped things up a lot, too.

And then – kind of ahead of its time – we started the Innovative Technology for Autism

Initiative.

Unfortunately, the iPad had not been invented yet, which I think has really brought things light-years ahead in terms of communication for nonverbal autistics.

So, now I have – Tom, I have two videos. One is about 10 minutes, and one is about 5 minutes.

So, should I go ahead and show them given the time we have?

Dr. Insel: Yes, let me get a sense from the group, because I see heads nodding. I have to confess I've seen these, and I think they're very compelling.

So, I would want you to show them, but –

Ms. Iversen: This first one – I don't think we very often see a video that is an autistic individual from under 1 year old to teens in less than 10 minutes. I mean, we usually see one period of time or another.

I think I will show this one.

Dr. Insel: Let's go ahead and do this.

Ms. Iversen: Okay. Because I think it also shows you a progression of what can happen with a nonverbal child.

(Video playing)

Ms. Iversen: Okay. I think I hit that and just ended it slightly early, but that's all right. Anyway, you can tell he's a democrat.

(Laughter)

Ms. Iversen: So, you probably saw him rubbing his eyes and his head a lot. I think because most of his life up until age 9, he was just randomly sort of looking around or looking at things. He was stimming.

When he started typing, it was like he got tremendous eyestrain. He still does sometimes.

So, you saw in there that we met someone who helped him begin to communicate. And I'm going to tell you a little bit about this, because I think there's something very important in it, which is someone noticed Tito as a little child who had already been diagnosed with mental retardation in India, staring at the calendar a lot.

I love this quote. He made very good eye contact with the calendar. And she had the genius to realize that he liked the numbers. And if she could find a way to use the numbers to teach him, this would be a very powerful thing because nothing else was working.

And she realized that if she could get him to show her that he was understanding sequence, for example, one, two, three, if she said what comes between one and three, and she was able to do this and actually was able to in this way using sequence, things in context of the other things, teach him the numbers up to a hundred fairly rapidly.

And then she had the next genius idea that she could do this with letters, and she was able to teach him the alphabet.

And once she taught him the alphabet, it just went from there, assigning a sound to a letter, putting the letters together, and so on.

I'm making it sound easy. It was a tremendous amount of work, and she actually taught him to handwrite, which took her something like 2 years of constant, diligent – it was very hard for him, but they didn't have any kind of a device.

So, any time she would take out something that he wrote, oh, it was in her handwriting, and there was always a lot of suspicion.

So, she very, you know, laboriously taught him to handwrite prompting him to go from one point to the next just to make a single line and learning actually every line that makes up the alphabet and putting it together so that he could write himself.

Interestingly, his visual attention remained so poor that if he were handwriting something, unless he were prompted to move to the right across the page, he would just write every letter on top of every letter, and of course you couldn't read it then.

Okay. And, anyway, I found out about him from Francesca Happe when she was at a conference we had. And she said, “You really have to meet this boy. He's got a very high IQ, but he presents like totally mentally retarded with the most severe autism.”

And of course that interested me because, having a son who also presented like that, I had never heard of such a thing.

Long story short, CAN sponsored for Soma and Tito to come to the United States. Here is Sarah Spence giving him the ADOS.

This points out a big problem in a lot of our testing systems. I mean, he would come out as nonverbal, because he couldn't really, in the way that it was designed, even do the language module, right? And this is how we define actually for research purposes.

This is a verbal person. This is nonverbal based on whether or not they can take the verbal section of the ADI or the ADOS, and she adapted it for him to use pointing.

And we wanted to make sure that he actually had a bona fide diagnosis of autism before we did a lot of other studies. So, he traveled around the country.

These are some of the places we went to do electrophysiologic and neurophysiologic studies.

We thought it was really a Rosetta Stone, that here was Tito who was so low functioning and couldn't speak, but could – it was a lot of effort for him – but he could communicate pretty well by typing and that we could ask a lot of questions that we had never really been able to ask a person like this before, and we found out some really astonishing things.

I'm not going to go into details, but basically he said that when he was very young, everything went together wrong.

If he looked at a cloud, heard the word "banana," they went together. And he couldn't – I'm putting it in a very quick nutshell –

but he couldn't make sense of his environment. So, he stopped looking at things and just listening.

So, we got the idea that maybe Temple Grandin had done something like that, but gone in the other direction, and had just concentrated on looking and not listening, you know, getting a more visual sense developed.

The studies we did, did bear this out. And also these things seemed to be very much a function of attention as well, so that when Tito was in a very hyperaroused state, things would go together too much. And when he was in a hypoaroused state, things would sort of fall apart.

Of course my big question to myself was, “Is Tito one in a million?” Okay. He is autistic, and we can show that he has a high IQ, but is he just this, you know – of course in the back of my mind I'm thinking, you know, could there be others who have this hidden kind of intelligence?

I didn't really even think to ask Soma to work with my son, because I figured she had worked with her son all his life, and everything we know about it says that, you know, you've got to start from the beginning, and you have to have early intervention with these – you know, any type of intervention has to start early – but she was able to actually very quickly teach him to start pointing.

And in the video you just saw, I think he typed out the word "group" and "stars." She said, “What is a galaxy?”

That was one of the first sessions he ever had with her. I mean, it was in the first month. So, there was a lot of cognitive ability there that we were unaware of.

And, in fact, he had a basic ability to read, which I suppose he probably got because we put words on every picture we ever showed him.

I asked him in the beginning, “What have you been doing all this time?” And this was his reply: He typed out the word "listening."

I have an idea that I'm just going to share with you, because I know it seems like magic and sort of crazy in a way that somebody could be so impaired and then suddenly, you know, have this side that is more developed cognitively.

My kind of theory about it, true or not, as good as any, is that if your communication system for whatever reason is severely impaired, you really – you can't speak, you can't write, and in the case of my son, really couldn't reliably shake his head yes or no – so everything you've got that you would normally use is broken for communication, and then somewhere between 6 and 8 years old developmentally, your brain becomes able to read, to actually learn the alphabet and learn phonics and read, and my thought is that literacy is not a form of communication in this basic way that I'm talking about. It is for everyone who can communicate; it's an advanced form of communication, but perhaps there are people like Dov for whom literacy is kind of an analog system that wouldn't naturally be used for communication, but could be used.

That's what I really emphasize – is that because someone can read, doesn't mean they can talk or that they can express their ideas.

It's kind of a little counterintuitive, but that literacy itself could be used as a framework, a structure, a predictable system where you could teach a child with no other communicative skills to use it for communication. And for that reason, it could take a long time.

It's not like they've got a brain that's working fine and you put them in front of a keyboard and something magic is going to happen, you know.

I mean, most of these low-functioning nonverbal kids really don't even know how to point with a single finger, which most infants know before they're 1 year old, which I think, by the way, is a gateway skill.

Tom mentioned I wrote a book about my experience, because I wanted to share it and wanted to be sure that Tito and Soma didn't go back, disappear in India, and that nothing was ever heard about this again.

It was translated into 13 languages, and I get an email pretty much every day, if not more than one, but at least every day from somebody somewhere saying that they're reading it and that they're trying these things, and in some cases it's really opening a door to communication.

This is just a quick point I want to make, which is, people often say to me, “Well, didn't you ever try him on a computer? You know, like why did it take all this?”

Well, of course we tried him on a computer. We tried him on everything, but there was this feeling, which I think this diagram probably explains, that the device itself was some sort of magic bullet, that if you gave it to the kid who had some cognitive ability, that they should be able to communicate just by virtue of having the device.

And I'll tell you now that in 99 percent of the cases, the device is absolutely useless without training. And this is something I would really recommend as a research focus for nonverbal autism is – and Connie Kasari, who I think you heard at the last meeting, has done some work with this, and April Benasich also at Rutgers, and I think that we have to realize that, you know, if we're going to go through behavior mod, you know, ABA, to get a kid to sit at a table and eat or something or put their clothes on or whatever it is we want them to do, we certainly can't expect somebody who spends most of their time stimming and cannot communicate to respond to a keyboard or some sort of a device or an iPad and communicate all of a sudden.

This is a very, very big intervention, and it has to do with joint attention, it has to do with pointing, it's a motor, it's a neurological, it's a behavioral, but it can be done.

And it is really striking when you think about it, why we don't think, you know, after a while why we don't think of teaching a basic gateway skill like pointing with a single finger, you know, pointing, voluntarily, you know, pointing to indicate something as the first thing that we would teach someone who is nonverbal.

Okay. Just to remind us all that, you know, communication is so basic. And when we think about all the medical problems and quality of life problems and everything, communication is certainly one of the most fundamental things we can treat in order to improve all those other things.

A visit to the doctor is certainly better if the kid can pick up the ice cube, you know, and put it there on their chest.

And I also want to just throw in one other thing. This is the work of Wurbel. It's a few years old, but there is some research to support the idea that you can have cognitive – you can do well cognitively and that can be disassociated from doing well socially.

And in this case, they took rodents and raised them in a highly stimulating environment but without social stimulation.

Usually those things are not uncoupled. They're considered all one thing, but in this case they did. And they really were showing that you could disassociate these things, and I think that is part of why you sometimes will have someone who it's surprising how much they have learned even though they can't speak and they can't communicate and their behavior is so severe. Still, they could have good intelligence. It is actually possible.

I want to quickly go over this part, but a very basic problem is if I want to come to you today and say, how much research is being done in nonverbal autism, I really can't do that because there isn't a word for it. And, in fact, we don't know what "it" is.

We don't know if we're talking about people who physically can't speak, or what about someone who can barely say 10 words? Is that someone we would call nonverbal?

Or what about someone who has a giant vocabulary, but cannot communicate? I mean, these are things that, you know, we began to work on in these three meetings that I told you about, but whether we figure it out or not, we need to at least come up with some kind of guidelines.

Because, for example, I went on the NIH site, and then I went on the IACC Autism Spectrum Disorder Research Portfolio Analysis site, which, by the way, I think is very good. And I know that was a lot of work, and it's very worth having there. It makes it so much easier to find stuff.

However, if you're looking for nonverbal – any way you put it, with a hyphen or without – I looked through 2010 and 2009, which are the years that are up there, and this is just a snippet, but out of 139 projects after I looked through them all by eye, there were 13 that you could even with the longest stretch of imagination say apply really to nonverbal autism specifically.

In 2009, out of 72, I think there were 12, but some of these were just things that I thought they were being done for the general autism population, but that they had some significance for the nonverbal.

So, let's ask how much of the population, you know, should we be concerned that, of whatever percentage the population of nonverbal is, is actually basically in the same position it was in when we started, when I started advocating 19 years ago, but things really haven't changed.

I think the feeling was, you know, great, we're getting research going. Okay, we better work on the people who will be compliant, who we feel, you know, doctors and people can work with. And then these other more difficult people like we saw with the catatonia slides and videos, well, you know, it's nobody's fault, we just can't get to them.

Well, I don't think that's really acceptable at this point. We've been in this now a good many years, and so let's talk about the numbers.

There really are none, but the best guess is that there is something like maybe 20 or 25 percent who you would say basically can't speak, you know, or they can say a few words, but they're hard to understand.

And then at least 25 percent, but probably quite a bit more, are the type who can speak, but literally have to borrow, you know, a cereal ad in order to ask for breakfast, or they can't generate their own voluntary language with meaning at all.

So, we're talking about somewhere between a quarter and half of the spectrum. I think that's a reasonable guess.

And, see, if I do animation in PowerPoint, I confuse myself. I shouldn't do it. I try to get tricky, right?

Nothing is really known about these individuals. They're not included in research.

So, first of all, there are almost no research programs that are looking specifically at them, and they are included in almost none that are ongoing that would, you know, could include a larger group.

There was a time when they said, you know, that children couldn't be researched. They were too difficult. And then eventually the NIH, you know, they became different.

So, I just want to say, you know, really from my experience of getting involved, you know, from early on, you know, when our son was like 2 and 3 and starting CAN, everything we had to do then about autism and autism research, the nonverbal group is the same. It is really the same. There are no good educational interventions.

The ones that do work to some degree for the rest of the population usually don't work. In fact, that's a lot of how people are defined as low functioning or nonverbal is the fact that they can't use the things that are out there, but I think we need to start thinking about what can we give them that they can use.

We need to make things for them and create things for them and understand them better rather than use the fact, you know, that they, you know, someone who has receptive language, but can't speak or write, will not be able to tell you that on the ADI or the ADOS.

So, okay. So, I want people to rethink the model. And I will just run through this quickly, but basically since 5 or 6 or 7 years ago when the copy-number variation studies began to come out and then also people like Matt State began to show that there were many very, very rare genetic causes and – okay. So, well, these are just examples. Again, my tricky PowerPoint skills here, but – so, you can sort of ignore the legend on the right, because I went over a whole bunch of papers, and none of them really agreed.

But I think roughly – would you say, Tom – this is sort of roughly – there's a whole bunch of little things in possibly a quarter of the pie, and then the rest is what we used to call "real autism."

And I went to a meeting about 5 or 6 years ago which happened to be about all these developmental disorders that we thought were autism, but then were like Rett or Fragile X, and there are some others as well that are more rare, and what struck me was that all of those disorders were light-years ahead of real autism in terms of finding ways of being treated, because they knew the molecular mechanism by then for each of these.

So, that's my hopeful note – is that if and when the pie starts to look like this, which my personal view is that it will, is that, you know, when we had our gene bank, we would remove these things like Fragile X, because they weren't really autism. And maybe all these things are really autism, but we just haven't found them all yet. That's kind of a suspicion I have, and some groups will be bigger than others, but let's look at the current model for one second.

So, basically, how I would like to convince you to think differently about nonverbal autism is that traditionally we have seen autism as a spectrum disorder ranging from mild to severe with a kind of Asperger's-like or higher functioning at one end and then the nonverbal part of the population being the hardest hit, quote/unquote.

And I can tell you I've heard like the best geneticists and the most cutting-edge molecular biologists tell me that this is the way things are. And I'll say, wait a minute, you know, what about, you know, that thing and that thing, you know?

How do we reconcile the idea that someone is in the hardest hit part of this giant pie, right?

So, just going back for a minute to look at this and this, and then we see that this just doesn't work. These things just, you know – you can't find two charts to make these go together.

You might say that there's a spectrum within any one of these slices. That could be true. And that you could start to grade these slices across the ones that seem to have more severe people in them, but you absolutely just certainly cannot say that if you're nonverbal, you have no cognitive ability or that you do or you don't, but the fact is we don't know, and we've got to find out.

And if anyone has any doubt that genetics are involved at this point, I want to show this slide, which is my husband and Dov at the same age just because I think it's so cute – especially the T-shirt.

So, the nonverbal group is likely to be very heterogeneous and a mixture of different things in all those little pieces of the pie. Low-functioning behaviors do not necessarily mean that there's no cognitive ability.

And on a human personal level, how many nonverbal children receive the lifelong diagnosis of mental retardation or low functioning or, you know, basically there's no hope if they aren't talking by 5?

I was just lucky that, you know, someone came along and was able to help my son communicate, you know, by age 9.

Now, this is a video that would really should I show it? It's like 4 or 5 minutes.

It's Temple Grandin interviewing Tito. And this is like one of the most interesting videos I have ever seen. And it really calls into question what is language, I think, because you would say that she was the higher functioning – better language – and Tito was the lower functioning, less language, but let's take a look. I hope you can hear it.

(Video playing)

Ms. Iversen: All right.

Dr. Insel: So, we'll have to wind this up because of where we are.

Ms. Iversen: Okay. So, I'll start to wind it up with your words, Tom. I thought this was a very nice quote. I don't know if you'd like to just – it says, clearly words like nonverbal and low functioning just don't cut it. And then it says, how many Titos are there? And at a more basic level, it calls into question some of our basic models of verbal communication as a proxy for sociality.

Okay. And I'm just about at the end, luckily. So, there are just some key questions, take-home questions.

How many of these people have receptive

language? What gateway skills can we teach to help them start to communicate, and what cognitive measures can be developed and adapted?

In other words, if they're taking the ADI or the ADOS or they're just simply taking tests to see what grade they should be in, we need to have tests for them.

And I want to give you two really concrete examples of studies – that this is my two cents. I was looking through all the research, and I think these, for example, are very important studies, and I hope they get – the research results – get disseminated.

Barry Gordon has one on – and I think isn't that the Science Foundation funding that? Is it, Alison? Do you remember – oh, no, no – Department of Defense.

And that is receptive vocabulary, knowledge in low-functioning autism by eye movements, pupillary dilation in event-related potentials like miniseconds, and things like that.

The second one is someone who worked in brain-injury patients and developed a portable noninvasive EEG/ERP system very easy to use.

And you would basically show a person a word and they would see a picture. And it was also done auditorily, and it was either a match or a mismatch.

And in this way, it was a very, very clear, clean signal not open for much interpretation about whether the person understood the word or not.

So, I think things like this are really important, especially for people who are really hard to work with and we just don't know what they've got going on inside – I mean, at every age, definitely.

So, just to conclude, we need research, we need noninvasive assessments of cognition in this population. We need to develop testing for them that they can – that is actually useful and appropriate for them. And we need to develop literary-based and communication-oriented pointing, and even more importantly, just the basic gateway skill of pointing at something with intention.

We also, I want to just emphasize, that this group is probably – this is again my two cents – I think they're going to be a goldmine in discovering the rare genetic conditions, metabolic conditions like the folate condition we heard of earlier and things like mitochondrial disorders – also, the catatonia and the GI problems.

The first things I mentioned, the genetic, metabolic, and so on, are things that actually – the more so-called low-functioning a kid or adult is, the more workup they should get and the more frequently.

They should get it at least every few years, because new things are being discovered in these areas and new tests are available, and you never know if there's going to be a treatment available.

So, I think they're more likely to have these things than the higher functioning part of the population.

And then, lastly, general medical care – I don't know if anyone in here has a challenging autistic child or adult who's nonverbal. It's very almost impossible to get good medical care.

And this is something that should be taken out into training for physicians, and I just would like to see some advocacy around this, because these people are not getting basic medical care, really.

Okay. Let me see. And there's a picture of Dov. This is my little visual why communication is good. And there he is with a friend and brother and sister.

Okay. So, I can't believe that I got all the way through. Thank you so much.

(Applause)

Dr. Insel: Thank you, Portia. We're going to have to break. What we'll do to try to recover some of the time is cut the lunch hour to something like 15 to 20 minutes.

So, I need everybody back here by 1:30 at the latest. Let me just check, because we were supposed to start public comment at 1:15.

Is there anyone scheduled to give public comment who can't delay by 15 minutes? Is that going to interfere with anybody's schedule?

(No response)

Dr. Insel: Okay. Hearing no objections, you can leave everything here. There's a cafeteria on the first floor in the A Wing, and you can grab something and bring it back here if you'd like.

Dr. Daniels: Right. So, please go get your lunch and bring it back. I doubt that people will have time to sit down and eat. It's probably going to be a little bit crowded in the cafeteria.

To get down to the cafeteria, take the elevators down and then go through the hallway straight ahead and then turn to your left, and the cafeteria is on the left.

(Whereupon, the Committee broke for lunch at 1:07 p.m. and reconvened at 1:35 p.m.)

Dr. Insel: So, we have a long list of people who have signed up to make public comments, I want to remind the Committee that their oral statements are available to you, because they were sent in to us, and they're in your package along with a group of written statements as well.

So, there are a number of things that you have already received by email to prepare for this meeting.

Because we won't have sufficient time to go through all of those statements in the detail that many of us would like, we want to make sure you take the time to look at them before you come.

While we're here, we do want to have each person who has signed up take about 3 minutes to tell us the main part of what they need us to hear.

And we do this in the order in which they submitted their comments. So, the first comment will be from Cassandra Oldham.

And, Ms. Oldham, you can either come to the microphone at the front of the room, or you can – the podium is probably easiest. But if you'd like, you can also – if it's easier – you can sit at the table.

Is Cassandra Oldham here? If not, let's move on to the second person, who is Eileen Nicole Simon.

Ms. Simon: Can you hear me?

Dr. Insel: Yes.

Ms. Simon: And I'm very bad at public speaking. What I'd much prefer would be to hear members of the Committee discuss the ideas that I have submitted.

And, basically, language and how it's disrupted in the brain should be the focus of research and how all of these additional causes affect these areas of the brain of high blood flow and metabolism.

And in the literature, for more than 50 years, there's evidence that these brain structures of high blood flow and metabolism are damaged by asphyxia at birth and toxic substances, and this is a double effect of asphyxia plus bilirubin.

I think pictures speak a thousand words. So, I think that's all I'll say and hope you'll discuss some of the ideas that I keep submitting over and over and over again. Thank you.

Dr. Insel: Okay. Thank you for being so brief. We will have time after the public comments for discussion. And I know you've asked the Committee to give some response to the comments you've made, both prior to this meeting as well as previous meetings. So, we'll take that into account.

The next person who had signed up was Jill Rubolino.

Ms. Rubolino: Good afternoon. Before I begin my statement, I just want to extend and take this opportunity to express my deepest gratitude to Dr. Buie and Dr. Frye for their extraordinary presentations. They validate our children's underlying medical issues and the absolute necessity that their physical symptoms be investigated.

My name is Jill Rubolino. I am the mother of a 10-year-old son who has recovered from autism and also the cofounder of the parent support group AIM: Autism Is Medical. I appreciate the opportunity to speak to you today.

This is my first time attending an IACC meeting, and I'm appalled at the tremendous disconnect between what is discussed here and the reality of what's happening to our children.

Because I have only 3 minutes, first I'm going to read 10 statements of truth followed by only three requests.

One, thousands of children become sick first and then get diagnosed with autism later.

Two, their illnesses create symptoms that are interpreted as behaviors only because physicians deviate from the basic practice of medicine and no physical or diagnostic assessment is ever performed.

Three, those behaviors are funneled into a diagnosis of autism, and the child is left untreated and becomes sicker.

Four, the parents are left to fend for themselves.

Five, there is no assistance or support.

Six, the children suffer in extreme pain while health care providers refuse to assess and treat their pain. Pain has been considered the fifth vital sign for over 10 years, and it's every patient's right to have their pain assessed and treated, as stated by the Joint Commission.

Seven, bowel disease, seizure disorder, immunological dysfunction, and mitochondrial disorders are common in autism, not rare. I think that was established here today.

Eight, these illnesses are not comorbidities, but causation, and they need to be investigated.

Nine, in the 7 years I spent recovering my child, I wasn't even aware that this Committee existed, nor am I aware of anything that's been accomplished by this Committee. I'm inspired by the clinicians that presented today, and I hope that IACC is accountable to their information.

Ten, medical neglect and discrimination against this exponentially expanding, acutely and chronically ill pediatric patient population will not go unchecked. Our children deserve the same access to appropriate health care as every other patient.

I have only three requests. One, 1 in 50 children are diagnosed as autistic, statistically outnumbering all other pediatric illnesses. I request that this Committee address this as the emergency that it is.

Two, I request a medically based standard of care for autism be developed and implemented across the broad spectrum of all health care settings, starting with the pediatricians. The first intervention should be a diagnostic test, not a referral for a developmental screening.

And three, lastly, I request that this Committee recognize that they are responsible for their own direction. Failing to make the medical needs of these children a priority is endorsing the continued denial of appropriate medical care and subsequent medical neglect of a generation of children. Thank you.

Dr. Insel: Thank you. Albert Enayati. And I should point out that there are some attachments that go with Mr. Enayati's presentation as well. That's in your package.

Mr. Albert Enayati: Okay. This is a video of my son Payam. He's 22 years old. And I want you to see what he does during the day.

(Video playing)

Mr. Enayati: Can you hear me now? As you can see, there is a patch of hair that is missing on his head because he hit himself so many times that he has no hair left.

You see how strongly he hits himself that it breaks my heart every minute of my life.

He bites. He attacks people. He's attacking me right now. He has broken all our kitchen cabinets. Broke all our dishes.

Numerous times he tried to kill my 13-year-old son, and now our family has been separated into two groups. My son, my older son – my oldest son and myself and him – live in one separate house, and my wife and my youngest son live in different house.

He peed all over our house. He threw up all over our house. And our house has become a war zone.

Before he become autistic, he had two languages. He behaved normally. Now, he’s lost his languages. He started biting himself, hitting himself against the wall, and running aimlessly in the house.

As you could see, he's a very good-looking boy. You see how – I can't even get close enough to hold onto his hand not to hit himself. I just cannot do it, because he attacks me.

My name is Albert Enayati. I'm a board member of SafeMinds, a volunteer organization aiming to eliminate the devastation of autism and use by mercury and other neurotoxins.

As a past president of New Jersey Cure Autism Now, currently Autism Speaks, I was working with Portia Iversen, and I was going to mention her name, but – oh, she's here.

So, I just want to let you know that all the accomplishment I have is just – the credit goes to Portia and John. And I'm so grateful to them to have me as part of their team at Cure Autism Now.

As a past president of New Jersey Cure Autism Now, currently Autism Speaks, we have drafted and introduced the Combating Autism

Act of 2006.

At Rutgers University, we established the first nationwide autism gene bank that included hundreds of twin siblings suffering from autism, and we established the first center of excellence in Nation for autism research.

I am co-author of "Autism: A Novel Form of Mercury Poisoning." I work closely with the United States Congress, FDA, NIH, and CDC to remove thimerosal from childhood vaccinations.

Sadly, despite of 18 years of work with advocacy, we are still unaware of the cause of this devastation with no medication or prevention in sight.

For the past 18 years, we have sought out the cause of autism, spending millions of dollars in many fields, and we have found nothing conclusive.

It is now time to dedicate our resources into the right path. Vaccines' role in autism epidemic must be included in the IACC research portfolio.

Mr. Chairman, many experts would have us believe that my son's condition was mere coincidence with his vaccination. However, as a trained scientist, my reading of vaccine literature indicates that many traits that define autism may be induced by vaccination.

The timeline for increasing the autism prevalence corresponds closely with introduction of two new vaccines – in particular, the Phase II introduction of HIV vaccine in 1985 to 1990 and the universal introduction of hepatitis B vaccine in 1991.

Dr. Insel: So, we're well beyond 4 minutes. I just want to make sure we get you to wrap up soon, because –

Mr. Enayati: I'm going to have two sentences, and that's it.

Dr. Insel: Okay, thank you.

Mr. Enayati: You may recall that after the space shuttle Columbia disaster, an investigative board was created by Congress to investigate the accident to get the truth. Now it is time to establish such an investigation board to explore the relationship between vaccine and autism.

Ladies and gentlemen, the U.S. immunization program must be regulated. The children are vaccinated without knowing the history of the mother’s or child’s immune system or recognizing if the child’s immune system can successfully respond to injected vaccine.

Multiple vaccines are injected in a single day without concern about side effects. Booster vaccines are injected without any testing to confirm if T and B lymphocytes have become protected.

One more minute. Mr. Chairman, since 2009 – that's very important, and I'm going to ask you to answer my question. Since 2009, the National Vaccine Advisory Committee recommended numerous time to this organization that a research program should be conducted within the field of vaccine and autism.

As a devastated father, I stand before you today sad and frustrated, as it seems that IACC does not care.

It is essential that IACC meets its obligation to thousands of concerned parents and immediately starts issuing RFAs as per recommendation of NVAC.

Additionally, the RFA needs to be issued to investigate the phased introduction of HIV vaccine and universal introduction of hepatitis B vaccine in relation to increased prevalence of autism and investigate the rate in the vaccinated and nonvaccinated children free of conflict of interest.

So, I need to ask you a question. Why – in 2009 this organization asked you to conduct research on the relation between vaccine and autism – why has nothing been done?

NVAC. It is on your portfolio. I want to know. I'm going through hell every single day of my life.

Dr. Insel: I appreciate that. There are other people –

Mr. Enayati: No, no, no, no –

Dr. Insel: – who are waiting and would like to speak.

Mr. Enayati: I need you –

Dr. Insel: You are not being fair to another seven people who are on the list.

Mr. Enayati: No, you need to answer me.

Dr. Insel: I will tell you very quickly so you and others understand: This Committee does not fund research. It does not issue RFAs.

What we do is provide advice to the Secretary. We do stay open as a public forum so people like yourself can tell us what they feel and think, but we're not in a position, we don't have a budget, to fund research.

We've never issued an RFA, and we never will.

Mr. Enayati: So, would you recommend that they recognize and consider thousands of parents across the country and investigate the relationship between vaccine and autism?

Dr. Insel: It's not going to be done by the members of this Committee. It can be done by any of the agencies represented. And your real question needs to be directed to any of those agencies. And that's a question that really gets down to, at a very fundamental level, the individual scientific programs that each institute or each agency runs.

That's as much as I'm going to be able to say. We're going to have to move on. Thank you for your comments.

We're going to move on to Jeanna Reed, who also has some additional material that she submitted that is in your packages as well.

Dr. Insel: I hate to be a stickler for time, but we've lost about a third of the time just getting you to set up.

Ms. Jeanna Reed: Well, then I can start talking.

Dr. Insel: Okay.

Ms. Reed: Initially, I sent all of you a longer version of what I was going to say, with photos that I really would appreciate that you take the time to actually look at them. So, I'll go ahead.

Good afternoon, and thank you for the opportunity to speak for 3 minutes on behalf of my son and other families.

My name is Jeanna Reed, and I am a mom to three beautiful boys. Today, I would like to speak to you about my oldest son, Ian, who suffered severe adverse reactions to his recommended vaccine schedule.

The pictures you see behind you reflect years of suffering, damage, and attempts at recovering my child.

Swelling, relentless high fevers, ataxia, rashes, horrendous diarrhea, seizures, aggression, immune dysfunction, mitochondrial dysfunction, self-injury, ear infections – the list goes on.

We watched in horror as our once

typically developing, loving child declined medically right in front of our eyes.

After multiple reactions to his vaccines, our pediatrician tried to put our son into a nice, neat box. A standard, if you will.

We were all very concerned, and our physicians clearly confused. He was miserable, febrile, and declining. And when some of the testing didn't quite yield expected results, symptoms were explained away and even dismissed. We were told to wait and see more times than I'd like to share with you.

When eventually diagnosed as severely autistic, our son was lost in a system that truly had no clue how to help him.

A school-based program and typical therapies were recommended, but none of this did anything to diagnose or treat the underlying medical problems he faced.

So, because of this, we were forced to travel to university hospitals across six states, mostly outside of Illinois where we live, to find him help, medical help, he so desperately needed.

This in turn allowed for us to form a team of specialists around our son, and we devised a plan to properly diagnose his medical conditions and treat each appropriately.

That team consisted of a neurologist, a mitochondrial specialist, gastroenterologist, geneticist, immunologist, pediatrician, nutritionist, family medicine, and countless therapists.

We worked together coordinating care to ensure all were on the same page and treatment was appropriate and optimal.

Collectively, we agreed his systems were damaged, dysfunction trying desperately to repair.

The medical approach to my son not only allowed for the opportunity to diagnose and treat him, but greatly improve his symptoms.

Eventually, the label of autism, which is a side effect to the underlying medical problems, peeled away, his pain relieved, and my child reemerged.

Can you imagine if we listened to our pediatrician, our immunologist, the first one we saw, the early intervention specialist, "Sorry, Mr. and Mrs. Reed, we can't test him when he's like this, the sensory issue is just too much." Really?

That was 2006, 2007, and I'm not sure much has changed since then. So, I ask you, what do you think would have happened to my child if we listened to that advice?

We are so grateful to our team – brilliant, forward-thinking physicians who refused to let the label of autism cloud their clinical judgment – their simple goal always to identify the medical condition and then treat it.

And, so, I stand here asking all of you today, shouldn't this be offered to all children?

Where is the comprehensive, interdisciplinary medical care, and why are we not banging on the doors of every medical specialist that treats these children to ask them what they're doing? How are you missing this as the priority?

The standard of care, in my opinion – it is criminal at this point that we do not have one for this patient population.

And I believe the AAP was here. So, maybe they can answer that for us at some point in time.

But from the moment these children present at their ped's office with concerns, the first thought should not be send them to early intervention. It should be a medical intervention right then and there, while the families wait for services that many times never even come.

Bottom line, the bulk of mainstream medicine is failing these children miserably. And, frankly, so is this Committee if you continue down this path with blinders on.

At this point, we are begging you to understand that autism is medical. So, please listen. Respectfully submitted on behalf of my son and family. Thank you.

Dr. Insel: Thank you.

(Applause)

Dr. Insel: The next public comment is from Nicholas, Carolyn and Andrew Gammicchia .

Mr. Nicolas Gammicchia: Hi, everyone. I am here to provide oral comment because I am very troubled.

On June 9th, a young man with autism who was 14 years old, died. As a person living with autism, this was very hard to hear about, because he was murdered.

This young man also was denied the medical treatment that he should have been able to obtain.

Alex Spourdalakis was a young man that was misunderstood for what his behavior was trying to communicate.

I, at one time, was like Alex. I would hurt my parents, and I was not getting the help I needed.

It was hard for me to communicate how I felt, tell people I did not feel well, or what could assist me.

My parents were able to get me the medical treatment that I needed and not going into the hospital that was suggested.

I am asking you today to once again form a safety committee to look at issues like what happened to Alex and is happening to many other individuals with autism across the country.

My Uncle Mark died due to restraints used in 1999 in a hospital in Michigan. He had autism and epilepsy and was denied medical treatment that caused his death after being restrained.

Things are not changing, and many more people are dying. We cannot let my Uncle Mark's death be in vain. We cannot let all of those that have died due to lack of medical care have died in vain.

We cannot let Alex's death go unanswered. We need to look at what is happening. People living with autism like me want choice in medical care. People living with autism also want to be safe. Please form a new safety committee ASAP to address this.

Thank you for listening to me today, and I am grateful to have this opportunity to let you and others know my concerns. Thank you.

(Applause)

Dr. Insel: Thank you.

Ms. Carolyn Gammicchia: We're all grouped together, so we get 5 minutes? We traveled all the way from Michigan, and we have to share our 5 minutes?

Dr. Insel: No, actually I think you get 3 minutes each is the way we've set this up.

Ms. Gammicchia : Oh, okay. Thank you. I do want to just say that we're here because we are in support of what Dr. Buie and Dr. Frye presented on today, and hopefully that Dr. Perrin will embrace, is medical choice for individuals with autism.

You have my statement. I'm not going to read everything that I went into in my written comment to you all today.

We do have – it's very emotional for us, because – let me see. I did – I lost my brother. Nicholas lost his uncle in 1999.

He was hospitalized for a medical condition he did not get medical care for. He was restrained both chemically and physically, and he died from a pulmonary embolism in his leg that went to his lung because he did not get proper medical care. That was in 1999.

Since that time, we've been advocating for effective change in Michigan. We closed every institution in our state, and we no longer institutionalize individuals with disabilities and treat them as though their lives have ended.

As Mr. Robison and Mr. Robertson

indicated today, adults with autism need to have medical choice.

Alex Spourdalakis was murdered by his mother on June 9th. He was 14 years old. We, as an agency, we run a nonprofit organization called L.E.A.N. On Us. We submitted a CRIPA complaint to the Department of Justice 3 months before Alex died, stating that he had been unjustly restrained chemically and medically by the hospital that he was being treated in.

We submitted that comment to the Department of Justice as an ADA complaint under CRIPA violation. We have yet to hear from them.

Alex subsequently died at the hands of his own mother, because he initially did not get proper medical treatment.

I will not discuss his murder, because it's not the way I want you to remember Alex.

You have his photo, and I do not want him to be an invisible victim like my brother was, like Alex is, like the child that wandered and was found dead in a car in Washington, D.C. yesterday.

We have a crisis that's happening to individuals with autism in this country. I don't care where you fall in the spectrum, we have victims of crime with autism living in the United States that every day that something happens to them, they are invisible.

We as an organization have contacted the Bureau of Justice and Statistics. We are provided a grant by the National Institute of Justice. We've presented at the National Center for Victims of Crime, the last two national conferences, on autism and victims and how they've been subjected to no treatment from the criminal justice system for their victimization and abuse.

What we're trying to do and what we are asking is that the data collection that police officers fill out every day in some way identifies the victim as having a disability.

We've been doing this and asking for this now for 6 years.

It would be very, very easy for us to file an OCR complaint against the Department of Justice, who they themselves ensure that ADA is in compliance, and say you're not collecting a demographic on the population that is more likely to be a victim of crime, an individual with a disability.

In 2007 we worked with the Department of Justice. We actually have an 8-hour curriculum that is specific to crime victims with autism.

That was a $50,000 grant. There is an 8-hour curriculum on safety training for law enforcement, corrections, any first responder in this country. That curriculum is waiting and sitting there, waiting to be used.

Within that research, we conducted a survey regarding victimization and abuse of individuals with autism. It has yet to be submitted as a national summary.

That information is now sitting there.

It's 5 years old. All the free materials created in that project are sitting there while we have more victims dying, more children eloping and wandering.

Our son was an eloper at one time. Our son had very severe autism. You see in the photos that I have presented to you, which we very rarely share because of the stigma that is attached to that type of domestic violence in the family that is living with autism. We very rarely share those photos, but that's what my son did to me when he was 11 years old.

We documented that to protect not only us as a family but also him as an individual living with autism.

We're here today because we feel that this group of people, no matter what agency you represent, and I was hoping that John O'Brien was going to be here, because I wanted to also discuss something within our son's Medicaid waiver, but we're hoping today within all the agencies that you represent, that this is something that you look at as not being represented.

We have invisible victims in this country. Every single person that has a disability, that is victimized every single day is not – there's no demographic on the report that police officers fill out.

Seventeen thousand police departments in this country fill out those reports every day. I know. I was a police officer for 21 years. My husband is still a police officer. We've created three curriculums to train law enforcement on disability, and it's not getting done.

So, if this coordinating council or Committee cannot coordinate something to get it done – there's going to be a very important presentation done this afternoon about agencies working together and collaborating on one issue, which is wandering and eloping, but we have quite a bit of other issues.

We have sexual assault. We have kidnappings, and we have abuse in schools. We have restraint and seclusion issues, not only in schools but also in institutionalized settings. We have no demographic to show that on a daily basis.

The young man that was found in the car yesterday, 7 years old, found dead in a car, is an invisible victim.

Dr. Insel: Ms. Gammicchia , I'm sorry to interrupt.

Ms. Gammicchia : So, when that police officer –

Dr. Insel: We're just at 10 minutes.

Ms. Gammicchia : Okay.

Dr. Insel: And we had 9 minutes for the three of you.

Ms. Gammicchia: When that police officer filled out that report about that child's death, there was no demographic to fill out that he had a disability.

So, no matter what you do in any type of crime, any type of elopement program, anything – we will never be able to have the data that shows if something is going to work.

So, if you come up today with a national alert system, those police reports are not going to tell us if a child has autism when they wander. All that needs to be done is a little bubble filled out that says a disability.

And I did a proposal for the National Institute of Justice. It will cost less than a half a million dollars to get that done across the country and do a training program that would be very easy.

I've got a proposal. If anybody wants it, you can have it, free. But, I mean, that's why we're here today. We're here because people keep dying and we don't have any data to show it. We have no – if we don't have the data, we don't have the appropriations to get funding to do prevention.

So, that's why we're here today. And I'm sorry if my husband –

Dr. Insel: Yeah, we're now at 11 minutes. I've given you 9, and it won't be fair to the other people who have signed up for public comment if we take any more time.

Mr. Andrew Gammicchia: We have updated comments from Nicholas that include the pictures that you should have got today. I just wanted you to be aware of that.

And she covered everything I was going to talk about.

Dr. Insel: Okay. Well, thanks to the three of you for coming.

Ms. Gammicchia: Thank you. Thank you.

(Applause)

Dr. Insel: Next public comment is from Ann Bauer.

Ms. Ann Bauer: Hi. My name is Ann Bauer. I'm a doctoral student in epidemiology at the University of Massachusetts in Lowell.

And I'm here today to ask the Committee to consider the need for research to investigate an understudied, yet highly prevalent, direct pharmaceutical exposure for both pregnant women and their offspring. This exposure is acetaminophen.

Close to 70 percent of U.S. women take this medication during pregnancy, and it's the most common drug administered to U.S. children.

Several lines of biologic and epidemiologic evidence suggest the plausibility of a causal relationship between its use and the development of autism in a susceptible population.

Our recent ecological study importantly identified a plausible explanation for the four to five times greater prevalence in males than females. Males are differentially exposed and differentially susceptible to acetaminophen toxicity.

Since the mid-1990s, guidelines from the American Academy of Pediatrics and the World Health Organization have suggested five to seven doses of acetaminophen be administered with a circumcision procedure.

Our study identified a 98-percent correlation between the country's circumcision rate and its autism rate. Several studies have identified a lower capacity to metabolize drugs, particularly acetaminophen, in those first few days of life.

This, on top of the inability to sulfate acetaminophen, that's been known to be part of autism, can lead to glutathione depletion and reduce detoxification capacity, inducing oxidative stress and immune dysregulation, which are commonly seen with autism.

Acetaminophen is known to cause liver damage, kidney damage, asthma. Is it possible autism?

Several animal studies have shown that acetaminophen induces apoptosis, necrosis, and neurotoxicity. Several studies have hypothesized this increased apoptosis and necrosis in the autistic brain.

A consistent finding in autism is a loss of Purkinje cells in the cerebellum. A recent study by Dean demonstrated the use of acetaminophen and other COX-2 inhibitors during the early postnatal life altered cellular Purkinje cerebral development, with atrophy only in males.

So, a little history about acetaminophen. In 1980, after sufficient evidence emerged of an association between aspirin and Reye's syndrome, acetaminophen essentially replaced aspirin as the primary treatment for pregnant women and children.

Since that date, acetaminophen consumption throughout the world has increased dramatically, with a similar trajectory to the autism prevalence rates.

Admittedly, two parallel, correlated lines are of limited inferential utility, but this link is strengthened by some observations that were made by Becker & Schultz.

They noted when there was contamination

of acetaminophen by – in 1982 and 1986 there was contamination with cyanide and in three different populations they showed that the curves, the autism curves had the same abnormalities – anomalies as the autism prevalence rates in those populations.

Dr. Insel: Ms. Bauer, I'm sorry to interrupt. I will need to have you sum up.

Ms. Bauer: Okay. So, I just want – so, consider acetaminophen. It's highly prevalent. There's a lot of biologic plausibility I didn't touch on. It has the same altercations in the epigenetic methylation pathways, microRNA, the serotonin pathways, the mitochondria, and the brain pathology as is seen in autism.

Dr. Insel: Thank you very much.

(Applause)

Dr. Insel: The next public comment is from Brooke Potthast.

Ms. Brooke Potthast: Good afternoon. You'll be happy to know that I slashed a lot of my comments. So, hopefully it will be shorter. Might not be quite as fluid.

My name is Brooke Potthast, and I'm the mother of four children, the youngest of whom has autism. I'm also the founder of the Shire School, which is a small school in Arlington, Virginia, for children with autism.

I want to thank you, Dr. Insel, and members of the Committee, for inviting public comment today.

I came last year as an observer to this very Committee meeting, the one that was held at L'Enfant Plaza, and I left with a lot of thoughts, emotions, and questions. Some of those I'd like to share with you today.

When I left that meeting last July, I had many friends and family ask me what I thought. And I said, it was like this. It was like watching a town council whose town is being destroyed by a huge flood coming from a dam. The flood is devastating everything in its path, and it will eventually destroy all that surrounds it. But the council is so busy discussing what life preservers to use, what color and size is best for which victim, that they're failing to focus on the most important factor: What is the cause of the flood? Where is the main crack in the dam, or where are the small cracks in the dam, and what can be done to repair them and stop the flood?

I just find it incredible that we have the technology and science to do so many things. For example, you know, you read in the newspaper when there's an *E. coli* outbreak, it's narrowed down to the most specific leaf and the specific field on a specific farm in a specific country, but we can't come up with a common consensus statement regarding the etiology of autism.

The best we can do, as stated by the Center of Disease Control, is it's a combination of environmental and genetic factors.

I know autism is very, very complicated, but I just don't understand why and how the prevalence numbers for this illness can go from 1 in 10,000 20 years ago to 1 in 55 today, and we do not have a public health official giving us any real explanation.

My next question for the Committee would be, is it possible, or have you already considered examining the medical records of children who were typically developing and then regressed into autism?

That was what happened with my son. It seems to me that some answers to causation would be found if a wide, systematic evaluation was done on the records of these children.

You know, most people agree that a mother's intuition is a very powerful and potent thing. What my intuition tells me went wrong with my son and what his medical records could back up, I think – I have intuition and information that I think would be helpful, and it would possibly prevent another child from regressing into autism.

I'm just going to share three factors that I think led to my son's descent into that disorder and I'm – just three of them.

Number one. I received IV antibiotics during labor and delivery. It was necessary as a precaution against the strep B infection. Those antibiotics killed all of my beneficial healthy gut flora and did not allow my son to establish his own healthy gut flora, which we know occurs in the first few days of life. This gut to our inner biosystem is foundational for good immune health and overall health.

Both my son and I should have been prescribed probiotics to replace what was eliminated and to give him a chance at establishing a healthy gut environment.

Number two. My son received a hepatitis B shot containing ethyl mercury when he was 5 days old and then a completion of that vaccine series in the first year of life.

A study published in October 2008 in *Toxicology and Environmental Chemistry* demonstrated a nine times higher risk of developmental disability in boys who were vaccinated with the full series of hepatitis B vaccine, as compared to boys who had not been vaccinated with it at all. Postponing that series could have possibly prevented his autism.

And the third thing, heavy metal toxicity. I know there's heavy metal exposure in a lot of places, and there are many sources. My son's urinary porphyrin test, his urine toxic metal tests, show high and toxic levels of mercury, lead, cadmium, tungsten.

When he started showing signs of immune dysfunction and inflammation and developmental delay, wouldn't it have been a good thing to test him for heavy metal toxification?

It didn't happen. I found it out about 5 years after he got sick. And actually treatment for heavy metals has improved his health and his symptoms of autism a great deal.

I have more reasons on my list that you would learn about if you studied his medical history. There are tens of thousands of children like him.

Would it be that expensive to go back and look for patterns and trends in medical records of these children? Don't you think it would be worth it to get some answers?

Currently, I have nieces who are – three nieces. They're all pregnant with little boys. And I know they want to know how to prevent their sons from having a life like their cousin.

They would like to get the information from their public health authorities, but it isn't available. And that is something that I think this Committee should be very concerned about.

I thank you for the opportunity to speak today. I cannot think of anything more tragic that's facing America today than the ever-increasing rate of autism.

Dr. Insel: Thank you.

(Applause)

Dr. Insel: Clinton Potocki.

Mr. Clinton Potocki: Yes, hello. My name is Clinton Potocki. I'm here to speak on behalf of my family and my sister, Dawn Loughborough, and relate highlights of lessons learned around regressive autism care from Dawn's recent and direct work with the family of Alex Spourdalakis, whose life was taken at age 14 by his mother and godmother in a murder-double suicide attempt. You have Dawn's complete comment in your handouts.

One, the patient care systems are not in place to support the basic medical needs of children with nonverbal regressive autism in pain management, gastrointestinal issues, seizure disorders, and metabolic issues.

Two, we need an expanded standard of care for autism as a special patient population and believe our consulting team and Autism Is Medical, or AIM, to be the go-to leaders in the trenches and in action on this endeavor.

AIM uses methodologies for the existing medical care model advising parents and hospitals. The hospital contacted AIM for help with Alex.

A national program developed by AIM is being offered as a solution to hospitals. The problems Alex encountered are not fixed, and we fear this will happen again.

Consider how costly this is to our Nation to have our children's underlying health issues not addressed, prolonged ER visits, and increased risk management. Starting last fall, Alex repeatedly entered the hospital system presenting with medical issues that were not properly investigated.

Alex was in pain. He had a change in status with sudden aggression, which in the pediatrics GI consensus paper is an indication of the need for GI investigation. He was never to receive a pain assessment at any of the hospitals where his family took him seeking medical care. The hospital struggled to get his psych medications correct, and he had adverse reactions to multiple drugs.

Alex's experience in the hospitals exemplifies medical neglect and discrimination against nonverbal, disabled children with autism.

Alex had bowel disease confirmed by Dr. Arthur Krigsman, known as a leading world's expert on autistic bowel disease, and confirmed by PillCam procedure.

Basic medical workups, blood tests, immune system and bowel disease referrals were never made at the pediatrician's office visits.

Alex had many problems with drugs he was prescribed. No assessment for drug allergies or drug interactions were conducted. Alex was in four-point restraint for over 22 days, with improper pediatric compliance issues that were reported to proper regulatory agencies. Family and thousands of public concerns and reports were filed at the hospital and the compliance agencies.

Alex was discharged from the hospital on May 31st after the family was told that their insurance would no longer permit him to stay, and he was medically cleared after receiving IV drugs just days before. Nine days later he was dead.

We request the standard of care for a special patient population is expanded with physiology at the heart of the care model. Autism is medical.

(Applause)

Dr. Insel: Thank you. And finally, Wendy Fournier.

Ms. Wendy Fournier: Thank you. Good afternoon. I'm Wendy Fournier. I am President of the National Autism Association, here to make a statement on behalf of our organization.

During the public comment period at your last meeting here in April, our Executive Director Lori McIlwain discussed serious co-occurring medical conditions that affect many individuals with autism.

And Lori also showed you a video of clips that were submitted to us by parents showing their children screaming, having grand mal seizures, throwing themselves to the floor, headbanging, writhing in pain.

For a lot of families that we serve in this community, that is a snapshot of just their day, and there's really nothing harder than to pick up a camera and try to document when something like that is happening with your child. But these are the families that cannot be in this room to share their experiences with you.

They're taking care of their child 24/7, and they cannot leave. And these are the kids and adults who are not able to self-advocate and speak for themselves.

So, we ask families to submit the video clips, and we hope that people will continue to do that so that everyone in this community is aware of the serious medical issues.

Unlike Dr. Perrin who – what a pleasure to meet him today – unlike Dr. Perrin and Dr. Frye and Dr. Buie who, by the way, I think you guys have thousands of autism moms across the country who would like to have your babies now but other than these guys, in general, physicians are just unaware of the medical issues that our kids face and that we're dealing with all the time.

And it's really not uncommon for us to hear from parents who say that they took their child to an ER, to a doctor, and their child was acting out and they knew their child was in pain and the physician said, “Oh, your child has autism. There's nothing wrong physically. It's just behavioral. That's how kids with autism behave.”

And that has got to stop. So, I'm really happy to see the doctors that you had on the agenda today.

The parent community has been saying their kids are sick for probably 15 years now. So, I'm really glad that we're starting to catch up.

The problem is that the mainstream medical community is not aware of these issues. So, we do need to expand it.

I'm hoping Dr. Perrin is going to make a big difference. Also, Lyn Redwood started to touch on suggesting that IACC work together with the AAP. I would love to see that happen.

In addition to IACC, I just think this is just too big. Autism is too big for you guys. There's too much going on, and it can't – a Committee that meets four times a year cannot be expected to fix everything that's wrong with autism. So, we really need to think bigger.

But, you know, when it comes to Lyn's suggestion about working with AAP, also, you know, I would say with AMA, national organizations like the National Autism Association of course would be happy to help. And I do think that stakeholder involvement is going to be key.

Also, again, parents have been saying these kinds of things for years now. Listen to the parents. We can help you jumpstart, you know, catch up the medical science by 10 years.

There was a study that came out last week saying that wheat and autism – there's some kind of connection there. I mean, if you had asked the mom 10 years ago, we could have answered that question for you.

So, endpoint is we really do need to treat the individual, not treat the autism. There are underlying medical conditions, and thank you for addressing those today.

(Applause)

Dr. Insel: Thank you. We wanted to set some time aside for discussion of public comment. I'm also mindful of our schedule and that we have a number of guests for the session that was scheduled to begin at 2:30.

So, what I'd suggest is we skip the break since we are late anyway, and let's take a few minutes for Committee discussion, and then we'll try to get into the 2:30 session as quickly as possible. Scott.

Mr. Robertson: So, one comment I wanted to make and since it was prevalent in a few of the public comments, was the murder of Alex in Michigan.

And I worry, and I have some concern and a lot of my other colleagues and friends and allies have concerns around the country that sometimes when not only autistic people are killed, murdered, but other people with disabilities, that we justify that killing saying, “Oh, life was so hard,” et cetera.

Of course you need to provide the right supports and services for folks, but I think we should also recognize that, like, murder is not good. That is the point. It should never be justified. It should never be condoned.

After the conversations, instead of talking about, okay, we need improved supports and services, we talk about, well, isn't life so horrible, of course it was okay that so-and-so killed their kid.

And, no, it was not okay for that to happen. And that worries me a little bit when I hear the theme come up often with folks who are subject to a lot of adverse situations as autistic people in the United States through, you know, abuse, neglect, and, you know, harassment and all sorts of different facets that happen that sometimes we don't look at the person.

We look at everybody else around them and that perspective take that there needs to be better empowerment and better understanding of, for instance, crimes and victimization of autistic people. Thanks.

Dr. Insel: Scott, just to clarify, I hope there was no misunderstanding. I don't think that we heard today anybody blaming the victim here.

Mr. Robertson: I just want to just quickly clarify on that. I don't mean directly from the statements here. I just want to bring it up in reference to the theme.

Dr. Insel: Okay.

Mr. Robertson: Because often the theme of when folks are, you know – it comes up in these discussions in newspapers, et cetera – it's like, well, no big deal that this murder happened.

And a lot of the media reports surrounding Alex's murder had that kind of a theme going on. And that's why I just wanted to say – I'm not saying that anything that was said today reflected that. I'm just saying that that's just a general concern in my head related to Alex's story and the story of a lot of other autistic people that have been, you know, murdered or killed.

A lot of other people with disabilities that we have held vigils for around, you know, showing that it's a sign we need to innovate supports and services so that doesn't happen to folks.

Dr. Insel: Okay. Just wanted to make sure we understood that. Sally.

Dr. Sally Burton-Hoyle: And thank you for the opportunity to be here to learn so much today from – so much new information for me.

I came to be a teacher educator because of my frustration with schools. I teach teachers, because when somebody has a different kind of behavior in schools as in other places, it's written off. It's not looked at. It's not analyzed.

There could be no bigger reason right now for cross-system collaboration than right now with the information that we have gotten today.

I consult in schools. I have student teachers in schools. And when somebody displays some of the behavior such as we saw in the videos today, everybody is written off. Everybody is written off.

The individual – and there's no thought to, well, how can we work together with the family to get the proper medical kinds of support? It's just the door is shut, and it's written off.

I see that in the adult system when anybody has different kinds of behavior. So, I think that we've got to use this information as a way to encourage systems to work together, you know.

Vocational rehab – if anybody has any kind of different behaviors, they're deemed not ready to work.

In school, they are deemed, you know, too, you know, too challenging, unsafe for other people.

And just as Scott was talking about, then there comes to be this kind of – nobody means to – but it becomes a sentiment of everything kind of being against the individual with autism as opposed to what are the things that all of us need to do so that we can work together to support that person whether it's medical, whether it's behavioral, and it takes everyone.

And after 1 year on this Committee, we've left schools completely, you know, unaccountable. This is not ever even brought up as a discussion, and I want there to be more emphasis with us on how it is we do involve schools in this – in all this cross-collaboration to support individuals.

Dr. Insel: John.

Mr. Robison: If I might speak to that last comment, we do have some fairly major Government-funded initiatives like CSESA, the Center for Secondary Education for Students with Autism, which are directed specifically at what you say, at improving the post-high school outcomes of young people growing up with autism.

And I actually think that groups like CSESA are a combination of people in education and people in autism and medical science – many of which are known to the folks here.

And I do feel that we are moving in that direction, and actually, you know, it might not be a bad idea to have more representation from the Department of Education and IACC, but I believe that what she asks is happening even though we don't discuss it right here.

Dr. Insel: Lyn.

Ms. Redwood: I want to thank all the families that came here today and wrote in public comments and took the time to travel to talk to this Committee.

And I find it impossible to address all of the comments, Tom, and I'm wondering if there might be a mechanism where the Committee responds back formally to some of the comments.

You know, the take-home messages that I heard are that we really need to listen to the families and their reports and their recommendations for leads for research – whether vaccines, antibiotics given at birth, acetaminophen, cord clamping early.

I think we need to somehow let them know that that's on our radar screen and we're going to try to incorporate those things somewhere in our Strategic Plan.

And maybe they're already there in our Strategic Plan, but we need to let them know what our response is to that.

We've heard it over and over again about the unmet medical needs. And I don't know if this is the place to bring it up or during the Committee discussions later on this afternoon, but I think it's something we urgently need to address with either a subcommittee or some type of task force work group to try to go and work on the things that we've already identified in the Strategic Plan, which are basically standards of care for evaluation and treatment.

I also think that there's a need to reestablish the Safety Subcommittee. It has been something that has somewhat fallen off the radar screen with the new Committee.

I know Alison and I had several very productive meetings with the past IACC, and I think it's critically important to bring that formation of that Subcommittee back.

So, those are my recommendations for today.

Dr. Insel: So, let me, in the interest of time, follow that up, and maybe we can move on to the next session.

I think you bring up really the key question, which is something many of us are feeling at the same time, which is we're hearing really passionate testimony from people who are in the trenches, and they get their 3 minutes, and they send something in, and they may have traveled from Michigan or California or Florida to share this with us.

And I think many of us have the sense

that there's no response or there's no – it's as if they're talking to a wall instead of to a group of people who are empowered to be responsive to public needs.

So, how do we do that, and what is the best mechanism? And by responsive, I don't mean necessarily even just the discussion which we've scheduled and hear abbreviated, but actually whether there are ways of drawing the lines between the comments that we hear and the written comments that we receive, as well which we don't talk about as formally, and then our statutory responsibilities of advising the Secretary, providing a Strategic Plan, updating the Plan, and then monitoring progress. And it hasn't been entirely clear to me where those lines get drawn.

We do have 30 or 35 minutes set aside for this, and there are often really substantive remarks here which kind of go unanswered. And I think that's what I hear you saying as well, Lyn.

So, maybe what we can do later in the afternoon is just give some thought to what is the right mechanism and what is the right process for us, besides having a brief discussion about it, to take from those comments something that is a little more not only responsive, but constructive, because there is real data in what we're hearing.

And it does feel to me like it's not adding up to anything other than a listening – a sounding board.

So, I'm not asking for an answer right now, but could I just invite everybody on the Committee to think about this in the way that Lyn has suggested, and let's take some time to put our heads together later and consider the best way to respond.

Unless there are any other pressing comments given where we are – Walter.

Dr. Koroshetz: So, we talked last time about potentially getting Department of Justice to the table.

Dr. Insel: They're here, and they're waiting to participate.

Dr. Koroshetz: Oh. So, there you go.

Dr. Insel: What a perfect segue. Thank you, Dr. Koroshetz. We are going to, since we will skip the break, puts us almost right on schedule, about 5 minutes behind, to have the panel on wandering.

And we have here – this is actually sort of a followup to discussions we've had at various times.

As Lyn just mentioned, we did have the Safety Committee that brought this back to the table a couple of times over the last 2 years. So, this is a chance to dig a little deeper on some of the issues.

There was a request to bring in people from the Department of Justice. And we have Jeff Slowikowski here with us who is – really appreciate your being here, sir, to help us understand the DoJ perspective.

We also have the Executive Director of

the Missing Children Division of the National Center for Missing & Exploited Children, Robert Lowery, who's here.

And then Wendy Fournier, who we just heard from, who was the person actually who brought this topic to the IACC initially many years ago – I think 4 or 5 years ago – got us started down this path.

And Alison Singer, who will tell us a little bit about what the IACC has done up until now.

So, the way we have this scheduled is, Wendy, you will start off giving us a sense of kind of what do we know, what do we need. Alison will take us up to date with what we have done. And then we're going to hear from our other guests about the AMBER Alert Program and whether there are options there to develop something that could be a solution.

Ms. Fournier: All set? Okay. I'm going to start – for those of you who may not be familiar with the wandering issue – I'm going to start by showing you a video that says a lot more than my words.

(Video playing)

Ms. Fournier: So, I want to thank Lori McIlwain and her husband Christian McIlwain for producing that video for us.

So, just to give you an update: When we first talked about wandering, actually it was Lori McIlwain who was here during public comment in April of 2010 – and we were invited back by the Committee in October of `10 to actually present on what we knew about the issue.

And what we did at that time was we gave you some case studies of what we were seeing in the community. We talked about the current AMBER Alert criteria, the need for data, because we did not know – all we knew was anecdotally we saw a lot of wandering going on in the community and a lot of kids were dying, but we did not have data, and we needed that for resources.

Also, the need for school response protocols should a wandering incident happen at school.

We talked about a comparison of resources for the Alzheimer's community versus the autism community. Alzheimer's patients tend to wander exactly like our children do, yet they have a lot of resources to address it and our kids do not.

We talked about the need for awareness, resources, policies, and training, training, training, training. I cannot express that enough.

We also discussed a medical diagnosis code and the fact that we thought we needed one and the effect of wandering on families.

Then we recommended an IACC Subcommittee on Safety Issues, which was established that day – an unprecedented move at IACC. Thank you, Lyn, and Alison and Geri Dawson especially for moving so quickly that day to establish that Subcommittee.

Since then, we do now have an *ICD-9* diagnosis code for wandering in diseases classified elsewhere. You will note that this does not say anything about autism. Autism is not connected to that diagnosis code.

This was put into effect by the CDC. Coleen Boyle and Cathy Rice were – they actually agreed with us, thought it was a good idea. They went ahead and put in the request for that to be added to *ICD-9*.

In the meantime, the IACC Subcommittee was still arguing about whether or not we needed to address wandering. So, anyway, now we do have the diagnosis code.

My hope is, and we touched on this briefly, is that physicians are going to become aware of this and start adding it as a diagnosis for some of our kids.

Because one of the reasons that we asked for it is so that things like tracking devices, which have monthly fees involved, can be considered medically necessary devices to keep our kids protected, and hopefully we're going to end up able to get insurance coverage on those types of devices.

So, the Safety Subcommittee in February of 2011 had sent their first-ever letter to Secretary Sebelius.

So, you know, as an advisory committee to the Secretary of HHS, the fact that it took that long to send out the first-ever letter to the Secretary advising her of an issue was pretty serious. I'm glad it was about the wandering issue. I'm glad that it went out.

I was extremely disappointed in her response, which was basically a form letter – thanks a lot; we'll give considerations to those recommendations. And nothing has been done since then.

So, one of the things that I mentioned before was that we needed data to show how often wandering was happening in the community.

Again, we did not want to wait on this.

So, actually starting that day in October, Lyn Redwood, Geri Dawson, Alison Singer, myself, Lori McIlwain – we made a few phone calls, and we had that study funded in less than 48 hours.

So, the study was funded, and the questionnaire was designed and put through IAN and eventually was published in the *Journal of Pediatrics*, I'm very happy to say, and we do now have some data on wandering – initial data.

So, what we know according to that questionnaire is that roughly half of our children with autism attempt to elope from a safe environment, which is the rate of nearly four times higher than their unaffected siblings.

And the reason that we ask that question is because we want to show that wandering is not an issue of neglectful parenting.

It may be in some cases, but for the most part these are not neglectful, bad parents.

More than a third of the children with autism who wander are rarely able to or are never able to tell you what their name is or where they live.

Half of families that have elopers had never received advice from any physician or professional, and we can definitely help and do better with that.

The effects on the family – we are living under great stress, lower quality of life – and this showed in the data from IAN, where a lot of us are unable to leave our homes, a lot of us are suffering from sleep deprivation, lack of support, understanding, resources.

A lot of families have fear of involvement from CPS or from law enforcement if their child does elope, and they're afraid that they're going to be accused of neglect.

And CPS workers have taken children who have wandered from the custody of their parents. And we need to start educating CPS workers that this is part of, you know, this is a behavioral issue with autism, probably a medically based behavioral issue that we need to study.

But instead of ripping a child from their home, we need to provide resources for that family to help that family keep their child safe.

Sixty-two percent of the families who were involved in this study said that they were prevented from enjoying outdoor activities or activities outside of the home, because they were just terrified that their child would wander and be injured or killed.

Forty percent of us have suffered sleep disruption due to fear of elopement. We have had parents call us and tell us that they sleep in the hallway outside the door of their child's bedroom, or they move the couch in front of the front door and they sleep on the couch so that they know their child can't get out of the front door in the middle of the night.

Some of the discussion that went on with the Safety Subcommittee was there was disagreement on whether we should address this issue or if addressing wandering would suddenly put this big umbrella on everybody with autism and we would restrict their personal freedom; we would put tracking devices on them, and we would prevent them from having self-determination.

I do not want my 13-year-old daughter to walk out of the house at 3:00 in the morning to go to the nearest pond or pool.

That self-determination is a skill that she does not need to have. This is not about restricting any freedoms for anybody. This is about keeping those who are at risk – at serious risk – resources to keep them safe.

This is not across-the-board, you have autism; we're putting a tracking device on you. And I want to make that perfectly clear, because there is no room for argument on this issue while our kids are dying.

The risk cycle affects on the family – we made this graphic just to show how exhausting it is.

The child can't sleep; the parents can't sleep; the nighttime dangers are, I mean, none of us really sleep. It's not a deep sleep. It's a sleep that you have when you have an infant in the house. You never really sleep. You're always listening.

You know, the parents are just completely exhausted and overwhelmed, and we get so many cries for help from parents who tell us they just don't know how much more of it they can take. It's exhausting. We need support for these families.

So, in addition to the IAN study, NAA has been collecting data on wandering. We monitor media reports on – every report in the media. So, this would be a serious wandering issue, serious enough so that the media actually became aware of it; a search was probably involved, and we've been keeping track of those.

And the lethal outcomes in cases just from 2009 to 2011 – accidental drowning accounted for 91 percent of the deaths associated with wandering; 68 percent of those individuals died either in a nearby pond, lake, creek or a river; 23 percent of them were in the care of someone other than a parent – so, a grandparent, a friend, a babysitter, possibly a teacher.

And interestingly, we don't know why, lethal outcomes in wandering in girls, the lethal outcomes were twice as high as they were for boys for some reason we'd like to know.

So, what we're seeing as far as trends go is that wandering does occur across all settings and under all kinds of supervision.

And based on our monitoring, we are seeing trends like during warmer months as soon as spring hits, we see this explosion of wandering incidents.

And we really think that it is climate related, especially in areas of the country like the northeast where I live, you know, you've been closed up all winter. Spring hits, you start opening the windows, you might have window fans in, your screen doors are open, and the kids, you know, suddenly have an easy way out.

Security patterns change in the home as the seasons change. I am constantly – once spring comes around – I'm constantly reminding everybody to lock all of the locks on our doors to keep Aly from walking out of the house.

We do see trends and, you know, frequency. So, certain events – your child is going to be more likely to be at risk. And that includes transitions; it includes moving to a new home, family gatherings and other parties.

We see a lot of kids that just walk away during an outdoor barbecue situation or something like that.

Camping and hiking – oh, my goodness. Don't take your child camping or hiking in the woods unless you have at least one, you know, two parents. One on each side so you have bookends or on, you know, but we see a lot of kids that do disappear in those kind of situations.

And then during times of stress or bolting. My daughter does two types of wandering. So, she will try to get to the neighbor's swimming pool in one instance, and then in another she'll become just overwhelmed on a sensory issue, and she will bolt away from me.

And I almost got arrested once in an airport because she did that. She bolted through security. And a second time also in an airport situation, she bolted into traffic.

And, thank goodness I had a tether from my wrist to hers, because she probably would have been dead.

But as you can see, the stress not only on the child will trigger the wandering, but the stress on families also is really something that we need to help with.

I had a heart attack in January. I'm talking stress. I had a heart attack and cardiac arrest, and I was dead in January. So, we need help as families.

So, in order to try to help the families, NAA has created some resources for prevention.

We established the Big Red Safety Box Program in 2011. So far we've provided 7,500 families with prevention tools and educational materials.

These boxes basically are visual aids, stop signs that can be put up in the house, forms that can be given to first responders, a sample IEP letter that can be placed in the child's IEP.

We have door and window alarms, a lot of printed materials, strategies, safety strategies, social stories, these kinds of things.

We've been able to provide 7,500 families with these boxes so far, and that is just a drop in the bucket.

The cost of these boxes is $35 each. So, we've put about $260,000 into this and only been able to help 7,500 families, but it is help and it is something and we do get emails saying that the resources in there have likely saved lives.

We created free toolkits for both caregivers and for first responders. They're available at awaare.org, the Website that we created back in 2010.

We've provided about a hundred thousand dollars’ worth of grants to law enforcement agencies for Project Lifesaver Tracking equipment so that kids can get on that program.

We did help with that IAN study. We helped to fund it, and we did help to write the questions for that IAN study so that now we do have that data published in *Pediatrics*.

And I did reach out to the Department of Justice, and, Mr. Slowikowski, I'm very happy that you're here with us today.

We had a conversation at least a year and a half ago that unfortunately we were not able to follow up on, but we were hoping for a meeting and some discussion about an alert system. So, I'm really glad to see you here today.

Around that same time I reached out, Lori McIlwain reached out to the National Center for Missing & Exploited Children. And that was where we met Bob Lowery, who you're going to be hearing from later today.

The National Center has been such a wonderful resource for us, and we have been working very closely with them.

NAA published a white paper on lethal outcomes related to wandering. That is available on our Website.

We also reached out to the YMCA

headquarters for a listing of Y's across the country that provide special needs swimming lessons.

Every family needs to have access to a water safety program, because so many of our kids are drowning.

We are providing first-responder, social worker, and parent training both in the U.S. and recently up in Canada.

And recently we just started a program called Give A Voice, providing a way for kids to help keep themselves safe, because we think a lot of these wandering issues would be avoided if the child had a way to communicate.

Most of these cases are nonverbal individuals. So, we're starting a program where we're going to be able to provide iPads and communication software for kids so they can say, “Hey, I want to go get French fries instead of bolting out of the house to go try to get their French fries.

This is just a picture of our Big Red

Safety Box. They are assembled by people with autism and other developmental disabilities.

This is a note we got recently saying that just the Road ID tag – and this is a little engraved shoe tag on her child's shoe that she got from the box – brought him home safely after he wandered.

This boy slipped out of the house. Nobody knew that he was gone. And a few minutes later there was a neighbor knocking at the door saying, I just found your kid. And I brought him home, because I see this ID tag that says he has autism, and your phone number was on there.

So, something so simple like an ID tag could very literally save a child's life. It's not that hard to get prevention resources out there.

We tell first responders always to search water first and to treat each case as critical. Our kids, sometimes they will die very, very quickly once they get out there.

This is an extraordinary case study that I wanted to point out that shows that searching for individuals with autism does prevent or presents unique challenges to search and rescue personnel.

So, in this particular case, this boy was not answering to his name, but he did answer to Ozzy Osbourne music.

These are two headlines that we pulled recently in Massachusetts and in Utah, where two individuals with autism were located by first responders who had had specific training on how to search for individuals with autism.

Training works, and we need this, and I hope the Department of Justice will consider getting involved in first-responder training.

And finally, what we need. Our children do not qualify for an AMBER Alert under the current criteria, and you know, typically an abduction has to be involved. So, there needs to be some discussion about an alert system.

Silver Alerts can be issued for missing

adults, but when the public hears "Silver Alert," they're thinking old person. So, we need to find some – we really need to have some discussions, either an Endangered Missing Alert, possibly a subclassification of AMBER, like an Autism AMBER Alert, but I would love for that discussion to be opened up today. It's important.

Benjy Heil – he was from Wisconsin. He was actually seen by a neighbor. So, some sort of an alert system may have helped him. And the neighbor just didn't realize – and this is part of the problem with wandering. Our kids are so, so gorgeous. Look at him. He's such a gorgeous kid. You would look at him and not think that there's anything wrong with this child.

He was 7 years old – kind of on the cusp of whether or not he would be safe to walk by himself, but a neighbor did see him and thought, “Oh, maybe he's walking to a friend's house,” and he didn't stop him.

And now, this poor neighbor can't forgive himself, because if he had stopped Benjy, he may not have drowned.

Same with Jack – He was also – he was in a busy shopping district. He was seen by multiple members of the public. Had an alert gone out, he possibly could have been saved.

Owen Black is a child who died very recently down in Florida. He was seen on – there was a guy on TV interviewed – “Oh, yeah, I saw him. I was wondering where his mother was. I had seen his mother with him earlier. Didn't know why he was on the beach by himself.”

But, again, didn't look like there was anything wrong with Owen, and he figured he was okay on his own.

This story broke our hearts. We were in Connecticut. We were doing – or not Connecticut. We were in Canada – first-responder training for police officers.

The search had been going on for 3 days

for Mikaela, who went missing in California, and we got a text message in the middle of our presentation that they had found Mikaela's body.

Mikaela was found – or actually seen by someone driving a vehicle, driving up the street. Another situation where an alert may have possibly helped.

This is Connor McIlwain, Lori McIlwain's son. He's had multiple incidents from school settings. And at one point, Connor was picked up by a stranger in a car.

He wasn't sure if he should pick him up, because, again, he might be okay, but it was kind of weird that the child was out during school hours.

He decided to go and pick him up and put him in his car, and of course Connor wasn't able to respond to him, because he was nonverbal at the time, and the school had not called the police.

So, this gentleman was driving around

trying to find out where Connor lived or where Connor belonged. Connor couldn't answer the questions.

The gentleman got the police involved. The police were driving around trying to find out where Connor belonged.

And the police, actually, we found out later, were a little bit mean to Connor, because they were asking him questions that he could not answer because he was nonverbal, and they did not recognize the signs of autism, and they thought that he was being uncooperative.

So, Connor's case emphasizes the need that AMBER Alert may have helped – first-responder training certainly would have helped with the way that he was treated by the police when they picked him up – and that the Department of Education has got to establish Federal guidelines for schools that mandate notification to law enforcement and to parents immediately upon wandering incidents that happen from school.

This is a recent headline. Kids pulled from water – water, water, water. This little boy was pulled from mud that was up to his neck. They got him just in time and pulled him out.

This boy, top case study, the boy was rescued from Lake Michigan. A 12-year-old left school and rode a tricycle through a busy road in Yonkers, New York, on rush hour, you know, Friday.

Just last month a passerby heard splashing, pulled a 5-year-old girl out of a pond. She was nonresponsive. The guy called 911, and they were able to walk him through CPR, and he was able to save that girl's life – so many close calls with water.

Dr. Guttmacher: Wendy, I'm going to have to ask you, so we can get the rest of the panel in, if you can close your comments.

Ms. Fournier: Yes.

Dr. Guttmacher: Thanks.

Ms. Fournier: I'm getting there.

This is a case of a child who was last seen on Saturday. This is an ongoing case. We are hoping that this boy will be found safely. However, it's out in California in the desert, it's over 100 degrees, and this child has not been seen since Saturday. There are hundreds of people involved in the search.

Since your last meeting here in April, nine children have died just since the last IACC meeting – nine children.

This is Drew Howell, 2 years old. Olivia Navarro, 3 years old. Christopher Morrison, age 5. Owen Black, age 7. Mikaela Lynch, age 9. Freddie Williams, age 14. Daven Williams, age 15. Donivan Martin, age 16. And Michael Kingsbury who was found dead right here in your back yard in D.C. yesterday, 7 years old.

These are children that have died just since your last meeting. We don't have time to wait anymore. We need resources for families, doctors, first responders, all professionals.

We need access to affordable home safety items, water safety programs for families.

We need insurance coverage, Federal funding for tracking technology for at-risk individuals with autism just like we have for at-risk individuals with Alzheimer's.

We need access to augmentative communication technology for those who are nonverbal.

We need medical research to find out what is causing this fight-or-flight reaction that our kids are having, the sleep disorders, the obsessive-compulsive behaviors that are making them wander away.

We need to talk about the AMBER Alert situation. I hope we can get somewhere with that today.

We need education and toolkits for caregivers to help understand and avoid wandering triggers, training for doctors – ask them to use the *ICD-9* code – resources for schools and specific response protocols.

And we need training for social workers, for school administrators, first responders and really would like to propose training summits or a series of webinars with multiple agency involvement, including HHS, Department of Justice, and Department of Education.

I'm going to leave that slide up for you guys. I want to thank you very much for the opportunity to come here and speak to you again about wandering, and we will help in any way that we possibly can to save more children's lives. Thank you.

(Applause)

Dr. Guttmacher: Thank you, Wendy.

As folks may have surmised, Tom has had to leave to rejoin his family. Everybody is well, but he has – there are two older grandchildren that he has some childcare responsibilities for because mom being in the hospital, et cetera, et cetera.

So, he has left us to do the rest of the meeting without him, but we will bring him up to speed on it afterward.

So, next up is Alison to talk about IACC activities to address wandering thus far.

Ms. Singer: So, it was a presentation just like Wendy gave today that she gave back in October of 2010 that immediately lit a fire under the IACC and made us realize we needed to respond right away because children were literally dying in front of our eyes.

So, I'm not sure how I – okay. Thank you. So, in October of 2010, as I said, Wendy and Lori McIlwain from the National Autism Association presented the tragic story of the fact that so many of our children are wandering.

We had anecdotal data only then, but those stories did not end well, as Wendy described.

We immediately formed a Safety Committee to investigate wandering, and it's been my privilege and honor to work with Lyn as co-chair of that Committee.

The first thing we decided we needed to do was to send an advisory letter to Secretary Sebelius outlining these points. And in that letter, we decided to focus on five key action items.

The first was, we knew we needed to collect data, because we had only anecdotal information. We had no hard data.

We knew we wanted to create a medical code for autism wandering for two reasons. One, we wanted to track the prevalence of wandering, and we wanted to be able to have pediatricians and other health care providers include discussions of wandering in their anticipatory guidance to families and just make them aware of the fact that children with autism might wander.

The third recommendation was to create an alert system tailored specifically to the needs of individuals with autism and focused on individuals with autism who are under age 18.

As Wendy started to mention, there were some members of the Committee who expressed concern about this being inappropriate for adults with autism who are independent. So, we focused our alert on children under 18 or individuals who were under their parents' guardianship.

The fourth action item was to develop programs to prevent wandering, including parent training, first-responder training, and teacher training.

And the fifth was to work with the Department of Education to develop practices, as Wendy said, for parental notification when there was a school-based wandering incident.

The Secretary responded. I agree that her three-paragraph letter in response to our five-page letter was somewhat of a disappointment, but she did encourage us to move forward with our five action items.

At the same time that we worked on the letter to the Secretary, the Committee also worked together to move forward with the wandering study. And several autism organizations worked together to fund this study: the Autism Science Foundation, Autism Speaks, the Autism Research Institute, the Global Autism Collaboration, and the National Autism Association.

And I think it was one of the few times when I think all of the organizations, many of which have different goals and focus on different areas of need, really came together and recognized that this was an issue that affected all of our children.

We started designing the survey in January, again just 3 months after the issue came to our attention.

We released the survey in March of 2011 through the Interactive Autism Network at the Kennedy Krieger Institute. It was a pretty large study with over 1,200 parents participating and parents of – and including over a thousand siblings.

And here are what the data show: As Wendy said, our children are wandering from school environments, our children are wandering from large family gatherings, our children are wandering from their own kitchens while they're eating their oatmeal.

The incidence of wandering was 49 percent. The data show that 49 percent of kids with autism had wandered at least once after they turned 4, which was four times the rate of the unaffected siblings.

The unaffected siblings are shown here in red, and the children with autism are shown in blue.

I kind of found it ironic that the wandering data is shaped a little bit like a shoe, but that was my – Paul Law assures me it's just a coincidence.

We also noted from the data that from age 8 to 11, 27 percent of children with autism continue to wander, while only 1 percent of unaffected siblings wandered after age 8.

Also in October of 2011, as Wendy started to mention, we were able to create an *ICD-9* classification code. That was the second action item on our list to Secretary Sebelius.

And I want to thank Dr. Coleen Boyle from the CDC, who is a member of the Safety Subcommittee, for spearheading that effort.

So, the *ICD* or the *International Classification of Diseases*, is a system used in health care settings throughout the U.S., and it classifies diseases, disorders, and other syndromes.

It's jointly maintained by CDC and CMS. And we were able to create Code V40.31, wandering and diseases classified elsewhere. And this went into effect in October of 2011.

And as I mentioned, the intention of the code was to promote better data collection, but also to really understand wandering and to enable pediatricians to discuss the potential for wandering.

And I was very disappointed to hear from

Dr. Perrin today that that the *ICD-9* code is not really being implemented, and I think that's another action item on our list.

Now that we have that code, we really have to take the next step and try to ensure that it's being utilized properly.

In May of 2012, the data from the wandering study were presented at the International Meeting for Autism Research, and in October of 2012, the data were published in *Pediatrics*.

One important step in terms of accompanying the publication of the data in *Pediatrics* was we had a coordinated media outreach.

We saw this as an opportunity to create awareness of the potential for wandering. So, all of, again, all of the organizations worked together to try to maximize our media coverage.

And we were able to get coverage of the wandering study in a wide range of publications, including *The New York Times*, *USA Today*, *U.S. News and World Report*. Lori McIlwain did a beautiful story on “Good Morning America.”

And we also were part of a half-hour program on WABC, which is the local news station in New York, that because it was a longer form program, we were able to focus not just on the study itself, but on the action steps that we needed to take in order to protect our children. And, in fact, that was the name of the show. It was “Protect Our Children.”

As Dr. Perrin mentioned, the AAP has created this family training document. It's part of the autism toolkit.

I wanted to point out that this document is based on material that was published by the National Autism Association from their Website AWAARE and on data that was collected by the autism advocacy organizations whose funding comes from parents.

And I was extremely disappointed, again, to find out that the AAP is actually charging doctors for this information, since this information was actually provided by the advocacy community. I think that's something that needs to change.

So, we're here today. I'm very excited that there is a representative from the Department of Justice, because, as I said, the third action item on our list to the Secretary was to focus on creating an alert specifically tailored to individuals with autism who wander or elope.

And so, at this point I'm going to say I'm going to hand the floor over to Jeff Slowikowski from the Office of Juvenile Justice and Delinquency Prevention at the Department of Justice and I'm really looking forward to making progress on this important topic today.

Mr. Jeff Slowikowski: Thank you.

So, I think what we're going to do – we, Bob and myself – we do want to have a good discussion about missing children and how the Department of Justice handles that.

We have been partnered with the National Center for 30-plus years implementing a lot of different programs, including the AMBER Alert Program, which is probably the most notable.

So, Bob is going to walk through a quick presentation of all the different things that we do, including how AMBER is part of that, and then we should have ample time to discuss what we at the Department of Justice can do and how we are working with all types of missing children.

Mr. Robert Lowery: Thank you, Jeff.

My name is Bob Lowery. I'm the Executive Director of the Missing Children Division for the National Center.

We've been around about 29 years, and just briefly about us is that we provide support to law enforcement, first responders, and families and caregivers with missing children and helping to locate them and return them to safe environments in cases of exploitation and protecting children.

Over the past couple of years at the Missing Children Division, we started noticing what we thought were increases in reports of children missing with special needs.

As a result of that, we were also seeing what we thought were abnormally high mortality rates associated with those missing episodes that concerned us, and we started taking a closer look.

At the National Center, we receive reports of missing children each day in our call center. We operate 24 hours a day, 7 days a week. We work on individual cases.

In fact, we had resources with working with the Metropolitan Police Department just yesterday on the tragedy involving Michael Kingsbury.

In fact, we have resources as well in California. Right now we have teams on the ground in Menifee helping in trying to find Terry Smith.

So, we do get a number of the children with special needs. It wasn't always just autism. We also saw cases of children with Down syndrome, but we didn't see the mortality rates as we do with autism that concerned us.

We also knew and we also identified challenges that first responders have to deal with when it comes to children with special needs that go missing. The behaviors are much different than an unaffected child.

I spent 30 years in law enforcement before I joined the National Center. I've been involved on the ground in a lot of these investigations myself, but I think there's a large misunderstanding, especially in the law enforcement community, about the issue of autism.

Of course, we talked about wandering and elopement of children that will bolt from safe environments. We don't often see that with unaffected children.

We also see the tendency for children to find themselves in enclosed spaces that can be overlooked fairly easily by search teams when they're in the field.

I know one of the theories of yesterday's tragedy was the fact that possibly Michael himself got into that vehicle – although, it's too early to tell. I think there's still an investigation going on, but that is not an unusual trait that we've seen in the past, that the children will do that and will actually hide from the teams.

We also see what we think, and we don't know for certain, but what appears to be a diminished sense of fear.

These children can wander through very dangerous terrains, through the darkness without – which doesn't seem to have the same level of fear that we see with other children.

As Wendy said, is that when we talk to our first responders, is that these children may not be able to respond to their name being called, which is a search technique used by law enforcement to simply call out the child's name and hope that they respond. Many of these children are unable to do that.

An interesting behavior – or not necessarily behavior – but an interesting fact is that these children can be very resilient.

We strongly encourage law enforcement, when we're looking for a child with special needs, to not give up searches too early. As we've seen with the case of Terry Smith, our folks are on the ground urging law enforcement to continue that search; don't assume the worst has happened until we know for sure. And I'll share with you some information about that in a second.

Unique behaviors offer a unique challenge for law enforcement, as we know no two children are alike. The search and rescue community has a saying that if you search for one child with autism, you search for one child with autism. Each one of these search criteria will be different.

We also know that these, as we said, the diminished sense of fear issue becomes very concerning to us because the children are often attracted to active roadways. They'll look for road signs on highways. Trains, active train tracks. Fire trucks. And, of course, the one we see most often is they're attracted almost immediately to bodies of water.

We also are with some of the children, especially the higher functioning children – the ones that we're told have Asperger's – we're seeing these children travel much further distances than we would see with an unaffected child.

Just in April of this year, 16-year-old Angelo Messineo, from Georgia – we found him 14 miles away from where he was last seen on foot.

We know that during his missing episode

of over 2 days, he probably traveled nearly twice that distance, because he was zigzagging and was spotted at different areas while he was gone.

Last year in June, Cahill, a 15-year-old child with Asperger's from Chicago, traveled by foot 25 miles.

And the reason I point that out is, when we set up search perimeters and we're looking for missing children, these search perimeters hardly ever exceed those distances. In fact, they're much, much smaller. So, we urge law enforcement to widen search perimeters when they're looking for these children.

We also know that search teams must consider innovative and creative ways of searching and looking for these kids.

Wendy stole my wind on the child from California, but it is a technique that we were very impressed with – to the fact that they found out that the child had an interest in Ozzy Osbourne music, Alan Jackson, and they started playing that music on loud speakers until the child came out and actually met the searchers.

We also encourage law enforcement maybe to use recordings of the voice of a caregiver that the child may respond to. We've been known to bring out the child's bedding into a wooded area, maybe lay out a favorite toy. We use glow sticks in the woods at night to help attract the child.

If we think the child may be interested in fire apparatus, we'll actually ask fire departments to bring their fire trucks down. We may even ask them to alert the sirens on their apparatus and see if it will bring the child out.

Or if the child has interest in helicopters – helicopters don't always work in some of these searches because of the dense terrain – but we'll fly over those dense areas and ask the helicopter to land nearby and see if the child may be interested in coming out and taking a look.

I talked about the mortality rates involving these children. The National Autism Association's records show 91 percent.

We do not collect this data at the National Center. Although, we do work the cases and it will tell you that anecdotally we don't disagree with that figure when it comes to drowning of these children.

Now, I do want to specify, though, that not every child with special needs that goes missing, dies. We just see abnormally high rates of mortality.

Of course, others are struck by vehicles, and then possibly, like what happened yesterday was exposure to the elements or the heat-related death that Michael may have endured while he was gone.

But I tell you, these kids do seem to go, when they do go missing, they do head straight for those water hazards for reasons that we only have theory. We don't really know.

To address this, and I just want to share with you some of the resources that are available and what the National Center is doing to help law enforcement with this issue and families, we brought in what we thought were – our SMEs last year to discuss the problem, discuss some possible solutions.

We brought Wendy and Lori in to help us understand the issue of autism. We brought our nationally recognized search and rescue expert who's under contract with the National Center, Mr. Robert Koester. Mr. Koester has written a book on lost person behavior, is a renowned expert on search and rescue.

We have Team Adam experts on our staff that are in our employ. We have some of the best search people in the business that actually work for the National Center that we dispatch out when a child is missing, and we brought them in as well – our national safety director, our call center staff, and our outreach teams to come in and examine this problem and discuss potential solutions.

What we kind of came up with is that we recommend now to law enforcement that any case of a missing child with special needs, regardless of the condition or diagnosis, should be treated critically and should also have an elevated response by that agency, which means additional manpower, resources, use of volunteers.

What we also know is that the actions of those first responders are critical to safely finding that child and returning them to a safe environment.

So, we know that when they arrive on scene, what they do almost immediately could mean the life or death of that child.

Wendy mentioned that we tell first responders to head for water. We even took that a step further. We're telling our 911 dispatch centers that when you get a call for a child with autism, to tell the caller to stay at that residence, but to alert their neighbors, their families.

We don't have time to wait for the first responders to get there, because, ladies and gentlemen, I have to tell you that, with most of the deaths that we've seen involving these children, the tragedies are probably over with before the officers can even arrive. So, we don't have time to wait.

So, if we can have neighbors, other family friends, and leave someone there to wait for the officer's arrival to let them know what's going on, but get someone down there quickly to head those kids off.

And then of course we try to contain those children in a defined area to help the search teams to get the kids found quickly.

We also learned that, you know – I could tell you from my experience as a law enforcement officer – when we received a child missing report, we would get a description of that child, ask where the child was last seen heading, and then head out that direction in search of that child.

We are now finding out that that search criteria and that response is inadequate when it comes to looking for a child with special needs.

We urge law enforcement to sit down and listen intently to the parents. We need them to quickly and accurately determine the risk factors to that child. And they can only determine that by talking to that caregiver or that parent who knows that child the best.

We need to know what interests that child, where they may be heading. If they're interested in heavy equipment, roadways, water, we need to know that right away, and has that child gone missing before, because of the repetitive nature of some of the children, they more than likely will return to places that they seem to like, and we need to send somebody out there quickly.

We also want to be careful when we're setting up search criteria, that we want to know from that caregiver how that child may likely react to searchers.

Will they run? Will they hide, or will they be fearful of that search team? Are they going to be able to respond if their name is called? And what will they do when we typically put out search dogs? Is that going to frighten that child?

And what we're concerned about – especially in cases like we saw in Virginia here in Hanover County – when you're in rugged terrain, we could inadvertently actually steer the child or chase the child into a more dangerous situation. So, we have to be extremely careful and mindful of behaviors and what reactions we'll get from the children.

So, law enforcement does have their hands full when they're thinking of those things so we don't inadvertently run the child into some more dangerous situation.

And, of course, do they need life-sustaining medications? And we need to know that pretty quickly.

The development of a search plan, as I said, is that we recommend that law enforcement to use the Incident Command System, which is simply a single point of contact with someone in charge. We want a very aggressive, but a very well-coordinated search.

In Hanover County, search teams were greeted with nearly 6,000 volunteers that showed up to assist them in the search for that child.

As you can imagine, without utilization of an Incident Command System and some way to organize that, that could quickly get chaotic. It could also have – be missing critical evidence and missing opportunities to find that child.

So, we recommend to law enforcement – and to set up that system, make sure that their searchers are trained, that their volunteers are organized, and they go out with someone that is trained so that we make best use of all possible resources that are available.

As we said, we do not give up until that child is found. This was the case of 8-year-old Robbie Wood, as I mentioned from Hanover, Virginia.

This child lasted and survived 6 days in some very rugged terrain in Hanover, Virginia.

I will tell you about 3 days into that search, some professionals from that county came and urged the sheriff to shift from search criteria to a body recovery. Fortunately, the sheriff was convinced to continue that search. And, fortunately, Robbie was found.

Now, the other thing I will tell you that was remarkable about Robbie Wood is this child lasted 6 days. There were no sightings of him in that search perimeter. Six thousand people were in there looking for him.

There were no sightings of him on the FLIR, from the helicopter. He was able to elude everyone. He was burrowing down. There was evidence that he was actually sheltering himself. He found nourishment from places we don't know, because Robbie is nonverbal. He was getting water.

So, we learned a lot from what happened with Robbie, but the only reason I have to tell you that Robbie was found, he was outside the search perimeter, was because he finally collapsed from exhaustion and the child was actually, according to medical professionals that examined him, was actually dying.

If he had not been found by, fortunately, a searcher just outside that perimeter, we may be telling a more tragic story.

We talked about and we're here to talk about AMBER Alert, but I thought it would be best – and Mr. Slowikowski and I discussed this – to share with you what resources are available not only at the National Center, but all the other available resources when a child with special needs goes missing.

We do operate a 24-hour, 7-day-a-week call center at the National Center. We take cases from family members, parents, law enforcement.

We watch all critically missing child reports coming over the news wires, and we intake those into the National Center and assign personnel no matter what time of the day to start working, providing resources.

One of those resources is Team Adam. It's named after Adam Walsh, the son of one of our founders, John Walsh.

Team Adam deploys trained, experienced former law enforcement officers. We dispatch them right to the scene of a missing child incident.

I'll just give you some quick statistics, but since 2011 our Team Adam has deployed on 26 cases, actually got on the ground 26 times for children with autism. Nine additional times we had teams on the way, and they were recalled.

Now, this number may seem very low to you, but I also want to remind you and point you back to many times when we have a tragedy involving a special needs child, it happens before the first responders can even get there. These were extended searches where the children were not found and our teams were there within about 2 hours.

Of those 26 deployments, 8 of those deployments, the children were victims of drowning. No other cause of death. The rest of the children were found and safely returned to their parents.

And I do want to mention that one of the children that were found was sitting on a cliff overlooking a river contemplating what we think was getting into that water when he was discovered.

I brought with me today, and I graciously had passed out our Best Practices Guide that we developed at the National Center, which is really an addendum to the Law Enforcement

Response Guide that the National Center distributes to law enforcement.

This is what we consider best practices when it comes to searching for a child with special needs. It is included now in all of our training at the National Center, because we believe that the awareness and education of first responders is going to be the key to saving the lives of these children.

And I do agree with Wendy. I think that this is an issue that, if we can get our arms around it, we can save lives, but I think the awareness and education piece is probably the most important.

I'll tell you just from firsthand experience, there is a large misunderstanding within the law enforcement or first-responder community about the behaviors of children missing with special needs.

We've also, ironically, seen it with caregivers and teachers that don't understand it when they're caring for children with special needs and especially autism.

I was surprised to learn how many were unaware of the wandering and elopement issue when we spoke to them about it.

So, awareness and education, we think, is vitally important – that we can let the public know and that – so that we can take steps on saving those kids' lives.

The role of call takers at the 911 centers – we do train 911 call takers at the National Center on what to do when they receive reports of missing children.

We've added that to our training of children with special needs and we also –this is where we also trained our 911 dispatchers – to tell the callers to please get whoever you can out to the – out to bodies of water to try to head these kids off.

And of course, we know that we need to focus on prevention to the parents, caregivers, educators, and anyone else we can get so that we can make them aware of the potential dangers.

Wendy mentioned we did have some consultations with some of the providers for electronic tracking devices.

I can tell you at the National Center we do not endorse products, nor do we associate ourselves with the names of these, but I will tell you in our experience at the National Center, tracking devices do save lives of these children.

As I said yesterday, just yesterday, I believe a tracking device on Michael would have found him within minutes as opposed to hours and maybe a couple of days and may well have saved that child's life. So, we do believe that this is a viable option that should be considered, but it should be up to the local jurisdiction.

We also at the National Center, based on that Best Practices Criteria, developed training packages that we've sent out to all of our teams. And so far we've trained over a thousand law enforcement officers and first responders on special needs missing children.

Our law enforcement outreach teams of Team Adam – we also have Project ALERT who will help us with long-term missing children – were given that training package and train-the-trainer training, and they are now delivering that regionally in their home bases.

We have representation in 48 of the 50 states, and they're out in each one of those states providing this training to law enforcement.

We also have published articles in professional publications. Most recently, the FBI National Academy magazine in its December issue ran on the cover the work that we're doing with finding children with special needs. So, we are getting the message out to law enforcement.

And I think we're also looking at a partnership with the International Association of Chiefs of Police and National Sheriff's Association.

We also trained all of the state missing-child clearinghouses. Each state in the Union has a missing-child clearinghouse. Each one of those has been given the information and the training when it comes to children with autism.

And just in the last couple of weeks, we had a meeting with the International Association of Fire Chiefs, and we've been engaging them to train fire personnel and paramedics on assisting on the search for these children and what they might do.

And then more recently, we were very pleased to find out that the National Search and Rescue Committee, which is really the governing body for the national search professionals, are going to include the protocols that we developed at the National Center. And the participating agencies are the Department of Defense, Homeland Security, Department of Interior, Department of Corrections, Transportation, the FCC, and even NASA, who now has the information when it comes to special needs children.

One thing that we found to be extremely useful as a tool when we have this child with special needs – because, as we said, time is the enemy – is that we use one of our partner organizations, A Child Is Missing.

It is essentially a reverse 911 system. We can target an area based on ZIP Code. We walk through law enforcement on accessing that system and putting out a message that will call each of the homes in that vicinity when that child is gone to alert them that we're looking for the child – and please check around their residences or please come out and help. So, that has been extremely helpful to us in finding these children.

AMBER Alert, just there are some information about AMBER Alert and certain criteria that is required, but AMBER Alert was something that came about as a result of a tragedy, as most programs do.

This was the case of Amber Hagerman of Texas went missing back on January 13th of 1996. She was actually a 9-year-old kidnapped. She was taken off of her bicycle by an offender, and then not long afterward she was found murdered.

As a result of that, the AMBER Alert Program came up to respond – to engage broadcasters, other community resources – to immediately notify the public when a child abduction has occurred.

It's a voluntary partnership, you know, and it was based on the theory or at least the research that we got from the Washington State Study that tells us that if an abducted child were to be killed, it would be done within the first 3 hours. So, we knew that, again, that time is the enemy and that we have to move quickly.

So, AMBER Alert was able to do that and

has done that very highly successfully since 2003.

The criteria that exist right now for AMBER Alert is there has to be a reasonable belief that a child abduction has occurred.

The Agency has to believe the child is in imminent danger of serious bodily injury or death and that there is sufficient descriptive information about the victim and the abductor for law enforcement issuing the AMBER Alert so that they can engage the public for the quick location and recovery of that child.

Now, those are only three criteria that are really required for AMBER, but it's why it makes the system the success it is today.

Is there enough information about that crime or that child to share with the public that can assist in that recovery?

And I will tell you that I think AMBER has now been responsible for the recovery of over 600 abducted children who were probably the most at risk since that system went in.

So, we're very proud of the accomplishments there.

Also, one misnomer or misunderstanding about the AMBER Alert Program – it is not essentially run by the National Center or the Department of Justice here in Washington, D.C. It's a regional program largely monitored and run by the states, who manage the system locally.

And there's a reason for that – is that it requires local resources to make that system useful and successful. So, each region in the United States – some states have more than one AMBER Alert system.

Texas has, I think, about 18. Ohio runs one in each one of their counties. Other than that, most states have just one system for their state.

And it's up to that individual state coordinator, following guidelines that they're provided, to make the decision on whether the case that is being reported to them by law enforcement meets the requirements of an AMBER Alert.

As I said, AMBER Alert is not useful on every case, you know. Most times what we find it to be most helpful on is that if we have a description of a vehicle and that we can engage AMBER, we can get our partners, in this case, Walgreens or the highway signs that we see popping up all over our highways, to share information that we're looking for a particular vehicle with a license plate number.

And then in addition to AMBER, the Department of Justice is also recommending that states adopt what we're calling the Endangered Missing Advisory system within their states and regions. Most states seem to have adopted this.

This is when the case may not reach all the way to an AMBER Alert status where there's enough information to share.

These are cases where maybe we just have a description of the child or there's other just descriptive information, but again that's up to those individual states to use that system. So, there are actually two systems when it comes to missing children: the Endangered Missing Advisory and AMBER Alert.

I've pretty much come to the end of my portion of this, and we can answer questions, or Mr. Slowikowski can, regarding AMBER Alert.

Dr. Guttmacher: Why don't we maybe have Jeff go, and then we can have discussion.

Mr. Slowikowski: Sure. And I wanted Bob to go through all of this, you know. The Department worked with the National Center from its foundation.

And when we talk about what we are doing, it's what we are really doing through primarily the National Center and the program we run. There's also some other technical assistance, training providers that we use in our Missing and Exploited Children's Program.

But I think, as Bob outlined in talking

about the different systems, the missing endangered, which is at kind of that secondary level of missing children that don't reach that AMBER level, to all the different trainings that go on, many of the, you know, the trainings that the Center does is training that is sponsored by the Department of Justice.

We also use a secondary – another provider – to do our AMBER Alert training. Parts of those trainings include, you know, you go through the criteria of what an AMBER Alert criteria is. It's what to do when you don't reach those criteria as well.

But for us, and I know that I've talked with NAA 4 years ago and it was kind of an eye-opening first time I had heard from this community saying we have a special group of kids that need some assistance.

And, frankly, you know, my first response was, “Well, you know, our AMBER Alert legislation says ‘abducted.’ And, you know, we can't at the Department of Justice change the legislation that says, you know, clear and simple, you know, this is for abducted children.”

But we, you know, certainly wanted to figure out what can we do to assist, because our role is not simply the abducted ones.

They are probably the most dramatic; they are the ones that we focus on probably more than others because of the high publicity they are and the numbers that we see, as well as the fact that we are the Department of Justice and these are crimes that are being committed against children, and that is probably our first and foremost concern, but we also recognize the resources that we've developed around trying to protect children from crimes, particularly abduction and exploitation, are of use to the rest of the public in many other ways.

And that's what we continually try to work with the National Center. The National

Center's role isn't specifically around justice issues. It's a much broader inability to work with all communities and all different types of children that is missing.

So, we have made, you know, genuine efforts to try to broaden this. We have developed resources around reaching out to law enforcement.

I think the piece that Bob brought up and that is the most critical to understand about AMBER, you know, is when you do look at that map – and there's 18 different ones in Texas – the criteria that each of them uses is, frankly, mostly different.

One criteria was must be under the age of 1. Well, that's up to each individual jurisdiction to develop their own criteria.

Some jurisdictions use under the age of 12. They don't have to go up to 17. So, they may have a 16-year-old, and it doesn't fit their own criteria, and then AMBER will not be issued for that.

Even if they know the child was abducted and even if they have suspect information and they have the vehicle information, it didn't meet their own AMBER criteria.

So, it's not up to us at the Department of Justice to say in all of these situations you must do this. It is a voluntary program that is done by the states. And as Bob pointed out, it can only be done with local resources.

We provide, through the Center and through Fox Valley Technical College, training on how to develop these plans and training of law enforcement on how to handle the missing children's cases as they move toward an AMBER, how to activate resources, but we do not provide states and the local AMBER communities resources to actually run their programs.

So, it's not real easy for the Department of Justice then to say to 18 different jurisdictions in Texas, you must do this.

What we do is we provide the training and continue to work with them, but we can't, also, say within the AMBER Program you must include children that are not abducted.

I mean, that, you know, it's a piece of legislation from Congress. And as the way things are in Washington, it will take an act of Congress to change that, but I think we also learned, I think, the Silver Alert is the other one that everybody is aware of.

Strangely, a little fact that the first several years that the Alzheimer's Association was very influential in getting funding, the funding came to the Department of Justice, actually to the Office of Juvenile Justice and Delinquency Prevention, which, frankly, left us scratching our heads of how did the Juvenile Justice Agency start getting Alzheimer's money?

But it was mainly, again, looking at – we had something that they were interested in, but that program is not real different than the AMBER Program.

I believe at this point 31 states are

participating in a Silver Alert Program. It is set up in a similar way using similar resources, again tapping into what was already established because of the work we have done, but it is a different set of criteria, obviously. And it is up to each State, each, you know, community to develop that AMBER or Silver plan for their constituents.

So, we're always interested in sitting and having these conversations and learning how we can be of help, but I do want to kind of caution that looking at AMBER and thinking that AMBER is the quick fix, you know, it really isn't.

And I think Bob, again, highlighted some of the ideas that, you know, we use AMBER very cautiously because of the oversaturation.

You know, we've talked about this frequently in our offices about, not just autistic children, but all special needs children.

You know, we don't want AMBER Alerts to

ever reach a place where we are today with car alarms. You know, you can walk through a parking garage and hear a car alarm go off and you don't even turn your head and look.

They're useless, because somebody can be breaking into a car, three cars down from you, and you're not even going to pay attention and say something.

So, we don't want to get to that point, but we do want to figure out how to use the resources that we have and how we can use the things that have been developed to assist in recovery of all the children that are missing.

Special needs certainly raise a higher level of concern for us, and we are looking to have good discussions about that and understand what we can do to support not only the autistic community, but all the special needs kids.

And I think Bob pointed out, and we certainly see in the data and I read the article in *Pediatrics* of the numbers, it does raise some alarms for us as to what we can do and how we can be better partners.

Dr. Guttmacher: Thank you, Jeff. And thank you, all of our panelists. Let me just – a little bit of time check for us. We're probably about, oh, half an hour, 45 minutes behind already.

We do need to end by 5:30, but this is very important. We obviously need to have some discussion, but let me ask the Committee members to try to be as short as you can with your comments so that we can make sure that we get through all the other important business that we still have to do.

Why don't we just head right down the table. David, I think you're the first one down the table with your hand up.

Dr. Mandell: This is really interesting information. Thank you for sharing it.

Is there a way to use the regional variation that you have in the kinds of programs that are being implemented across the country to identify models of excellence?

So, if you have different states or jurisdictions within different states doing different things, are you able to attach that to data on successful recovery of missing children and successful recovery of missing children with special needs?

Mr. Slowikowski: I don't think we have any – I've never seen data that gets into really assessing the quality of the different AMBER systems.

I don't know that we –

Mr. Lowery: You know, I don't believe we – we don't actually keep that data. But as Mr. Slowikowski said, each state runs a little bit different – their criteria are different – but I can tell you it's probably on the missing children side of the house, probably the most successful program we've seen on finding these children.

Dr. Mandell: So, let me re-ask the question. Do you have data on the – do you have data by geography of the number+ of missing children with special needs and their recovery?

I mean, as you pointed out, AMBER Alert is just part of the programs that are being run.

Many programs probably also have implemented different kinds of trainings. We have other kinds of materials or processes that they may be disseminating.

And if you're able to, within a geographic area, tie that to the number of children who go missing and are recovered, then it might offer you some insight into the effectiveness and actually cost-effectiveness of these different kinds of programs.

Mr. Lowery: If I may, we don't track the data. Matter of fact, a lot of the data that we get regarding missing children with special needs we get from the National Autism Association.

So, the National Center's role isn't to

collect data in that sense, but we do work individual cases. We look for trends.

And what we wanted to share with you today was that the trends that we were seeing was – and I agree with what Wendy said – it is seasonal.

I will tell you that we've had one of the worst weekends we've seen in quite a while this past weekend because of the holiday. And so, we're on higher alert when that happens.

So, what I can tell you is, is that the 91 percent mortality rate with the children – we don't dispute that, although, we can't confirm. Does that help you?

Dr. Guttmacher: John.

Mr. Robison: What I'm hearing is that from the Department of Justice perspective, first of all, AMBER Alerts are designed for abductions, not wandering away.

And abduction is the 1 percent problem in special needs wandering, and the rest of the situations are kids who wander off voluntarily.

Now, in your Committee, Alison, you talked about tracking devices or alert devices for kids under 18 so they could be found, but really it sounds to me from hearing that 91 percent drowning statistic like we should be strongly advocating for automatic flotation vests like people who work commercial ships are required to wear.

Certainly if we were going to fit an autistic, you know, kid with something, an automatic collar that would inflate and keep him from drowning would do the job better than an alert device that would find him.

And I guess I would raise that question, and I think that speaks also to the issue of deprivation of freedom.

Nobody would reasonably argue that a protective lifevest is depriving you of your freedom in a way that, say, a tracking device might.

And I think, then, that leaves our

concern with the Department of Justice more in the realm of law enforcement and search training, which really wasn't the focus of this and maybe we need a different focus for that.

What do you think about that? I know it's out of turn for me to ask you, but you were –

Ms. Singer: I think that the point you're making is really echoing what Mr. Lowery said earlier, which is that the kids with autism who wander present a unique set of circumstances and require a unique protocol to be implemented in order to rescue them successfully.

So, my feeling is, given that that's the case, what would be the reasons not to, for lack of a better word, brand that protocol as an autism alert so that that word would communicate the need for that specific protocol to be implemented?

And then my question for you is, really are you saying that in order to get this done, what we need to do as a next step is go to Congress and try to get the equivalent of the Silver Alert in order to get this specific autism brand that communicates the specific protocol? Is that your advice to us?

Mr. Slowikowski: So, as a Federal employee, I could not and will not urge anyone to lobby Congress for any particular thing, but I think you could surmise from the things that have “alert” after them that they have a powerful lobbying organization that has had success in getting targeted funding for their issues.

I mean, that is what has happened in the past.

Dr. Guttmacher: All the Federal bureaucrats around the table were smiling how deftly you handled that. I think you made the answer very clear without breaking the law.

Mr. Robison: Alison, you didn't answer at all the question, though, about drowning protection.

I didn't mean that frivolously. I thought that was a serious question. Did you have a thought on that?

Ms. Singer: I absolutely think it's serious. And I think Wendy addressed that issue there.

You know, this is one thing that we need is the alert, the specific autism alert that conveys that specific protocol, but we also need to have equal access to those tracking devices.

Right now it's available to families who are able to pay out of pocket. They're not covered by insurance.

We need other types of interventions to specifically focus on drowning, like universal swimming lessons for children with autism.

I mean, my daughter, we've tried to teach her how to swim numerous times, and she is not a swimmer. And that's extremely scary. But if we were able to try to create an ABA-based approach to swimming, I think that would be a great value to a lot of families.

I absolutely did not mean to minimize your comments. I think we saw from the data that the vast majority of the children do die from drowning.

But what I was trying to point out is that that is one of the unique pieces specific to the kids with autism, and it has to be approached in a unique way.

Ms. Fournier: Alison, can I try to answer that? Just, I have to. I'm sorry.

John, it's a really good point that you're trying to make. However, the situation is with our kids who wander who are at risk of drowning, they need something that's going to be on them all the time. So, a tracking bracelet that is not removable, is on 24/7.

Our kids, when they want to wander out, they're not going to stop to put on a flotation device before they walk out the door. So, it has to be something that never comes off their body.

Mr. Robison: Yes, that's what I proposed. You know, the commercial maritime industry has learned the hard way that automatic flotation is a more effective protection against drowning than swimming lessons.

Because the fact is, when you fall into the water in the middle of the night, the shock will overcome you even if you know how to swim.

And I'm thinking of the kind of stuff that we issue to people who work commercially, which is very wearable and absolutely designed to be on you all the time.

Dr. James Ball: Hi. This is Jim Ball.

Dr. Guttmacher: Jim, go ahead.

Dr. Ball: I appreciate all that's being said. And when we really look at it, I mean, from all the early intervention work that I do, we focus on water safety, we focus on teaching appropriate water skills and then work on – it was brought up earlier in some of the research about pointing being one of those neurological things that we tend not to teach to early kids.

But when you look at the critical life skills that our young ones really need, the first one that I always, and the people that I work with always, focus on are all of those water safety skills.

So, if they do, in fact, wander, I mean, I've had several instances where kids that I've worked with have wandered, have gotten into water, but have survived that instance because of that water safety skill.

So, I go back to Alison's point when saying that some of our kids, it's a little bit tougher to teach them. But if we start at a very young age and we teach them how to be safe around water, that when they do wander that's one thing that we don't have to look toward.

There might be other things that may happen, but that's one of the things that, you know, for sensory reasons they're drawn to, but they're already understanding what to do around it.

And we've worked a lot with that with the Autism Society, especially around our Safe and Sound Campaign on really teaching that water safety skill.

Dr. Guttmacher: Idil.

Ms. Abdull: Hi. First, I want to really thank Wendy for staying on this, and 2010 October was also my favorite IACC meeting. That's when they funded the Autism in Somali kids in Minnesota.

And I have a few comments, I guess. Number one, Dr. Insel always reminds we make recommendations to Congress and to the Secretary.

And I think one of the recommendations that maybe we should make is autism wander alert or whatever it is we want to call it.

In addition, as advocates and as parents, we can start advocating just like some of you have done for getting that study, in getting

Congress asking them, maybe starting with the Congressional Autism Caucus. There are over a hundred elected officials there.

I would start with the ones that are up for election next year. They are usually more eager to listen.

And I also wanted to make a comment and say that every state – I know John is not here now – but every state has home- and community-based waivers through CMS, which is for people with disabilities, including autism, to get home safety modifications whether it's the alarms or whether it's the safety tracking.

If your state has it, be persistent. Ask; even if you are not able to get the AAP to use the code, you can go to your county, you can go to your state Medicaid agency, and you can ask for this. And I think they have to because it's necessary; I don't see them denying that.

I think a lot of it has to do with parent education. I don't think parents are aware of this, and I don't think a lot of families know.

And for home safety modifications, the alarms that they would get – the wall pads – I have them in my house. It's probably if you can get in, you can't get out. There's so many locks and so many – it has so many different locks and so many alarms that go off – and we know he's trying to get out the backyard versus the front, because it makes all different noises.

I think we, just as parents and as advocates, we have to be very, very persistent. Every state has home- and community-based waivers that are designed to help people with disabilities. And that includes autism.

And finally, in terms of getting the tracking to pay for insurance, I may be – I know Dr. Dawson, United Autism Speaks, but maybe they can start one of the things slated for insurance and go state by state.

Sometimes you just have to take one step out of the thousand steps and do it that way.

Dr. Guttmacher: Next, Lyn.

Ms. Redwood: We've been discussing this issue since 2010. And my understanding was the reason that we had this meeting today was to get some sort of firm guidance.

One of the questions that was still remaining was regarding an alert system. So, I'm asking the experts here today – based on the systems that are in place now – the AMBER Alert, the Silver Alert, the Missing Advisory Alerts – that are in place and the information that you've heard presented from the National Autism Association regarding the statistics – what can we do today to get an alert system in place?

Is this something – are you saying that it's going to take a very long time to get something similar to an AMBER Alert or a Silver Alert? Should we start locally?

I know that I get alerts on my phone. There was a gentleman with Alzheimer's just last week who was wandering in a local municipality that I was alerted about at one o'clock in the morning.

So, from the presentation, there were several children whose lives could have been saved where people saw them wandering and didn't do anything.

So, that's why we have this panel here today, is to know what can we do to get this alert.

So, that's my question to Jeff and to the other experts here, because I really want some closure on this. I want an action item. I don't want this to go over to another meeting and we hear again that more children have died.

Mr. Slowikowski: Well, I'm not sure, you know, that I can provide the exact answer to that.

I mean, I think there is, again, I think we have a number of existing systems that are helpful and being used, but I don't, you know

– if you are saying how do you set up an autism alert specifically to autism versus all special needs or all endangered missing children that don't qualify under an AMBER Alert – think we already have that type of system in place.

Now, to make it more specialized towards AMBER, I would say that, you know, I'm not sure if you want to establish an autism alert – I mean, I think that part takes a lot more time, because then you are developing specific criteria that distinguish that population from other missing endangered special needs kids.

And you, you know, I'm a little bit, you know – What system are you using? – because in most cases, highway signs are not going to be of help for that search and rescue, you know.

If you're talking about secondary – the use of secondary alert systems, you know, using things like Facebook and others where we've had, you know, we have partnered with them under AMBER Alerts to help regionally direct alerts in other ways – there are some good models out there that could be used.

But in many cases they're already being used and I don't –

Ms. Redwood: How can we tap into them?

Mr. Slowikowski: Well, I think any time that a child is missing and law enforcement makes – and I think we've done a really great job of reaching out to law enforcement to say when a child is reported missing, you need to call the National Center, because the National Center mobilizes resources from the existing training that's been done – and it, you know, whether it's the training of the 911 operators on how to handle different populations, to mobilizing, you know, the secondary alerts and other things that get people out of their house or get people aware of missing children.

So, I don't know that –so, my answer is we have a lot already in place that I think we are doing a great job recovering thousands of missing kids every year.

We are not a hundred percent. There's no doubt about that. And I think we can do more, and we are going to continually look for how do we, you know, train law enforcement better, how do we make more people aware of special needs kids that are missing, but I don't know that – if you're asking me for how to establish a specific autism alert – you're getting into a much bigger place.

Dr. Guttmacher: Let me –

Ms. Redwood: Not a specific autism alert, but some type of system that's going to be effective to mobilize people locally and how do we go about –

Dr. Guttmacher: Let me take the right of the chair, Lyn.

Ms. Redwood: Okay.

Dr. Guttmacher: Hearing very much what you're voicing that I think is coming from a lot of people around the table, we've heard a lot, and we'd like to do something. So, I think a lot of us have been educated by the whole panel and the discussion over the last months and months about this.

How about if we, I mean, because – well, the new folks around the table clearly add to the discussion – I think it's probably up to us to figure out the solution. And there's expertise around this table to do it as well as I think obviously the commitment to it.

So, it seems to me that, whether it be the Services Research Policy Committee, that we have some group of this group come together to really kind of come out based upon what we've all learned with some concrete – what are the things we could do.

There are some things we might wish for that we can't do, but there are some options that we could maybe bring back then to the whole Committee to move further with.

Does that make sense? Because I don't think we're going to be able to gel on something right now in the next few minutes.

Mr. Slowikowski: Well, let me say – I

mean, Lyn, I mean, we're certainly willing to sit down and talk more. And I know you want an action item today, but I also would bring Bob into this conversation, you know; we would jointly meet with you, but I would also want to know, you know, from what we do now for endangered missing children, special needs children when we reach out, when people reach out to the National Center, you know, what is it that we can do better? What is it that we're not doing enough of?

I mean, if there's not enough outreach, if there are things we need to do differently, I would welcome those recommendations so we can try to figure out how to help improve it.

Mr. Lowery: Could I add just one point? AMBER is just one piece of the puzzle when it comes to missing children, and just you have to keep that in mind.

And not every critically missing child under any circumstances always meets the AMBER criteria, as we tried to explain.

In fact, very few child abductions are ever really witnessed, if you can understand that piece. A lot of them are just unexplained disappearances of children.

But in answer to your question, though, as what this Committee can do – as one of the uphill challenges that we face at the National Center is education and the awareness piece, because I think there's a big disconnect when it comes to the understanding of autism and what happens when the children go missing.

One thing that we do at the National Center is we monitor those reports 24 hours a day. We also have unprecedentedly allowed access to the National Autism Association and would welcome other organizations as well to call our 800 – the loss number – 24 hours a day when you become aware of a child with autism that's become missing in your community that we're not yet aware of, and we'll mobilize resources very quickly for you and at faster paces than you can imagine. And we've been doing that right now with National Autism and we welcome other groups.

Dr. Guttmacher: So, let me say we've got to come to closure within the next couple of minutes, literally.

So, if you have not just comments, but ideas specifically about how the group should move forward, then keep your hands up and we'll go around the table, but it's got to be very quick and very brief, please.

Dr. Donna Kimbark: Okay – very quick, very brief. Okay. You had the answers, some of the answers, right in your presentation. Some of the presentation that we saw was very successful recovery of children because of the fact law enforcement was properly trained.

If we had an autism alert that meant that if we send out a message to law enforcement, you have an autism alert where you have – immediately law enforcement knew that they were looking for an autistic child or an autistic adult – they would know exactly what to do, because they were trained properly. That's one.

Number two, during the Arab Spring, I knew exactly what was happening because of the fact that I went on social media: Facebook, Twitter, and so on.

We have to use social media. This is a technologically advanced society. Why aren't we using social media better? That's something that we could do today.

Dr. Guttmacher: Scott.

Mr. Robertson: So, I'm just wondering, briefly, if, I mean, I think we've had very informative discussion on wandering and it's been discussed, as folks have mentioned, over the last few years.

I'm just wondering if this can help inform broadening the discussion to other victimization issues, including that exploited side of the National Center, folks that are victimized in abuse – you know, sexual abuse – because autistic individuals, you know, like everybody with disabilities may be more likely to those things.

And, for instance, you know, there are kids who are dying from things like committing suicide because of bullying victimization. That never gets discussed here, but you know, kids – I have known of situations with that.

So, I think we have to make sure that we don't get too narrow on victimization issues, that we consider all these issues that affect autistic teens and adults, you know, every day.

They're not always getting discussed at this table, but I hear about in the community and around the country when I visit around a lot of the challenges that face folks in victimization across the lifespan.

Dr. Guttmacher: Keep coming up to the table.

Dr. Anshu Batra: Two things. From what I'm understanding, I think we have to do this locally initially. And I think training the first responders through Autism Speaks or the wonderful family here that already has a written protocol for first responders would be, I think, helpful.

And then secondly, as a pediatrician, now I'm more aware, but a code for wandering – I already use anticipatory guidance for my families for children that are more likely to elope – but I think encouraging pediatricians to write a prescription for tracking devices with the code that's been provided to hand to the parents before the child is able to run, I think, would be helpful.

Dr. Guttmacher: Walter, your hand is still up.

Dr. Koroshetz: Yes, I think if a group could get together and work on this, I think we could do a lot.

Some things might take a long time, but there's a lot of stuff we could do quick.

I'm reminded of previous health campaigns that I've been involved with where you have to have multipronged approaches. And if you do have, you know, the organizations who can reach out to the families and have local presence, you can get it done.

From the Government's standpoint, we'll never get this done, but I think we as a group could move it.

Ms. Redwood: Is that a motion for reestablishing the Safety Subcommittee?

Dr. Guttmacher: Alison.

Ms. Singer: So, in response to your, what specifically should we do with the missing and endangered alert through the National Center, if there was some way to subbrand that autism alert so that it communicates to all of the first responders the unique protocol that needs to be implemented when you have a child with autism versus a child with other types of special health care needs, I think that would be one step forward.

And then, I would also want to know what would we need to do in order to initiate the system that Lyn was describing to get local texts?

I mean, we saw several cases that Wendy presented where people saw the kids and they just didn't know that they were missing.

So, if those local texts were able to be sent out through phones, through Facebook, I think that would significantly help, because we know that the kids tend to stay local.

They're not getting in cars. They're not being driven across the state line. So, no, we don't need the highway signs, but we do need texts to all of the neighbors at one time so that everyone in my neighborhood, for example, would know if they saw my daughter roaming through the woods behind their house that they might want to go and get her and bring her back. So, those would be my two suggestions.

Dr. Guttmacher: Coleen.

Dr. Boyle: So, just quickly – I guess maybe learning from the lessons with the *ICD-9* code – I mean, we can make a code; we can make an alert. If we don't have the complementary programs, education, incentivize all of the things that go with it, it doesn't do anything.

So, I think that, you know, we have to really think about that, and I would second Walter and Lyn's suggestion to, you know, reestablish our Committee to go forward on this.

Ms. Redwood: And to also take Jeff up on his offer to meet with us more and then have the Safety Subcommittee come back with recommendations for our next meeting.

Mr. Lowery: If I could, the missing child or the Missing Endangered Alert would fit into the criteria of a child with autism.

We use that when we have the unusual disappearance or the unexplained disappearance of a child, because it doesn't reach the AMBER.

And keep in mind that AMBER does require the abduction, but also enough information to share with the public that will help in the recovery of that child.

So, the system is in place for that and that you were asking for.

Ms. Singer: So, that's communicating it to the first responders, but we also have to communicate it to just local neighbors who may be in a position to –

Mr. Lowery: Yes, and you're absolutely right. This is why we use a Child Is Missing to do the reverse 911 and the calls to each one of those homes so we can alert all the neighbors, and we do that now with children with special needs.

Dr. Guttmacher: Okay, Geri, you get the last comment.

Dr. Dawson: Okay. That's the nice thing about being last, is almost everything has been said.

I think the thing that you said – and, by the way, I thought your presentation was extremely thoughtful, and you outlined a beautiful training plan right there and – but what really struck me is you said, “We've trained a thousand people.” And, you know, that must be a drop in the bucket, really. And so, I think training is key.

And what I'd like to do is to move that we reestablish the Safety Subcommittee with at least two goals.

One is to work with the two of you on both the – particularly with an emphasis on training, because I think training is critically important, but other suggestions that might come out of that discussion – as well as to work with Jim Perrin to see what could be done with respect to providing the free access, for example, to the toolkit, anticipatory guidance, and so forth, as well as any other suggestions that might come up in the context of that conversation.

Dr. Guttmacher: I'm getting some whispering from staff that we have so many Committees now that staff – the question whether we have staff to staff another standing committee as opposed to creating an ad hoc group to deal with this that would meet briefly, whatever, but I think there's some concern we just don't have the staff to establish another standing Committee.

Is that a correct read into the situation, Susan?

Dr. Daniels: So, we do have two subcommittees now. We could form other planning groups under those subcommittees. We could form another subcommittee, but then there was another proposal for another subcommittee. We need to form another seven Planning Groups this fall.

It's just a lot of different groups for everybody to be involved in. And so, I don't know if we can use any present structures to get this done and if this is something that's a short-term group that would get together and get a project done, or if it's a standing group that you need to have exist until the end of the Committee.

Dr. Dawson: How about this? We have some meetings of the Subcommittee on Policy and Practice, I guess, and –

Dr. Daniels: Services and Research?

Dr. Dawson: –right, the Services and Research and that there be a focus on this. And the people that are interested in attending that meeting –

Dr. Daniels: I think that that would be a little bit cleaner –

Dr. Dawson: – could attend.

Dr. Daniels: – to have that group of people and not – I think even the Committee members are starting to get a little mixed up about what group you're on, because you're on so many different groups.

And so, if we can kind of keep the groups a little bit more organized, that will help, but we could have a special meeting on this topic.

Dr. Guttmacher: So, you're moving that we assign this task for a special meeting of that group. And then others who wanted to join the group for this purpose could do so.

Dr. Daniels: If that would work for the Committee, it's one possible way to do it.

Dr. Guttmacher: Is there a second to that motion?

Dr. Boyle: Second.

Dr. Guttmacher: All in favor?

Dr. Boyle: Aye.

Dr. Guttmacher: Opposed? On the phone, I should ask, on the phone all in favor?

Response from Committee members on the phone: Yes, in favor.

Dr. Guttmacher: Any opposed on the phone?

Response from Committee members on the phone: On the phone all in favor.

Response Committee members on the phone: Aye.

Response Committee members on the phone: Yes, in favor.

Dr. Guttmacher: I think it's unanimously supported and thank you all very much –

Dr. Kimbark: No, we –

Dr. Guttmacher: Excuse me.

Dr. Kimbark: – dissented over here.

Dr. Guttmacher: I missed it. Okay. I think there was a clear enough vote that – given the hour, given that we're 55 minutes behind, I believe, at the moment and only an hour left – this is going to be quite a trick.

So, thanks again, everyone, for that discussion. It was obviously a very rich one, and it's beyond time to move on to tips for early-care and education providers. Shantel Meek will be talking with us about that.

Ms. Shantel Meek: Thank you. Good afternoon. In the interest of time, I'll be as brief as possible.

So, I'm here to discuss today tips for early-care and education providers that the Administration for Children and Families and NICHD jointly worked on together and disseminated to early-care and education providers around the country.

Before I dig into the meat of the actual project, I wanted to lay a little bit of context just to explain where we come from.

So, the Early Childhood Development Office within ACF oversees the Head Start program, the Federal childcare program and various other early childhood initiatives that help children and families prenatally through age 5.

To give you a bit of an overview on how vast our reach is – not only directly through Federal programs, but through the whole early-care and education system –nearly 11 million children under the age of 5 are in some type of childcare setting every week for an average of about 35 hours.

Nearly 1.7 million children receive Federal childcare assistance from the Childcare and Development Fund, and the Head Start Program serves nearly one million children.

So, given the numbers of children and families that we serve, I thought it would be appropriate to look at the workforce and the people who are actually supporting our kids during their time in the classroom or in homes.

And so, unlike the K-12 system that has very set requirements in terms of degree requirements, training, things like that, the early-care and education system is very varied.

It depends on what state you live in. It depends on what funding stream you are getting money from. It depends on what program it is.

And so, a recent study found that just over 40 percent of center-based, early-care and education providers listed a high school diploma as their highest degree attainment.

For home-based providers, which is where the majority of our infants and toddlers are, we found that over 50 percent of those providers listed a high school degree as their highest degree attainment.

For the Head Start Program, it looks a little bit different because there are statutory requirements that at least half of all teachers have bachelor’s degrees.

So, for the Head Start Program, which provides services for 3- and 4-year-olds, we have 64 percent holding a BA, whereas for Early Head Start, which serves mothers prenatally through children through age 2, we have 60 percent with at least a 2-year degree. So, a little bit better.

But given that context, given the millions of children and families that the early-care and education system is touching on a daily basis and given, you know, the critical period from birth to age 5 that we know is so important for early identification, for early intervention, ACF teamed up with NICHD, and we queried a handful of early-intervention autism researchers around the country, and we asked them, if you could give early-childhood providers nationwide one tip for working with children with autism in inclusive settings, what would it be?

And of course we had them keep in mind varied education and literacy levels assuming no supplemental support or training, assuming all these, you know, low wages and resource for classrooms, et cetera.

And so, we got about a 54-percent response rate from researchers. We modified some of the language to simplify, bring down the reading level a bit. We added a few tangible examples where there weren't any.

We circulated to our partners at CDC and others at NIH. We returned to the researchers for final review, and then we disseminated to all our early-childhood systems.

So, these in the next slide I'll show are the tips that we got. We got no duplication, which was great, and the tips really covered a wide array of developmental domains and different strategies.

So, we – engaging children in play, using children's interests, promoting child participation, visual cues, playing together, joint attention, book sharing, uncovering learning potential, peer-mediated support, predictable spaces and routines, and then distracting and redirecting children to engage in more appropriate behavior.

And so, I'm not going to go in depth with all of these tips, but I'll go in depth with one of them just to kind of illustrate what the structure of the document looked like.

So, Connie Kasari, which – a researcher out of UCLA who actually presented at the last IACC meeting – submitted her concept or tip, and it was engaging children in play.

And so, the first thing we asked researchers for was really the what. So, what concept are we trying to portray, what exactly is it that we're asking providers to do?

And so, she goes on to describe that social play involves, you know, engagement between a peer and – or a teacher and the target child and an object.

And then we asked all of the researchers to really describe why it was important. Because if providers understand a little bit better what the end goal is or what these skills and this practice is related to, they're a little bit more likely to do it.

And so, social object play is an important developmental skill that increases social engagement and communication between partners.

And then finally and probably the most important part, we asked them to really break down – step by step in the simplest language possible – how to implement the concept that they had proposed.

And so, you see here Dr. Kasari – Step 1, provide developmentally appropriate toys, follow what the child is looking at to see what interests them. Once the child begins to play with the toy, join in and imitate what the child is doing. Build on the activity by taking turns and making sure turns are balanced.

Once the play routine is solid, expand on the play routine. We provide a couple of examples. So, if you're taking turns stacking blocks to build a tower, you might expand it by knocking down the blocks, which may increase motivation and also make the interaction longer.

If the child has mastered taking turns building and knocking down the blocks, you might add a toy figure to the top of it or add a truck to run into it to knock over the blocks to extend it even more.

And the final step is really kind of an evaluation piece to look to the child's attention and engagement and enjoyment of the activity to see if the play routine is motivating. Because the more motivated the child is, the longer the play routine and the greater the opportunities for communication skills.

And so, like I said, I'll just go into one, also, because of shortness of time, but the complete document – I'm not sure if you have it in hard copy in your packets – but it's on the IACC Website.

A couple of next steps for this immediate project: There's been discussions between CDC, NICHD, and ACF to potentially add corresponding videos, to potentially create a hybrid version of the document for further simplification for lower literacy audiences. So, doing this by paring down the language and then adding picture-by-picture steps into how to implement each of these concepts.

But I think the larger question that ACF is really kind of grappling with and that this group should also probably be thinking about is what research we need to really appropriately support our early-care and education providers nationwide.

We need to be looking into what the

minimal education, training, and knowledge is necessary to have our providers provide appropriate support to our kids on the spectrum and kids with other developmental disabilities as well.

We need to know what effective strategies can be embedded in existing routines and be implemented with fidelity.

Is it reasonable to expect – without additional training and support – for them to be able to embed these simple tips into everyday routines?

And then finally, assuring that our systems are really linked and that the early-intervention system is looping back with the early-care and education system.

And that's, you know, we don't expect childcare providers to be the early interventionists, but we think it's reasonable to expect that they at least understand the services that their students are getting outside of the classroom or home in the early-intervention system so that they can support and further advance the child's goals.

So, as a very simplified example, if a child is in speech therapy practicing the T-H sound and the childcare provider is aware of this, they can provide countless additional opportunities throughout the day to advance their goals.

And then, finally, I think the last kind of point to make and to wrap up quickly is that making sure that early-childcare providers are – have the skills they need and the knowledge they need to appropriately support our kids on the spectrum is not only good to improve children's skills and to help them grow faster in their interventions, it's also a big step toward inclusion.

Because if early-care and education providers feel supported, feel like they know what they're doing, like they know what autism is, they're more likely, potentially, to foster an attitude, an environment of inclusivity rather than be nervous about accepting a child with autism if they don't know at all what to do with very low training and education levels.

And so, I think looking more into kind of the research of what exactly we need to really support our early-care and education providers, given the 0 to 5 range and how important we know it is and given the numerous hours that we see kids in early-care and education settings, it would be a great step.

So, with that, I will wrap it up, make it short and sweet.

Dr. Guttmacher: Thank you very much, Shantel. Aware of both the time and the fact that we're perilously close to losing our quorum, in which case we would have to cease business for the day, and not wanting to do that, I think we best move on.

We are going to condense the 20 minutes that are there for the scientific update into less than 5 minutes, correct?

First, Susan is going to very quickly go through the slides just to show you – give you a glimmering of what's happening.

Maybe while we're waiting for that to cue up, I will very quickly tell you one thing that Tom wanted to make sure that I mentioned to you, though some of you experienced it in person, because I remember seeing you there, that it's worth noting that on April the 2nd, which not coincidentally was National Autism Day, the President held an event in the East Room of the White House in which he announced the launch – along with Francis Collins, the Director of the NIH – announced the launch of the President's Brain Initiative, which is clearly still being defined, but it is a multiagency part of the Federal Government, but very definitely with private partners, Federal investment in the upcoming fiscal year of $110 million to get it launched with the hopes that it would grow, because the science will be so compelling.

The initial work really being to try to better define exactly what this could do, but the idea that it really is the most ambitious coordinated effort to really understand the workings of the human brain and that very clearly this will be not about atypical human brains, but about human brains in general, including having a developmental lens to it, and I think many things.

Again, it's not a coincidence that it was announced on National Autism Day, but clearly that's one of the enunciated interests of the administration in launching this.

So, I think we have high hopes for it but are still waiting to see better definition for it.

I would imagine that at some point when it is a little bit more mature, it's something that the Committee might well want to hear and discuss fully, I think. So, we should consider in the future when we might do that, but just again, Tom wanted people to make sure that everyone was aware of that.

And, Susan, you have a quick slideshow for us?

Dr. Daniels: Yes. And I just wanted to check, is there anybody on the phone with us still?

Dr. Birnbaum: Yes. This is Linda, and there were two or three things I wanted to briefly mention if possible.

Dr. Daniels: Okay, sure.

Dr. Birnbaum: Okay. So, one of them is that there was a press announcement this morning about work coming out of the MIND Institute showing specific antigens that are, you know, brain antigens that are attacked by maternal antibodies in a significant number of children, you know, with autism, that their mothers had these antibodies.

So, they could be detected as early as 13 weeks. And by 30 weeks, these antibody levels in the fetus are about half that of the mother and at birth, even greater than the mother.

So, this, I think, is an intriguing new finding that goes along with some of the stuff we heard this morning on antibodies.

I wanted to also mention that there is additional data showing an association between air pollution exposure and autism. And this one is coming from the longitudinal Nurses’ Health Study, where those women that were followed for many years are now looking at their children related to the exposure these women had related to where they lived and the traffic that they were associated with.

And I did really want to mention that NIEHS will be sponsoring a virtual community forum as a webinar on autism and the environment on Tuesday, September 17th, and I'll be sending out information about that.

I just wanted to make those points.

Dr. Guttmacher: Great. Thank you, Linda. And do send that information. We'll get it out to the whole Committee.

Ms. Laura Kavanagh: And this is Laura

Kavanagh. I'm still on the phone as well.

Mr. John O'Brien: And, Susan, this is John O'Brien. I joined in by phone.

Dr. Daniels: Oh, thanks, John. So, we still have a quorum. I just wanted to quickly at least flash the titles up here of what was in the Science Update. These will be online.

One of the papers that Linda mentioned is in here, but I know that I couldn't do justice to this the way Tom would. And I know that – but the Committee is very interested in what he usually pulls out for the Committee during the Science Update. And he would have liked to have been here for this.

So, I'll just flash this up here, and then we will put this up online so that it's available.

And we also at this time are providing all the links online to the papers or at least to the PubMed entry for each of these papers so that you can look at it yourselves.

So, quite a lot of different advances

covering a good variety of areas within the Strategic Plan. So, I know that you'll be interested in reviewing some of those papers, and we have the links available for you.

Dr. Birnbaum: Can you just email those as well as putting them up online? Just send them to the group, just the titles?

Dr. Daniels: I'll send you the link.

Dr. Birnbaum: Okay, thanks.

Dr. Daniels: I think that would be better than sending the whole --

Dr. Birnbaum: Agreed.

Dr. Daniels: – presentation. In fact, yes, the link is going to be up soon. So, we can send that out.

So, I wanted to give you a very, very brief update on our staff. We've had a number of staff changes in red.

I'm just showing we have a number of part-time detailees working in the office right now to help us out over the summer, and as well as a couple of new staff members who have joined.

So, we have Wen Chen from the National Institute on Aging as a detailee in the office this summer; Savina Kim, who's been a summer science policy intern; Chumba Kitur, our new operations coordinator; Stephanie Mok, who's been a science policy detailee over the past couple of months and will be joining us full time in August; Sarah Naylor who is a part-time detailee this summer; and Kerri Wachter, who is our new science writer and editor, as well as familiar faces: myself, Nicole Jones, Miguelina Perez and Sarah Rhodes.

So, I just wanted you to be familiar with those that you'll be interacting with.

Next, we wanted to give a few moments to Geri Dawson to talk about the *DSM-5* Planning Group and what happened with them in their most recent meeting. And this is a list of the people who are on that Planning Group, including a few people who are not members of the IACC who were invited.

Dr. Dawson: Great. Well, I'll be brief. We have been actively meeting. We've met twice now since the last time that this group met, and we have added four new members to round out the expertise.

So, Laura Carpenter, who is at the University of South Carolina, who is the person who is the PI on the Autism Speaks-funded study to look at the impact of the *DSM-5* on prevalence estimates using a total population sampling strategy in South Carolina.

So, as we raised issues around the impact of the *DSM-5* on prevalence for [unintelligible], I think, will be very helpful.

We also added to the Committee Diane Paul, who is the Director of Clinical Issues in Speech Language Pathology for the American Speech-Language-Hearing Association. And we added her because of lots of questions around the new diagnosis of social communication disorder.

We also added Sue Swedo, who was the former chair of the Neurodevelopmental Disorders Working Group for the *DSM-5*.

And we added Amy Wetherby, another expert in the area of early language, again, because of a lot of discussion around the social communication disorder diagnosis.

We decided to set two, kind of, sets of goals for the Planning Group. One was to address questions, concerns around the impact of the *DSM-5* on research.

And we have had pretty rich discussion about a whole range of potential impacts – from the impact on assessing prevalence over time, as well as the need for tools for reliably implementing aspects of the *DSM-5*, such as the functional impairment rating scale, which does not really have any set of tools to implement that.

And then the second is around impact on policy, practice, and training. And that one has to do with questions around the IACC making recommendations regarding how the diagnosis of social communication disorder might translate into treatment recommendations and insurance coding.

So, with respect to those two goals for the research goals, we've decided to draft a set of recommendations that could be considered as objectives for the IACC Strategic Plan.

Coleen Boyle has volunteered to draft and summarize our discussion to date on these research objectives.

And then the second would be an IACC – basically a policy kind of statement – that would pertain to policy and practice and including recommendations for training of clinicians, and I have volunteered to draft that.

And we will be meeting again in August with – our deadline is to have drafts of these before that call so that we can discuss them on the call.

And then in addition, the OARC has added or will be adding a Webpage on *DSM-5* – will be – okay, the OARC will be adding a Webpage that provides information on the *DSM-5* on the IACC Webpage.

Dr. Daniels: Yes, and we got permission to be able to publish the criteria on our Website.

Dr. Dawson: Oh, great.

Dr. Daniels: So, that was really nice of them to give us that permission.

Dr. Guttmacher: Any questions for Geri?

(No response)

Dr. Guttmacher: If not, Susan – OARC and IACC business update.

Dr. Daniels: And we will be scheduling our next *DSM-5* meeting, I believe, at some time toward the end of August. We have a date. I did send it out to folks, and we came up with a date based on a few responses, although, we need to probably get a few more responses to make sure people can make it. And we are working on some other dates upcoming.

Just wanted to update you quickly. I sent this out to everyone. The letter to the Secretary on health coverage for early intervention was sent out on March 2013. And there are a couple of key points here that we shared in the last meeting. And this letter is online in IACC publications under that tab.

We received a response from the Secretary on July 2nd, 2013, and it's in your packets. It's also up on our Website. And it was basically a thank-you letter saying thanks for this advice and that the Secretary already had some plans in place for health coverage but appreciated the guidance of the IACC. And so, you'll want to look at that letter in detail, and I think most of you already have, because I sent it out earlier. And so, members of the public may also want to review that.

I wanted to go through the Strategic Plan updating process for this fall. From the last

Committee meeting, we had the Question 1 Planning Group and the Committee together talk about a plan for how we were going to be preparing for this next update of the Strategic Plan.

And Lyn is giving me a very worried look, but maybe you might want to listen to – you already disagree? I haven't even gone through the slides yet to talk about how we are going to do this.

We have discussed within the Question 1 Planning Group and this full Committee what the steps would be. And so, I just wanted to go over these with you.

And if the Committee has any concerns or wants to change any part of this process, you're welcome to bring up your thoughts about how we can make this process work best for you.

The Committee will assess progress made over the past 5 years. So, one of the differences in preparing the next Strategic

Plan update is it's going to be a more comprehensive review of data not just looking back over 1 or 2 years, but actually over the past 5 and looking at projects that have been funded, programs and funding, biomedical and services research progress, remaining gaps, new opportunities, outcomes and impacts wherever that is possible, and possibly looking at the barriers to progress and potential solutions to that.

So, the plan that was discussed probably a little bit more loosely in the previous Committee meeting, but I tried to put it out into clearer bullets; but if you have other thoughts, you're free to give us some guidance on this, but the Committee will assemble seven Planning Groups, one for each of the seven Strategic Plan questions.

That the Planning Groups will be composed of IACC members, external experts, and community stakeholders.

And we will start with the 2012 Planning

Group members and allow you all to decide if you want to change groups this year and be a part of a different group.

And also to make any adjustments needed in terms of the external experts and community stakeholders that you'd like to have take part.

And that we would begin assembling these Planning Groups this month and try to get that in place so that we're ready for the work in the fall.

So, in terms of the work that will be done, you'll have a data review. And from the Question 1 Planning Group, the understanding that I had – that our group had, the OARC – was that the Planning Groups would like to review data from the Portfolio Analyses from 2008 through 2012.

And so, the 2011 and 2012 Portfolio Analyses are currently underway, but we have the data already for 2008 through 2010.

There was a request for cumulative

funding tables, objective progress charts, funder total tables, funding distribution across the Strategic Plan for each year, funding distribution across the objectives in each question for each year, listing of all projects for each objective for each year.

And so, our Office has been very busy providing – preparing all of these documents for the Committee. And so, we've made tremendous progress in getting all of those together. And we are currently working on the 2011 and 2012 data to add into these different products, but we have many of those things close to being finished.

And we will plan to have a meeting of the Question 1 Planning Group by phone to review the Question 1 Group of these documents to see if there are any other documents that you want, if you want us to make any revisions to anything that we have there.

And once you've approved a set of documents, we'll make sure that the same type of documents are available for all the Planning Groups. And the Planning Groups will also have access to other sources, including summary of advances, the Strategic Plan updates, publications analysis, the Combating Autism Act report to Congress, and any other documents that the Planning Group would request for us to make available.

Invited experts and community stakeholders will share input on progress gaps and opportunities, outcomes, and barriers.

And so, the process that we are proposing would be to hold two to three phone meetings per Planning Group in September and October.

And in October, that the Planning Groups would begin synthesizing information and to draft updates, including new objectives and assessment of completed objectives and prioritization, which are the three areas that the OARC heard from you all at the last meeting that you would really like to, for example, be able to prioritize objectives more, but you'd also like to be able to create new objectives or determine maybe some objectives that you feel have been completed.

The two Subcommittees would review the drafts in November, and then the full Committee would review and approve the final Strategic Plan update by December 31st, 2013, which is our deadline given to us by Congress.

So, this is the process that we have laid out to try to give some structure to this. But if the Committee has any feedback, any, you know, suggestions of something that needs to be adjusted, I'd like to hear that feedback so that we can get it adjusted to the way you need it to get your work done this fall, and we will do the best we can to facilitate you.

So, do you have any comments or questions? Walter.

Dr. Koroshetz: What's the context of the objective progress table?

Dr. Daniels: The objective progress table, it's sort of – it's basically – we called it "Appendix A" in the portfolio analysis. It's the table that has each objective, and then it has a stoplight chart, basically, a dashboard-type red light, green light, yellow light to indicate at least levels of funding. It's based on the levels of funding. So, that's what we have.

In terms of the more qualitative analysis, that would come from the invited experts and community stakeholders interacting with the Committee to give you more information about the feel in the community about progress, the feel in the scientific community about scientific progress, but the OARC data would really be quantitative data on projects that have been funded and funding levels.

Denise.

Dr. Dougherty: Is this on? Okay. So, I'd like to suggest, and I don't know if this is allowed in this report, but hearing the frustration of people about this Committee, I'm wondering if there's any opportunity to have a section on what the Committee has done and potentially accomplished.

Even though we probably don't want to give ourselves red lights, green lights, or yellow lights, probably most of it would be yellow lights, but I just think that there's a sense sometimes that the Committee doesn't progress on things.

And we may not get to the, you know, the solution where we have the ideal outcomes for everybody, but I think if we could demonstrate and articulate what the Committee has done, I think it would be very helpful.

Dr. Daniels: We do have plans for – the Combating Autism Act report to Congress is due this fall. And that has an entire section on the IACC that is pretty detailed. And that will have more information about what the Committee has done in terms of activities, because it's a narrative type of a report.

If the Committee wanted to do some

collapsed version of that, we could put something into the Strategic Plan itself that is probably on a shorter level, because I'm sure that with the Strategic Plan you want to focus more on the needs and opportunities and objectives.

Mr. Robison: Should we email you as to which question group we want to either remain on or move to?

Dr. Daniels: You can email me or I actually will send something out and you can respond to it if that's easier for you.

We'll try to get all of those squared away this month so that we know which groups everyone wants to be on and can start getting the recommendations of any changes in the experts that you would want if you need to add experts, or some experts might not be available this fall that you had last year. And so, we'll just want to get that all adjusted.

Alison?

Ms. Singer: So, my concern about this process is that it looks very siloed in that each of the Planning Groups is going to meet independently and the full Committee won't actually see materials from the other Planning Groups until it's almost too late in December.

Last year, the process was that the Planning Groups would write the drafts, and then all of the Planning Groups would come together in October with all of the outside experts and stakeholders to discuss all of the drafts prior to submitting them to the full Committee. And that meeting was cancelled because of Hurricane Sandy. So, that never happened.

And I think that was unfortunate that we missed out on that opportunity to have the expert review of all of the sections. So, I'm wondering if it's possible to add that in this year and have a meeting in maybe early October where we bring all of the groups together to have input into the drafts. And then in our scheduled meeting at the end of October, present it to the Committee where it's not too late to actually make changes.

Dr. Daniels: I guess if you have all of the Planning Groups together, you have the full Committee pretty much. So, that would essentially –

Ms. Singer: Not every member of the IACC is on –

Dr. Daniels: Not everyone. But if you have more than a quorum of the Committee, it's the Committee. So, you would have pretty much – I'm fairly sure that you would have at least a quorum by the time you did that.

So, that would be a full Committee meeting.

Ms. Singer: I just I know that last year we had issues of the Chapter 5 Planning Group was working on some of the same issues as the Chapter 6, and we didn't know that until the Subcommittee met.

So, I just think it would be beneficial

to learn from some of what we went through last year.

So, maybe what we need to – we could consider using the scheduled October 29th meeting to bring the experts –

Dr. Daniels: To have a workshop like what you were planning last year, but –

Ms. Singer: Yes, but involving –

Dr. Daniels: Or really something to more go over the drafts or –

Ms. Singer: But involving more – to go over the drafts, but to include the outside experts who we've brought into the Planning Groups who would then have the opportunity to comment not only on their siloed group, but to look more broadly at the whole plan so that there is a little bit more consistency and coordination across the chapters.

Dr. Daniels: So, would you envision a meeting that is really focused on looking at drafts versus having presentations from –

Ms. Singer: Looking at drafts.

Dr. Daniels: Looking at drafts. We were pretty tight on finding dates that were available in October, because the full Committee is scheduled to meet in October.

I'm not certain if we can get both in, in the same month, but we can try. But would the Committee's preference be to have a workshop like that instead of a full Committee meeting like the one we had today if it came to that and we couldn't find another date?

Is there anybody that's opposed to that idea?

Ms. Redwood: Susan, I thought also we were going to hear back – we've formed this Planning Group to sort of look at how we would update the plan.

And I think we had one meeting by phone and maybe a few emails, but I was still thinking that we were going to get a product back or have more meetings to really sort of congeal what would be the best process for updating the plan.

And we also discussed, you know, how to sort of objectively look at the objectives and determine whether or not they were actually met with some consistency across the Plan and also bringing in stakeholders to see if the question itself had been answered beyond just what's been funded.

So, that's the part that I'm still a little fuzzy on, how that will be accomplished.

Dr. Daniels: Well, I think that's what I mentioned about the expert consultation. You would have those experts there, the community members and so forth, but not really with the Question 1 Planning Group.

So, with the Question 1 Planning Group, we were going to get you back, all of your materials to look at, see if there – what you were requesting.

And if you had other guidance that you wanted to send out to the rest of the groups for consideration, that would work.

Although, we did hear from the Committee that it sounded like, for example, some of the services objectives might have different sets of criteria people might want to use versus some of the more basic science objectives. And so, there might not be a one-size-fits-all for everything.

I don't know if that's true, but that's what I recall hearing from the Committee.

Ms. Redwood: So, now with Alison's suggestion, there will be a separate meeting of all of the Committee groups together? Is that correct, to go over the Strategic Plan updates?

Dr. Daniels: What we could do is have a meeting that's sort of like – in 2009 we had that scientific – the Strategic Plan work – it was a scientific workshop, and we invited all these experts and we looked at – so, basically it could be like that.

I don't know if we would want to split it into too many separate little subgroups, but we could have basically everybody that wants to be involved in reviewing drafts together at that meeting.

Ms. Singer: I think the key, though, is for each Planning Group to come to that meeting with a draft so that you're not starting from ground zero. That definitely was a key learning from the 2009 meeting.

Dr. Daniels: And so, October 29th is actually a good date for that, too, because you would have enough time to get a draft together to be reviewed by that time.

Mr. Robison: Susan, I have a 5 o'clock taxi pickup, and I see we've lost a lot of members.

Is there anything we need to vote on that I should be present for before I leave?

Dr. Daniels: We were going to just go through quickly the Services Research and Policy Subcommittee – the planned projects – just to mention that the letter to the Secretary was completed.

There was a possible letter to the Secretary regarding adult services. This is just an update. The group is going to meet separately.

There's an adult services project that the Subcommittee wants to look at. OARC has prepared a list of toolkits on adults and children and all the other issues that the Committee asked for.

And so, we will be providing that to the Subcommittee to review and then try to decide what direction you want to go in for your adult services project.

You also would have a chance to talk about a health disparities project if you want to continue to work on that, and now we've also added wandering as a special meeting.

So, Services Research and Policy Subcommittee will have a number of things to discuss at their next meeting, and we're trying to schedule that.

Mr. Robertson: Is the Services Research

and Policy – so, you might have potential dates for when that – is that a phone meeting, or is that an in-person meeting?

Dr. Daniels: It will be a phone meeting.

Mr. Robertson: Okay.

Dr. Daniels: And so, I've spoken with Denise and David, and they both don't have availability until the end of August, so that we would need to send out a meeting planning Doodle message to you all to try to get a date set for that, but these different topics as well as wandering then would be on the list for that group.

Idil.

Ms. Abdull: I was wondering if I could add a comment about the letter from the Secretary. And I'm hoping that it could be used nationwide, hopefully, or other states will take up.

In Minnesota because of the letter that we wrote, we were able to advocate with the Governor and the state legislature and they put in – because usually you hear the private insurance fight.

So, we were able to get 12 million dollars for public insurance for children that have autism not just to get ABA, but also to get developmental and behavior therapy. And then it goes up to 25 million each biennium or every 2 years.

So, I just wanted to add that, and hopefully from now on, we can advocate both developmental and behavior and then also public and private at the same time.

Dr. Daniels: Thanks.

Lyn?

Ms. Redwood: Yes, circling back around from the discussion this morning on comorbidities with the American Academy of Pediatrics, I had made a suggestion at that time to establish some type of subcommittee to work on the medical issues that face individuals with autism.

And from what I'm hearing from the last

discussion is that we don't have staff to be able to add another subcommittee. So, I'm wondering if this can then turn into a Planning Group, because I'm not familiar with the structure.

But it seems as though with the Planning Groups, you can bring in outside members that are not members to the IACC, which would be perfect to bring in people like Dr. Perrin and members of the ATN and some of the clinicians to work on these issues surrounding the medical conditions of children with autism.

So, I don't know, does that need a Committee vote to be able to establish –

Dr. Daniels: We do need a Committee vote. I don't know if we have 15 people here.

Do we have 15? Do we have three people on the phone?

Dr. Ball: I'm on the phone, Jim Ball.

Dr. Birnbaum: Linda Birnbaum.

Dr. Matthew Carey: Matt Carey.

Dr. Daniels: Matt Carey, okay. So, we

have 15.

Unidentified Speaker: So, quickly, let's vote before John has to leave.

Dr. Daniels: So, would you like to vote to form a Planning Group that would be – it would be under the BTR Subcommittee?

Ms. Redwood: Right. Exactly. And that Planning Group could also help feed in for new objectives as well into the update for the treatment portion of the Plan.

Mr. Robertson: Why don't we vote just so I know the specs of -

Dr. Daniels: So, Lyn, your proposal is to have a Planning Group of the BTR Subcommittee?

Ms. Redwood: Yes, similar to what we've been doing with *DSM-5* to address some of the issues and medical problems.

Mr. Robison: I will second Lyn's motion for that.

Dr. Daniels: All in favor?

Response: Aye.

Dr. Daniels: Is there anyone opposed?

(No response)

Dr. Daniels: Is there anyone who abstains?

Dr. Guttmacher: Let me ask just one point of clarification. If other people can turn their mics off, because mine won't come on, you mentioned childhood, I think, in that.

Were you restricting it to medical problems of children, or based on the earlier discussion today were you just restricting it to medical problems of the autistic population/community?

Ms. Redwood: The second.

Dr. Guttmacher: Thank you. Good.

Ms. Redwood: But also, Susan, just to be clear on the safety, the group that we've just established, that will also be a safety Planning Group, the one that we talked about earlier with the wandering and elopement.

Dr. Daniels: I thought the wandering and elopement was going to be covered by the Services Research and Policy Subcommittee and that it will be a special meeting of that, and if they need to have multiple special meetings, but now it's on the agenda for that group to take that up.

Ms. Redwood: Okay. Because I was just going to say something that would be – I just don't know if everybody on that Committee has an appetite for this issue, and it would be nice to bring in outside experts like the gentleman who was just here from the Department of Justice and the other gentleman.

And I just don't know within the structure of an IACC subcommittee, can we bring in outside members?

Dr. Daniels: We can bring in speakers and people that can't vote, but you can bring in outside experts to inform the subcommittee.

Ms. Redwood: Okay, thanks for that clarification.

Dr. Daniels: And other members of the Committee who want to come to that meeting, can.

I'm trying not to confuse the Committee too much, but I have been starting to send out subcommittee notices and planning group notices even to people who aren't on those Groups, because I notice with this particular iteration of the Committee people seem to be interested in trying to attend meetings that they're not officially members of.

And so, I'm trying to keep that straight, but also give you the opportunity to sit in on any meetings that you're interested in. And of course all of our meetings are open to the public.

So, I believe that the motion carries. It looked like we had a unanimous vote to have a Planning Group on comorbidities.

I think we can do round robin.

Dr. Guttmacher: We'd like people to stay if you're willing, because we can do the round robin without having to vote, but I think it's awfully nice at these meetings to be able to talk about what our organizations have been up to and other things in the autism world that we want to alert people to.

So, those of you who can stay a little longer, please do.

Dr. Daniels: We did leave a little bit of time for discussion. Although, I think it got eaten up with all the presentations that we had, which were all very important and very informative for the Committee.

So, if anyone would like to –

Ms. Singer: Can I just state the meeting is scheduled to go on until 5:30. So, I think it might be a nice idea if OARC were to instruct the travel agency that books people's travel to let them know that if they're a member of the Committee, they're expected to stay for the entire length of the meeting.

I think this is sad to look around this table and see all the people who are not here.

Dr. Daniels: Sure. And we can give people that guidance. I guess we do tell them the timing of the meeting, but we also can't really restrict people if they have personal commitments they need to go to. We do hope that people can stay for the length of the meeting.

And we've also been having the longer meetings to try to accommodate more of what the Committee wants to hear. So, we can send that out.

Dr. Kimbark: Is there a reason why we can't have a 2-day meeting? I mean, it's like we have so much that has to be done, and we never get to actually discuss the public comments, we never actually get to discuss what we heard except in little snippets here and there, and I just kind of always feel like I never got anything done.

I came here, I got a lot of information, and I go home and I digest it all by myself. And we can't, like, have an email conversation, because that's not FACA compliant. So, I kind of think that we need more than a 1-day meeting.

Dr. Daniels: There are new conference regulations that are extremely prohibitive and –

Dr. Kimbark: Oh, you don't have to tell me. I'm with the DoD.

Dr. Daniels: So, to get a 2-day meeting, it has to be pretty important for -

Dr. Guttmacher: And the budget because of sequestration -

Dr. Daniels: I'm not saying that autism isn't important, but it has to come to an extremely high level to be approved -

Dr. Kimbark: I have 2-day meetings --

Dr. Daniels: -in the budget.

Dr. Kimbark: - for peer review and programmatic review. I'm with the DoD. We've been underneath these travel restrictions for 2 years now.

Dr. Guttmacher: Ours are different from yours. And I think my guess would be if we were to do that, we'd have to have 2-day meetings instead of two 2-day meetings.

Dr. Daniels: So, we could start having phone followup meetings. It's just more and more meetings and we - for the fall, I didn't go over that carefully. But, with the seven working groups, if we're having two to three calls, that's somewhere around 15 to 20 some calls this fall.

Plus, if we're having special meetings of all these subcommittees, you can see that it adds up, and it's just challenging to get all that in, and I know you all have very busy schedules as well.

So, we're trying our best to accommodate and -

Dr. Kimbark: Well, is there a way to decrease the number of people we're hearing from?

I know we want to hear a lot of people and we want to do this, but I still feel as if we hear so much and nothing is done with the information.

I just feel kind of - I feel like it's

futile. I think that we need to do -

Dr. Daniels: I think that many -

Dr. Kimbark: I think that if we had less, if we had less in a day, then possibly we would get more done, actually. I don't know. Maybe I'm the only one here -

Dr. Tiffany Farchione: Well, I feel like if you look at the agenda, there's always time budgeted. It's just that we don't really ever stick to the allotted time for each individual presentation.

I mean, and even today we got started like 5 or 10 minutes late, and then it just kind of snowballed from there. And it's always a little bit – and I don't know if maybe it's the presenters don't understand what their time constraint is or if it's something -I'm not sure, but it's always, always over time.

Mr. Robertson: So, isn't part of the issue also that we – the legislation charges us with a lot of responsibilities. And so, we have to get public comments in, we have to, you know, there's a lot of things that have to happen in that one day, and you know, we just have to handle it all.

I do agree that maybe we could keep tabs a little bit better on time, because I think sometimes we're better in some parts of the meeting with doing that than other parts, and we may want to have a more, you know, uniform standard with slight relaxation, but I think, you know, what happens is we go over and then we try to pick up and then we end up losing breaks, which, I'll tell you, it's nice to have a 5-minute break so I don't, like, miss things, but still can keep my brain flowing in the middle during an 8-hour meeting.

But I do think if we could maybe keep people on, you know, try to keep on task – if we give people 4 minutes, just we'll stick to it and use that better than just – and I feel like people go past the lights and the lights don't really have much meaning anymore.

Dr. Daniels: Yes, we could try

flashcards. I think that it's just that every one of these issues is so important to people, and everyone feels like their issue needs a little more time.

And then the Committee is so interested, you want to ask a lot of questions, and pretty soon the time does get away.

And we do put things on the agenda that the Committee has requested and so forth, and we're trying to accommodate the wishes of the various members of the Committee and representing various topics.

So, it's challenging. We could cut down on presentations, but then those who ask for presentations might have to realize that we might not get to the presentation you would like to have, because we are cutting it down. So, that's something the Committee might have to decide as a whole.

Larry.

Dr. Wexler: Susan, yes, I really think this is about meeting management. I do work at

UNESCO. And let me tell you, if you have 4 minutes to speak, at 4 minutes you're off. It's as simple as that, and there's a uniform rudeness.

There is a reliable, consistent – that when you get to your time, they play music so loud you just couldn't even think of speaking. And, you know what? Everyone adheres to their time as a result.

I think that it's reasonable to set a standard for an amount of time for someone to speak whether it's the Committee, its presenters, it's the public, and simply stick to it.

And you just have a designated SOB that sits in the front that takes care of it. It's as simple as that.

Dr. Guttmacher: It would be a cultural change, and you're right: It would not just be the speakers, it would be the Committee.

Can I just see a show of hands to make this simple sort of, you know, rude and on time as opposed to sort of the way we have been doing it, which is maybe a little squishier.

How many folks would be for the more Draconian kind of – and how many people would prefer the current trying to thread the needle being somewhat more lenient?

Dr. Wexler: You can blame me. It's fine. I'm with education. We're used to it.

Dr. Guttmacher: On the phone.

Dr. Birnbaum: Can I just say something, Alan? This is Linda Birnbaum.

I think that we do need to speak – stick to times. I think, you know, we set -let's set times that make sense, and let's hold to them.

And if there's additional information that people want to communicate, we should always at the end of the day have some kind of time to bring issues back, but there are many, many meetings where people stick to the time, and I do think that we have to – if we let people know that that's going to be the new rule, I think people will respect it.

Dr. Daniels: We can try flashcards the next time. They tend to be a little bit more effective, although – and it is a little bit difficult to interrupt people who are talking about issues that are so important to them.

But I think that if the Committee is feeling that way, we can certainly try to do that.

Dr. Guttmacher: Susan and I will transmit this message to Tom.

Ms. Redwood: Also, I think the issue is that when you look at the agenda, typically the IACC business is at the very end of the day. And so, that's what gets cut.

And so, there are important things that come up during the day that we're then told, well, we'll discuss that at the end of the day during the IACC business, and then it's constantly shored.

We don't get to really work together as a Committee, and I think it makes us dysfunctional, and I know I personally feel very frustrated.

I think the other problem is we have a disease that we're trying to address that affects, you know, 1 in every 50 children, and we don't have the resources on this Committee to do this.

We need an around-the-clock, full-time staff, you know. To think that this Committee with people who chair institutes can dedicate their time to this issue with four, six meetings a year just, you know, is very impractical.

Dr. Daniels: In terms of the timing, I have heard that feedback about wanting to do business earlier in the day.

However, with the speakers, I always get speakers who want to have their talks in the morning so that – or in the early afternoon – because they want to get out of the meeting and be able to fly home.

And if we want to secure those speakers, that's what I've had to do to accommodate getting the speakers that you want to have come to the meeting.

Ms. Kavanagh: This is Laura Kavanagh. Is there another option where we could have some of the outside speakers present via webinar and then do followup, in-person meetings where we could have more of the Committee work accomplished?

Dr. Daniels: We could do that. We could have webinars. Again, it's more meetings. That's talking about adding onto the number of meetings, but we could have interim meetings in between meetings or have more meetings per year.

Dr. Birnbaum: Was the point that you actually could have some of the speakers who only want to be there to give their talk, do that via a webinar as part of the meeting?

Ms. Kavanagh: Well, no. I'm thinking you could have –I don't know – a 2-hour webinar that would either precede or follow the in-person meeting so you could have the presentation part, but leave the time when we're together in person for more discussion.

Dr. Daniels: Anshu.

Dr. Batra: I wanted to make a comment. I felt like today's meeting was fantastic in terms of the content. It really addressed, you know – sitting here for a year, I would leave every meeting very frustrated after having read all the public comments, the written and oral, and not having any way to comment or you know, at least give feedback or do something about it.

I felt like today's meeting addressed a lot of the frustration that the public has been voicing for years, I think. So, this was a good start, and I would like to see more of this.

I think that just the nature of the multidisciplinary sort of nature of this disorder, I think you're going to have a lot of different opinions and speakers. And so, I don't want to take away from that.

I think I want to go back to what Tom had mentioned earlier about how do we address the comment section and what ideas people have, because I think that has always left me feeling very ineffectual, and I leave here feeling yucky, because people spent a lot of time and effort and are clearly very invested and passionate about coming here and having a 3-minute voice, and we're so fortunate to have, you know, more than 3 minutes.

So, I'd like some suggestions, but, you know, one thing I was thinking is we, after the meeting, you give us maybe a week to comment on those, and then OARC can generate a response to the questions so that there is some closure to people's questions in the best way that we can.

I mean, very often there are questions that there are no answers, but at least people know they have been heard and that we are looking into it, that we are planning a speaker symposium on this in 6 months or something so that at least it's addressed in some way.

Dr. Daniels: I don't think that OARC can take the responsibility to respond to those comments.

I mean, we can - if the Committee wants to get together and draft responses to comments, they can, but then we need to schedule meetings to do that, but it's not really for our Office to presume how the Committee would respond.

We can't be the voice of the Committee in that sense. Because if it's the Committee's response, the Committee needs to draft it just like –

Ms. Redwood: I think what Anshu is suggesting, though, is that if the Committee members, after they reviewed both the oral and written comments, want to specifically comment and say, yes, this is an important thing and we are already looking at this in this particular objective or in some way respond back, it wouldn't be something that the staff would have to draft, but that the Committee members could draft. And then the Committee could review and approve whether or not those go out just like we approve the minutes.

I mean, I feel the same way as you do. I feel horrible sitting here when people are asking us direct questions to do something, and we just don't even respond.

Dr. Daniels: If the Committee decides that they want to put together responses, they can. It's just, on a practical level, you do get a lot of comments.

And so, if you would be picking and choosing certain comments to respond to and others not to respond to, it can get a little bit sticky.

Mr. Robertson: Yes, that was going to be just my quick comment on that – is I don't – I would only be in favor of that if we didn't, you know, pick, you know, we have to be more uniform on that, because I don't think it would necessarily be fair, you know. Everyone can equally submit comments to, you know, because of a frequency of the topic or something, you know, only choose certain groups to be responding to.

I mean, I think we would have an obligation to, you know, be addressing things across the board on all the different topics that are being raised by people.

Otherwise, if we responded to only certain parts, the other people would be like, why aren't we getting a response, too? Because they had the same equal process to put their comment in, and there's no ranking or hierarchy on their comments. I mean, everyone is equal in the comment system.

Ms. Redwood: Is there a way to make just one response back that sort of summarizes? Because a lot of the things we heard you could put into categories today.

So, if there was one sort of summary

response back from the Committee, I mean, we do that now when we make comments on the comments. And we don't address everyone’s comments when we do have an opportunity to address them, but I just feel like we need to do something. Otherwise, it just falls into a void, and you know, it makes us feel unproductive.

Dr. Daniels: Well, the purpose of public comments in a Federal advisory committee really is to bring that input in and for it to inform the Committee as you're thinking about all the different projects you're doing, and it's not necessarily the purpose to have to respond to each individual question.

Although, if the Committee wants to respond to each individual question, you can, but typically committees take that into account and use it as you're forming objectives in a Plan, as you're writing letters to the Secretary, as you're planning workshops.

So, in all of your activities, you're supposed to be really taking that feedback in.

And I think that the Committee really is doing that. But if you feel that you need to go a level further, someone would have to take that on to be responsible to draft something. And then we would need to circulate it to the Committee for approval. And so, there would be some process involved in that.

Ms. Redwood: But if we're doing that, and I think we are, we need to communicate that back out to the public, though, in terms of how we're using the comments and let them know that, you know, some type of response back.

Dr. Daniels: I actually just finished updating the public comment tab on our Website. And perhaps if the Committee wanted to have sort of a uniform statement about how you perceive and use public comment, we could post something, but that's different from an individual response to an individual person.

And if you want to personally respond to all of the comments, just at some points you get 70 comments in one meeting, it's just a lot to take on unless you feel that you have the time and the Committee is going to have the time to review and approve all of it.

Dr. Carey: Susan.

Dr. Daniels: Hello.

Dr. Carey: This is Matt Carey. If I could throw one more thing in there: There's a very different thing when we're discussing around the table and I say, here's a thought about this comment, and the entire Committee responding to a comment.

I think by the time we would try to do something like that, like you say, we would have to draft it, it would have to go to the whole Committee and become a formal statement of the whole Committee. I don't know –

Dr. Daniels: Exactly. It would have to be a statement that the whole Committee approved of versus our verbal comments here. Each person can say how they feel and it's not representing everybody else on the Committee, but – and then you also have collective thought. You can bounce your ideas off each other and be able to form some collective thoughts, but I understand the sense of giving somebody back something that's more concrete.

Dr. Guttmacher: I also think at the end of the day that most of the people who come to make comments to the Committee judge on our response not by if we send them a written response, but by what the Committee does.

I mean, I can just probably write, you know, the right criteria we all are using looking at it. So, I think at the end of the day, it's probably people aren't going to be so moved by what we send back to them a week later. They're going to want to see over the next year did they have an impact on the work the Committee is doing in terms of setting priorities, taking, you know, areas of interest on those kinds of things, I think.

Dr. Batra: And that's why I think today's meeting was so powerful, because it did send a message out to the community as well.

I mean, personally I just think this was the best meeting I've sat in. And it not only was so informational, but it just addressed the common theme that I've been hearing for the last year in terms of, you know, from parents like me about, you know, comorbidities and sleep and GI issues and things. So, thank you guys for setting that up.

Dr. Guttmacher: Any last words? We still do have 2 minutes left.

Ms. Redwood: Okay. Alan, before we had talked about including comorbidities in a program that NICHD was working on and having some discussion there related to autism specifically. What's the status of that?

Dr. Guttmacher: So, I'm not sure exactly what you're speaking about specifically.

I think that folks from NIMH and NICHD met with Tim Shriver and folks in Special Olympics to talk about this. And we are as recently as yesterday, in email exchanges back and forth about trying to come together on a conference that would look – it's still in the works, but the most recent version is to focus on mental health comorbidities. That those are the ones that for various reasons the feeling was it was important to have a focus, not be so broad that the meeting would just present rehashing of stuff that's been discussed before, but really lead to some kind of action items whether they would be RFAs or other kinds of things.

So, that's the current – it's in discussion. It's going back and forth – late fall or early spring, probably.

Ms. Redwood: Alan, I'm so sorry. She asked me a question about the Cab. So, there will be discussion with autism. You said it would focus on mental health.

So, are you just –

Dr. Guttmacher: –other mental health comorbidities for those with intellectual developmental disabilities, which would in turn include autism.

Ms. Redwood: So, but nothing like seizures in autism or metabolic –

Dr. Guttmacher: Specifically on autism would be about intellectual development disabilities, which would include autism.

Ms. Redwood: But are the comorbid issues just mental health?

Dr. Guttmacher: Yes.

Dr. Daniels: So, Alan, when NICHD and NIMH, I guess I may receive word of that through NIMH as well, when that comes out we certainly can inform the Committee –

Dr. Guttmacher: Oh, absolutely.

Dr. Daniels: – so the Committee can be aware of when that is happening and –

Dr. Guttmacher: Yes.

Dr. Daniels: – participate if they wish.

Dr. Guttmacher: Yes.

Dr. Daniels: Well, I think that we are coming to a close here. So, thank you so much, Alan, for helping out. And thank you to the last folks who stayed –

Dr. Guttmacher: Yes, all of you who stuck around, thank you.

Dr. Daniels: – for this portion that was not a decisionmaking portion of the meeting, but –

Dr. Guttmacher: Thank all of you on the phone for sticking with this.

Dr. Daniels: We appreciate it. Thanks so much. We're adjourned.

(Whereupon, at 5:28 p.m., the Committee adjourned.)