

00:01:07 - 00:01:10

Welcome to the IAT student meeting. My name is Dr.

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Megan Kaneane and I am the DFO for the ICC Ma's

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British IIT team learning and in my day job I'm

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a senior advisor to the director of the Mass University of Mental Health. I want to welcome

00:01:21 - 00:01:24

this new iteration of the IAPP. I'm joined by

00:01:25 - 00:01:28

Dr. Johnson. We'll have a few minutes of talk about this.

00:01:31 - 00:01:34

Good morning. I'm delighted to welcome you to

00:01:34 - 00:01:37

this first convening of the new member of the

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interagency autism coordinating committee. It's always an exciting

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time. We have joined the committee.

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And it's really wonderful to have you all here. I am Jennifer Johnson

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and I'm the deputy commissioner for the administration on

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disabilities. And we are in the administration for communities

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living, which is part of hhs. I've had

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the privilege of engaging with the IAC throughout

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my more than 20 plus year federal

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career. And really enjoyed the

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opportunity to connect with the committee and to be able to

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address really pressing issues

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that autism community faces. And so I really

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deeply value the role that this committee plays in helping to

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shape federal policies and our efforts as well.

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This committee, as you all know, brings together people

00:02:32 - 00:02:35

with autism, their family members and other

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experts who are really working alongside

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federal partners to identify an advanced solutions

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that best support autistic people to live well.

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As we bring on new members into the IAC, we are entering

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into a new chapter in the life cycle of the committee.

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And as new members, you join a strong legacy of

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service of those who came before you. But you also bring

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new insights and energy and a renewed focus on the needs of the

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autism community. And I'm really grateful that you've chosen

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to be a part of this work. As part of this new

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chapter, I want to briefly note that we are in a period of

00:03:16 - 00:03:18

transition regarding the support structure for the

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IF. And Diana Diaz

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Harrison, who found to my left.

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She is the principal deputy of the administration on disabilities at

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acl. And she is also the national autism

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coordinator, and she'll be providing more details on that transition

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shortly. So I want to thank you again for your service

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and for your dedication. And I'm very much looking forward to the

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important work that we will do together.

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Great. Thank you, Jennifer. And I will start off by making with you

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housekeeping notes if I can.

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Here we go.

00:04:02 - 00:04:06

Starting off reading materials can be found on the icc website, and they've also been

00:04:06 - 00:04:07

sent to the members in advance.

00:04:10 - 00:04:13

A transcript and a video recording of the meeting will be posted shortly after the meeting.

00:04:14 - 00:04:18

Closed captioning is available in zoom for committee members and

00:04:18 - 00:04:21

on video cast member of the public. A sensory room is

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available if you exit to the out of the

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room. The first room on your left conference room C

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if you need to use that. Please do not use that room for any

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noisy activities or calls. We do have another dedicated conference room

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called sensor and D, which is a little farther down the hall. I think also on the

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left, there should be clearly labeled. Feel free to use that room for any

00:04:43 - 00:04:46

calls or noisy activities that need to do.

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Restrooms are located off the main lobby. You would have passed the

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message name in from the elevators.

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And please be sure to silence yourself.

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We are going to ask that you keep comments brief during the discussion today because we

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do have a very packed schedule.

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And then finally for those meeting current services, please

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scan this.

00:05:12 - 00:05:14

QR code. I will leave this up for a minute.

00:05:16 - 00:05:19

For today's meeting, we are excited to welcome 43 members of the

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icc, including 20 new public members and 23

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federal agency representatives. At today's meeting, we will have an opportunity

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to hear from each of the new members and learn about their priorities. Following

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introduction, we will discuss public comment received by the

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received by the committee from the autism community. And following a lunch break

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from the launch into the committee business portion of the meeting. We will hear three

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topical presentations prepared by members of the committee to address

00:05:44 - 00:05:47

need to remain. Now I'd like to turn it over to Dr.

00:05:48 - 00:05:48

Matthew

00:05:51 - 00:05:54

director of NIH to give more brief open advice.

00:05:57 - 00:05:57

Morning everyone. Thank you.

00:05:59 - 00:06:02

Welcome to NIH. It's great to see you all here.

00:06:03 - 00:06:06

It's really a pleasure to be here and I'm grateful to have the

00:06:07 - 00:06:09

opportunity to be part of this meeting today.

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First, I want to recognize Dr. Diana Diaz Harrison

00:06:14 - 00:06:16

for her leadership bringing this new committee together.

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That really took a lot of commitment. So I really, really want to just

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extend our thanks. For your leadership here and commitment to

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the IACC. Secondly, I want to thank our

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NIMH colleagues for arranging this

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meeting, getting us to this point and bringing us all together here on the

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NIH campus. Again, a lot of hard work went into bringing this

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together. So really thank you all for your work.

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NIH's mission is to pursue really fundamental knowledge

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about science and then turning that into improvements in people's

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health. And research on autism is squarely

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in the middle of that mission. And so, you know, I think I speak

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for all my NIH colleagues that we are committed to that

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research and continuing that mission.

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NIH's investment in autism research has grown steadily over time.

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Supporting a broad portfolio that spans foundational science

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interventions and services with hundreds of projects underway across multiple

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institutes and centers. Last September, we launched the

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autism data science initiative, investing \$50 million in

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autism research. This is one of the most significant

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autism research commitments that NIH has made in recent

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years. These projects integrate data across many

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areas, including environmental exposure, prenatal factors.

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Immune responses and long term outcomes. Bringing information

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together in ways that simply was not possible before.

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A key feature of the initiative is ex-PISOMITS, looking comprehensively

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at how environmental factors like air pollutants, pesticides and maternal

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nutrition interact with genetics. We need to understand the full

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picture. We've built in independent replication and validation

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hubs to make sure findings hold up across diverse populations.

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Because reproducibility is not optional. This is a coordinated

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effort across NIH and every research team is working in direct

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partnership with the autism community.

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Autistic individuals, caregivers and service providers are helping

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to shape this research. That's the right way to do this work.

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At the same time

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and just as importantly, NIH is expanding efforts to leverage

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real world data working across like

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CMS to better understand.

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All aspects of autism, understanding diagnosis

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trends, outcomes, access to care and disparities across

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populations. Importantly, our work is not only about

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understanding causes, it's about improving

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services, support and outcomes across the

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lifespan, including for individuals with more complex needs.

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I'm here today representing NIH leadership. Dr.

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Botticeryari apologizes he couldn't be here. He's in Montana meeting

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with the tribal council. But you have my attention.

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And your perspectives matter and will help inform how we continue to shape our work going

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forward. So I'm genuinely looking forward to the meeting and I'll stop there

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and let you all take over. Thank you.

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At this point. I'd like to introduce Diana

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Diazson, who I think he mentioned a couple times

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already. As I mentioned, she is the principal

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deputy commissioner of the administration on disabilities and ACL.

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And also the national autism coordinator, a role

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he was appointed to in February of this year.

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It's really been a delight working with Diana and getting to know

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her. She brings, if you know her immense passion to

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this work and a deep commitment to advancing opportunities for

00:09:49 - 00:09:52

people with autism across the lifespan. Before

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joining ACL, she served as the deputy assistant secretary for

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the

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secretary for this office of special education and rehabilitative services

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in the US Department of Education. And she is the founder

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of autism. Arizona autism charter

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schools, which was the nation's first autism

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focused charter school network. She also created

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the national accelerator of autism charter schools.

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Her leadership has been recognized nationally through honors such as

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the Yaz prize and the national title one distinguished

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school award. Please join me in welcoming Diane.

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Thank you, Jennifer, and thanks to everyone who

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made this meeting possible, especially our chair Dr. Sylvia

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Fogle. It's been an honor to collaborate with her

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and the team in getting ready for this meeting, which is a long

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time coming.

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So as it was mentioned, in addition to serving in this

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autism specific role, I also serve as

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principal deputy commissioner for disabilities at hhs's administration

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for community living. In partnership with Commissioner

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Rebecca Hines.

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And Dr. Jennifer Johnson, who is deputy commissioner.

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I come to this work not only in an official capacity

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as I am a new government employee, but as a mother.

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And we can move forward with slides. I don't have a clicker. Next

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one.

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Before yes. My 23 year old son, Sammy, has

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profound autism and epilepsy.

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Like so many of the distinguished members of this

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committee, I know firsthand both the joy and the

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daily challenges of loving and caring for someone

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who requires 24/7 round the clock support.

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That experience grounds me and gives so much urgency and meaning

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to every decision we make here today.

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As it was mentioned, I also bring professional experience to the role.

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From my home state of arizona, where I founded educational programs

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that serve students across the autism spectrum.

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Along with workforce development programs for young adults on the spectrum

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and a specialized healthcare clinic. Through that work, I've seen

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what's possible. And I've also seen where the gaps

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remain. I believe Secretary Kennedy appointed

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me and this committee because he understands that this

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moment calls for urgency and action.

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Our community cannot wait. We must move forward with

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purpose beyond identifying gaps. To

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create an improved services research and

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healthcare. And we need to do so with

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coordination, accountability and speed.

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Next slide.

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I want to briefly share the foundation for this role.

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The national autism coordinator, I think if you click one over

00:12:56 - 00:12:58

the definition will be there. Is a congressionally

00:12:59 - 00:13:02

mandated position under the autism cares act

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with the first coordinator being appointed in 2016.

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While housed within HHS, the role is implemented across

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federal agencies charged with aligning efforts across

00:13:15 - 00:13:18

research services and supports. For people with autism

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and their families.

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A central responsibility of the position is to support the

00:13:24 - 00:13:27

implementation of the IAC initiative and

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strategic plan in close partnership with federal

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agencies and with meaningful input from the

00:13:34 - 00:13:34

public.

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I'm fortunate to be supported by the existing office of national

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autism coordination. And I'm especially pleased that

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Beth Tigner, also a political appointee and fellow

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autism mom, has joined the team. As many of you

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may know, the office of national autism coordination is

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currently housed at nimh, but there is a

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thoughtful process taking place to relocate the

00:14:01 - 00:14:04

onac to the administration for community living where

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other disability programs are housed. Looking ahead.

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And we'll go to the next slide, we are committed to turning

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strategy into action. To support implementation

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of the priorities we set forth here. We will

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convene quarterly meetings of the federal interagency working group on

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autism known as the FIWA.

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We will also engage directly with individual

00:14:31 - 00:14:34

agencies to ensure that the initiatives we identify

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are carried out with focus and follow through.

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To our federal partners in the room.

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This work cannot succeed in silos. I invite

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you to partner with us to champion these priorities

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within your agencies. To find a way to elevate them

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and to help drive the kind of change that families

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across this country are waiting for. On world

00:14:59 - 00:15:02

autism data passed April 2nd. Many of you were there.

00:15:03 - 00:15:06

Secretary Kennedy spoke to families from across the nation and made

00:15:07 - 00:15:09

a clear promise. That they are not alone.

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That we together are committed to building the support and the

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safety net that America's autism community deserves.

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He has selected each of you to serve on this

00:15:22 - 00:15:25

committee because your voices matter because your

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expertise, lived experience, and your leadership are

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essential to shaping policies that improve quality of life.

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For children, teens and adults on on the spectrum.

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Please know that the work we do here is a top priority for the

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secretary and for me. I look forward to working alongside

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you. And to share our progress as we move this mission

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forward on behalf of people with autism across

00:15:51 - 00:15:51

America.

00:15:56 - 00:15:59

And with that, I will turn it over to our

00:15:59 - 00:16:01

chair, Dr. Sylvia Fogle.

00:16:03 - 00:16:07

Thanks Diana. Welcome to all IAC team

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members, federal and public, as well as our guests and

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observers. Thank you to Secretary Kennedy for the opportunity

00:16:14 - 00:16:16
to serve to Diana via

00:16:17 - 00:16:19
Harrison, our national autism coordinator for your leadership

00:16:20 - 00:16:24
and to the office of national autism coordination and NINH leadership.

00:16:24 - 00:16:26
For organizing today's meeting.

00:16:27 - 00:16:31
And a special thanks to those who submitted public comments. Your perspectives

00:16:31 - 00:16:31
are invaluable.

00:16:33 - 00:16:36
I am a physician with over 20 years of clinical experience.

00:16:37 - 00:16:39
I've worked with hundreds of autism families and caregivers.

00:16:41 - 00:16:44
These families love and deeply value the individuals

00:16:44 - 00:16:47
they support. They celebrate their full humanity

00:16:48 - 00:16:52
and advocate tirelessly in symptoms that have not kept

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pace with a community now affecting one in 31

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children.

00:16:57 - 00:17:01
But alongside that love, especially for those with the most

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complex needs. Is deep exhaustion.

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And a constant terrifying question. What will happen

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to their loved ones when they can no longer provide care?

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I am also a mother to three children including my 17

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year old son Theo who has profound minimally speaking

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autism and complex medical needs. He requires

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continuous 24/7 care. From a

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deeply personal perspective. I understand the challenges

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facing individuals and families with the highest support needs.

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I recently came across a social media post from a desperate autism

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family. They are young teenage daughter non speaking

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is seen wearing a rubber helmet and large hand mitts.

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Banging her head and hands against any solid surface she

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can find.

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After being kicked out of her group home and after multiple

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emergency visits without answers or effective

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treatments, the family turns to social media for

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help.

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This family is not unique. Countless families struggle with

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severe self injury without appropriate medical

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evaluation and without access to effective treatments.

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Some autistic individuals are thriving. Improved recognition

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and supports have made that possible and that progress is worth

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celebrating. In addition to my son, one of my

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daughters has autism, although hers looks very different.

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She is articulate, independent, successful

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with a wicked sense of humor. Despite challenges, she is

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able to use her talents across school, work and life.

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And yet many individuals like her, with the lowest support

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needs. Also experience real challenges.

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Including with co-occurring medical conditions, anxiety and

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loneliness.

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As a clinician, I've seen a false tension drawn between

00:19:01 - 00:19:02

acceptance and treatment.

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Focusing on treatment does not diminish a person's inherent value.

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Rather, it reduces distress and helps individuals more fully

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express their strengths and talents.

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But for many families, adequate medical treatment is also necessary

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to address abject suffering.

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Many in the autism community are facing intense daily hardship

00:19:27 - 00:19:30

driven by undiagnosed or undertreated medical and psychiatric conditions.

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Safety risks, and increased mortality.

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Some experienced significant physical pain that they can't communicate

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from conditions such as gastrointestinal disorders, dental issues.

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Or chronic headaches or migraines. Pain that leads to

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behaviors that are too often dismissed as just

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part of autism. I have witnessed this repeatedly

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in my two decades of practice. It is unacceptable.

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And I can help but wonder if the young woman I saw on social media

00:20:02 - 00:20:05

is suffering from pain from a medical issue that has been overlooked.

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The care of individuals across the entire autism spectrum matter

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and there is more that unites this community than divides it.

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But some of today's proposals are specifically aimed at addressing the

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chronically underserved needs of those with the highest support

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requirements. Who have waited too long to be seen.

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I welcome robust discussion and debate as we evaluate

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proposals that address clear and correctable gaps

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in medical care, safety and policy recognition.

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Particularly for those with the highest support requirements. These

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are practical evidence based proposals that address a failure

00:20:46 - 00:20:49

of translation implementation and

00:20:49 - 00:20:52

coordination. They can be carried out with an existing

00:20:53 - 00:20:56

authority and directly align with the statutory responsibilities

00:20:56 - 00:20:58

of the autism cares act of 2024.

00:21:00 - 00:21:03

That law states that we, the IACC

00:21:04 - 00:21:07

shall monitor autism research services and supports across the

00:21:07 - 00:21:10

lifespan and shall make recommendations to the secretary

00:21:11 - 00:21:11

incorporating public input.

00:21:14 - 00:21:18

These duties are not optional. Congress did not

00:21:18 - 00:21:21

use the words should or may with respect to these

00:21:21 - 00:21:24

obligations. It used the word

00:21:25 - 00:21:28

shall. We are charged to act. Thank you.

00:21:31 - 00:21:34

For these inspiring words from Diane on that and so

00:21:35 - 00:21:38

yeah we appreciate. I will now do the

00:21:39 - 00:21:41

roll call. Starting with the federal members.

00:21:43 - 00:21:46

When I call your name, please turn on your microphone and say you are here or present.

00:21:48 - 00:21:50

And if you I mispronounce your name please correct me.

00:21:52 - 00:21:53

Jennifer Hight.

00:21:55 - 00:21:58

And at the right. Thank you Rebecca Hine.

00:21:59 - 00:21:59

Here.

00:22:02 - 00:22:02

Christina.

00:22:04 - 00:22:05

Present it's the code.

00:22:08 - 00:22:09

Matthew Maynor.

00:22:11 - 00:22:11

Here.

00:22:13 - 00:22:14

Please check. Snap.

00:22:19 - 00:22:19

Nicole Williams.

00:22:21 - 00:22:21

Present.

00:22:26 - 00:22:27

About Robertson.

00:22:29 - 00:22:30

Christy k.

00:22:32 - 00:22:34

Present. Elaine Cohen Hugo.

00:22:36 - 00:22:37

And Humble present.

00:22:42 - 00:22:43

Margaret Bush?

00:22:45 - 00:22:48

Present. Leah lore.

00:22:50 - 00:22:53

I'm President Leah thank you lo. Nson

00:22:54 - 00:22:55

Marcella Raniak.

00:23:01 - 00:23:02

Wonderful thank you Matthew Emily.

00:23:04 - 00:23:04

Present.

00:23:08 - 00:23:08

Deborah.

00:23:13 - 00:23:16

Present. Andrea Beckelmnir.

00:23:18 - 00:23:19

President? Amy Adams.

00:23:25 - 00:23:26

Present.

00:23:31 - 00:23:33

Moving to the public vendors Lisa Ackerman.

00:23:36 - 00:23:37

Elizabeth Gonker.

00:23:39 - 00:23:39

Laura.

00:23:43 - 00:23:44

Here. Sylvia.

00:23:46 - 00:23:47

Here John Gilmore

00:23:49 - 00:23:49

Crystal Higgins.

00:23:51 - 00:23:54

Here Daniel Keeley here

00:23:54 - 00:23:55

Hayden L.

00:24:03 - 00:24:06

Cheer thank you Elena hello

00:24:06 - 00:24:08

no monarch present.

00:24:14 - 00:24:15

Bill olden?

00:24:19 - 00:24:21

Oh thank you. Jennifer Fillitt.

00:24:23 - 00:24:25

Honey Renzella. Here.

00:24:27 - 00:24:30

John Rodriguez. Redak is here thank you

00:24:31 - 00:24:34

Dannie Raphignel. Right here.

00:24:35 - 00:24:35

Tracy.

00:24:38 - 00:24:38

Here.

00:24:42 - 00:24:43

Ginger Taylor here.

00:24:45 - 00:24:48

Is a reader light. Present walters

00:24:50 - 00:24:50

here.

00:24:53 - 00:24:56

Now I would like to provide a brief overview of the

00:24:56 - 00:24:58

IPC and the federal government.

00:25:01 - 00:25:01

Okay wonderful.

00:25:03 - 00:25:06

So as you all are probably aware the

00:25:06 - 00:25:09

IAC is a federal advisory committee that coordinates federal efforts and

00:25:10 - 00:25:13

provides advice and secretary of health and human services on autism.

00:25:14 - 00:25:17

As you heard the committee was originally established under the

00:25:17 - 00:25:20

Children's Healthcare act of 200 and then was reestablishment

00:25:21 - 00:25:24

by combating autism active 22006.

00:25:25 - 00:25:28

With three optimal revisions every five years. The most recent

00:25:28 - 00:25:31

reauthorization was from the autism cares act in 2024.

00:25:33 - 00:25:36

You can see the current ICT membership this is the public non

00:25:37 - 00:25:38

federal members that we just called out.

00:25:40 - 00:25:43

And the current IACC members who are represented by by

00:25:45 - 00:25:46

call today.

00:25:50 - 00:25:52

To go over a little bit about what the ICC cannot do.

00:25:53 - 00:25:56

It is the federal advisory committee so it is not in charge of funding

00:25:57 - 00:25:59

research or allocating federal research dollars not

00:26:00 - 00:26:03

in charge of direct funding or implementation of federal

00:26:03 - 00:26:07

programs. It cannot check or create federal

00:26:07 - 00:26:10

policy and it cannot create policy for states or

00:26:10 - 00:26:12

non governmental organization.

00:26:16 - 00:26:16

S.

00:26:19 - 00:26:23

Can do is to convene at least twice annual the first meeting of

00:26:23 - 00:26:26

this fiscal year. Coordinate federal activities related to

00:26:26 - 00:26:30

autism gather public input on issues related to

00:26:30 - 00:26:33

autism. Develop and finally update a

00:26:33 - 00:26:36

strategic plan for autism and the Congress will be mandated.

00:26:37 - 00:26:40

Additionally to develop an annual summary of advances and

00:26:40 - 00:26:42

autism resource which is also congressionally mandated.

00:26:46 - 00:26:49

Federal activities related to autism. And make recommendations to the

00:26:49 - 00:26:50

CHS secretary.

00:26:52 - 00:26:55

This is an ICD core value that was established by the

00:26:55 - 00:26:59

ICC from 2021 to 2023. It is able

00:26:59 - 00:27:02

to be revised by the so desire. But you can see that

00:27:02 - 00:27:06

I think these are in a spirit of the IACC with broad

00:27:06 - 00:27:09

participation community focus. Spirit of collaboration between

00:27:10 - 00:27:12

the federal and non federal members responsiveness

00:27:13 - 00:27:15

excellent impact.

00:27:17 - 00:27:20

The IHD typically needs three times a year. We are still working on

00:27:22 - 00:27:25

other dates for this year. Typical meetings include time

00:27:25 - 00:27:28

for the business with rule work on this afternoon and that will

00:27:28 - 00:27:30

include working on the

00:27:32 - 00:27:35

strategic plan and the summary of the basis. The

00:27:35 - 00:27:38

ICT is also authorized to get presentations from federal agency or other

00:27:39 - 00:27:42

community organizations as well as researchers in the field. We

00:27:42 - 00:27:44

do take public comments at every meeting.

00:27:45 - 00:27:49

And generally get an update from the national or out of the coordinator

00:27:49 - 00:27:52

Dr. Yes Harrison and update from IFSB members.

00:27:53 - 00:27:56

Again additional preparation presentation are allowed by other

00:27:57 - 00:27:59

committee members. That will be up in the community to decide what you are interested in hearing

00:27:59 - 00:28:00

about.

00:28:02 - 00:28:02

In the past these are the

00:28:05 - 00:28:08

components that have been discussed by previous IACs.

00:28:09 - 00:28:12

So with these presentation are all available by

00:28:12 - 00:28:15

videocast. So if you have any interest in what the previous

00:28:15 - 00:28:19

IPs have heard about, they are available to you. And more

00:28:19 - 00:28:21

information can be found on the IAC website.

00:28:23 - 00:28:26

So now I will turn it over to Jennifer for the introduction of the public members.

00:28:28 - 00:28:28

You want to go through.

00:28:30 - 00:28:31

The protocol.

00:28:42 - 00:28:45

So we wanted to do introductions now of

00:28:45 - 00:28:48

the public members of the committee.

00:28:50 - 00:28:50

And we are

00:28:52 - 00:28:55

again delighted to have you join the committee

00:28:56 - 00:28:59

and share introductions about yourself. We ask

00:28:59 - 00:29:03

then you keep your introductions to 1 to 2 minutes.

00:29:04 - 00:29:07

We have a full agenda and we want to make sure that we are able to

00:29:07 - 00:29:11

get through all the items on the agenda. And so again

00:29:12 - 00:29:15

we ask you to keep to that time frame. If you do

00:29:15 - 00:29:18

begin to run over time, we will provide a gentle

00:29:19 - 00:29:22

signal to you all to wrap up your

00:29:22 - 00:29:26

introductions and know that there will be additional opportunities

00:29:26 - 00:29:29

to share your priorities and your

00:29:29 - 00:29:32

expertise with the committee as we go through our

00:29:33 - 00:29:36

agenda today and in future meetings. For your

00:29:36 - 00:29:37

introductions.

00:29:44 - 00:29:47

We ask that you state your name and

00:29:47 - 00:29:48

affiliation.

00:29:50 - 00:29:53

And please note whether you are an autistic individual

00:29:54 - 00:29:57

family member or have some other kind of connection to the

00:29:57 - 00:30:01

autism community. We ask that you briefly highlight

00:30:01 - 00:30:04

any relevant personal and professional experience that you bring.

00:30:06 - 00:30:09

And we welcome a short statement about your priorities

00:30:10 - 00:30:13

for your service on the I. And so we will begin with

00:30:13 - 00:30:15

our introductions.

00:30:22 - 00:30:25

Yeah. So we'll just go through the list

00:30:25 - 00:30:26

here. First we have.

00:30:31 - 00:30:34

Secretary Kennedy and thank you to this team and administration for making

00:30:35 - 00:30:38

autism a strategic priority. My name is Ackerman. I'm

00:30:38 - 00:30:42

the co founder and executive director of autism community in action.

00:30:43 - 00:30:46

I'm the mother of two grandmother of one. My son

00:30:46 - 00:30:50

Jeff is 29 and was diagnosed after experiencing

00:30:50 - 00:30:54

a severe regression at 15 months. At

00:30:54 - 00:30:56

that time when I reviewed the 22 symptoms of

00:30:57 - 00:30:59

autism, Jeff had 19 of them if he was awake.

00:31:00 - 00:31:03

I'm proud to say with access to medical care and therapeutics

00:31:05 - 00:31:06

is a bright light.

00:31:08 - 00:31:11

He's worked so hard to get where he is and he's thriving

00:31:11 - 00:31:15

a college graduate. Employed driving and

00:31:15 - 00:31:18

an accomplished musician. My family's journey

00:31:19 - 00:31:21

continued with my grandson diagnosed with

00:31:21 - 00:31:24

autism, his regression experience was different.

00:31:25 - 00:31:28

But the less important through his uncle

00:31:28 - 00:31:29

Jeff have made a big difference.

00:31:31 - 00:31:34

Over 26 years we've worked with 100,000 families

00:31:35 - 00:31:38

and it's no secret I've been a critic of the UCC and

00:31:38 - 00:31:42

I'm grateful to be here. It is an

00:31:42 - 00:31:43

honor to serve.

00:31:44 - 00:31:48

And there's three things that I really hope we can accomplish. One

00:31:48 - 00:31:51

support families. Strengthening the connection through research

00:31:51 - 00:31:55

and care is so important. Second addressing the

00:31:55 - 00:31:59

diagnostic backlog. The families are waiting 12

00:31:59 - 00:32:01

to 48 months for a diagnosis across the United States.

00:32:03 - 00:32:06

Third strengthening special education waivers

00:32:07 - 00:32:10

resources and accountability. These are all critical services

00:32:11 - 00:32:14

families need access to and we want to help them. I'm grateful

00:32:15 - 00:32:18

to begin this work with this incredible committee. And I'm honored

00:32:19 - 00:32:22

to have the legacy of Dr. Bernard Renwen be my guide.

00:32:23 - 00:32:27

And I just want to say working for together to provide

00:32:27 - 00:32:30

the rigorous science strengthening services and improving outcomes.

00:32:31 - 00:32:35

My one motivation is to keep working until families no longer need us to

00:32:35 - 00:32:38

fight so hard for answers. And for every person with

00:32:38 - 00:32:42

autism. To lead a healthy and independent life. Thank

00:32:42 - 00:32:42

you.

00:32:44 - 00:32:44

So much.

00:32:46 - 00:32:47

Next Elizabeth Bonker.

00:32:51 - 00:32:54

Hello, I'm Elizabeth Banker, Executive Director of

00:32:54 - 00:32:57

Communication for All. More than 99% of

00:32:58 - 00:33:01

non speakers have not been taught to communicate as Cayden and I do.

00:33:02 - 00:33:06

Non speakers are misunderstood and underestimated. We

00:33:06 - 00:33:09

have a motor disorder called full body apraxia that should not be

00:33:09 - 00:33:13

confused with intellectual disability. I advocate

00:33:13 - 00:33:16

for IAS to focus on three priorities. Communication

00:33:17 - 00:33:20

safety and co occurring medical conditions that are urgent needs for

00:33:20 - 00:33:21

non speakers.

00:33:22 - 00:33:25

For communication, I advocate for HHS to one

00:33:26 - 00:33:29

increase access for non speakers by issuing federal guidance

00:33:29 - 00:33:33

clarifying communication rights found in the Americans with Disabilities

00:33:33 - 00:33:36

Act. 2 give families choice by including

00:33:37 - 00:33:39

Medicaid coverage for typing training and support.

00:33:41 - 00:33:45

The communication section of the autism cares act to focus on

00:33:45 - 00:33:49

full communication for non speakers and research that makes typing easier

00:33:49 - 00:33:53

including interventions that mitigate full body apraxia and improve

00:33:53 - 00:33:56

regulation. For safety. I advocate for

00:33:57 - 00:34:00

HHS to 1 issue guidance on wandering and drowning prevention

00:34:01 - 00:34:04

including elopement protocols and cameras in classrooms and schools.

00:34:05 - 00:34:09

2 Require law enforcement autism training to avoid autistic

00:34:09 - 00:34:10

people being misunderstood and harmed.

00:34:12 - 00:34:13

And 3 we must stop the shock.

00:34:15 - 00:34:18

No autistic person should be shocked to stop quote behaviors.

00:34:19 - 00:34:22

We are people not lab rats. For

00:34:22 - 00:34:26

co-occurring medical conditions. I advocate for HHS

00:34:26 - 00:34:29

to focus on how to help autism families with their most urgent medical

00:34:29 - 00:34:32

needs, including seizures, dysregulation

00:34:33 - 00:34:36

autoimmune issues, whole body apraxia and

00:34:36 - 00:34:37

gastrointestinal disorders.

00:34:38 - 00:34:42

Life is agony if you cannot communicate, feel afraid or not

00:34:42 - 00:34:45

well. We can and should do more for families

00:34:45 - 00:34:46

who face these challenges every day.

00:34:48 - 00:34:51

With communication, safety and wellness. We can live happy

00:34:52 - 00:34:54

productive lives. Thank you.

00:34:59 - 00:35:02

Laura Cellini. Hi, my name is

00:35:02 - 00:35:05

Laura. Thank you. I'm the mother of

00:35:05 - 00:35:08

Jonathan, a young adult with autism whom suffer to severe regression

00:35:09 - 00:35:12

when he is a title arc. We didn't know it at the

00:35:12 - 00:35:15

time, but later we would learn that Jonathan also suffered from a

00:35:15 - 00:35:19

coronary immune deficiency. And other co occurring medical

00:35:19 - 00:35:19

conditions.

00:35:21 - 00:35:24

And it was later that treating those underlying and

00:35:25 - 00:35:28

co-occurring medical conditions allowed us to alleviate and reduce

00:35:28 - 00:35:31

the symptoms of autism. So that experience

00:35:32 - 00:35:35

is really inspired me. To promote

00:35:35 - 00:35:39

a better understanding of how those underlying and cocurring

00:35:39 - 00:35:42

conditions are contributing to the

00:35:42 - 00:35:45

synthesis of their autism. That is one of my

00:35:46 - 00:35:48

priorities for this committee is that we would promote

00:35:50 - 00:35:53

research that is very cohort based and individualized

00:35:54 - 00:35:57

so that we can get better insights and

00:35:57 - 00:36:00

treatments that might be more effective. My experience

00:36:01 - 00:36:04

is as a policy advocate. I

00:36:04 - 00:36:08

was a political scientist before this and I worked

00:36:08 - 00:36:11

in Illinois establishing numerous laws around

00:36:12 - 00:36:15

autism. I previously served on other

00:36:15 - 00:36:18

statewide advisory councils for autism, including the early

00:36:18 - 00:36:21

intervention. The autism task force as well as

00:36:23 - 00:36:26

leading the Medicaid waivers subcommittee for the

00:36:26 - 00:36:30

adoption of our waiver here in Illinois. I look forward to

00:36:30 - 00:36:31

working with everyone. Thank you.

00:36:34 - 00:36:37

Thank you. Next, being sylvia

00:36:37 - 00:36:38

fogl.

00:36:41 - 00:36:43

Ike I've already got my introduction so I'm good.

00:36:48 - 00:36:49

Next we have John Gilmore.

00:36:55 - 00:36:58

So my name is Dawn. I am the executive director of the

00:36:58 - 00:37:02

autistic network or a national 501 sequel organization that

00:37:02 - 00:37:05

works on disabilities and at the medical creed

00:37:05 - 00:37:08

of initiatives. I've also the father of

00:37:09 - 00:37:13

a son. Luke who is a 26 year old man diagnosed with autism.

00:37:14 - 00:37:17

His symptoms that the criteria for a level three designation.

00:37:18 - 00:37:22

Loop of breast several times as an infant at two months he stopped

00:37:22 - 00:37:25

nursing development. He did not want to be co

00:37:26 - 00:37:28

or touched and developed asthma and eczema over most of his body.

00:37:30 - 00:37:33

At one year he regressed again. He lost the bomb and the one word you got

00:37:34 - 00:37:37

fired at that point. And the belt load range of odds and symptoms, including

00:37:37 - 00:37:41

the appearance of being dubbed staring for long periods and moving objects like ceiling

00:37:41 - 00:37:44

ants. Using its peripheral vision to look at things flapping

00:37:45 - 00:37:46

among other symptoms.

00:37:48 - 00:37:51

Loops both loops regressions follow the days of multiple rounds of vaccines.

00:37:53 - 00:37:57

He was diagnosed with PDD and OS approximately 18 months.

00:37:58 - 00:38:02

Which still has full bodied spraxia, severe gastrointestinal issues

00:38:02 - 00:38:05

that be constant monitoring and OCDs that control much of his

00:38:06 - 00:38:07

and our family's life.

00:38:08 - 00:38:12

Luke is not speaking, but fortunately in the past several years he has not communicated

00:38:12 - 00:38:13

back the way he used motherboards and keyboards.

00:38:15 - 00:38:19

Prior to Luke's regression we my wife and I had

00:38:19 - 00:38:22

no experience of autism. However during college my wife

00:38:22 - 00:38:25

worked summers at a date camp with people with developmental disabilities.

00:38:26 - 00:38:30

Almost all the campers in the 1980? S at Down syndrome and she does not

00:38:30 - 00:38:33

recall anyone who she would consider is having autism. Today

00:38:33 - 00:38:36

the same CH, which is blocked. Serves a population

00:38:37 - 00:38:40

overwhelmingly composed people with autism and only if you people with

00:38:40 - 00:38:41

Daniel syndrome.

00:38:42 - 00:38:46

When loop progressed we did not officially know the causes of autism. We

00:38:46 - 00:38:48

had no treatments, no known prevention, no cure.

00:38:49 - 00:38:52

And the first round of ADV amp numbers had just come out, which was one in

00:38:53 - 00:38:56

158 year olds. But they were not sure at that time

00:38:57 - 00:38:58

if the increase was real.

00:38:59 - 00:39:02

Today 26 years later 20 years after the combating

00:39:03 - 00:39:06

oxen act was first passed. We still don't know initially

00:39:07 - 00:39:09

the causes of autism. We have no treatments.

00:39:10 - 00:39:14

No known prevention. It's no cures latest 80 amp numbers say

00:39:14 - 00:39:17

1 and 31 8 year olds have autism. Which apparently is

00:39:18 - 00:39:21

one out of 12 boys in California. But we still haven't done the

00:39:21 - 00:39:24

work to save it penalty if the numbers have gone off. So we

00:39:25 - 00:39:29

basically have not produced anything new of use to loop or people with

00:39:29 - 00:39:30

autism and families as far as I'm concerned.

00:39:32 - 00:39:36

Another more questions we had about autism 20 years old have

00:39:36 - 00:39:38

been answered. And I think this law of progress

00:39:39 - 00:39:41

is basically a public health and human capacity.

00:39:43 - 00:39:45

During salute's lifetime. Autism has to retire

00:39:46 - 00:39:49

redefine three times. As original PVD NOS

00:39:49 - 00:39:52

DAC diagnosis was scrapped. Along with Asperger's.

00:39:53 - 00:39:57

Right now the label autism includes people with symptoms far worse than

00:39:57 - 00:40:00

loops putting seizures, supp inquiry elopement lack of valve control

00:40:01 - 00:40:04

and many others. But also also includes highly

00:40:04 - 00:40:07

articulate people with no visible disability who have successful academic

00:40:07 - 00:40:10

professional careers. Spouses and children, people who

00:40:11 - 00:40:13

need health care models related to have full productive lives.

00:40:15 - 00:40:18

The extremes are so wide that today autism is nearly a meaningless label.

00:40:19 - 00:40:22

My hope is going forward we were able to identify biological markers for the

00:40:23 - 00:40:26

variety's autism identify the causes of autism.

00:40:26 - 00:40:29

Do the epidemiology necessary to understand the scope of the

00:40:30 - 00:40:33

office epidemic. Development.

00:40:34 - 00:40:36

Develop curves and prevention as

00:40:36 - 00:40:39

well. I hope we had started with. That as soon as possible.

00:40:40 - 00:40:40

Thank you.

00:40:44 - 00:40:45

Crystal Higgins.

00:40:46 - 00:40:50

Hello, my name is Crystal Higgins and I'm the executive director of the

00:40:50 - 00:40:54

national authoring association. I was the teacher at a pediatric

00:40:54 - 00:40:57

hospital before leading to care for my oldest daughter who was born with

00:40:57 - 00:41:01

severe CI and complex medical issues. And

00:41:01 - 00:41:04

it was odds in parents I met while teaching who guided us to her most detective

00:41:04 - 00:41:07

treatment. It's clear there are many urgent issues

00:41:08 - 00:41:11

in our community that demands attention. Today I ask that we confront

00:41:11 - 00:41:14

one of the most critical one that's a matter of life and death.

00:41:15 - 00:41:17

And one where the data gives us a clear path to prevention.

00:41:18 - 00:41:19

Wandering and elopement crisis.

00:41:21 - 00:41:24

Despite how common this risk is in how well documented the fatality profile has

00:41:24 - 00:41:28

become the response by federal and state authorities has remained

00:41:28 - 00:41:31

navigable. The consequences are devastating.

00:41:32 - 00:41:35

We're losing an average of the individuals a month and that is likely an

00:41:35 - 00:41:39

underestimate. Children with autism face significantly higher risk

00:41:39 - 00:41:42

of injury and death in their neurotypical care. To members of the

00:41:42 - 00:41:46

media covering today's meeting. Please report on the deadly crisis

00:41:46 - 00:41:50

as you would any other preventable pediatric cause of death.

00:41:50 - 00:41:54

Other causes with bus fatalities. Have triggered coordinated

00:41:54 - 00:41:57

federal campaign national messaging surveillance and

00:41:57 - 00:42:00

policy reform. These children deserve the same emergency.

00:42:01 - 00:42:04

We have effective ways to reduce these tragedies and support families

00:42:05 - 00:42:08

living in survival mode. 24 hours a day. And I

00:42:08 - 00:42:12

plan for some months later today. If you have met the autism

00:42:12 - 00:42:15

parents I have, they are like no other parents I know. Awake through

00:42:15 - 00:42:18

the night engineering safety solutions. Advocating

00:42:19 - 00:42:21

tirelessly carrying peers few could comprehend

00:42:22 - 00:42:26

yet loving with extraordinary death. There is no greater devotion.

00:42:26 - 00:42:30

These families are not unaccepting of their children. They are fighting

00:42:30 - 00:42:34

for basic human rights, effective communication meaningful peer

00:42:34 - 00:42:36

relationships, the ability to contribute to

00:42:36 - 00:42:39

society, equitable and non discriminatory access to

00:42:40 - 00:42:43

effective health care, education and safety. We must

00:42:43 - 00:42:46

align our priorities. By triaging the most critical means

00:42:47 - 00:42:50

with tough issues and they deserve immediate action. Thank you. I am

00:42:50 - 00:42:52

grateful to be here with all of you.

00:42:54 - 00:42:54

Thank you.

00:42:56 - 00:42:57

Daniel Keeley.

00:43:01 - 00:43:04

My name is Daniel Key. I am a high school senior.

00:43:05 - 00:43:08

I was nonverbal until second grade. My early

00:43:08 - 00:43:11

years involved intense therapies and medical support

00:43:12 - 00:43:15

as doctors work to diagnose and treat my complex medical

00:43:15 - 00:43:19

conditions. Over time we identified

00:43:19 - 00:43:20

and addressed

00:43:21 - 00:43:23

cerebral folate to fit deficiency.

00:43:25 - 00:43:26

Mitochondrial dysfunction

00:43:27 - 00:43:31

and abnormal immune system activation. These

00:43:31 - 00:43:34

treatments along with the discovery of an underlying genetic condition

00:43:35 - 00:43:36

affecting my mitochondria.

00:43:39 - 00:43:42

Allowed me to improve significant. My journey

00:43:42 - 00:43:46

highlights the complexity of autism and shows why science

00:43:46 - 00:43:49

must move beyond simple genetic

00:43:49 - 00:43:52

explanations to embrace a multidisciplinary approach.

00:43:55 - 00:43:56

Most importantly, we need to gather

00:43:58 - 00:43:59

investment in medical research.

00:44:01 - 00:44:04

And treatments so children can recover before losing

00:44:05 - 00:44:05

precious time.

00:44:08 - 00:44:11

I am truly grateful to be part of this interagency autism

00:44:11 - 00:44:14

committee. And hopeful that my voice and experience

00:44:15 - 00:44:18

can help make a meaningful difference in the lives of individuals

00:44:18 - 00:44:19

with autism.

00:44:21 - 00:44:24

Another area I urge the committee to focus on is providing

00:44:24 - 00:44:28

better support and accommodations for artistic

00:44:28 - 00:44:30

individuals in hot and health care settings.

00:44:32 - 00:44:35

Sensory sensitivities can make standard hospital

00:44:35 - 00:44:38

environments overwhelm them. Bright

00:44:38 - 00:44:41

lights, loud noises, unfamiliar textures

00:44:41 - 00:44:44

often heighten anxiety and discomfort. Pain

00:44:45 - 00:44:48

perception can also differ what might feel mild to others

00:44:49 - 00:44:52

may feel amplified to me through sensory processing differences.

00:44:54 - 00:44:57

Simple accommodations such as allowing the use of noise canceling

00:44:57 - 00:45:00

headphones, a mobile device, my service

00:45:00 - 00:45:04

dog, a trusted support person, quiet

00:45:04 - 00:45:06

spaces for adaptive pain management

00:45:07 - 00:45:10

protocols. To make a tremendous difference.

00:45:12 - 00:45:16

These changes would reduce barriers, lower stress and lead

00:45:16 - 00:45:18

to better health outcomes for many autistic people.

00:45:20 - 00:45:23

I appreciate the opportunity to share my perspective

00:45:23 - 00:45:27

as a young autistic adult. And look forward to the

00:45:27 - 00:45:30

committee's continued efforts to provide meaningful

00:45:30 - 00:45:33

research, better health care access and

00:45:33 - 00:45:35

supports that empower us to thrive.

00:45:38 - 00:45:39

Thank you.

00:45:40 - 00:45:41

Hayden Larsson.

00:45:43 - 00:45:44

My name is

00:45:47 - 00:45:47

Mtext.

00:45:49 - 00:45:52

Where I was able to communicate. I was trapped in silence until I was 20

00:45:52 - 00:45:53

years old.

00:45:54 - 00:45:57

Learning spell changed everything for me. It gave me a

00:45:57 - 00:46:01

voice, the opportunity to express what I believed and what I wanted

00:46:01 - 00:46:01

to do.

00:46:03 - 00:46:06

Ultimately spelling saved my life when I had an infection without a

00:46:06 - 00:46:10

fever during chemotherapy. If I hadn't been able to tell my doctors

00:46:10 - 00:46:11

that I was in pain, I would have died.

00:46:13 - 00:46:16

Because spelling has been such a revolution in my life. One of my

00:46:16 - 00:46:19

primary areas of focus is expanding access to spelling based

00:46:19 - 00:46:23

communication skills for all non speakers and ensuring it is

00:46:23 - 00:46:26

taken seriously. Research rigorously may be widely available.

00:46:27 - 00:46:31

I also want to emphasize the importance of appropriate therapies

00:46:31 - 00:46:35

and support services for all people with autism. Making sure they are matched

00:46:35 - 00:46:38

for the needs of the individual, which can vary widely in autism.

00:46:40 - 00:46:43

Interventions like the ADA and occupational therapy were helpful

00:46:43 - 00:46:47

for me, especially in developing the motor planning and regulation skills

00:46:47 - 00:46:50

that make communication possible. We need more

00:46:51 - 00:46:54

research that looks at how different kinds of therapy work for different types of people

00:46:54 - 00:46:55

with autism and why.

00:46:57 - 00:46:59

Second important area of focus for me is safety.

00:47:01 - 00:47:04

Too many autistic individuals are dying from wandering. These are

00:47:04 - 00:47:07

almost always preventable deaths, and we still do not fully

00:47:07 - 00:47:10

acknowledge the scale of the problem. I support the

00:47:11 - 00:47:14

development of alert systems. But I also believe pneumasco

00:47:14 - 00:47:18

further upstream to prevent these tragedies altogether and discard awareness

00:47:18 - 00:47:19

of the problem through active surveillance.

00:47:21 - 00:47:23

I am deeply interested in medical research.

00:47:25 - 00:47:28

Many of the medical problems I experienced would dismiss or incorrectly

00:47:28 - 00:47:31

attribute it to autism. I had frequent stomach pain

00:47:32 - 00:47:34

that got a lot better with diet and special treatments.

00:47:35 - 00:47:38

A lot of people with autism experience unnecessary pain and

00:47:38 - 00:47:41

discomfort. And doctors dismiss their problems saying that's just absent.

00:47:43 - 00:47:46

Autism should not be used to overshadow or minimize real medical conditions

00:47:46 - 00:47:49

that require proper diagnosis and treat.

00:47:50 - 00:47:53

Finally, I want to address something direct. We cannot continue denying

00:47:54 - 00:47:56

that autism ranks have been increased to a sad level.

00:47:57 - 00:48:00

Autism is a tsunami, and it represents a growing public health

00:48:01 - 00:48:03

challenge that demands urgent honesty. And action.

00:48:04 - 00:48:07

We need to figure out the causes and stop the tsunam.

00:48:08 - 00:48:11

Thank you for listening. And many look forward to participating on

00:48:11 - 00:48:14

IHCC and to contributing to the good work of this great group.

00:48:18 - 00:48:18

Thank you.

00:48:20 - 00:48:21

Elena, man. A.

00:48:23 - 00:48:26

Hi, I'm Elena monarch. I'm the founder of the

00:48:26 - 00:48:30

Lyman pans treatment center. I've been working as a neuropsychologist

00:48:30 - 00:48:31

and health psychologist for 30 years.

00:48:33 - 00:48:36

For the last two decades, I've been studying and treating patients with

00:48:37 - 00:48:40

neuroimmune conditions. Such as pans and pandas.

00:48:41 - 00:48:43

Many of whom carry autism diagnoses.

00:48:45 - 00:48:48

Like regressive autism, pans and pandas involves sudden changes

00:48:49 - 00:48:52

in a child's neuropsychiatric status. With behavioral

00:48:52 - 00:48:56

regression. Extreme anxiety often in the form

00:48:56 - 00:48:58

of. Obsessions and compulsions.

00:48:59 - 00:49:01

Vocal and motor ticks and sensory problems.

00:49:03 - 00:49:06

Pans and pandas can easily be missed diagnosed as a psychiatric

00:49:06 - 00:49:10

condition. But in reality, the child progression is due to

00:49:10 - 00:49:13

being. Overburdened with infectious

00:49:14 - 00:49:17

and non infectious sources of inflammation. In conjunction

00:49:17 - 00:49:20

with a leak in their protective blood brain barriers.

00:49:21 - 00:49:24

Allowing immune responses to reach the brain. Despite

00:49:25 - 00:49:28

the severity of regression, when children with pans and pandas

00:49:28 - 00:49:32

are diagnosed properly and the underlying drivers

00:49:32 - 00:49:34

of their brain inflammation are treated, many can

00:49:35 - 00:49:38

recover. And oftentimes the recoveries are dramatic.

00:49:39 - 00:49:42

There's evidence that many individuals with autism show signs of

00:49:42 - 00:49:46

neuroinflammation. In fact, in one postmortem study of

00:49:46 - 00:49:49

autistic individuals of all ages, two thirds of their

00:49:49 - 00:49:52

brains showed. Significant markers of

00:49:53 - 00:49:56

neuroinflammation. These types of studies should compel

00:49:56 - 00:49:59

us not to assume, but to investigate.

00:50:00 - 00:50:02

How far back did their neuroinflammation begin?

00:50:04 - 00:50:07

Was there a trigger, an immunological or nervous system event?

00:50:09 - 00:50:10

Regressive autism is a signal.

00:50:14 - 00:50:16

A meaningful clinical signal that demands investigation.

00:50:17 - 00:50:20

When an infant or toddler suddenly regresses, we should have

00:50:21 - 00:50:24

all hands on deck. To understand why

00:50:25 - 00:50:25

this happened.

00:50:27 - 00:50:30

Reading through the public comments for our committee meeting today, it was clear that

00:50:30 - 00:50:33

parents would like us to cast a wider net.

00:50:34 - 00:50:37

As we look into what predisposes triggers

00:50:37 - 00:50:41

and exacerbates profound autism and regressive autism.

00:50:42 - 00:50:45

In line with the public comments, I would like to see a paradigm shift in how we

00:50:45 - 00:50:49

conceptualize regressive and profound autism. The diagnosis

00:50:49 - 00:50:52

should not explain anything away. For example

00:50:53 - 00:50:57

early and periodic screenings of children with autism should take

00:50:57 - 00:51:01

pain behaviors very seriously. Pain behaviors such

00:51:01 - 00:51:04

as crying and self harm do not come along with

00:51:04 - 00:51:07

autism. Expressions of pain are physiological clues.

00:51:08 - 00:51:11

And cries for health. It has been my clinical experience that

00:51:11 - 00:51:15

investigating pain behaviors and understanding sources of

00:51:15 - 00:51:18

neuroinflammation. Leads to surprising

00:51:18 - 00:51:21

answers, solutions and decreased suffering.

00:51:26 - 00:51:26

Thank you.

00:51:28 - 00:51:29

Elizabeth Mumper.

00:51:41 - 00:51:44

I am a board certified pediatrician with 45 years

00:51:44 - 00:51:48

of experience. That includes five years as medical

00:51:48 - 00:51:50

director of the autism research

00:51:50 - 00:51:53

institute. And many years as both a

00:51:53 - 00:51:57

medical academy of pediatrics and special needs faculty

00:51:58 - 00:52:01

and board member. I have spent the last 25 years

00:52:01 - 00:52:04

of my career treating children with

00:52:05 - 00:52:07

autism and complex chronic

00:52:07 - 00:52:10

illness. My priorities include

00:52:11 - 00:52:14

a recognition that we actually see autisms

00:52:15 - 00:52:18

with an S. So I want to recognize that we

00:52:19 - 00:52:22

need to support and nurture the spellers

00:52:22 - 00:52:25

like Kate and Elizabeth, as well as taking care of

00:52:26 - 00:52:28

the people that have postbound autism.

00:52:30 - 00:52:33

Second priority is to emphasize that people

00:52:34 - 00:52:36

with autism often have significant medical

00:52:37 - 00:52:40

problems with the gut, the immune system,

00:52:40 - 00:52:44

neuroinflammation, mitochondrial defects, metabolics

00:52:44 - 00:52:47

and detox. And we need to make this more

00:52:48 - 00:52:52

mainstream because pediatrician do not know how to

00:52:52 - 00:52:52

identify

00:52:54 - 00:52:57

the triggers, the antecedents and the mediators of these

00:52:57 - 00:53:01

problems. So my passion is for medical

00:53:01 - 00:53:04

education. And through this committee, I hope that we can

00:53:04 - 00:53:07

find ways for us to reach

00:53:08 - 00:53:11

the pediatricians that are going to be at the front line

00:53:12 - 00:53:14

and to help them screen for and identify

00:53:16 - 00:53:19

the medical problems as opposed to just screening for

00:53:19 - 00:53:22

autism and then referring for behavioral therapies.

00:53:23 - 00:53:23

Thank you.

00:53:29 - 00:53:29

Bill Ol. Am.

00:53:35 - 00:53:38

Ander Mary. Thank you. It's a pleasure to join this committee

00:53:39 - 00:53:41

and thank you for the opportunity to be of service.

00:53:53 - 00:53:57

Thank you. First of all, thank you for the opportunity to be here. Thank you

00:53:57 - 00:53:58

for the opportunity to serve with this committee.

00:54:00 - 00:54:04

I've had a 30 year career in healthcare and technology as both an entrepreneur

00:54:04 - 00:54:05

and an investor.

00:54:07 - 00:54:10

More importantly, I am the father of three boys. Two of whom

00:54:10 - 00:54:13

are non speaking and have profound autism with

00:54:14 - 00:54:17

mitochondrial disease. My boys, Gareth and Corlin are now

00:54:17 - 00:54:20

21 and 19. And have benefited greatly for medical treatment

00:54:21 - 00:54:24

and ABA. And are rapidly becoming proficient with their

00:54:25 - 00:54:28

letter boards and keyboarding skills to allow them to share their voice

00:54:28 - 00:54:29

with us.

00:54:31 - 00:54:34

In our community. I've been proud to lead the TLI foundation, which has launched

00:54:34 - 00:54:37

a program called the autism knowledge gateway sharing thousands

00:54:39 - 00:54:42

of peer-reviewed journal articles to help enhance

00:54:43 - 00:54:46

the quality of information available to both physicians and

00:54:46 - 00:54:48

families for the research that is there.

00:54:50 - 00:54:53

My focus, I'm also happy to serve, by the

00:54:53 - 00:54:56

way, as the board chair for the autism community in

00:54:56 - 00:54:58

action. Just help many families over the years.

00:55:01 - 00:55:04

I'm focused in the area of profound autism. I would love to see

00:55:04 - 00:55:07

us explore better data science projects.

00:55:08 - 00:55:12

Defining the phenotypes, allowing for better differentiation between

00:55:12 - 00:55:16

subgroups and diagnostic clusters. I'd like for

00:55:16 - 00:55:19

us to engage data and trial design to collaborate

00:55:19 - 00:55:22

better with pharma to bring more solutions to the

00:55:23 - 00:55:26

families that need desperately need them. I'd also like to

00:55:26 - 00:55:29

continue to explore work that allows us to grow our

00:55:29 - 00:55:31

clinician base to improve access to care.

00:55:33 - 00:55:36

I'd also like to focus on what my family is facing now

00:55:36 - 00:55:39

as well, which is lifespan challenges for families to develop

00:55:40 - 00:55:43

solutions to improve the quality of life for

00:55:43 - 00:55:47

both the autistic adult as well as their

00:55:47 - 00:55:50

family and caregivers. I'd also like to specifically

00:55:50 - 00:55:54

thank the members of the public who submitted comments.

00:55:55 - 00:55:58

All 540 pages of those were meaningful

00:55:59 - 00:56:02

and they deserve our attention. And I'm proud to have the opportunity to serve and help

00:56:03 - 00:56:04

our community. Thank you.

00:56:06 - 00:56:06

Thank you.

00:56:08 - 00:56:09

Jennifer Fillips.

00:56:13 - 00:56:16

I would first like to express my deepest gratitude to President Trump

00:56:17 - 00:56:20

and Secretary Kennedy for being such steadfast champions for our

00:56:20 - 00:56:24

children. Thank you. My name is Jennifer Fillips

00:56:24 - 00:56:27

and I'm the founder of Make Cor Autism. And the mother

00:56:27 - 00:56:30

of a daughter profoundly affected by regressive autism.

00:56:31 - 00:56:35

On MCH stand for autism.org you can find a full video testimony

00:56:35 - 00:56:36

of that experience.

00:56:37 - 00:56:40

I would like to suggest consideration and

00:56:40 - 00:56:43

diagnostic assumption for the segment of the autism

00:56:43 - 00:56:46

population that experiences neurodevelopmental

00:56:46 - 00:56:49

regression. Described in research as a

00:56:50 - 00:56:52

documented loss of skills following a period of typical

00:56:53 - 00:56:53

development.

00:56:55 - 00:56:58

Experienced as the loss of your child as you knew them.

00:56:59 - 00:57:02

Who will require care for the rest of their life. This was our

00:57:02 - 00:57:06

daughter's experience after falling ill with a common childhood infection

00:57:06 - 00:57:09

at the age of two. This group represents

00:57:10 - 00:57:14

30 to 40% of individuals with autism and may

00:57:14 - 00:57:17

carry distinct medical profiles. With real implications

00:57:17 - 00:57:20

for prevention, diagnosis and treatment.

00:57:21 - 00:57:24

Today we are going to discuss the term profound autism.

00:57:25 - 00:57:28

It has been repeatedly shown that children who separate

00:57:28 - 00:57:31

neurodevelopmental regression are more profoundly affected

00:57:32 - 00:57:35

and have worse long term outcomes than those who do not.

00:57:37 - 00:57:41

In all my years of advocacy dimension of neurodevelopmental

00:57:41 - 00:57:44

regression has always elicited the largest and most

00:57:45 - 00:57:48

passionate responses from the community. The

00:57:48 - 00:57:51

outcry from these families who have witnessed the disappearance

00:57:52 - 00:57:54

of their children as they knew them.

00:57:56 - 00:57:57

Is absolutely heartbreaking.

00:57:58 - 00:58:00

Today I give those families a voice.

00:58:02 - 00:58:05

The autism cares act calls for investigation into causes

00:58:06 - 00:58:09

including possible environmental causes. Prevention and early

00:58:09 - 00:58:10

detection.

00:58:11 - 00:58:14

This cohort precisely because there is a distinct before

00:58:15 - 00:58:18

and after may represent one of the most actionable

00:58:19 - 00:58:22

biological research opportunities available to this committee.

00:58:24 - 00:58:27

Hear this well. We cannot continue to

00:58:27 - 00:58:31

explain away autism regression as autism

00:58:31 - 00:58:32

progression. Any longer.

00:58:40 - 00:58:40

Thank you.

00:58:42 - 00:58:44

Honey Renaissella.

00:58:48 - 00:58:51

Thank you. I am so honored to be here today. I am here as the mother of

00:58:52 - 00:58:55

25 year old twins with autism as an autism advocate

00:58:56 - 00:58:59

and is the executive director of the medical academy of pediatrics and special

00:58:59 - 00:59:02

means. I spent the last two decades in

00:59:02 - 00:59:06

advocating for this community and my sons alongside that community.

00:59:06 - 00:59:09

Have taught me that autism is not just

00:59:09 - 00:59:12

behavior. It's a complex whole body medical condition involving

00:59:12 - 00:59:16

neurological immune metabolic and systematic

00:59:16 - 00:59:19

factors. And for many can become life threatening when those needs are

00:59:19 - 00:59:22

ignored. My voice today is dedicated to three

00:59:22 - 00:59:26

areas. First we need real medical standard of care for autism

00:59:26 - 00:59:29

across the lifespan. Infancy through adulthood.

00:59:30 - 00:59:33

Every child and young adult with autism deserves a full medical review of

00:59:33 - 00:59:36

systems, not diagnostic, overshadowing. We continue to hear from

00:59:36 - 00:59:39

families who describe clear medical changes. Progressions

00:59:40 - 00:59:42

or loss of skills and they're never fully investigated.

00:59:43 - 00:59:46

And instead are met with a behavioral diagnosis. Without

00:59:47 - 00:59:50

comprehensive medical evaluation. This is fixable and we already

00:59:50 - 00:59:52

have training models that demonstrate how to do this well.

00:59:53 - 00:59:57

Comprehensive system based care that looks beyond behavior and addresses underlying medical

00:59:57 - 01:00:00

needs. Families have been left to coordinate this

01:00:00 - 01:00:02

fragmented system on their own. And that is not

01:00:03 - 01:00:06

sustainable, nor is it acceptable. My one

01:00:06 - 01:00:10

son's life threatening seizures have been completely eradicated by the keen eyes

01:00:10 - 01:00:13

of a trained physician. He is now 15 years

01:00:14 - 01:00:17

seizure free. He is a maple wish recipient. 15 years.

01:00:18 - 01:00:21

The level of training should be baseline expectation including programs like

01:00:22 - 01:00:25

MAPS foundations. Which equips clinicians like mine to

01:00:25 - 01:00:27

recognize and then address complex medical needs.

01:00:28 - 01:00:32

Second, the communication access must be treated as a civil right and

01:00:32 - 01:00:35

a safety issue. For non speaking and minimally speaking

01:00:35 - 01:00:38

individuals access to their communication method must follow

01:00:39 - 01:00:42

them everywhere. Community settings hospitals procedure school

01:00:43 - 01:00:45

emergencies and all through their adult services.

01:00:46 - 01:00:49

Without communication, there is no consent. No acute care, no

01:00:49 - 01:00:53

autonomy and no protection. Third, we need accountability for outcomes.

01:00:53 - 01:00:56

Across the lifespan. Children with autism become adults.

01:00:57 - 01:01:00

With autism. Families age and the most medically complex individuals

01:01:00 - 01:01:04

cannot continue to be left behind because systems stop paying attention.

01:01:05 - 01:01:08

This is not about starting from scratch. It's about enforcing what already

01:01:08 - 01:01:11

exists. And closing the gaps where systems, particularly for

01:01:11 - 01:01:15

adults. Are still incomplete or absent. So

01:01:15 - 01:01:18

the system can then deliver the level of care, safety and dignity

01:01:19 - 01:01:21

that individuals with autism and their families have always

01:01:22 - 01:01:22

deserved.

01:01:26 - 01:01:26

Thank you.

01:01:28 - 01:01:29

Dawn Roddakis.

01:01:32 - 01:01:35

To my fellow public and federal members and those watching by

01:01:35 - 01:01:39

video. My name is John Redakis. For the past 12 years I've

01:01:39 - 01:01:42

run the nf1 autism research foundation to identify

01:01:42 - 01:01:46

and fund potential breakthroughs. In ASD and many of

01:01:46 - 01:01:49

the countries in the world's top institutions. I'm also father

01:01:49 - 01:01:52

to one of the purest souls I've ever met. Every day inspires me

01:01:53 - 01:01:56

to be a better person and to find breakthroughs for him and the millions of other children

01:01:57 - 01:02:00

like him. I have a degree in molecular biology and spent much of my career

01:02:01 - 01:02:04

in medical venture capital. I'd like to share two priorities

01:02:04 - 01:02:06

I hope we can explore further in later meetings.

01:02:07 - 01:02:11

First, I'd like to add significant broadening of

01:02:11 - 01:02:14

NIH's biomedical research efforts in ASD beyond genetics.

01:02:15 - 01:02:18

While genetics can be very important in ASD, the vast majority of

01:02:18 - 01:02:22

individuals, some estimates as high as 80% have no identifiable

01:02:22 - 01:02:26

genetic anomaly. This despite the fact that we now have

01:02:26 - 01:02:29

over a thousand potential autism risk genes. At this point the evidence

01:02:30 - 01:02:32

is overwhelming. There's more at work than simply genetics.

01:02:33 - 01:02:36

If the vast majority of research funding, both public and private

01:02:36 - 01:02:39

means concentrated there. I would like to aspirate

01:02:40 - 01:02:43

deliberate, meaningful and measurable effort to

01:02:43 - 01:02:46

broaden NIH's research agenda into other high potential

01:02:46 - 01:02:49

domains. Such as the immune system, the

01:02:50 - 01:02:53

microbiome and mitochondrial cell metabolism. This isn't about

01:02:53 - 01:02:56

replacing genetics, but I believe that by broadening our

01:02:56 - 01:02:59

lens, we will discover breakthroughs applicable to the other 80%

01:03:00 - 01:03:03

A second priority likely falls to the purview of the FDA.

01:03:04 - 01:03:07

At present there is not a single approved treatment for the core symptoms of

01:03:07 - 01:03:11

autism. I believe part of this failure comes from how we approach clinical

01:03:11 - 01:03:13
trials. But it's fixable.

01:03:14 - 01:03:18
Conventional clinical trials work well in homogeneous populations.

01:03:19 - 01:03:22
For a poorly suited to the highly heterogeneous conditions like autism.

01:03:23 - 01:03:26
Some may say it's a failure of the treatment themselves that time and again

01:03:26 - 01:03:30
in autism clinical trials we see a familiar pattern. Where a subset of patients

01:03:31 - 01:03:34
with a strong, meaningful response to a treatment. However, because that

01:03:34 - 01:03:37
response isn't broadened up across the group, the trial fails to achieve

01:03:38 - 01:03:41
statistical significance. As a result promising treatments

01:03:42 - 01:03:46
often with favorable safety profiles never reach the patients

01:03:46 - 01:03:49
could benefit from them. I believe this will solvable. We've seen

01:03:49 - 01:03:52
the FDA address similar challenges in other heterogeneous condition

01:03:53 - 01:03:56
including cancer through more adaptive and flexible trial designs.

01:03:57 - 01:04:01
I hope that we can convene a working group with the

01:04:01 - 01:04:04
FDA to explore trial design and can better account for

01:04:04 - 01:04:07

autism heterogeneity to help bring safe and effective

01:04:07 - 01:04:10

treatments to patients who respond to them. Thank you.

01:04:15 - 01:04:18

Danielle Rosigel thank you my name is Dan

01:04:18 - 01:04:21

Rothenthal. I would like to thank Senator

01:04:22 - 01:04:25

Kennedy, Secretary Kanede for inviting me to serve in this committee. I'm

01:04:25 - 01:04:28

excited to be on the IACC and the contributor's

01:04:28 - 01:04:31

work. I'm a board certified family physician currently in private practice

01:04:32 - 01:04:35

with over 30 years of clinical experience. During my medical school

01:04:35 - 01:04:39

medical school and residency residency training, I saw only

01:04:39 - 01:04:42

a handful of patients with autism. The rate of autism diagnosis

01:04:42 - 01:04:45

included much lower than it is now and not seen was not a major focus

01:04:46 - 01:04:49

of my medical training. I now live and practice California

01:04:50 - 01:04:53

where the latest CDC data shows auto prevalence of

01:04:53 - 01:04:56

about one in 13 boys approximately 8% Underscore

01:04:57 - 01:04:59

how dramatically landscape has changed since my medical training people can

01:05:00 - 01:05:03

debate how much of the change reflects a true increase in

01:05:03 - 01:05:06

autism, changes in diagnosis or increased recognition. But

01:05:06 - 01:05:10

from a clinical public health standpoint one thing is clear no matter how

01:05:10 - 01:05:13

we look at the data there are many individual autism we need thoughtful evidence

01:05:14 - 01:05:17

based care and support. My connection autism is both professional and

01:05:17 - 01:05:20

deeply personal. Both my children were diamonds

01:05:20 - 01:05:23

autism, the first in 200. That experience

01:05:23 - 01:05:27

changed direction my career. Looking back I believe God gave me two

01:05:27 - 01:05:30

autism to lead me down this road. In the beginning we were told

01:05:31 - 01:05:34

our children might never speak. Today they speak in sentences.

01:05:34 - 01:05:38

My children are now 22 and 25 years old. My youngest is in the

01:05:38 - 01:05:41

third year of college and my oldest is graduated from high school. And is one

01:05:41 - 01:05:45

of the sweetest people you ever meet. Autism is classified as a

01:05:45 - 01:05:48

nerve developmental condition in psychiatry, but in clinical practice

01:05:48 - 01:05:52

many individual authors and have significant co-occurring medical conditions also

01:05:52 - 01:05:55

called comorbidities. These medical issues can affect sleep,

01:05:55 - 01:05:58

seizures, gastrointestinal function, metabolism, inflammation,

01:05:58 - 01:06:01

immune function behavior, communication quality of life.

01:06:02 - 01:06:05

For that reason, I believe autism care must include careful attention to the medical

01:06:05 - 01:06:08

conditions that may be present alongside the core features of autism.

01:06:09 - 01:06:12

I have seen how easily narcolepsies be missed in individuals with

01:06:12 - 01:06:16

autism in my practice of care for three children dependents

01:06:16 - 01:06:19

were initially appendicitis with administration for constipation.

01:06:20 - 01:06:23

In the emergency setting they were sent home and each lady developed a

01:06:23 - 01:06:26

recurrent appendix. One nearly died and remained hospitalized for a whole month.

01:06:28 - 01:06:30

Experience like these are reinforced to me that communication differences

01:06:31 - 01:06:35

atypical presentations and diagnostic overshadowing can have serious even

01:06:35 - 01:06:36

life threatening medical condition.

01:06:37 - 01:06:41

S. I was trained in evidence based medicines for my passion reviewing

01:06:41 - 01:06:44

synthesizing the medical literature especially through systematic reviews and meta analysis.

01:06:45 - 01:06:48

In that work we sometimes view hundreds of papers and slides of findings into

01:06:48 - 01:06:51

a single document. I've authored approximately 80 publications

01:06:52 - 01:06:54

in autism with that first one occurring in 2006.

01:06:55 - 01:06:59

Over the past 23 years I cared for about 8,000 kids with

01:06:59 - 01:07:02

autism exclaiming. I also served as president of the medical

01:07:02 - 01:07:05

academy of pediatric health and needs for about 10 years, which is an organization.

01:07:06 - 01:07:09

That focused on training physicians and other based medical evaluation and treatment

01:07:09 - 01:07:13

of children in individuals with autism and neurodevelopment disorders.

01:07:14 - 01:07:17

So my current clinical and research interests include function co-occurring

01:07:17 - 01:07:20

medical conditions. Also talked for morbidities such as

01:07:20 - 01:07:23

mitochondrial dysfunction, folic metabolism, feeble photo

01:07:23 - 01:07:26

deficiency, seizures, sleep problems, inflammation

01:07:26 - 01:07:30

gastrum problems and others. So in my practice, I've seen

01:07:30 - 01:07:33

meaningful improvements in children and families quality life in these medical

01:07:33 - 01:07:37

conditions are identified and treated. One most important things I've learned is that many

01:07:37 - 01:07:40

of these mal conditions of such autism identifiable and treatable

01:07:41 - 01:07:44

and adjusting them can meaningfully improve function quality.

01:07:45 - 01:07:48

We treat these medical problems, we often improve not only the child's daily

01:07:48 - 01:07:52

functioning but also entire family burden,

01:07:52 - 01:07:55

hope and quality life. This matters not only clinically but economically

01:07:56 - 01:07:59

published US estimates suggest that the lifetime cost of supporting individual

01:07:59 - 01:08:03

autism is approximately 1.4 million. Without intellectual disability and

01:08:03 - 01:08:06

2.4 million with intellectual disability with major cost

01:08:07 - 01:08:10

drivers including special education services and parental productivity loss.

01:08:11 - 01:08:14

If medical treatments can improve these online COVDs, then the cost

01:08:14 - 01:08:15

savings

01:08:16 - 01:08:20

and caregiver work loss and education support there could be

01:08:20 - 01:08:23

meaningful savings for families and slighties. I'm currently involved in several

01:08:24 - 01:08:25

clinical trials in

01:08:29 - 01:08:32

so my hope is that after the research and policy routine move behind behavior alone

01:08:33 - 01:08:36

and more fully adjusting their conditions affect community and autism cross lifespan.

01:08:36 - 01:08:37

Thank you.

01:08:40 - 01:08:41

Next we have

01:08:42 - 01:08:44

Tracy Slutson sorry.

01:08:46 - 01:08:47

Lots of it. Thank you.

01:08:49 - 01:08:52

Hello and good morning. My name is Blotzevich and I am the

01:08:52 - 01:08:55

proud mother of a 20 year old son with autism.

01:08:56 - 01:08:59

At the age of one. My son regressed into his state of autism.

01:09:00 - 01:09:02

Not knowing what was going on.

01:09:04 - 01:09:07

And I was told that my son would need care for the rest of his life.

01:09:08 - 01:09:10

And he would not leave lead a fully functional life.

01:09:12 - 01:09:15

I feel like I'm one of the blessed ones and I'm one of the lucky

01:09:16 - 01:09:19

families because with biomedical intervention my son was able to

01:09:21 - 01:09:24

recover and live a full life as to where he works he drives.

01:09:25 - 01:09:25

And he travels the world

01:09:27 - 01:09:30

and he is not fully disabled. But I

01:09:30 - 01:09:34

am one of the lucky ones. And with that my son gave me

01:09:34 - 01:09:37

purpose. I am the founder of the autism

01:09:37 - 01:09:40

health summit and autism health which is a 501

01:09:41 - 01:09:41

nonprofit organization.

01:09:43 - 01:09:46

Dedicated to advancing research education and access

01:09:46 - 01:09:50

to care. For individuals with autism. I

01:09:50 - 01:09:53

am a certified integrative health practitioner and air force veteran.

01:09:54 - 01:09:57

And the bestselling author of war your mom, a mother's journey

01:09:58 - 01:10:01

and healing her son with autism. I am educated in the field of

01:10:01 - 01:10:04

alternative medicine and I have spent over 17 years

01:10:05 - 01:10:08

researching treatments and therapies to address underlying

01:10:09 - 01:10:12

medical condition associated with autism and other

01:10:12 - 01:10:15
neurological conditions. Which very much benefited my

01:10:15 - 01:10:15
son.

01:10:17 - 01:10:20
A top priority for me is advocating for more comprehensive

01:10:21 - 01:10:25
model of care. One that acknowledges medical needs

01:10:25 - 01:10:29
for individuals with autism and ensures families have

01:10:29 - 01:10:32
access to appropriate care and advanced treatments

01:10:33 - 01:10:35
and therapies covered by insurance.

01:10:37 - 01:10:41
Lastly I truly feel that we must take a

01:10:41 - 01:10:44
deeper look into the increasing surveillance

01:10:44 - 01:10:47
of autism, particularly cases associated

01:10:48 - 01:10:49
with regression.

01:10:51 - 01:10:54
Families including my own are asking important question regarding

01:10:54 - 01:10:58
environmental factors that may be affecting early childhood

01:10:58 - 01:11:01
development. If we are truly committed to progress

01:11:02 - 01:11:05

we must be willing to explore these areas with

01:11:05 - 01:11:09

scientific rigor transparency and an open

01:11:09 - 01:11:12

mind. Focus not only on support but

01:11:12 - 01:11:15

also on understanding and prevention.

01:11:16 - 01:11:19

I am honored to be a part of this committee. I am grateful

01:11:19 - 01:11:23

to secretary kennedy for all his hard work and I look forward to

01:11:23 - 01:11:25

working together with all of you to create meaningful

01:11:26 - 01:11:27

change. Thank you.

01:11:31 - 01:11:34

Katie Sweeney. Good morning and thank you

01:11:35 - 01:11:38

to secretary kennedy for the honor to serve. My name is

01:11:38 - 01:11:42

CD Sweeney the medical academy of

01:11:42 - 01:11:45

pediatrics and special needs. I work with the autism

01:11:45 - 01:11:48

action network. And on my board member of Cohab, a

01:11:48 - 01:11:51

theater group serving a developmentally disabled population.

01:11:52 - 01:11:55

But I am also a proud mother of my son

01:11:56 - 01:11:58

Dustin, 28. Has profound autism.

01:11:59 - 01:12:02

Stage three Lyme disease. Is a non speaker speller.

01:12:03 - 01:12:07

And will require 247 care for the rest of his life.

01:12:08 - 01:12:09

For 27 years.

01:12:10 - 01:12:14

My son was presumed to be cognitively impaired. He was

01:12:14 - 01:12:17

not. He was unreachable. He spent 18

01:12:17 - 01:12:21

years in aba. Speech therapy special

01:12:21 - 01:12:24

ed. And nothing gave him a reliable way to communicate.

01:12:26 - 01:12:29

As dustin has since told us the time before

01:12:30 - 01:12:33

talking was hell. I was treated like I was cognitively

01:12:33 - 01:12:35

impaired all my life.

01:12:37 - 01:12:39

Through spelling Dustin found a way to express himself.

01:12:40 - 01:12:43

What emerged was not impairment. But intelligence.

01:12:44 - 01:12:47

The mind was always there. It was trapped. By

01:12:48 - 01:12:51

apraxia, a brain body disconnect that prevents the body from doing

01:12:51 - 01:12:54

what the mind intends. So let me be very clear

01:12:56 - 01:12:59

he did not have 27 years of cognitive and.

01:13:01 - 01:13:04

Yet 27 years of system failure. That brings

01:13:04 - 01:13:08

me to my three priorities. First we must

01:13:08 - 01:13:11

formally and recognize and prioritize those with profound autism.

01:13:12 - 01:13:15

And apply a systems based root cause approach to diagnosis

01:13:16 - 01:13:19

and treatment. The autism diagnosis is based on observed

01:13:19 - 01:13:22

behaviors, not biology. And it has become so broad

01:13:23 - 01:13:26

it groups completely different realities. Yet those most severely

01:13:27 - 01:13:30

effective are still approached primarily through behavior. This

01:13:30 - 01:13:34

is not just incomplete. It is harmful. For many

01:13:34 - 01:13:37

this is a complex whole body medical condition involving neural inflammation.

01:13:38 - 01:13:41

Immune dysfunction metabolic and mitochondrial disorders. And

01:13:41 - 01:13:45

gastrointestinal pathologies seizures and more.

01:13:46 - 01:13:49

If we define autism by behavior alone. We will miss what is driving

01:13:50 - 01:13:53

that and continue managing symptoms. Instead of addressing

01:13:54 - 01:13:57

root cause. Second, we must enforce communication

01:13:57 - 01:14:01

rights communication is a human right yet for non

01:14:01 - 01:14:04

speakers access to effective communication methods like

01:14:04 - 01:14:08

spelling and typing. Is often denied. Not by lack of

01:14:09 - 01:14:12

success, but by institutional resistance. When you

01:14:12 - 01:14:16

deny someone a means to communicate, you are not just limiting

01:14:16 - 01:14:19

expression. You are erasing identity. Autonomy

01:14:20 - 01:14:23

and potential. And third, we must confront the reality of

01:14:23 - 01:14:27

adulthood. With autism much attention and

01:14:27 - 01:14:29

emphasis is on kids. As that is when it typically presents.

01:14:31 - 01:14:33

I say often they are kids for 20 years

01:14:34 - 01:14:38

and adults for 60 plus more. That is what keeps us

01:14:38 - 01:14:41

parents up at night who is going to take care of them, support their

01:14:42 - 01:14:45

needs, safeguard their health. Protect them from abuse.

01:14:46 - 01:14:49

When we have left this earthly sphere. Individuals like my son

01:14:50 - 01:14:53

who cannot advocate for themselves in traditional ways are among the most

01:14:53 - 01:14:55

vulnerable members of our society.

01:14:56 - 01:14:59

Without meaningful change, vulnerability becomes

01:14:59 - 01:14:59

inevitable.

01:15:01 - 01:15:05

This is not abstract. This is not rare. These are

01:15:05 - 01:15:08

urgent real world issues that demand alignment between

01:15:09 - 01:15:11

policy, research and lived experience

01:15:13 - 01:15:16

and a willingness and openness to rethink the

01:15:16 - 01:15:18

systems we have built. Thank you.

01:15:22 - 01:15:23

Chinir Taylor.

01:15:25 - 01:15:29

Hello, I am the mother of a 24 year old young man.

01:15:29 - 01:15:31

Who was diagnosed with autism

01:15:34 - 01:15:37

at age. Three who regressed

01:15:37 - 01:15:39

shortly after his 18 month old child.

01:15:45 - 01:15:47

We threw ourselves in teams recovery.

01:15:48 - 01:15:51

Quickly. And his is a success story.

01:15:53 - 01:15:56

We addressed many things that we're going to be talking about today. His

01:15:56 - 01:15:59

inflammation, his gut issues. And we saw

01:15:59 - 01:16:03

dramatic changes in him even within the first year. So I say we got him

01:16:03 - 01:16:05

halfway back. So I'm very excited for.

01:16:06 - 01:16:10

This committee to start looking at the amazing successes like

01:16:10 - 01:16:13

spelling like medical inventions that we have with kids. I'm also

01:16:14 - 01:16:16

concerned with. Maternal health.

01:16:18 - 01:16:18

We are.

01:16:21 - 01:16:24

Unfortunately largely a group of women who have recovered

01:16:25 - 01:16:28

a lot of kids at a lot of expense both

01:16:28 - 01:16:29

financially.

01:16:30 - 01:16:33

And this includes, you know, autism moms and dads.

01:16:35 - 01:16:38

And grandparents are my parents and my husband parent.

01:16:40 - 01:16:42

Carry considerable burdens. Financial burden for his

01:16:43 - 01:16:46

recovery. And this needs to end. This is

01:16:46 - 01:16:49

something that parents need to have the resources. To take on these challenges.

01:16:52 - 01:16:54

In my own case, we have mothers who are

01:16:56 - 01:16:59

children are just coming of age. What we've already lost a lot of

01:16:59 - 01:17:03

mothers to hard tax drugs and cancer.

01:17:03 - 01:17:06

S. So and I am in that group that I

01:17:06 - 01:17:10

just took two years ago. And so I asked the community of indulgence. My

01:17:10 - 01:17:13

basal ganglia was damaged in the process. And so I

01:17:14 - 01:17:17

cry a lot. Very embarrassing. And if I lose control of

01:17:17 - 01:17:20

myself, please ignore it and I will try to bring that in as soon as possible.

01:17:22 - 01:17:25

But there's a lot of sad things I'm talking about. And so I hope that I

01:17:25 - 01:17:29

speak the voice of the mothers who have been.

01:17:30 - 01:17:33

Doing everything possible to recover their kids. Both the

01:17:33 - 01:17:35

tragedies and success stories.

01:17:37 - 01:17:39

And the idea that we're here, we, we went through.

01:17:41 - 01:17:41

His injury.

01:17:43 - 01:17:46

Reverend clicked me and realizing how we lost a house, how expensive it

01:17:46 - 01:17:50

is, how there isn't any help, how you have to fight with the doctors to get them to understand

01:17:50 - 01:17:54

gut issues. And this is in 2004. By the end of the

01:17:54 - 01:17:57

year, I met John Gilmore online. And he

01:17:57 - 01:18:00

said, hey, we're going to do a passing parallel disposal. Come on. Let's get

01:18:01 - 01:18:03

going. And we passed the

01:18:04 - 01:18:07

2006 commenting onto the method created this committee.

01:18:08 - 01:18:11

And then watched for 10 years to this committee to ignore the

01:18:11 - 01:18:15

things that we created to do. So I'm excited to

01:18:15 - 01:18:15

be here.

01:18:17 - 01:18:19

I am excited to be with some of the people that have been

01:18:21 - 01:18:23

some of the doctors who have been so instrumental in helping us recover our

01:18:24 - 01:18:27

son. The advocates who have, you know, broadened horizons

01:18:28 - 01:18:31

and sellers who are who teach me. So

01:18:32 - 01:18:34

I collect advanced speaks on my friends and say, we hope that

01:18:36 - 01:18:40

the government members of this committee will join us with the passion that we've

01:18:40 - 01:18:43

had. To serve these kids who are now

01:18:43 - 01:18:45

adults. And right now.

01:18:48 - 01:18:51

In 1978, I guess Brenny Roman

01:18:51 - 01:18:54

published the first vitamin B study

01:18:55 - 01:18:58

on vitamin B for autism treatment. And I say

01:18:58 - 01:19:02

three, he published their first diet study on a fine

01:19:02 - 01:19:04

gold diet improvement, autism. And today.

01:19:06 - 01:19:09

The American Academy of Pediatrics has its clinical

01:19:10 - 01:19:13

guidance for autism treatment. And pediatric care that

01:19:13 - 01:19:16

reads many interventions, including many nutritional interventions

01:19:17 - 01:19:20

do not have evidence to support their use at this time.

01:19:21 - 01:19:24

The idea that we knew something when I was nine years old.

01:19:26 - 01:19:29

The pediatricians have not been given that tool. It doesn't

01:19:29 - 01:19:32

serve the patients and it doesn't serve on a pediatrician who want to help the

01:19:32 - 01:19:36

children. And this committee has to interrupt

01:19:36 - 01:19:39

you. Could you wrap up? I'm done. Okay. Thank you.

01:19:43 - 01:19:45

Next we have lisa meter light.

01:19:48 - 01:19:48

Good morning.

01:19:50 - 01:19:53

My name is lisa weeder light. I want to take this opportunity to share my appreciation

01:19:53 - 01:19:57

for this extraordinary opportunity to make measurable, significant and positive change

01:19:57 - 01:19:59

for the autism community. It means more than you can know. Thank you.

01:20:01 - 01:20:04

I'm a single parent of a 25 year old young man who have rushed into autism

01:20:04 - 01:20:07

at 13 months. He has so many co occurring conditions

01:20:08 - 01:20:11

that his last individualized educational plan had multiple disabilities

01:20:12 - 01:20:15

as his primary disability. In addition, he suffers from inflammatory

01:20:16 - 01:20:19

bowel disease. When I was studying public policy in graduate

01:20:19 - 01:20:22

school, I could never have imagined how useful this education and background

01:20:22 - 01:20:26

could be. As my son's proud mother, I have been

01:20:26 - 01:20:28

advocating on behalf of the autism community for translational

01:20:29 - 01:20:32

research, appropriate public policy, innovative and necessary

01:20:32 - 01:20:35

programs and greater accountability for over 20 years.

01:20:36 - 01:20:40

This would include a focus on those for people with autism, their caregivers

01:20:40 - 01:20:44

and service providers. I run an organization that is focused on

01:20:44 - 01:20:46

creating integrated community living opportunities in which people

01:20:47 - 01:20:50

with developmental disabilities, veterans and older adults will have access

01:20:51 - 01:20:54

to appropriate housing solutions and supportive amenities that will allow

01:20:55 - 01:20:58

them to thrive. The creation and support of housing for those with

01:20:58 - 01:21:01

autism and urgent need. In fact, it is nothing less than

01:21:01 - 01:21:05

homelessness prevention. Already research is showing that people

01:21:05 - 01:21:08

with autism comprise a significant percentage of the homeless

01:21:08 - 01:21:10

population. This is a crisis situation

01:21:11 - 01:21:14

and must be actively addressed as soon as possible across the nation.

01:21:15 - 01:21:18

In my prior work, I help to co found the autism safety

01:21:18 - 01:21:21

coalition. Now I am involved in the Maryland autism

01:21:21 - 01:21:24

coalition, a public private partnership, which also focuses on safety.

01:21:25 - 01:21:28

As someone who worked diligently to help pass cabinet avante's law, which

01:21:28 - 01:21:31

provides federal funds for preventing and addressing wandering in children with

01:21:32 - 01:21:35

developmental disabilities, I know that is critical and we must continue to

01:21:35 - 01:21:39

address public safety for our community. Finally, as

01:21:39 - 01:21:42

a Marylander who is extremely concerned about the implementation of medic fee

01:21:42 - 01:21:46

waivers in our state, when I am told actually our state

01:21:46 - 01:21:49

is not alone in waiver implementations and destabilizing

01:21:49 - 01:21:53

ways in the United States, I'm recognizing a contrast between the

01:21:53 - 01:21:56

rights conferred by the Americans with Disabilities act. And the Olmstead

01:21:56 - 01:21:59

decision, which must be addressed. People with developmental disabilities

01:22:00 - 01:22:03

and their family caregivers are losing the support they desperately need to stay

01:22:04 - 01:22:07

safe. Fully access the community and maintain financial

01:22:07 - 01:22:10

stability. So we must identify what is causing these issues to occur

01:22:11 - 01:22:14

and persist and to solve the problems. I'm looking forward to participating

01:22:14 - 01:22:17

actively in the IECC to make a significant difference in the lives of people

01:22:18 - 01:22:20

with autism and those who love them. Thank you.

01:22:25 - 01:22:26

Walter Zaharni.

01:22:28 - 01:22:31

Good morning. I'm Walter Saharodni. I'm a

01:22:31 - 01:22:34

psychologist, the clinical psychologist that directors New Jersey

01:22:35 - 01:22:35

medical school.

01:22:37 - 01:22:41

I provided care and support to families

01:22:41 - 01:22:45

with autistic children and children with other complex developmental needs

01:22:45 - 01:22:49

for over 30 years. And for 25 years, I've been

01:22:49 - 01:22:52

the director of the New Jersey Autism Study, which

01:22:53 - 01:22:56

is the New Jersey iteration of the

01:22:56 - 01:22:58

CDC atom network.

01:22:59 - 01:23:02

I have three priorities that I bring to this important committee.

01:23:04 - 01:23:06

One, identification and addressing of the

01:23:07 - 01:23:10

drivers of the three decade long surge

01:23:10 - 01:23:12

in autism prevalence that we've observed.

01:23:15 - 01:23:18

To promotion of early detection and diagnosis of children

01:23:18 - 01:23:19

with autism.

01:23:20 - 01:23:23

And three, establishing a process for providing

01:23:25 - 01:23:26

life's lifespan medical needs.

01:23:28 - 01:23:32

For the population disabled by autism. Thank you very

01:23:32 - 01:23:32

much.

01:23:34 - 01:23:38

Thank you. And that concludes the introductions of our public

01:23:38 - 01:23:41

members. I want to thank you so much. For sharing

01:23:41 - 01:23:45

information about the experience that you bring to the committee

01:23:45 - 01:23:48

as well as your knowledge and clear commitment and passion.

01:23:49 - 01:23:50

To Megan.

01:23:52 - 01:23:56

To Jennifer for a really inspiring story. Now

01:23:56 - 01:23:58

we'll go through the federal community of the federal

01:23:58 - 01:24:01

members. If you can say your name, your title, your

01:24:02 - 01:24:05

agency, a brief description of how your agency

01:24:06 - 01:24:09

mission overlapped both autism relevant activities. And if you'd like to bring

01:24:10 - 01:24:12

any personal experience to the table, you're welcome to go

01:24:13 - 01:24:15

again. I ask you to keep your comments to one to two minutes.

01:24:17 - 01:24:19

And we'll start with Jennifer Beat.

01:24:22 - 01:24:25

Hi everybody. My name is Jennifer Haight. I am representing

01:24:26 - 01:24:29

a administration for Children and Families. And I am

01:24:30 - 01:24:33

the deputy associate commissioner over the Children's Bureau.

01:24:34 - 01:24:37

Which is one of many operating

01:24:37 - 01:24:41

divisions at ACF that support and

01:24:41 - 01:24:44

work with Child and Families serving systems. Those

01:24:44 - 01:24:47

systems receive federal funding and are subject to federal

01:24:48 - 01:24:50

regulation, monitoring and oversight.

01:24:52 - 01:24:55

We at ACF are very intentional about building knowledge about specific

01:24:56 - 01:24:59

and vulnerable subpopulations such as people with autism.

01:25:01 - 01:25:02

So that we can better support

01:25:04 - 01:25:07

their health, their safety and their wellbeing. Because they

01:25:07 - 01:25:10

have every opportunity to thrive in ways that they need

01:25:11 - 01:25:14

both at the meeting have demonstrated. Are possible

01:25:15 - 01:25:17

and have demonstrated that there is still a lot

01:25:17 - 01:25:20

of. I'm very grateful to be part of this group

01:25:20 - 01:25:23

and it is working meeting so that I can build my knowledge.

01:25:25 - 01:25:28

And focus on the kinds of actions that will support

01:25:29 - 01:25:33

the kind of improvement that are necessary and

01:25:33 - 01:25:33

can be

01:25:35 - 01:25:39

actualized through the work at ACS. So thank

01:25:39 - 01:25:39

you.

01:25:41 - 01:25:42

Thank you Rebecca. Hine.

01:25:47 - 01:25:48

I'm Rebecca Hines. I'm here.

01:25:49 - 01:25:53

Representing the administration on community living. I am the

01:25:53 - 01:25:55

commissioner of the administration on disabilities.

01:25:57 - 01:26:01

At the administration on community living our work revolves around

01:26:01 - 01:26:05

providing opportunities and services for

01:26:05 - 01:26:08

adults. With IDD.

01:26:10 - 01:26:13

And specifically, I think our largest and my colleague, Jennifer can

01:26:13 - 01:26:17

correct me if I'm wrong, but is the focus on

01:26:17 - 01:26:20

independent living. So we

01:26:21 - 01:26:22

work across the country

01:26:24 - 01:26:27

helping to ensure that people have access to services

01:26:27 - 01:26:28

that provide the most.

01:26:30 - 01:26:32

Independence. Possible.

01:26:35 - 01:26:38

And my background is actually as

01:26:39 - 01:26:42

a college professor in the field of special education. So it's

01:26:43 - 01:26:45

been interesting to transition into a role.

01:26:48 - 01:26:48

Where.

01:26:49 - 01:26:53

The focus is on making sure that people have the

01:26:53 - 01:26:56

opportunity to go from school.

01:26:57 - 01:27:01

To successful independent living. But as someone who has lived

01:27:01 - 01:27:02

in this world

01:27:03 - 01:27:05

for 40 years on the disability side.

01:27:08 - 01:27:09

I very clearly understand the challenges.

01:27:11 - 01:27:14

And my earliest experiences in education were working.

01:27:15 - 01:27:18

With students with significant support needs.

01:27:19 - 01:27:20

Many of whom.

01:27:21 - 01:27:24

Were on the autism spectrum. With severe

01:27:25 - 01:27:26

and profound needs.

01:27:29 - 01:27:31

I share that because I think that.

01:27:35 - 01:27:37

All of us bring some level of personal experience.

01:27:39 - 01:27:41

Or predisposition towards topics that we'll hear about.

01:27:45 - 01:27:45

From many lenses.

01:27:47 - 01:27:48

Now. I've seen.

01:27:50 - 01:27:50

Opportunities.

01:27:52 - 01:27:54

But I deeply recognize the barriers because there are people

01:27:55 - 01:27:57

with a level of need that the general public.

01:27:59 - 01:28:02

Cannot recognize unless they have been immersed in a setting that included

01:28:02 - 01:28:06

those individuals. So I thank you too.

01:28:07 - 01:28:10

Our members who are here representing families and to

01:28:10 - 01:28:11

my colleagues at the federal level.

01:28:14 - 01:28:16

Thank you, Christina Chapone.

01:28:18 - 01:28:22

Good morning everyone. I want to thank President Trump and Secretary

01:28:22 - 01:28:25

Kennedy on their autism initiative and priorities. My name is

01:28:25 - 01:28:29

Christina Chacone. I'm a senior advisor over at the

01:28:29 - 01:28:31

agency for healthcare research and quality, also known as

01:28:32 - 01:28:35

AHRQ. ARC's mission is to enhance the quality, appropriateness

01:28:36 - 01:28:39

and effectiveness of health services and access to such services.

01:28:40 - 01:28:43

Through the establishment of a broad base of scientific research

01:28:44 - 01:28:47

and through the promotion of improvements in clinical and health system and

01:28:47 - 01:28:50

practices. Including the prevention of diseases

01:28:51 - 01:28:54

and other health conditions. Prior to joining the federal

01:28:54 - 01:28:57

service, I worked in the healthcare sector for just under four years.

01:28:58 - 01:29:02

I have served on many volunteer organizations with individuals

01:29:02 - 01:29:06

with autism, as well as having family members

01:29:06 - 01:29:09

with autism. I look forward to being a part of your committee

01:29:10 - 01:29:12

and all the work that we will be together. Thank you.

01:29:16 - 01:29:17

Matthew Maynard.

01:29:22 - 01:29:26

Good morning. I'm Matt Manner. I'm with the Center of the Disease Control

01:29:26 - 01:29:28

and Prevention and Barry. We've seen addition to this group.

01:29:29 - 01:29:33

I'm the chief of the Child Development and Disability branch at the national center

01:29:33 - 01:29:35

and Breath Effects and Developmental Disabilities, which is where

01:29:36 - 01:29:38

CDC's autism activities are located.

01:29:39 - 01:29:41

CDC has three public health autism programs.

01:29:42 - 01:29:46

The autism and developmental disabilities monitoring network or atom

01:29:46 - 01:29:49

network generates population-based data and occupant prevalence

01:29:50 - 01:29:53

characteristics and finally identification in communities around the country.

01:29:54 - 01:29:58

There's also the study to explore early development or

01:29:58 - 01:30:01

seed, which began as a research study of young children with

01:30:01 - 01:30:05

autism, other developmental disabilities and typically developing

01:30:05 - 01:30:08

children largely to look at risk factors for autism.

01:30:09 - 01:30:12

Those participants are now followed as adolescents and young adults

01:30:12 - 01:30:14

in order to understand what happens when they grow up.

01:30:16 - 01:30:19

What they need and what can be done. The third program

01:30:19 - 01:30:22

is learning signs up early, which aims to improve

01:30:23 - 01:30:26

early identification developmental rates and

01:30:26 - 01:30:29

disabilities, including autism by facilitating

01:30:29 - 01:30:32

developmental monitoring and screening subprogram and the families conduct

01:30:33 - 01:30:35

the services and support they need as soon as possible.

01:30:36 - 01:30:39

I appreciate the opportunity to participate in this

01:30:39 - 01:30:42

committee. My first experience with autism was

01:30:43 - 01:30:46

25 years ago when I was in college. I worked with Children of

01:30:46 - 01:30:49

Autism. Often they had very, very

01:30:50 - 01:30:53

challenging behaviors and Mar language and working with their

01:30:53 - 01:30:57

families and their homes at schools in the

01:30:57 - 01:31:00

community has had an enormous influence

01:31:00 - 01:31:03

on natively. And so

01:31:04 - 01:31:07

I look forward to meeting everybody and working together. Thank you.

01:31:10 - 01:31:11

Caprice. Map.

01:31:13 - 01:31:16

Good morning. Thank you so much for having me. My name is Caprice Napp. I'm

01:31:16 - 01:31:20

the principal deputy at CNCS, which is the Center for Medicaid and CHIP

01:31:20 - 01:31:23

services. I'm here with my colleagues, Kirsten

01:31:23 - 01:31:26

Jensen and Charlotte Mango, and we appreciate this opportunity. Thank

01:31:27 - 01:31:30

you also to the secretary, to administrator Oz and

01:31:30 - 01:31:33

Commissioner Hines for including us in this important

01:31:33 - 01:31:35

conversation. As you all know, we represent

01:31:36 - 01:31:39

70 million Americans who are enrolled in either Medicaid or CHIP.

01:31:41 - 01:31:44

And our center covers everything from eligibility to

01:31:44 - 01:31:47

benefits financing to manage care,

01:31:47 - 01:31:49

etc. And I'm sure you all have experience

01:31:51 - 01:31:53

with your state and how your state has interacted with us.

01:31:55 - 01:31:58

We also administer 1915

01:31:59 - 01:32:03

waivers, 115 demonstrations. And we oversee state

01:32:03 - 01:32:06

plan amendments for states. In a prior role, I was the

01:32:06 - 01:32:09

Medicaid director in North Dakota. Where we oversaw

01:32:10 - 01:32:11

autism waiver services.

01:32:13 - 01:32:16

And we had a state only funded for autism

01:32:17 - 01:32:20

for services that were not covered by Medicaid. We also had an

01:32:20 - 01:32:23

autism registry and we worked

01:32:24 - 01:32:27

to start a 1915 waiver to provide even

01:32:27 - 01:32:31

broader services. We appreciate the opportunity to

01:32:31 - 01:32:34

come today and learn from you all. And thank you so

01:32:34 - 01:32:35

much, Diana, for including us.

01:32:37 - 01:32:39

Thank you, Nicole Williams.

01:32:41 - 01:32:45

Hi, my name is Nicole Williams. I'm representing the Department of War

01:32:46 - 01:32:49

through our autism research program, which is one of

01:32:50 - 01:32:53

34 now for FY 26.

01:32:54 - 01:32:57

Peer reviewed programs. That are directed by

01:32:58 - 01:33:01

Congress. So we started back in 2007.

01:33:02 - 01:33:05

So we've been around for quite a while. As I

01:33:05 - 01:33:08

mentioned, we find peer reviewed autism

01:33:08 - 01:33:12

research. As of late, our focus has really been

01:33:12 - 01:33:12

on

01:33:14 - 01:33:17

research director that access to services across the

01:33:17 - 01:33:19

lifespan, transition to

01:33:19 - 01:33:21

adulthood, co-occurring

01:33:21 - 01:33:25

conditions, and then more recently kind of

01:33:25 - 01:33:28

focusing efforts on mental health issues

01:33:28 - 01:33:31

and the autistic community, as well as providing

01:33:32 - 01:33:36

support, I should say research

01:33:36 - 01:33:37

that supports quality of life.

01:33:39 - 01:33:43

For current and former military members, as well

01:33:43 - 01:33:43

as

01:33:44 - 01:33:47

adults, perhaps

01:33:47 - 01:33:49

physical, mental and other quality

01:33:50 - 01:33:53

issues. So I'm happy to be back again if you've been a great learning

01:33:54 - 01:33:56

experience and I look forward to working with everyone.

01:33:58 - 01:34:00

Thank you. Deidra Essay.

01:34:06 - 01:34:09

Good morning everyone. My name is Deirdre and I'm a faculty advisor

01:34:10 - 01:34:12

for office of justice programs of the department of justice.

01:34:14 - 01:34:17

And then roll I oversee a number of grant programs that

01:34:17 - 01:34:20

include the collaborative crisis response

01:34:22 - 01:34:25

intervention training program with prioritize education and de-escalation

01:34:26 - 01:34:29

for law enforcement officers responding to people with intellectual and developmental

01:34:29 - 01:34:29

disabilities.

01:34:31 - 01:34:34

And other law enforcement responses to people with behavioral health

01:34:34 - 01:34:38

challenges. My office also oversees the

01:34:38 - 01:34:41

Community Bio grants. Prior to joining the

01:34:42 - 01:34:43

office of justice programs, I work with

01:34:45 - 01:34:48

mobile crisis respondents skill building must do

01:34:48 - 01:34:50

what in application substances.

01:34:56 - 01:34:57

Thank you, Scott Robertson.

01:35:02 - 01:35:05

Good morning. My name is Dr. Scott Michael Robertson. I am an

01:35:05 - 01:35:08

autistic person with other significant disabilities.

01:35:09 - 01:35:12

And I am a senior policy advisor in the US Department of Labor

01:35:13 - 01:35:16

Office of Disability Employment Policy or

01:35:16 - 01:35:19

ODEP ODEP for short. Thank

01:35:19 - 01:35:22

you, NIH leadership. Coordinating this

01:35:22 - 01:35:25

IACC meeting and also to our federal partners.

01:35:26 - 01:35:30

ODIP's agency mission is to develop and influence

01:35:30 - 01:35:33

policies and practices that increase the number and quality of employment

01:35:34 - 01:35:36

opportunities for people with disabilities, all disabilities.

01:35:38 - 01:35:40

Including people on the options spectrum like myself and many others.

01:35:42 - 01:35:45

We envision a world in which people with disabilities have unlimited

01:35:46 - 01:35:47

employment opportunities.

01:35:48 - 01:35:52

ODEP runs our research support services for employment of young adults

01:35:52 - 01:35:56

on the autism spectrum project or the RES

01:35:56 - 01:35:59

project for short. In collaboration with our

01:35:59 - 01:36:01

contractor, our federal contractor, MAP Monica.

01:36:02 - 01:36:06

Funded since FY 2021, this \$2.9

01:36:06 - 01:36:09

million multi-year project for autistic people

01:36:09 - 01:36:12

aged 16 to 28 originally began after

01:36:13 - 01:36:16

requests by Senate and House Appropriations. The

01:36:17 - 01:36:20

RES project's ongoing survey of youth and young adults on the

01:36:20 - 01:36:24

office of spectrum. Integrates an emphasis on ensuring participation

01:36:24 - 01:36:27

by very people on the option spectrum. It includes

01:36:28 - 01:36:31

autistic people who experience complex communication and

01:36:31 - 01:36:33

verbal language challenges. And secondary condition.

01:36:36 - 01:36:39

S. This job accommodation network or DAN for short, one of our

01:36:39 - 01:36:42

technical assistance centers. Also has an extensive web page on

01:36:43 - 01:36:46

workplace supports and accommodation for people on the office spectrum.

01:36:47 - 01:36:50

Named online a to Z library. I look forward to continuing to

01:36:50 - 01:36:54

collaborate and partner with all of you all. And I'm

01:36:54 - 01:36:55

very excited to be here

01:36:57 - 01:36:57

and we so enjoy

01:36:59 - 01:37:02

prostate agency work and the work of all you of the wonderful

01:37:03 - 01:37:05

public members who are here as well and the staff.

01:37:07 - 01:37:10

And I'm so glad to contribute and look forward to the rest of

01:37:10 - 01:37:13

this meeting and continuing meetings with the ICC and the great work

01:37:14 - 01:37:16

we can accomplish to help improve the

01:37:18 - 01:37:21

quality of life. And health and wellness of all people

01:37:22 - 01:37:23

on the autism spectrum. Thank you.

01:37:27 - 01:37:28

Christy Kavelik.

01:37:29 - 01:37:33

Hi, I'm Christy Kavlick representing the US Department of

01:37:33 - 01:37:36

Education. I am within the office of

01:37:37 - 01:37:40

special education and rehabilitative services. I serve as the

01:37:40 - 01:37:43

director of the research to practice division. Within the

01:37:44 - 01:37:45

office of special education program.

01:37:47 - 01:37:49

OSEP administers the individuals with disabilities

01:37:50 - 01:37:53

education act or IDEA. Which provides grants

01:37:54 - 01:37:57

to states to provide early intervention and special education

01:37:57 - 01:38:00

services. For children with disabilities and their families.

01:38:01 - 01:38:04

We also fund national activities to support the

01:38:05 - 01:38:08

implementation of IDEA. And the

01:38:08 - 01:38:10

use of evidence-based practices.

01:38:12 - 01:38:15

OSERS also has the rehabilitation services administration

01:38:16 - 01:38:19

which supports vocational rehabilitation, employment

01:38:19 - 01:38:23

and independent living. I look forward to participating on the

01:38:23 - 01:38:23

IAF.

01:38:25 - 01:38:25

Thank you.

01:38:27 - 01:38:28

Elaine Cohen Hubble.

01:38:38 - 01:38:40

We can't hear you. I think might be unmute.

01:38:42 - 01:38:43

We're unable to hear you.

01:38:50 - 01:38:53

Want to move to the next person and I'll get in touch with you later.

01:38:53 - 01:38:54

Sure. Yes.

01:38:57 - 01:39:00

Good morning, recall coming to you from the United States Food and Drug

01:39:00 - 01:39:03

Administration. I'm looking forward to being here together and learning

01:39:04 - 01:39:06

from you all. I'm a senior advisor in the Office of

01:39:06 - 01:39:08

Commissioner. We focus on a lot of enterprising

01:39:09 - 01:39:12

work. If you don't know anything about the FDA, our goal is to protect and

01:39:12 - 01:39:12

promote

01:39:14 - 01:39:17

public health across a gamut of commodity groups. We regulate

01:39:18 - 01:39:21

drugs, biologics. We regulate devices

01:39:22 - 01:39:25

as well as some products. Like tobacco

01:39:28 - 01:39:31

and veterinary medicine and products as well, which is probably of lesser importance today.

01:39:32 - 01:39:35

But looking forward to come together. Two goals I'll share with you current admission

01:39:36 - 01:39:39

priorities with secretary kennedy's leadership. As well as Commissioner

01:39:39 - 01:39:42

McCary would be one food is medicine restoring the

01:39:43 - 01:39:46

back in food and drug administration. You might have heard of some of the work going on

01:39:46 - 01:39:49

in the last couple years or in the last year on food dyes.

01:39:50 - 01:39:53

This is particularly important, I think, in this group with this setting.

01:39:54 - 01:39:57

On the note of food is medicine. And we learn more about ex

01:39:57 - 01:40:01

besomics as we learn more about epigenetics. As well as the

01:40:01 - 01:40:04

microbiome. And determinants of health outcomes that are

01:40:04 - 01:40:08

intrinsic in some of those. And how we can best regulate it as the

01:40:08 - 01:40:11

regulator of nearly a quarter of every dollar in the

01:40:11 - 01:40:15

United States economy. Secondly patient focused drug

01:40:15 - 01:40:18

development program. We want to make sure that we're accelerating

01:40:19 - 01:40:22

cures, but accelerating meaningful cures for the patient populations that

01:40:24 - 01:40:27

drug program developers will put into the pipeline. This is really important for us.

01:40:28 - 01:40:32

And we recognize that for conditions like autism

01:40:32 - 01:40:35

spectrum disorder, there is a lot of heterogeneity of patient

01:40:35 - 01:40:38

population. So working together with federal partners, this is super

01:40:38 - 01:40:41

key. Some of our NIH colleagues here, we appreciate that

01:40:42 - 01:40:44

work together working with researchers, working with

01:40:46 - 01:40:49

clinicians and physicians. But especially working with patients to make sure

01:40:50 - 01:40:53

that the endpoints that we're looking at are clinical trials the way that we're designing

01:40:53 - 01:40:56

our clinical trials together with partners. As well as

01:40:57 - 01:41:01

the surrogate endpoints and the biomarkers. And as we validate them

01:41:01 - 01:41:05

and as we qualify them, we're doing so with the functional

01:41:05 - 01:41:08

status, the biological process, but especially the patient voice.

01:41:08 - 01:41:12

Throughout the process. So we need your help. We

01:41:12 - 01:41:14

can't do this in a vacuum to the FDA and we're excited to learn together.

01:41:16 - 01:41:19

To grow together and to really share and investigate

01:41:19 - 01:41:20

this. So looking forward to working together.

01:41:22 - 01:41:24

Great, thank you. Do we have Dr. Kohen Huddle?

01:41:27 - 01:41:29

Okay, we'll move on. Margaret Bush.

01:41:32 - 01:41:36

Good morning. Thank you for the opportunity to participate. I also just

01:41:36 - 01:41:39

want to say thank you to the advocates and families for sharing their personal

01:41:39 - 01:41:43

stories. My name is Margaret Bush. I'm the beauty administrator at the

01:41:43 - 01:41:46

Health Resources and Services Administration, or HRSA.

01:41:47 - 01:41:50

Our mission is to improve access to health care for people who are

01:41:50 - 01:41:53

geographically isolated and those who are economically or medically

01:41:53 - 01:41:56

vulnerable. Within that mission, our autism

01:41:57 - 01:42:00

and other developmental disability portfolio focuses

01:42:00 - 01:42:04

on improving care and outcomes for children, adolescents and young

01:42:04 - 01:42:07

adults. We do this by strengthening the workforce, advancing

01:42:08 - 01:42:10

research and supporting states and delivering high quality care.

01:42:12 - 01:42:15

Particularly as youth transition to adult services. A major

01:42:15 - 01:42:18

part of our work is training through programs like the leadership

01:42:19 - 01:42:21

education and neurodevelopmental and other related

01:42:22 - 01:42:25

disabilities or IEN and our developmental behavior

01:42:26 - 01:42:29

pediatrics program. We prepare providers to better

01:42:30 - 01:42:33

screen, diagnose and care for children with autism and other developmental

01:42:34 - 01:42:37

disabilities. We also invest in research to improve

01:42:37 - 01:42:40

services and support. Our work focuses on early

01:42:40 - 01:42:44

identification, developing reliable screening tools and advancing

01:42:44 - 01:42:47

interventions that support physical and behavioral health and communication.

01:42:48 - 01:42:51

On a more personal note before coming into this role, I practice

01:42:52 - 01:42:55

as a nurse for 12 years. And I care for patients with autism

01:42:55 - 01:42:58

and developmental disabilities and solve firsthand the challenges

01:42:59 - 01:43:02

individuals and families. Face. Thanks again for the opportunity

01:43:02 - 01:43:04

to be here today. I look forward to the discussion.

01:43:06 - 01:43:09

Great, thank you. Do we have Dr. Cohen Hubble?

01:43:12 - 01:43:15

We still can't hear you. Sorry, I'll pop in.

01:43:16 - 01:43:18

No, this is aiming with support. I'm trying to get in touch with

01:43:19 - 01:43:21

Dr. Hubble. You can check your email, please. Thank you.

01:43:23 - 01:43:24

Thank you. Leah.

01:43:27 - 01:43:31

Hi, good morning. I'm Leah Loger. I'm here representing the US Department of Housing

01:43:31 - 01:43:34

Urban Development, or HUD. I work in their office of policy development

01:43:35 - 01:43:35
and research.

01:43:37 - 01:43:40
Has been a member of the IACC since I believe 2019.

01:43:41 - 01:43:44
I have served on previous iteration of the committee, and I'm looking forward to the

01:43:44 - 01:43:48
work of the new committee in terms of why is

01:43:48 - 01:43:50
housing here. HUD offers a number of programs

01:43:51 - 01:43:54
not specific for people with autism, but a number of housing programs

01:43:56 - 01:43:58
for disabilities. So I'm looking forward to the work of the committee. Thank you.

01:43:59 - 01:44:02
Thank you. Marcel Ronick.

01:44:05 - 01:44:08
Y. Good morning. Thank you very much. I was hoping my audio

01:44:08 - 01:44:11
was working. My name is Marcella

01:44:11 - 01:44:14
Runyak. I am in dual role right

01:44:14 - 01:44:17
now. I am the deputy director at the Office of Funko

01:44:17 - 01:44:21
Performance and Health Impact. And I'm also the acting director within

01:44:21 - 01:44:24
the Office of Clinical and Preventative Services at the

01:44:24 - 01:44:25
Indian Health Service.

01:44:27 - 01:44:30
I was on the IAC as IHS representative.

01:44:32 - 01:44:34
In previous years, and I am acting as an alternate to

01:44:35 - 01:44:38
Dr. Hartley from Indian Health Service.

01:44:40 - 01:44:43
I am also a member of the Pablo Confederating tribes in Washington state

01:44:44 - 01:44:47
and a very proud mom, autistic

01:44:47 - 01:44:50
savant. My son is 16 years old and is a senior

01:44:51 - 01:44:54
at the University of Arizona working on a pre-med track

01:44:54 - 01:44:58
wanting to be an oncologist. So I come to this committee

01:44:58 - 01:45:02
both as a federal employee and also as a proud parent of

01:45:02 - 01:45:05
someone with autism. We honestly have quite

01:45:06 - 01:45:09
the story with my son that I've been able to share with me

01:45:09 - 01:45:12
from both perspectives as a federal employee looking at how

01:45:13 - 01:45:15
we can strengthen. Our collaborative

01:45:15 - 01:45:19
efforts. I also started the interagency

01:45:19 - 01:45:22

autism coordinating committee with Indian Health Service back

01:45:23 - 01:45:24

in 2018. So with that

01:45:26 - 01:45:29

committee as an honor. To also

01:45:30 - 01:45:33

represent IHS where our mission is to raise the

01:45:33 - 01:45:36

physical, mental, social and spiritual health of American

01:45:37 - 01:45:40

Indianaska natives, we do provide care to about

01:45:40 - 01:45:44

2.9 million American Indian, Alaska natives. And we are the

01:45:44 - 01:45:47

18th largest healthcare system elimination. Most people don't know

01:45:47 - 01:45:50

that. We're a little secret service behind healthcare

01:45:51 - 01:45:54

that provides services to all of our stakeholders. Our

01:45:54 - 01:45:58

vision is to have a health system that embraces traditional knowledge and

01:45:58 - 01:46:01

practices that can foster living and

01:46:01 - 01:46:05

thriving communities for seven generations. We have four

01:46:05 - 01:46:08

strategic goals, which is one is being a leading healthcare organization.

01:46:10 - 01:46:13

Two is to ensure comprehensive cultural respectful health care

01:46:13 - 01:46:14
services.

01:46:15 - 01:46:16
Free is to

01:46:17 - 01:46:20
optionalize operations through effective stewardship.

01:46:22 - 01:46:25
And finally forth to promote proactive intergovernmental and

01:46:25 - 01:46:28
external partnerships. I do have to say it is such

01:46:28 - 01:46:31
an honor to be a part of the IAC

01:46:31 - 01:46:34
committee. I can say that my son was one who went

01:46:36 - 01:46:39
and testified in front of Congress. To ensure that the

01:46:39 - 01:46:42
autism cares act was resigned in

01:46:42 - 01:46:45
2020. So thank you so much and I look forward to

01:46:46 - 01:46:49
continuing to work the way. Thank you.

01:46:51 - 01:46:51
Matt Emily.

01:46:55 - 01:46:58
I think for the most part I gave my introduction just for a little more background on

01:46:58 - 01:47:01
me. I am an infectious disease physician

01:47:02 - 01:47:05

and internist and I've been a microbiologist working here for over

01:47:05 - 01:47:06

20 years.

01:47:09 - 01:47:11

Great thank you. Rohan Hoer.

01:47:13 - 01:47:17

Good morning everyone. I'm Rohan Hasra. I'm currently in the

01:47:17 - 01:47:20

role as the acting director of the Eunice Kennedy Shriver

01:47:20 - 01:47:24

National Institute of Child Health and Human Development, which is the Child Health Institute

01:47:24 - 01:47:28

one of 27 institutes and centers here at NIH.

01:47:28 - 01:47:31

I'm a pediatric infections disease physician by training and

01:47:31 - 01:47:35

have spent more than actually longer than that more than 25

01:47:35 - 01:47:37

years here at

01:47:37 - 01:47:40

NIH. I've been in this current role for just

01:47:41 - 01:47:44

two months today. In fact, I just realized today is two months since I became

01:47:44 - 01:47:47

the acting director. Prior to that I was

01:47:48 - 01:47:52

the scientific division director at ICHD. And

01:47:52 - 01:47:52

so I just wanted to walk through.

01:47:54 - 01:47:57

Some of the programs that we have that are very, very relevant to

01:47:58 - 01:47:58

the autistic

01:48:00 - 01:48:04

community and the research portfolio. So first of all

01:48:05 - 01:48:08

intellectual research on intellectual and developmental disabilities was part of

01:48:08 - 01:48:12

our core legislation that Secretary Kennedy actually signed in

01:48:12 - 01:48:15

1962 to establish the Child Health Institute. So it has been

01:48:15 - 01:48:18

a part of our core mission right from the beginning

01:48:19 - 01:48:22

right from when we were founded. Our mission is to

01:48:23 - 01:48:26

lead research and training to understand human development, improve reproductive

01:48:26 - 01:48:29

health, enhance the lives of children and adolescents

01:48:29 - 01:48:32

and optimizabilities for all. And some of our

01:48:33 - 01:48:35

research, we have two of our largest

01:48:35 - 01:48:38

branches, child development and behavior branch and our

01:48:38 - 01:48:42

intellectual and developmental disability brand. And so there we have a lot of

01:48:42 - 01:48:44

work going on on typical and atypical

01:48:44 - 01:48:47

development. The intellectual and developmental

01:48:47 - 01:48:51

disabilities branch with four other institutes

01:48:51 - 01:48:54

and centers leads the autism centers of excellence

01:48:54 - 01:48:57

program that's been in place since I think

01:48:58 - 01:49:01

2007. But there are two other branches I'd want to also

01:49:01 - 01:49:04

highlight. One is that we know that premature birth increases

01:49:04 - 01:49:08

the risk of autism. And so we have a very large portfolio

01:49:08 - 01:49:11

of research on prematurity in our pregnancy and

01:49:11 - 01:49:14

perinatal branch. And then finally very relevant to I think a number of

01:49:15 - 01:49:18

different discussions today. We have a major focus in our

01:49:19 - 01:49:21

pediatric trauma and clinical illness branch on injury

01:49:21 - 01:49:25

prevention. And one of that branch's priorities is drowning

01:49:25 - 01:49:28

prevention. And we actually have a highlighted topic currently on drowning

01:49:28 - 01:49:31

prevention. And so really have research that touches on multiple

01:49:32 - 01:49:33

areas across

01:49:34 - 01:49:38

the, in fact, on the developmental disability program in addition to having a

01:49:38 - 01:49:41

specific branch in that in that area. On a personal note, I have

01:49:42 - 01:49:46

a cousin's son who I've watched from

01:49:46 - 01:49:50

birth. And we actually, my wife and I both be nutrition. We had

01:49:50 - 01:49:53

suspicions that he had autism much before he

01:49:53 - 01:49:57

actually was finally diagnosed. He was unfortunately quite late

01:49:57 - 01:49:59

diagnosed, but then has really inspired us with how

01:50:01 - 01:50:03

he's grown. He's now in his late 20s

01:50:04 - 01:50:08

and living in a group home, but able to care for himself

01:50:09 - 01:50:13

and engage in lots of different hobbies. And

01:50:13 - 01:50:16

he's also very musically talented. So just really

01:50:16 - 01:50:18

inspiration. I look forward to working with all of you.

01:50:20 - 01:50:24

Great. Thank you. I think we have Elaine, Cohen coupled back

01:50:24 - 01:50:24

on now.

01:50:29 - 01:50:32

Can you try to speak? No, we're still getting here though. Let me go.

01:50:33 - 01:50:36

Okay, great. Deborah Chiche.

01:50:38 - 01:50:41

Good morning everyone. I'm Deborah Toy. I'm director of

01:50:41 - 01:50:44

the National Institute on deafness and other communication

01:50:45 - 01:50:48

disorders. And the portion of our research portfolio

01:50:48 - 01:50:51

that relates most to autism is our work

01:50:52 - 01:50:55

in disordered language development and communication. And so

01:50:55 - 01:50:58

we've been very involved in that aspect of

01:50:59 - 01:51:02

this committee. And I look forward to working with all of

01:51:02 - 01:51:04

you, especially in that area.

01:51:06 - 01:51:09

We'll also be joined later by NIDCD's

01:51:09 - 01:51:12

deputy director Dr. Judith Cooper. She is a speech

01:51:12 - 01:51:16

language pathologist by training. So she's been involved with

01:51:16 - 01:51:19

this committee for many years. Thank you. Thank you.

01:51:20 - 01:51:22

Courtney, Wimbley.

01:51:29 - 01:51:29

Hopefully you can hear me.

01:51:31 - 01:51:34

Again. Good morning. Thank you. I'm Courtney Wimberley. I'm

01:51:35 - 01:51:38

the health firm specialist in the office of the Director at the

01:51:38 - 01:51:40

National Institute of Environmental Health Sciences.

01:51:41 - 01:51:44

NIH, part of the MH. And I'm

01:51:44 - 01:51:47

a piece of service the ultimate representative today for NIE access

01:51:47 - 01:51:49

directors. How else?

01:51:51 - 01:51:55

I support the DIC interdisciplinary research portfolio and health advance.

01:51:56 - 01:51:59

Program planning project distribution and alignment with

01:51:59 - 01:52:00

scientific intelligence.

01:52:02 - 01:52:06

And at EHS is focused on understanding how environmental exposures

01:52:06 - 01:52:09

influence human health and disease including factors that affect child

01:52:09 - 01:52:12

health, development and neurodevelopment and network is highly relevant

01:52:13 - 01:52:16

throughout the new threats, particularly as we seek to better understand how

01:52:17 - 01:52:20

environmental and biological factors may shape developmental outcomes

01:52:21 - 01:52:24

and contribute to health across the lifespan. My background

01:52:24 - 01:52:27

includes neuroepidemiology research, regulatory

01:52:27 - 01:52:29

coordination, data analysis and research

01:52:29 - 01:52:32

dissemination. And in this work, I'm especially mindful that research

01:52:33 - 01:52:37

and policy are most meaningful when they reflect the real experiences

01:52:37 - 01:52:40

of individuals and families and remain responsive.

01:52:41 - 01:52:44

To needs across the lifespan. I'm grateful for the

01:52:45 - 01:52:48

opportunity to be a part of this meeting and the work that you are all doing

01:52:49 - 01:52:52

and I look forward to contributing to the insightful discussions that help

01:52:53 - 01:52:56

advance research. And improve outcomes for people with

01:52:56 - 01:52:58

autism and their families. Thank you.

01:53:01 - 01:53:01

And Rebecca.

01:53:04 - 01:53:07

Thanks very much for the opportunity to be here. I am currently the

01:53:08 - 01:53:11

acting director for the National Institute of Mental Health as well as the

01:53:11 - 01:53:15

deputy director of the NIH Brain Initiative. So representing

01:53:15 - 01:53:19

the agency, I'd like to tell you a little bit about the research

01:53:19 - 01:53:22

that we support basically three areas

01:53:23 - 01:53:23

at NIMH.

01:53:25 - 01:53:28

We explore fundamental brain mechanisms and processes

01:53:29 - 01:53:32

at the cellular and circuit level. We also have

01:53:32 - 01:53:36

a large portfolio in what we call translational research, which

01:53:36 - 01:53:39

further explores and expands the knowledge base. To better understand

01:53:39 - 01:53:43

people with autism and develop safe and effective treatments.

01:53:44 - 01:53:45

And finally, we have a large investment

01:53:47 - 01:53:50

in science that improves services and services

01:53:50 - 01:53:53

delivery for people with autism. It is a pleasure to be

01:53:54 - 01:53:57

here. It's a privilege to serve alongside all of you, and I look forward

01:53:57 - 01:53:58

to our partnerships.

01:53:59 - 01:54:03

Thank you, Amy, Adam. Thank you

01:54:03 - 01:54:06

so much. It's a privilege to be here today, and I really

01:54:07 - 01:54:10

appreciated all of the advocates and sharing their

01:54:10 - 01:54:11

very personal stories.

01:54:14 - 01:54:17

Very emotionally moving. Thank you. They are candid.

01:54:18 - 01:54:21

So I serve as the acting director of the National Institute of Neurological Disorders

01:54:22 - 01:54:25

and stroke. Our mission is to understand the brain and

01:54:26 - 01:54:29

the nervous system and to use that knowledge to improve neurological

01:54:30 - 01:54:30

health for all people.

01:54:32 - 01:54:35

With respect to autism research, our focus

01:54:35 - 01:54:38

includes studies that focus on the brain and nervous

01:54:38 - 01:54:41

system. For example, research on the

01:54:41 - 01:54:44

genetic, molecular, cellular and circuit level mechanism.

01:54:45 - 01:54:48

For example excitatory and inhibitory processes

01:54:49 - 01:54:52

that shape the nervous system development. And function

01:54:53 - 01:54:56

in autism. We also focus on

01:54:56 - 01:54:59

translational and clinical work. To improve the

01:54:59 - 01:55:02

diagnosis and treatment. Of neurologically

01:55:02 - 01:55:06

relevant features of autism. This includes

01:55:06 - 01:55:09

work on sensory and sensor motor aspects of autism.

01:55:11 - 01:55:14

Pain experience and mechanisms, which I've heard from many of you today.

01:55:16 - 01:55:20

An association of autism with co-occurring neurodevelopmental

01:55:21 - 01:55:23

and neurological conditions across the lifespan.

01:55:25 - 01:55:28

I really appreciate the opportunity to contribute to the discussions today

01:55:28 - 01:55:30

and to learn from all of you. Thank you.

01:55:34 - 01:55:35

Thank you, Rick Lambert.

01:55:37 - 01:55:41

Thanks for the opportunity to be here. And I want to thank many speakers for

01:55:42 - 01:55:45

the inspiring and moving words. And especially for your vulnerability.

01:55:46 - 01:55:46

Thank you.

01:55:48 - 01:55:51

So I'm a physician. I work at SAMHSA, the Senior

01:55:52 - 01:55:55

Advisor there. I have almost 40 years of clinical experience. Most

01:55:55 - 01:55:56

of it is in the

01:55:58 - 01:56:00

multiple trained in acupuncture. So I do appreciate alternative approaches.

01:56:02 - 01:56:05

And most recently became certified in psychedelic assisted therapy and research.

01:56:06 - 01:56:10

Which is my main area of focus attempts. I'm sure most of you are

01:56:10 - 01:56:13

aware of the executive order regarding psychedelics

01:56:14 - 01:56:18

that Secretary Kenny and President Trump shared on national PD about

01:56:18 - 01:56:21

10 days ago. I believe these medicines will eventually be

01:56:21 - 01:56:24

transformative in the field of behavioral health. And I also

01:56:25 - 01:56:27

believe we can have several different applications to offer.

01:56:29 - 01:56:32

I approach this work with the understanding that autism is a form of

01:56:32 - 01:56:35

neurodiversity and that individuals on the spectrum have a wide range of

01:56:36 - 01:56:38

strengths, aged and lived experiences.

01:56:39 - 01:56:42

At the same time, many autistic individuals face significant barriers

01:56:43 - 01:56:47

for stress, particularly in accessing appropriate respectful and effective

01:56:47 - 01:56:49

mental health and substance abuse service. S.

01:56:50 - 01:56:53

SAMHSA's role to help ensure that behavioral health systems are accessible.

01:56:54 - 01:56:58

Person-centered and responsive across the lifespan. That

01:56:58 - 01:57:01

includes advancing trauma-informed care, strengthening

01:57:01 - 01:57:04

community-based supports. And improving crisis response

01:57:04 - 01:57:07

systems like 988. So they work well for

01:57:07 - 01:57:11

neurodiverse individually. For example, there are resources on our

01:57:11 - 01:57:14

website through the National Child Traumatic Stress Network and how

01:57:15 - 01:57:18

youth with intellectual and developmental disabilities experience traumatic stress.

01:57:20 - 01:57:23

And how parents and caregivers can support them. I'm here to

01:57:23 - 01:57:26

listen, bring a behavioral health insistence perspective to the

01:57:26 - 01:57:30

community's work. Look forward to working together to improve quality of life.

01:57:31 - 01:57:33

Access to care and outcomes for autistic

01:57:33 - 01:57:35

individuals, their families and communities.

01:57:37 - 01:57:39

Thank you, Allison Burbon.

01:57:46 - 01:57:49

Good morning. I should check to see that you can hear me after

01:57:49 - 01:57:51

the. We can. Thank you.

01:57:52 - 01:57:55

Okay, I'm Alex Humaldrn, and I'm honored

01:57:56 - 01:57:58

to represent the Social Security Administration.

01:57:59 - 01:58:03

The Social Security Administration is an administrative agency

01:58:04 - 01:58:06

that delivers Social Security services and provides support.

01:58:08 - 01:58:11

Through individuals, including those on the author from Spectrum and

01:58:11 - 01:58:13

their families. Throughout their life journey.

01:58:16 - 01:58:19

Behind the branch chief of AI and advanced

01:58:19 - 01:58:19

analytics.

01:58:21 - 01:58:24

My predictive modeling and advanced analytics teams extensively support

01:58:25 - 01:58:27

SSI operations, customers of living quality review.

01:58:29 - 01:58:32

By AI team is actively working to improve the 800 number

01:58:33 - 01:58:34

and interactive voice response experience.

01:58:36 - 01:58:39

I'm a statistician and health sciences research by training.

01:58:40 - 01:58:44

And before joining the social security administration. I was

01:58:44 - 01:58:47

the research manager of the Ian project, the interactive

01:58:47 - 01:58:50

autism network. At the Kennedy Krieger Institute.

01:58:51 - 01:58:54

That if some of you remember that it's at one point the largest online

01:58:54 - 01:58:57

mediated autism registry and research

01:58:58 - 01:59:01

program. And that experience gave me the opportunity

01:59:02 - 01:59:05

to connect with individuals on the

01:59:05 - 01:59:07

autism spectrum and their families.

01:59:09 - 01:59:12

I also was affiliated with the Wendy Klag Center for autism

01:59:13 - 01:59:16

and developmental disability disabilities at Johns Hopkins

01:59:16 - 01:59:19

Bloomberg School of Public Health. I'm grateful for the

01:59:19 - 01:59:23

opportunity I had with these groups

01:59:23 - 01:59:26

that I was able to publish extensively in the order of

01:59:26 - 01:59:29

autism research. I look forward to

01:59:30 - 01:59:34

continuing to represent Social Security on this important

01:59:34 - 01:59:35

committee. Thank you.

01:59:37 - 01:59:38

Thank you, clever.

01:59:55 - 01:59:58

Can you hear me now? Oh, yes, we can. Yay.

01:59:59 - 02:00:03

I could not apologize more. Elaine Cohen

02:00:03 - 02:00:05

Hubble with BPA's office.

02:00:07 - 02:00:08

Applied science and environmental

02:00:09 - 02:00:12

solutions. ECA's mission

02:00:12 - 02:00:14

is, of course, to protect human health in the environment.

02:00:16 - 02:00:19

And it is current agency policy to protect children

02:00:20 - 02:00:22

from environmental exposure by consistently

02:00:23 - 02:00:26

and explicitly considering early life exposures

02:00:26 - 02:00:29

and potential long lifelong health impacts

02:00:30 - 02:00:33

in all of the human health decisions. So these exposures

02:00:34 - 02:00:37

and impact would do include effects of

02:00:37 - 02:00:41

environmental exposure during early life, beginning

02:00:41 - 02:00:43

with parental reproductive health.

02:00:44 - 02:00:47

Continuing through infancy, early childhood, adolescence

02:00:48 - 02:00:49

and through to adulthood.

02:00:51 - 02:00:54

In implementing this policy, EPA works with our federal partner

02:00:56 - 02:00:59

to identify, evaluate and use in

02:01:00 - 02:01:03

our decision making information on environmental factors.

02:01:04 - 02:01:05

Including those related to

02:01:06 - 02:01:08

autism.

02:01:10 - 02:01:10

I think my third

02:01:13 - 02:01:14

round on this

02:01:14 - 02:01:17

committee. I'm incredibly energized.

02:01:18 - 02:01:20

Hearing the public. Members.

02:01:22 - 02:01:25

Priorities and by action.

02:01:26 - 02:01:29

I'm also really, I think

02:01:29 - 02:01:31

EPA is going to really be able to take advantage of

02:01:33 - 02:01:36

information that's being developed. Through the

02:01:36 - 02:01:38

application of exosomic

02:01:40 - 02:01:41

fidelity than we heard early.

02:01:43 - 02:01:46

In the meeting. That there is new and significant funding

02:01:47 - 02:01:47

being put

02:01:49 - 02:01:53

specifically on exosome and autism. So look

02:01:53 - 02:01:56

forward to serving and continuing to

02:01:56 - 02:01:59

just really learn about this community. Oh, and like everybody

02:01:59 - 02:02:03

has dear family members, young

02:02:03 - 02:02:06

adults, all of them at this stage. Who

02:02:07 - 02:02:10

are part of the autistic community. Thank you. Thank you for

02:02:10 - 02:02:11

your patience.

02:02:13 - 02:02:16

Thank you and thank you for persisting and joining us. Thank you to all the

02:02:16 - 02:02:19

federal members and all of the public members for your comment.

02:02:21 - 02:02:23

We are going to have a 10 minute breakaway. A tiny bit behind.

02:02:24 - 02:02:27

I just want to remind you, please don't discuss any

02:02:28 - 02:02:31

committee business during the break. That all needs to be in the public

02:02:31 - 02:02:34

forum. So we'll see you back at 11:10. Thank you.

02:02:44 - 02:02:44

Right.

02:14:46 - 02:14:49

The comments that we received reflected a broad range of perspectives on

02:14:49 - 02:14:51

research, services and policy.

02:14:52 - 02:14:56

And in order to assist with the discussion today, our

02:14:56 - 02:14:59

office, the office of national autism coordination or od act conducted an

02:14:59 - 02:15:02

analysis. Of themes in the public comments to inform the committee

02:15:03 - 02:15:03

discussion.

02:15:06 - 02:15:07

The results of that analysis

02:15:09 - 02:15:12

or the methods used for that analysis, 15 things were developed.

02:15:14 - 02:15:16

Each comment was coded to a maximum of three themes allowing for

02:15:17 - 02:15:20

identification of recurring themes. Quantification of

02:15:20 - 02:15:24

topic frequency. And representation of multi topic comments.

02:15:25 - 02:15:28

A full summary of the analysis and theme definitions is available in the

02:15:29 - 02:15:31

first few pages of the public comment packet that's posted online

02:15:33 - 02:15:34

and that all the members receive by email.

02:15:39 - 02:15:42

So these are the themes that were represented. Sorry, it's a little hard to see

02:15:42 - 02:15:45

in the room, but the most frequently represented themes included

02:15:46 - 02:15:50

etiology and causation. Mental health behavioral

02:15:50 - 02:15:50

supports and safety.

02:15:52 - 02:15:54

Individuals with high support needs or profound autism.

02:15:56 - 02:15:58

Services access and system barriers, adult

02:15:59 - 02:16:02

services, housing and long term care. And

02:16:02 - 02:16:05

caregiver impact economic straining and family supports.

02:16:06 - 02:16:09

So again, if you look at the public comment packet, you can see all of the categories

02:16:09 - 02:16:12

that were developed and the number of comments coded to each of those.

02:16:18 - 02:16:21

Public comments received for this meeting addressed a wide range of topics across

02:16:21 - 02:16:25

the 15 themes. Many of the comments reflected multiple overlapping

02:16:25 - 02:16:28

issues. And comments as provided feedback on research

02:16:28 - 02:16:32

priorities and services needs. Highlighting gaps, concerns

02:16:32 - 02:16:36

and areas of emphasis to inform IACC discussions. So thank you

02:16:36 - 02:16:39

to all of you who submit it written comments.

02:16:40 - 02:16:43

And now I believe we'll hear from the oral commenters.

02:16:47 - 02:16:51

We are now going to hear from 13 commenters who

02:16:51 - 02:16:54

are going to provide oral public statements. We're going to

02:16:54 - 02:16:57

begin with those who are joining us virtually, and then we will.

02:16:59 - 02:17:02

Turn to those in the room. Who will provide comments

02:17:03 - 02:17:06

in person. For those that are providing public

02:17:06 - 02:17:09

comments, we thank you for writing

02:17:09 - 02:17:13

your comments to us today and being here. And we

02:17:13 - 02:17:16

thank you in advance for keeping your remarks within the

02:17:16 - 02:17:20

allotted time, which is three minutes. So we will

02:17:20 - 02:17:23

be good first with Stephen.

02:17:25 - 02:17:28

Janzik. Thank you so much for allowing me to

02:17:28 - 02:17:29

meet with you guys today.

02:17:31 - 02:17:34

So as she said, my name is Stephen Kelly. I am an autism dad.

02:17:35 - 02:17:38

I also want to say thank you to my mentors, Dr.

02:17:38 - 02:17:41

Jayanucci, Dr. Adams. Christina Flynn.

02:17:42 - 02:17:45

Peter Lloyd Thomas. To my beautiful wife and family who

02:17:45 - 02:17:49

encouraged me to talk to you guys today. Jacane, I also want to mention that

02:17:49 - 02:17:51

I don't own any genitech stock, which is important.

02:17:53 - 02:17:55

I have one very simple request.

02:17:56 - 02:17:59

And that is to have the allergy food med go

02:17:59 - 02:18:02

layer slash amalizumab. Added to the Trump

02:18:03 - 02:18:03

Rx website.

02:18:05 - 02:18:09

And so why do you ask that even, well, what if there was a

02:18:09 - 02:18:12

drug that would help stop elopement?

02:18:13 - 02:18:17

So you wouldn't be finding kids drowning in a pond or running away and getting

02:18:17 - 02:18:20

in the street. What if there was a drug that could help

02:18:21 - 02:18:24

a child with profound autism? Sleep throughout the night?

02:18:26 - 02:18:28

I don't know. I just have a personal experience.

02:18:30 - 02:18:34

I have two autistic bodies, one with

02:18:34 - 02:18:36

profound autism, the other one with mild autism.

02:18:38 - 02:18:40

They both have folate receptor auto

02:18:40 - 02:18:44

antibodies, both blocking and bindings for you, Dr.

02:18:44 - 02:18:46

Rasmine. Hill. They have high levels of

02:18:47 - 02:18:48

microbial metabolites.

02:18:51 - 02:18:54

They haven't primed immune system from maternal immune

02:18:54 - 02:18:57

activation, which definitely needs a rebrand.

02:18:58 - 02:19:01

Because we don't need to be attacking our mothers in regard to autism.

02:19:02 - 02:19:05

Furthermore, they also had a clear genetic

02:19:05 - 02:19:09

full sequencing genome, no autistic genes showed on

02:19:09 - 02:19:10

either of. Those.

02:19:13 - 02:19:16

So our autism journey has started with solar for over two years

02:19:16 - 02:19:16

now.

02:19:18 - 02:19:22

With that, we have seen increased cognition. Increased

02:19:22 - 02:19:25

language. Decreased elopement. Decreased sleep

02:19:25 - 02:19:25

jagging.

02:19:27 - 02:19:30

My son, both potty trained, was no longer required

02:19:30 - 02:19:34

diaper. And when I mentioned this, I'm talking about optimism. I'm

02:19:34 - 02:19:36

not talking about autism where I could talk to you like

02:19:38 - 02:19:40

one of my profound son, Steven is nonverbal.

02:19:42 - 02:19:44

But because of zoler, he was able to follow direction.

02:19:47 - 02:19:51

Both of them, actually my younger son, is able to go to a private

02:19:51 - 02:19:52
school. Because of it.

02:19:55 - 02:19:58
My younger son, Leo, can read a book now because it's nowhere.

02:19:59 - 02:20:02
Furthermore, they're also very proficient swimmers.

02:20:03 - 02:20:06
And I also attribute that to their understanding and their technician

02:20:06 - 02:20:10
has increased because of the land. So I just want

02:20:10 - 02:20:13
other parents to be able to experience the same joy that I've experienced.

02:20:14 - 02:20:17
To have your child be able to say, I love you is amazing.

02:20:18 - 02:20:18
Furthermore.

02:20:20 - 02:20:23
It's not based off of total IgE and

02:20:24 - 02:20:27
underscore that. So usually when you are prescribing dual

02:20:27 - 02:20:30
layer, you need to have a total IgG above. My

02:20:31 - 02:20:32
IG, Leo is 11.

02:20:36 - 02:20:36
02.

02:20:39 - 02:20:42
Another food for thought. We're going to have to ask you to

02:20:43 - 02:20:45

wrap up your comments. Thanks. No problem. Sorry.

02:20:46 - 02:20:49

Long story short in the layers \$450

02:20:50 - 02:20:53

in America. \$5,000. So that's why I needed on

02:20:53 - 02:20:54

trump RF. Thank you.

02:21:02 - 02:21:05

Shawn Bleich. Thank you for the

02:21:05 - 02:21:09

opportunity to speak. Dear members of the IACC and

02:21:09 - 02:21:12

autism parents around the world. My name is Sean Reimer. I'm a

02:21:12 - 02:21:16

father to a 10 year old non speaking boy with profound autism named

02:21:16 - 02:21:19

Theo. I'm also a functional medicine coach trained by the Functional

02:21:19 - 02:21:23

Medicine Coaching Academy and the founder of the Pure Living Family

02:21:23 - 02:21:26

Foundation, a 501c three nonprofit

02:21:26 - 02:21:30

supporting families of kids with autism pandas, pans and epilepsy.

02:21:31 - 02:21:34

I'm a parent who spent seven years in the trenches trying learning

02:21:34 - 02:21:38

failing and finding what works for my son and for our family.

02:21:38 - 02:21:42

I want to share what we've learned and make three specific requests of

02:21:42 - 02:21:45

this committee. I like to call this the field protocol.

02:21:46 - 02:21:49

First nutritionist foundational real organic whole

02:21:49 - 02:21:52

foods matter enormously for children on the spectrum.

02:21:53 - 02:21:56

But for many kids, this is not simple. It wouldn't

02:21:56 - 02:21:59

allow food near him. His entire system was rejecting the very

02:22:00 - 02:22:03

things that could help him. The intervention that changed this was a

02:22:04 - 02:22:07

fecal microbiota transplant. I want to acknowledge Dr.

02:22:07 - 02:22:10

James Adams and autism father and researcher doing remarkable

02:22:10 - 02:22:14

work in this area at Arizona State University.

02:22:15 - 02:22:18

After FMT was diet expanded dramatically, he now

02:22:19 - 02:22:22

eats almost anything we give him. The microbiome, it turns out

02:22:23 - 02:22:26

controls our cravings. When you heal the gut, the child can begin to receive

02:22:26 - 02:22:26

the nourishment.

02:22:28 - 02:22:31

Second, even after gut intervention, he was autoimmune

02:22:31 - 02:22:34

neuroinflammation remained. Like many children on the spectrum who

02:22:34 - 02:22:38

carries other comorbidities and co infections, the

02:22:38 - 02:22:41

standard protocols do not adequately address. We

02:22:41 - 02:22:44

have pursued a series of stem cell and exosome treatments that show genuine

02:22:45 - 02:22:48

promise. But the cost is a lot and the access is extremely

02:22:49 - 02:22:52

limited and most families cannot reach these treatments without leaving the country.

02:22:54 - 02:22:57

My three requests to this committee, one microbiome and

02:22:57 - 02:23:01

gut brain research for autism, the connection between microbiome and

02:23:01 - 02:23:04

autism outcomes is not fringe science. It is emerging science that deserves

02:23:05 - 02:23:08

serious federal research investment. Families like mine are already using

02:23:08 - 02:23:12

these interventions. The research needs to catch up. To

02:23:12 - 02:23:15

create a pathway for families to access stem cell and exosome

02:23:15 - 02:23:18

therapies domestically. I'm not asking this committee to endorse

02:23:19 - 02:23:22

unproven treatments. I'm asking for research funding and grant pathway

02:23:22 - 02:23:26

that allows families who understand the risks. And have exhausted standard

02:23:26 - 02:23:28

options too. Access these treatments safely.

02:23:29 - 02:23:33

Three recognize spelling to communicate as a legitimate form of communication.

02:23:34 - 02:23:37

My son is non speaking. He has a mind, thoughts and things to say.

02:23:38 - 02:23:41

The current clinical standards that govern which communication methods receive recognition

02:23:42 - 02:23:44

and reimbursement are leaving non speaking individuals without a voice.

02:23:46 - 02:23:49

Literally. I'm genuinely excited for the parents that make up this

02:23:49 - 02:23:52

board. Thank you for hearing me and let's teach our country

02:23:52 - 02:23:54

about systems biology. Thank you.

02:24:03 - 02:24:07

Sorry, I get distracted by the comments and burst in the

02:24:07 - 02:24:09

comments being made. Next we have Caroline Rogers.

02:24:12 - 02:24:16

My name is Caroline Rodgers. I am a peer reviewed

02:24:16 - 02:24:19

author who has spent two decades investigating what may be causing

02:24:20 - 02:24:23

autism. Today I am focusing on reduced

02:24:23 - 02:24:26

synaptic pruning. A disruption in normal brain

02:24:27 - 02:24:30

development found in many people with autism. Which

02:24:30 - 02:24:34

leads to an overabundance of the neuronal connections that

02:24:34 - 02:24:37

have very high energy needs. While this is

02:24:37 - 02:24:40

a common biological finding, we still do not understand

02:24:41 - 02:24:44

why pruning is reduced or how this relates to autistic

02:24:45 - 02:24:48

outcomes. Several biological pathways that

02:24:48 - 02:24:51

reduce pruning are already under investigation.

02:24:52 - 02:24:56

Each can contribute to excess synapses and each has been

02:24:56 - 02:24:59

associated with autism. But what remains unclear

02:24:59 - 02:25:03

are the upstream factors that create these conditions.

02:25:04 - 02:25:08

In my article mitochondrial dynamics in regressive

02:25:08 - 02:25:10

autism and the surprising link to genius.

02:25:12 - 02:25:14

I outline a conceptual framework that connects

02:25:15 - 02:25:18

synaptic overabundance mitochondrial capacity

02:25:18 - 02:25:22

and developmental outcomes. The model proposes that

02:25:22 - 02:25:26

autism arises when the developing brain retains an

02:25:26 - 02:25:29

overabundance of synapses. In some children

02:25:30 - 02:25:32

where mitochondrial capacity is insufficient.

02:25:33 - 02:25:36

This imbalance can lead to regression. In

02:25:36 - 02:25:39

others, robust capacity may support exceptional

02:25:40 - 02:25:43

abilities. The common denominator is the balance

02:25:43 - 02:25:46

between synaptic load. And available

02:25:46 - 02:25:47

energetic resources.

02:25:49 - 02:25:52

This perspective may also clarify why

02:25:52 - 02:25:55

sensory features are so prominent. If complex

02:25:56 - 02:25:59

higher order circuits, such as those required for verbal

02:26:00 - 02:26:03

and social engagement are paused or shut

02:26:03 - 02:26:06

down, newly available energy may shift

02:26:07 - 02:26:09

toward a lower level sensory pathways.

02:26:10 - 02:26:13

These circuits then become highly active. Creating

02:26:14 - 02:26:17

a feedback loop in which active circuits are protected from

02:26:17 - 02:26:20

pruning. This may help explain why

02:26:21 - 02:26:24

sensory hypersensitivity is common among

02:26:24 - 02:26:28

people on the spectrum. I encourage the committee to

02:26:28 - 02:26:31

highlight research that examines the upstream

02:26:31 - 02:26:34

factors that shape pruning during early development.

02:26:35 - 02:26:38

And to consider how synaptic globe and energetic

02:26:38 - 02:26:42

capacity interact to produce the diverse

02:26:42 - 02:26:45

developmental trajectories seen across the

02:26:45 - 02:26:47

autism spectrum, including regression.

02:26:48 - 02:26:51

Exceptional abilities and everything in between.

02:26:52 - 02:26:52

Thank you.

02:26:58 - 02:26:58

Candace.

02:27:06 - 02:27:09

Thank you for the opportunity to provide public comment today. My

02:27:09 - 02:27:12

name is Candice Edwards and I am from Massachusetts and the parent of

02:27:13 - 02:27:16

an 11 year old child with autism. I want to bring attention

02:27:16 - 02:27:20

to an issue too often overlooked in autism discussions.

02:27:21 - 02:27:24

The use of seclusion and restraint in school serving children with

02:27:24 - 02:27:27

developmental disability. My son was repeatedly

02:27:28 - 02:27:31

subjected to inappropriate and traumatising restraint and seclusion

02:27:32 - 02:27:36

I was never told and I was left completely in the dark watching my child

02:27:36 - 02:27:39

crumble before my eyes until one day he found the

02:27:40 - 02:27:42

words help me. To this day he lives with the

02:27:42 - 02:27:45

trauma, a PTSD diagnosis, disruptive

02:27:46 - 02:27:49

education and ongoing mental health needs and we are not alone.

02:27:50 - 02:27:53

Federal civil rights data shows that while students with

02:27:53 - 02:27:56

disabilities make up about 15% of

02:27:56 - 02:27:59

enrollment, they account for roughly 80% of

02:27:59 - 02:28:02

restraints and 77% of seclusions

02:28:03 - 02:28:06

and the numbers are even higher in many states. This

02:28:06 - 02:28:09

disproportion demands immediate federal attention.

02:28:10 - 02:28:14

In healthcare and law enforcement restraint and seclusion are

02:28:14 - 02:28:17

governed by clear federal standard in school.

02:28:17 - 02:28:20

Calaba protection vary greatly by

02:28:20 - 02:28:23

state leaving children, educators and families at risk.

02:28:24 - 02:28:28

I respectfully urge the committee to recommend the following federal

02:28:28 - 02:28:31

actions. First require same day parent

02:28:31 - 02:28:34

notification whenever restraint seclusion or significant removal

02:28:35 - 02:28:38

occurs, especially for children who cannot communicate what

02:28:39 - 02:28:42

happened. Second, improve timely and consistent national

02:28:42 - 02:28:45

data collection. Current reporting is delayed

02:28:46 - 02:28:49

and often measures favorable informal isolation and repeated

02:28:49 - 02:28:52

removals. Third, establish a uniform

02:28:53 - 02:28:56

federal definition of seclusion and restraint as proposed in

02:28:56 - 02:28:59

the keeping all student safe act. With outstanding

02:28:59 - 02:29:03

definition, the exact same practice can be officially reported in

02:29:03 - 02:29:05

one state, but completely hidden in another.

02:29:07 - 02:29:10

Require an automatic IEP or 504 review

02:29:11 - 02:29:13

if the student is removed multiple times in a month.

02:29:14 - 02:29:17

Repeated removals show that current supports are failing and need to be

02:29:18 - 02:29:18

reevaluated.

02:29:20 - 02:29:23

Fifth on evidence based alternatives that reduce reliance

02:29:23 - 02:29:26

on restraint and seclusion including proactive

02:29:27 - 02:29:30

trauma informed neuroscience based and neurodiversity

02:29:30 - 02:29:34

affirming approaches. Prevention is far more effective than

02:29:34 - 02:29:37

repeated crisis response. And sit

02:29:37 - 02:29:40

strengthened enforcement and accountability so civil rights complaints

02:29:41 - 02:29:44

are resolved in a timely manner rather than taking years.

02:29:45 - 02:29:48

Federal law already provides authority through the IDEA.

02:29:49 - 02:29:52

Section 504 and ADA. What's missing is

02:29:52 - 02:29:56

consistent implementation. The keeping all scores safe

02:29:56 - 02:29:59

app will help close that gap and establish consistent nationwide

02:29:59 - 02:30:02

protections. Every child deserves to learn without fear and

02:30:02 - 02:30:06

former parents reserve transparency and educated

02:30:06 - 02:30:09

deserve better tools and support. Thank you for your time.

02:30:11 - 02:30:11

Thank you.

02:30:13 - 02:30:14

Erin Siri.

02:30:15 - 02:30:18

Good morning. This committee has existed for

02:30:19 - 02:30:22

25th years and under its leadership, autism has risen

02:30:23 - 02:30:23

precipitously.

02:30:25 - 02:30:28

So I'm hoping for longstanding members of this committee in particular

02:30:28 - 02:30:29

to hear what I'm about to say.

02:30:31 - 02:30:34

National childhood acting and draft in 1986 explicitly

02:30:34 - 02:30:37

provided, quote, the secretary of HHS will complete a review

02:30:37 - 02:30:41

of all relevant medical and scientific information and the

02:30:41 - 02:30:44

nature circumstances and extent of the relationship, if any, between

02:30:44 - 02:30:48

vaccines containing pertussis and the following illnesses

02:30:48 - 02:30:51

and conditions. And it listed only 11 of them. One of them being

02:30:51 - 02:30:54

autism. 1991, the Iowa conducted that review

02:30:55 - 02:30:58

and it said it couldn't find any studies with regard to the tussle.

02:30:59 - 02:31:03

And that does vaccine and autism. Fast

02:31:03 - 02:31:06

forward to 2009, the CDC and HRSA again

02:31:06 - 02:31:09

commissioned the island. To again review all the medical

02:31:10 - 02:31:13

literature with regard to plus investigation and autism in the

02:31:13 - 02:31:17

Iowa again came back and said it could now find a single study that supported

02:31:17 - 02:31:20

the that vaccine did not consult with and found one study that did

02:31:21 - 02:31:24

find an association between the Control vaccine autism. But

02:31:24 - 02:31:27

it's, it threw it out. It was quote, it lacked an unvaccinated comparison

02:31:28 - 02:31:28

population.

02:31:30 - 02:31:33

In 2014, AHRQ again

02:31:33 - 02:31:36

conducted the same review. Consider the most comprehensive review

02:31:37 - 02:31:41

as of that time on vaccine safety according to HHS. It

02:31:41 - 02:31:44

again study whether DPAP does not call autism. It

02:31:44 - 02:31:48

also looked at hype B vaccine autism. And again, Colony found one study.

02:31:48 - 02:31:52

And that study found it three times risk of Roth is amongst

02:31:52 - 02:31:55

those that that had to be in for Colonial life. So it's disability outside

02:31:55 - 02:31:59

of the University of Sternbook. In 2017, I interacted with Josh

02:31:59 - 02:32:02

Bill Gordon, former head of this committee for a long time

02:32:03 - 02:32:06

again asking, could you provide the study to show that the vaccine given the first year of

02:32:06 - 02:32:10

life six months of life? Five of them do not close out to me.

02:32:10 - 02:32:12

He never provided me a single study. In

02:32:12 - 02:32:16

2019, we sued the CDC on behalf of a nonprofit

02:32:16 - 02:32:20

ican for the studies that support the vaccines given in the

02:32:20 - 02:32:23

first six months of life. D tafi hip, IPV and PCV

02:32:23 - 02:32:26

three times each non consultant. They were not able to provide a single

02:32:27 - 02:32:30

study and re-ventilated order for itself on high blood

02:32:30 - 02:32:34

site. That is why today finally the CDC website

02:32:34 - 02:32:37

correctly states pursuant to the data quality

02:32:38 - 02:32:41

act which requires federal agencies to ensure the quality of fertility

02:32:41 - 02:32:44

utility and integrity information is disseminated to the public.

02:32:44 - 02:32:48

This webpage has been updated because the statement vaccines

02:32:48 - 02:32:51

do not result is not an evidence based

02:32:51 - 02:32:54

claim. Scientific studies have not ruled out the possibility that infant

02:32:54 - 02:32:58

vaccines contribute to development of autism. However,

02:32:58 - 02:33:01

this statement is historically being disseminated by the CDC and other federal health

02:33:01 - 02:33:04

agencies within HS prevent vaccine hesitancy.

02:33:04 - 02:33:08

Approximately one in two survey parents with district children

02:33:08 - 02:33:12

believe vaccines played a role in their child's autism often pointing to

02:33:12 - 02:33:15

vaccine to the Children's T in the first month of life deposit.

02:33:16 - 02:33:19

Earlier. That reality stands necessarily need to ask you to wrap

02:33:19 - 02:33:22

up your comment. Okay. We shouldn't ignore the parent

02:33:22 - 02:33:26

complaints. You shouldn't ignore the epic studies and we shouldn't ignore the biological basis

02:33:26 - 02:33:27

for the next. And thank you.

02:33:30 - 02:33:30

Thank you.

02:33:32 - 02:33:32

Now going to

02:33:34 - 02:33:37

hear from individuals who are here in person to provide

02:33:37 - 02:33:38

their public comment.

02:33:41 - 02:33:42

And first we have Kailey Cooper.

02:33:46 - 02:33:47

You can go to the front podium.

02:33:59 - 02:34:02

Thank you for the opportunity to speak to this committee. My name is

02:34:02 - 02:34:06

Kayleigh. The government relations lead for concerned citizens of

02:34:06 - 02:34:09

self direction in Maryland. I am also a parent of teenage twins

02:34:10 - 02:34:12

that were born three months early. Both of them have had

02:34:13 - 02:34:16

developmental disabilities since birth and both have been diagnosed

02:34:16 - 02:34:19

on the autism spectrum. One is now on a

02:34:20 - 02:34:22

1915 waiver where I work as his

02:34:22 - 02:34:25

caregiver. I'd like to highlight a simple but critical

02:34:25 - 02:34:29

truth. Parents and family caregivers should be recognized

02:34:29 - 02:34:32

as a foundational model of care for both minor

02:34:32 - 02:34:35

children with disabilities and adults with autism and

02:34:35 - 02:34:38

disability nationwide. According to

02:34:39 - 02:34:42

2025 caregiving in the US report by

02:34:42 - 02:34:45

AARP and the national alliance for caregiving

02:34:46 - 02:34:49

roughly one in four American adults is a family caregiver.

02:34:50 - 02:34:53

59 million caregivers are caring for adults ages 18

02:34:54 - 02:34:57

and older and 4 million of us are caring for a child under

02:34:58 - 02:35:01

18. Family caregivers play critical role in supporting

02:35:01 - 02:35:04

relatives with autism and other disabilities across the

02:35:04 - 02:35:08

lifespan of the individual. Parents and family caregivers

02:35:08 - 02:35:11

provide the most consistent, safest and most

02:35:11 - 02:35:14

individualized care possible. This is especially true

02:35:15 - 02:35:18

for children with autism and complex medical or behavioral

02:35:18 - 02:35:21

needs. Familiarity, trust and continuous

02:35:22 - 02:35:24

observation can mean the difference between stability and

02:35:25 - 02:35:28

crisis. No system, no matter how well

02:35:28 - 02:35:31

designed, can replicate the depth of knowledge that a parent has about their

02:35:31 - 02:35:35

child or family has for their loved one. The

02:35:35 - 02:35:38

Supreme Court established in Olmsted versus Ic that

02:35:38 - 02:35:42

individuals with disabilities have the right to receive services in the most

02:35:42 - 02:35:45

integrated setting appropriate to their needs. I

02:35:45 - 02:35:49

agree. And I would argue that the most integrated setting isn't

02:35:49 - 02:35:51

just about location. It's about

02:35:51 - 02:35:54

relationship. A child with autism being cared for by

02:35:55 - 02:35:58

a parent through intense meltdowns that include spitting,

02:35:58 - 02:36:02

fighting, punching, kicking and more a parent who knows

02:36:02 - 02:36:05

their child's nonverbal cues, their triggers and their medical

02:36:05 - 02:36:08

history. That child is receiving care in the most

02:36:09 - 02:36:12

integrated, far less restrictive environment than

02:36:12 - 02:36:15

the same child being cared for by a stranger from a home health

02:36:16 - 02:36:19

agency. When states like Maryland cut family caregiver

02:36:19 - 02:36:23

wages or caps their hours, it doesn't just destabilize the

02:36:23 - 02:36:26

individuals and their families. It pushes individuals with

02:36:26 - 02:36:30

disabilities away from their most natural and most integrated support

02:36:30 - 02:36:33

system. This is the opposite of what Olmstead intended

02:36:34 - 02:36:37

removing or limiting that continuity of care can introduce

02:36:38 - 02:36:40

trauma regression and unnecessary

02:36:40 - 02:36:43

risk. Parents and family caregivers are often the ones

02:36:44 - 02:36:47

already filling in the gaps. And most times they're doing it without financial

02:36:47 - 02:36:50

reimbursement, allowing parents and family caregivers to

02:36:51 - 02:36:54

act as paid staff in place of strangers prevents

02:36:54 - 02:36:58

crisis situations that too often can lead to emergency

02:36:58 - 02:36:59

interventions or institutionalization.

02:37:01 - 02:37:04

This approach doesn't just benefit the individual or their

02:37:04 - 02:37:07

family. It strengthens it for please wrap up your comments.

02:37:08 - 02:37:12

As you consider policy and priorities, I urge this committee to

02:37:12 - 02:37:15

recommend federal standards that protect family

02:37:15 - 02:37:18

caregivers as the foundational care model. Thank you.

02:37:20 - 02:37:21

Thank you.

02:37:23 - 02:37:24

That's it. Anthony Tucci.

02:37:33 - 02:37:36

Good morning. It's my distinct pleasure to offer these comments this

02:37:36 - 02:37:39

morning. My name is Anthony Tucci

02:37:39 - 02:37:43

and I am the proud father, a 22 year old son who

02:37:43 - 02:37:46

has profound autism and is minimally verbal. We live

02:37:46 - 02:37:49

in New York City. My brief comments

02:37:50 - 02:37:53

will offer two distinct different stories about

02:37:54 - 02:37:57

communication science involving non speakers and

02:37:57 - 02:38:00

minimally verbal individuals with autism. One of the

02:38:00 - 02:38:04

story of science at its best and the other story is

02:38:04 - 02:38:07

a story of science and its greatest discontents.

02:38:08 - 02:38:11

Communication science is one of the most powerful tools we have

02:38:12 - 02:38:14

to improve the lives of individuals.

02:38:15 - 02:38:18

With autism, especially those that are minimally verbal.

02:38:24 - 02:38:26

It all fits a way to understand support and

02:38:28 - 02:38:30

help expand human expression. At its best

02:38:31 - 02:38:34

communication science aligns with communication rights.

02:38:35 - 02:38:39

It affirms that every individual has the right to express themselves

02:38:39 - 02:38:43

and to have their preferences and choices respected. These

02:38:43 - 02:38:46

principles are embedded in the American and

02:38:46 - 02:38:49

Disabilities act, the United nations conventions of the rights

02:38:50 - 02:38:53

of persons with disabilities and the ethical foundations of clinical

02:38:53 - 02:38:56

practice. But we must also confront some hard

02:38:57 - 02:39:00

truth. One complex communication challenges are

02:39:00 - 02:39:04

difficult to study. And require a multidisciplinary research

02:39:04 - 02:39:08

that is still evolving. Research in this area is

02:39:08 - 02:39:10

slow. And significant gaps remain.

02:39:13 - 02:39:17

Non speaking autistic individual remain unrepresented in

02:39:17 - 02:39:18

research and in policy.

02:39:19 - 02:39:22

There is progress and it matters. The

02:39:22 - 02:39:25

MIDCD is advancing research priorities. For

02:39:26 - 02:39:29

minimally verbal and non speaking individual focused on

02:39:29 - 02:39:32

improving communication outcomes and engaging

02:39:33 - 02:39:34

families in settings of research.

02:39:36 - 02:39:39

The autism cares act of 2024 strengthens this effort by

02:39:39 - 02:39:43

supporting evidence based practices and expanding access to

02:39:43 - 02:39:46

communication tools and interventions. But let's now turn

02:39:46 - 02:39:50

to the other story. A story that does not reflect

02:39:50 - 02:39:54

science at its best. But instead a clear expression of science

02:39:54 - 02:39:55

and its greatest discontents.

02:39:58 - 02:40:01

This is a form of unbounded and misguided scientific

02:40:01 - 02:40:01

advocacy.

02:40:03 - 02:40:06

It resists. And acknowledging limits of knowledge

02:40:07 - 02:40:09

and existing research gaps. It seeks to

02:40:10 - 02:40:13

be legitimize communication preferences and choices of

02:40:13 - 02:40:16

non speaking individuals. That seeks to reinterpret

02:40:17 - 02:40:21

established communication rights and frameworks. The question is not

02:40:21 - 02:40:24

whether we trust communication science. It is whether we apply

02:40:24 - 02:40:28

it as it was intended. With humility. And with

02:40:28 - 02:40:30

respect for communication rights.

02:40:31 - 02:40:34

In closing, I respectfully ask the ICC to create

02:40:35 - 02:40:38

a subcommittee and to conduct workshops. To

02:40:38 - 02:40:41

strengthen federal research and policy ensuring both

02:40:42 - 02:40:45

expanded and higher quality communication research

02:40:46 - 02:40:49

and to address the risks identified in the second

02:40:49 - 02:40:52

story. This is essential to ensure

02:40:53 - 02:40:56

communication by remains what it is at

02:40:56 - 02:40:59

best. A force for human progress rounded in evidence

02:40:59 - 02:41:02

and guided by communication rights. Thank you.

02:41:04 - 02:41:04

Thank you.

02:41:06 - 02:41:07

Tony Stevens.

02:41:24 - 02:41:27

All right. Thank you for having me. After a three hour drive, I was ready to get this done.

02:41:29 - 02:41:32

All right. So my name is Cody Stephen. I'm a father of a 10 year old with

02:41:32 - 02:41:35

a developmental disorders. I'm also an uncle to a nephew

02:41:36 - 02:41:39

with autism. And I'm a caregiver and an advocate representing thousands

02:41:39 - 02:41:42

of families in Maryland with intellectual and developmental disabilities.

02:41:43 - 02:41:47

I'm also a co-leader that concerns citizens of the self-direction Maryland. And the

02:41:47 - 02:41:50

executive director of the anchor initiative, a nonprofit created on the eastern shore of

02:41:50 - 02:41:53

Maryland specifically to help support families with disabilities going through

02:41:54 - 02:41:57

crisis. What's happening in Maryland is not just a state

02:41:57 - 02:41:59

issue, as you guys know. It's a warning sign for the rest of the country

02:42:00 - 02:42:04

and a real example of how quickly community based systems can shift in ways that

02:42:04 - 02:42:06

create unintended and far reaching consequences.

02:42:07 - 02:42:10

A joining representing over 4,000 families supporting individuals with intellectual and

02:42:10 - 02:42:14

developmental disabilities, including many with autism. These

02:42:14 - 02:42:17

individuals rely on self-directed Medicaid services to live safely,

02:42:17 - 02:42:20

meaningfully and with dignity and the least restrictive, most integrated

02:42:21 - 02:42:24

setting possible. Self direction is a model that puts individuals and

02:42:24 - 02:42:27

families in control, allowing them to choose caregivers and direct care with a set

02:42:27 - 02:42:31

budget. For men with complex needs. This is what ensures the stability

02:42:31 - 02:42:34

of care environment and long term outcomes. At the

02:42:34 - 02:42:37

center of the system, it's family caregivers. They are not a backup

02:42:37 - 02:42:40

plan. They are the foundation of this care. And critical

02:42:41 - 02:42:44

often under recognized by the broader care workforce and care economy.

02:42:45 - 02:42:47

Right now this foundation is being dismantled in our state.

02:42:49 - 02:42:52

Recent policy changes in Maryland have resulted in a wave reductions to 30% or more

02:42:53 - 02:42:56

profoundly caregivers. Despite performing the same duty to the non family

02:42:56 - 02:42:58

professionals who continue to get paid a larger amount.

02:42:59 - 02:43:03

At the same time families are also captive 60 hours per week per household

02:43:04 - 02:43:07

where it used to be 80, taking 20 hours away each week.

02:43:08 - 02:43:12

The message is clear. Do the same work. For less pay

02:43:12 - 02:43:16

with less time. The consequences are already unfolding as

02:43:16 - 02:43:19

real system as real time system impact are taking place

02:43:20 - 02:43:23

and whispers of waste, fraud and abuse are constant surrounding leadership

02:43:23 - 02:43:24

running these program.

02:43:25 - 02:43:29

S are being forced out of these program providers are leaving accelerating the

02:43:29 - 02:43:32

workforce attrition and destabilization. And the system is shifting

02:43:32 - 02:43:35

towards reliance on uncompensated care for informal workforce substitution.

02:43:37 - 02:43:39

When finally caregivers are pushed out, there is no safety net in Maryland.

02:43:41 - 02:43:44

Their only outcome, such as increased emergency utilization, preventable hospitalization

02:43:45 - 02:43:48

and higher rates of institutional placement. All of which represent a

02:43:49 - 02:43:52

far greater downstream cost than the supports that are being reduced.

02:43:53 - 02:43:56

For individuals who rely on routine and trust, the loss of a

02:43:56 - 02:43:59

caregiver introduces clinical risk factors, including regression, behavioral

02:43:59 - 02:44:03

crisis and long term decline. If services or reduced

02:44:03 - 02:44:06

for or eliminated, the result will not be theoretical. There will be immediate

02:44:07 - 02:44:09

and will be life threatening. Families will break

02:44:10 - 02:44:13

individuals will lose the care that keeps them safe and the system will undermine

02:44:14 - 02:44:17

will undermine the cost effectiveness and long term sustainability.

02:44:18 - 02:44:21

This is not just about policy. It is about whether self-direction remains the model both

02:44:21 - 02:44:25

on personal centered decision making, equitable access and true program identity.

02:44:26 - 02:44:29

Because when an individuals can no longer choose their caregiver and caregivers can afford to

02:44:29 - 02:44:31

provide this care for direction no longer exist.

02:44:32 - 02:44:34

Maryland please wrap up your comments. Yes ma'am.

02:44:36 - 02:44:39

We ask you to pay attention to the gap between policy design and lived experience

02:44:40 - 02:44:43

and how quickly that gap is growing. We ask you to look into the

02:44:43 - 02:44:46

current crisis and consider federal oversight into this matter.

02:44:47 - 02:44:50

And to help us get the support that we need. Because what happens in Maryland will not

02:44:51 - 02:44:54

be contained. It's already spreading. It can become a blueprint

02:44:54 - 02:44:57

for either protecting lives or for putting them at risk. Thank you.

02:45:02 - 02:45:02

Crystal Ericson.

02:45:15 - 02:45:18

Here and members of the committee. My name is Crystal Ericson. I live

02:45:18 - 02:45:21

in Washington, D. C and come from the perspective of a sibling.

02:45:22 - 02:45:24

My younger brother Calvin is 30 years old

02:45:25 - 02:45:28

nonverbal with profound autism. He lives in Texas

02:45:29 - 02:45:32

with her father and is still on the Medicaid waiver wait list today.

02:45:33 - 02:45:36

By the time our family understood the system and that the waiver

02:45:36 - 02:45:39

wait list often starts up application she had already lost

02:45:40 - 02:45:43

years of access. Our experience is not unique.

02:45:44 - 02:45:46

I've spoken with other families and disability professionals

02:45:47 - 02:45:50

and hear the same pattern. The benefits exist. The

02:45:51 - 02:45:54

clear coordination and guidance do not. I want

02:45:54 - 02:45:58

to focus especially on the transition to adulthood. Between

02:45:58 - 02:46:02

ages 14 and 22 families face multiple changes at

02:46:02 - 02:46:05

once. School services and supplemental

02:46:05 - 02:46:08

security income is redetermined under adult criteria.

02:46:09 - 02:46:12

Families make high stake decisions about long term care

02:46:12 - 02:46:16

and continuity. There is no standardized guidance

02:46:16 - 02:46:19

on what to do or when. Families often learn

02:46:20 - 02:46:23

the rules by luck. Through word of mouth or by missing them.

02:46:24 - 02:46:25

I recommend three actions.

02:46:27 - 02:46:30

First fund benefits navigation model focused specifically on the

02:46:31 - 02:46:34

transition to adulthood. Not just employment. Measure

02:46:34 - 02:46:37

their effectiveness through improvements and enrollment rate

02:46:38 - 02:46:41

time to active benefit and total dollars and benefits access.

02:46:42 - 02:46:46

Second direct the social security administration to conduct

02:46:46 - 02:46:49

more targeted outreach on disabled adult child

02:46:49 - 02:46:52

benefits. These benefits are among the highest value

02:46:53 - 02:46:56

support available for adults. Yet are widely underutilized

02:46:56 - 02:46:59

by families across the United States. Many eligible

02:46:59 - 02:47:03

families don't claim them because they don't know if they exist or find out

02:47:04 - 02:47:07

too late. Third direct the department of health and

02:47:07 - 02:47:10

human services and the administration for community living

02:47:11 - 02:47:14

to publish standardized transition transition guidance at

02:47:14 - 02:47:17

ages 12, 14 and 17. Adult

02:47:17 - 02:47:20

planning should start as early as possible in a child's

02:47:20 - 02:47:23

lifetime. Digit cover at bare minimum

02:47:24 - 02:47:27

SSI disabled adult child benefits ABLE account

02:47:28 - 02:47:31

and state Medicaid waiver. It should clearly state the waiver

02:47:31 - 02:47:34

enrollment should happen as early as possible given many states

02:47:35 - 02:47:37

multi year wait list and clarify that many adult

02:47:38 - 02:47:41

benefits remain available regardless of prior family

02:47:41 - 02:47:44

income. These are high leverage actions.

02:47:44 - 02:47:48

They do not require new benefits, but only clearer guidance on

02:47:48 - 02:47:51

how to access them and sequence what already exists.

02:47:52 - 02:47:52

Thank you.

02:47:55 - 02:47:58

Thank you and my apologies. I skipped over Steven

02:47:58 - 02:47:58

Bess.

02:48:13 - 02:48:16

To be ignored. So thank you. I would like to thank

02:48:16 - 02:48:18

the entire committee for allowing me to speak.

02:48:20 - 02:48:23

My name is Steve Betts. My son Michael is an almost

02:48:23 - 02:48:26

24 year old. With what's now being called

02:48:27 - 02:48:29

autism. He regressed at about 18 months.

02:48:31 - 02:48:32

Like many others.

02:48:34 - 02:48:37

And although he can speak, we often have to

02:48:38 - 02:48:41

act as decoders for what he says. And interpret

02:48:41 - 02:48:45

for him what other people are saying to him. And sometimes if you want to talk about Mary

02:48:45 - 02:48:48

Kart, you get the right the first time. So anyway.

02:48:50 - 02:48:51

To get quick today.

02:48:54 - 02:48:57

I have three items that have come up since the

02:48:58 - 02:48:58

written.

02:49:14 - 02:49:17

That are often found in autism. That can affect the uptake and release of the

02:49:17 - 02:49:21

drugs. Just yesterday my son had an ear operation.

02:49:21 - 02:49:25

So it's kind of current. The support

02:49:25 - 02:49:28

staff was wonderful, but they were a little concerned and confused

02:49:29 - 02:49:32

as why took it from so long to wake up fully. My

02:49:32 - 02:49:35

wife and I weren't really that confused or concerned

02:49:36 - 02:49:39

because everybody in our family with the same genetics had the same profile

02:49:41 - 02:49:44

when going under anesthesia. Six hours later he was

02:49:44 - 02:49:47

perfectly able to move. It ended up well. He was doing well right

02:49:47 - 02:49:50

now and being watched by two members of my family.

02:49:54 - 02:49:57

So it's important topic to address as very few parents even know to

02:49:58 - 02:50:01

talk to their doctors about it and depending on the seizures, it can

02:50:01 - 02:50:04

be life or death thing. I had download information

02:50:05 - 02:50:06

for a dentist from

02:50:09 - 02:50:11

the taco website to teach her how to.

02:50:13 - 02:50:15

Teach her and how not to harm my son. Then I changed dentists.

02:50:16 - 02:50:19

Anyway, the next is continuity of

02:50:19 - 02:50:21

care. As I've noticed, a lot of us are getting older.

02:50:23 - 02:50:25

So the folks have been going to conferences with forever.

02:50:26 - 02:50:30

Have a little more on the gray hair side than they used to and just

02:50:30 - 02:50:33

a little bit older. We've been doing this for 22 years so it works out

02:50:33 - 02:50:37

the way. But he's always had a team of doctors and practitioners

02:50:37 - 02:50:40

to help them with the underlying medical conditions associated with autism.

02:50:42 - 02:50:45

Our concern is that if or when something happens to us.

02:50:46 - 02:50:50

The state will substitute their experts for hours and he will immediately have

02:50:50 - 02:50:51

negative consequences.

02:50:55 - 02:50:58

Since most doctors choose to be ignorant about the underlying medical issues with

02:50:58 - 02:51:02

autism. They could look at all the research that other

02:51:02 - 02:51:04

doctors look at. They choose not to.

02:51:06 - 02:51:10

It's extremely unlikely that they will continue with medicine supplements and other

02:51:10 - 02:51:13

treatments that keep my child healthy and reasonably stable.

02:51:15 - 02:51:18

One of the items he gets regularly is helps with his

02:51:18 - 02:51:21

speech. If he doesn't get that for a week, he loses words.

02:51:24 - 02:51:24

And

02:51:26 - 02:51:30

that covers that one. And just I'll just name it out loud. The last

02:51:30 - 02:51:33

is compounding due to her supplements and medicines due to food

02:51:33 - 02:51:36

allergies. We can't always get things off rack.

02:51:37 - 02:51:40

That are safer and to have. Insurance does not pay for

02:51:41 - 02:51:44

it. There are mechanisms that perhaps this committee could recommend. That would

02:51:44 - 02:51:47

allow that to happen. Thank you very much again for allowing me to

02:51:48 - 02:51:48

speak.

02:51:50 - 02:51:51

Thank you. Next we have

02:51:52 - 02:51:53

saran.

02:52:05 - 02:52:09

I am Sarah Kearnian, founder of Inchtan's and

02:52:09 - 02:52:11

a mother of two children with profound nonseeking autism.

02:52:12 - 02:52:16

Millie, who is 11 and Mac who is eight. Inch stones

02:52:16 - 02:52:18

is a platform that I built. To document what institutions

02:52:20 - 02:52:22

routinely minimize the daily logistical truth.

02:52:23 - 02:52:26

Of profound disability. The systemic decision that

02:52:26 - 02:52:30

intensify harm. I published through insulin

02:52:30 - 02:52:32

sub stack and the InShone podcast and the work is

02:52:32 - 02:52:36

ongoing. The work is current. The work is brown

02:52:36 - 02:52:37

in what families are living right now.

02:52:39 - 02:52:42

And shouldn't exist because families like mine have learned the very hard way that

02:52:42 - 02:52:46

awareness is not the same as safety. Access

02:52:46 - 02:52:49

or outcomes. My work is not theoretical. It is

02:52:49 - 02:52:50

not retrospective.

02:52:52 - 02:52:52

It is not sanitized.

02:52:54 - 02:52:56

Through writing and recorded conversations with families in the

02:52:57 - 02:52:59

trenches, I track repeating patterns that determine whether a child

02:53:01 - 02:53:03

receives communication access appropriate placement.

02:53:04 - 02:53:06

Meaningful education. And basic dignity.

02:53:08 - 02:53:11

Whether they are denied services warehouse restrained isolated.

02:53:12 - 02:53:13

And pushed towards crisis.

02:53:15 - 02:53:17

These are not rare exception.

02:53:18 - 02:53:21

You are repeatable failure mode produced by predictable incentives.

02:53:23 - 02:53:26

Fractured accountability and policies that assume families have infinite

02:53:27 - 02:53:29

money. Legal literacy and emotional capacity.

02:53:31 - 02:53:34

What this committee needs and what families across the country are asking this committee to

02:53:34 - 02:53:37

receive is what is often most missing

02:53:38 - 02:53:38

in formal hearings.

02:53:40 - 02:53:43

Ground truth intelligence from families living the consequences

02:53:43 - 02:53:46

now, a clear articulation from families.

02:53:48 - 02:53:51

Where systems fail at execution, IEPs

02:53:51 - 02:53:54

eligibility placement communication supports and safety

02:53:55 - 02:53:59

logically sound actionable recommendations rooted in what actually

02:53:59 - 02:54:02

happens in homes and schools. A perspective that cannot be

02:54:03 - 02:54:06

replicated by institutional summaries or abstract

02:54:06 - 02:54:09

language. The IACC's mandate is

02:54:09 - 02:54:11

to improve outcomes for all autistic

02:54:12 - 02:54:14

individuals, including those with the highest support

02:54:14 - 02:54:18

needs. That mandate cannot be fulfilled without the voices

02:54:18 - 02:54:21

of the families whose lives are shaped by these exact

02:54:21 - 02:54:25

decisions every day. This committee does not need another

02:54:25 - 02:54:28

overview. It needs truth with operational clarity.

02:54:29 - 02:54:32

The kind that systems often avoid because it forces

02:54:33 - 02:54:34
accountability. Thank you.

02:54:36 - 02:54:36
Thank you.

02:54:40 - 02:54:40
John Martin.

02:54:49 - 02:54:52
Upon realizing that autism is the

02:54:52 - 02:54:55
epidemic, it was important to

02:54:56 - 02:54:59
discern whether there is an infectious component.

02:55:01 - 02:55:04
Now I've described in the written comment

02:55:05 - 02:55:08
research on viruses causing chronic

02:55:09 - 02:55:09
vacation drug.

02:55:11 - 02:55:14
Directly to the culturing of the same type of

02:55:15 - 02:55:15
viruses.

02:55:17 - 02:55:20
From the majority of well over 100 children

02:55:21 - 02:55:24
with autism. Now these viruses

02:55:25 - 02:55:28
are atypical in that they do not normally

02:55:29 - 02:55:29

cause inflammation.

02:55:32 - 02:55:34

To hallmark a most infectious diseases.

02:55:36 - 02:55:39

I refer to these viruses as being

02:55:39 - 02:55:40

stealth adapted.

02:55:43 - 02:55:46

Best studied stealth adapted viruses. Are

02:55:47 - 02:55:49

derived from the cytomegaloviruses.

02:55:51 - 02:55:54

Of the types of monkeys. That were used

02:55:54 - 02:55:58

to their kidneys from the monkeys were used to make

02:55:59 - 02:56:01

polio vaccines. These viruses have

02:56:02 - 02:56:04

lost or changed

02:56:06 - 02:56:09

the few pots that the cellular

02:56:09 - 02:56:12

immune system normally recognize.

02:56:13 - 02:56:15

But they can also incorporate.

02:56:16 - 02:56:18

Additional genetic sequences

02:56:20 - 02:56:21

from cells and from bacteria.

02:56:24 - 02:56:26

These viruses are now infecting many people

02:56:27 - 02:56:28

and can produce symptoms.

02:56:30 - 02:56:32

Especially when the brain is involved.

02:56:35 - 02:56:36

Now.

02:56:38 - 02:56:41

The animals that have shown that these viruses

02:56:43 - 02:56:46

can pass the placenta and affect the developing

02:56:46 - 02:56:46

brain.

02:56:50 - 02:56:51

We can stay clinically insignificant

02:56:53 - 02:56:56

until the child's brain is called upon to engage

02:56:57 - 02:56:59

in more advanced functions such as

02:57:00 - 02:57:03

speaking. And interpersonal interactions.

02:57:05 - 02:57:08

Now on a more encouraging note also described

02:57:09 - 02:57:10

in the handout that I

02:57:10 - 02:57:13

provided. The

02:57:14 - 02:57:17

self adapted viruses can be suppressed

02:57:17 - 02:57:17

by

02:57:20 - 02:57:22

non immunological names. They can be suppressed by

02:57:23 - 02:57:24

an alternative

02:57:25 - 02:57:28

cellular energy or eight

02:57:28 - 02:57:32

party. This is a form of which

02:57:32 - 02:57:35

the body receives cellular energy different

02:57:36 - 02:57:39

than from the calories in food. And there are

02:57:39 - 02:57:41

various ways of enhancing

02:57:43 - 02:57:46

this ace pathwork. What the

02:57:46 - 02:57:49

IACC committee can do is request

02:57:50 - 02:57:53

government virologists to review the information

02:57:54 - 02:57:56

on stealth adapted viruses.

02:57:58 - 02:57:58

And to help

02:57:59 - 02:58:03

in patients, their parents and other caregivers.

02:58:04 - 02:58:07

Understand this alternative cellular energy pathway.

02:58:09 - 02:58:11

As a natural non-inflammatory

02:58:13 - 02:58:16

defense mechanism that can provide benefits to

02:58:16 - 02:58:17

patients.

02:58:23 - 02:58:23

Thank you.

02:58:25 - 02:58:27

Last we have Carla Harris.

02:58:44 - 02:58:47

Hello and thank you for this opportunity to spotlight conditions that

02:58:48 - 02:58:51

imitate autism. My goal is to convince you to take

02:58:52 - 02:58:55

action to ensure these conditions that mimic autism

02:58:56 - 02:58:59

are ruled out or confirmed before a diagnosis of

02:58:59 - 02:59:02

autism is made. Seven key questions for

02:59:03 - 02:59:06

ASD autism research are outlined in the

02:59:07 - 02:59:11

IAC's strategic plan for ASD. The first question

02:59:11 - 02:59:14

is how can we improve identification of autism?

02:59:15 - 02:59:18

A review of recent publications show part of the answer must be

02:59:19 - 02:59:23

by first ruling out or confirming conditions that imitate

02:59:23 - 02:59:26

autism. A growing list of studies and reports shows

02:59:27 - 02:59:30

there are more than 10 conditions that imitate autism.

02:59:31 - 02:59:35

Many of them also show that the symptoms that were diagnosed as

02:59:35 - 02:59:38

ASD are reversed when the conditions are properly

02:59:38 - 02:59:41

treated. Examples of conditions that imitate

02:59:42 - 02:59:44

autism include T gondia

02:59:44 - 02:59:48

infection, excess free glutamate, vitamin D deficiency

02:59:49 - 02:59:50

and lead and mercury toxicity.

02:59:52 - 02:59:56

As support I offer, the CDC reports over 40 million

02:59:56 - 02:59:59

people in the u. S are infected with t gondii

02:59:59 - 03:00:02

from cats and foods. Most of us know

03:00:03 - 03:00:06

ultra processed foods are a primary source of excess free

03:00:06 - 03:00:06

glutamate.

03:00:08 - 03:00:11

But he found the lower the vitamin D level, the more severe

03:00:12 - 03:00:15

the core symptoms of ASD. Also, a

03:00:15 - 03:00:19

study showed there was decline in the autistic symptoms

03:00:20 - 03:00:23

when, with the decrease in the lead and mercury levels in blood.

03:00:25 - 03:00:27

These treatable conditions do not cause autism

03:00:28 - 03:00:31

because autism is lifelong. Their symptoms

03:00:32 - 03:00:35

imitate autism, inflating autism diagnoses

03:00:36 - 03:00:39

even faster than genetics. Not to mention the impact on

03:00:40 - 03:00:43

elementary school classrooms. So how can these conditions be

03:00:43 - 03:00:46

detected before an autism diagnosis is made?

03:00:47 - 03:00:50

I'm glad you asked. Recent studies and reports

03:00:50 - 03:00:50

dictate

03:00:53 - 03:00:55

ASAP pivoting. That is pivoting from the current

03:00:56 - 03:00:59

autism diagnosis protocol to an autism

03:00:59 - 03:01:03

symptom evaluation protocol,

03:01:03 - 03:01:06

ASEP. ASEP would include an evaluation for

03:01:06 - 03:01:10

autism, but focused primarily on documenting

03:01:10 - 03:01:14

dietary habits, infection status, nutritional

03:01:14 - 03:01:17

levels and environmental factors to rule

03:01:17 - 03:01:20

out or confirm conditions that imitate

03:01:21 - 03:01:22

autism. So what needs to be done?

03:01:24 - 03:01:28

Restructure and broaden pediatrician guidelines for

03:01:28 - 03:01:31

diagnosing autism around an autism

03:01:32 - 03:01:36

symptom evaluation protocol and most

03:01:36 - 03:01:39

importantly educate parents about conditions that

03:01:39 - 03:01:41

imitate autism. Thank you very much.

03:01:46 - 03:01:49

That concludes our public comments. I again want to thank all of those that

03:01:49 - 03:01:52

provided public comments and share to your perspective

03:01:53 - 03:01:56

and recommendations to the committee. We are now going to

03:01:57 - 03:01:59

have committee discussion about the public

03:01:59 - 03:02:00

comments.

03:02:02 - 03:02:04

And open it up for that session.

03:02:06 - 03:02:09

First, I just wanted to thank again everyone who made public comments

03:02:11 - 03:02:12

both here today and also submitting comments

03:02:13 - 03:02:16

online. Your perspectives and contributions are

03:02:16 - 03:02:19

invaluable and we really appreciate the

03:02:19 - 03:02:22

time, especially those of you supporting individuals with autism

03:02:23 - 03:02:26

who are short on time. So thank you. I want to open up for

03:02:26 - 03:02:27

committee discussion.

03:02:29 - 03:02:32

I think we should focus on sort of what we heard today and also

03:02:33 - 03:02:34

what was in the written comments.

03:02:36 - 03:02:40

I think much of it resonates with some of the priorities

03:02:40 - 03:02:43

and interest rates by the public members. But let's open it up for

03:02:43 - 03:02:46

discussion. Sorry. And just one logistics note, if you

03:02:46 - 03:02:50

could, if you're when you speak, if you can say your

03:02:50 - 03:02:52

names or note takers are able to make sure that we attribute

03:02:53 - 03:02:56

comments appropriately. So if you're in the room, you can raise your hand. If you're on

03:02:56 - 03:02:59

zoom, you can raise your zoom hand and we'll open it up to

03:02:59 - 03:03:02

comments. Can we see the people on zoom now on the screen?

03:03:05 - 03:03:08

Yes, we can try to get that pulled up, but I'll just note that Allison Marvin

03:03:09 - 03:03:10

online has her hand up.

03:03:16 - 03:03:18

Why don't we start with Allison Marvin? Then?

03:03:26 - 03:03:29

From the Social Security Administration. I just wanted to respond

03:03:29 - 03:03:32

to one of the themes I noted in the public comments

03:03:33 - 03:03:36

relating to the vitally important issue of the transition to

03:03:36 - 03:03:40

adulthood. There were several comments noting that it was difficult

03:03:40 - 03:03:43

to find information about the disabled adult

03:03:43 - 03:03:46

child, the AC benefits, which are social security

03:03:47 - 03:03:50

disability insurance, SSDI payments to adults

03:03:50 - 03:03:53

with disabilities that began before age 22

03:03:54 - 03:03:56

based on a parent's social security

03:03:56 - 03:03:59

record. In response to your comments,

03:03:59 - 03:04:03

SSA is going to revise the SSA.gov.

03:04:05 - 03:04:08

Web page of transition resources to add links to make

03:04:08 - 03:04:11

it easier to learn about these DAC benefits.

03:04:13 - 03:04:16

In the meantime there are some resources relating to DAC

03:04:16 - 03:04:19

benefits including information on ssa.gov

03:04:20 - 03:04:24

family. so just look out for SSA.gov

03:04:26 - 03:04:29

for those transition resources and it will be updated. I don't have a time

03:04:30 - 03:04:33

frame yet, but that is on the list of things to

03:04:33 - 03:04:36

get fixed up. I do also want to recommend that people apply

03:04:37 - 03:04:38

for my social security account

03:04:40 - 03:04:43

and you can receive personalized information about any

03:04:43 - 03:04:46

application status of any applications, estimate future

03:04:46 - 03:04:49

benefits, manage benefits already received

03:04:50 - 03:04:53

and it's available for people who, whether they receive benefits or not.

03:04:53 - 03:04:54

Thank you.

03:04:59 - 03:05:01

Jennifer Fill. Er.

03:05:02 - 03:05:05

I would like to just point out that on the topic of regression

03:05:06 - 03:05:09

that it is not a fringe comment among the

03:05:10 - 03:05:13

259 comments that have been submitted. Nearly

03:05:13 - 03:05:17

one in five commenters bring it up. And that it is heavily

03:05:17 - 03:05:20

concentrated among the highest support needs and profound autism

03:05:21 - 03:05:22

diagnoses.

03:05:32 - 03:05:35

I really appreciate all the comments and I want to echo when people are

03:05:36 - 03:05:38

talking about waivers profound autism alternative

03:05:39 - 03:05:42

communication and support for caregivers. It's a crisis

03:05:43 - 03:05:47

and it's an honor to hear their comments and know they need the

03:05:47 - 03:05:48

help and we want to get that for them.

03:05:52 - 03:05:52

Scott Robertson.

03:05:55 - 03:05:58

Thank you Scott Robertson at the US Department of Labor

03:05:59 - 03:06:02

and I just wanted to note that the

03:06:03 - 03:06:06

written comments have about 81 mentions of employment or careers

03:06:07 - 03:06:08

and especially emphasizing

03:06:10 - 03:06:13

which particular resonated with me is the difficulties in sustaining employment

03:06:13 - 03:06:16

and accessing employment that fits folks skills interests

03:06:16 - 03:06:20

talents. So we are hard at work at

03:06:20 - 03:06:23

that and we will continue to work on that and prove the access and opportunity

03:06:25 - 03:06:27

for all people in the office inspection and other folks with

03:06:27 - 03:06:31

disabilities. And I'm really, really happy that folks continue to emphasize

03:06:31 - 03:06:34

that in the written comments to the ICC

03:06:36 - 03:06:39

and OS and others accountable in our federal partners and other organizations

03:06:39 - 03:06:43

we collaborate with to continue to improve employment and

03:06:43 - 03:06:44

career pathways for

03:06:46 - 03:06:49

all. People on the autism spectrum and to have the opportunities

03:06:49 - 03:06:51

that they should be able to access that we should be able to access.

03:06:53 - 03:06:54

Thank you. Tracy Sutts.

03:06:56 - 03:06:59

Thank you. I'd like to respond to Mr. Aaron

03:06:59 - 03:07:01

series comment in regards to.

03:07:04 - 03:07:07

A safety study being done on vaccinated versus

03:07:08 - 03:07:11

unvaccinated individuals with autism. There was a study

03:07:11 - 03:07:14

done out of Henry Ford in Michigan

03:07:15 - 03:07:17

and it was a vax versus unvacci, but it was

03:07:18 - 03:07:21

unpublished. But it did show a significant

03:07:22 - 03:07:26

entry rate in regards to allergies,

03:07:26 - 03:07:28

asthma, cancer, addh

03:07:29 - 03:07:33

autism in many other conditions that were

03:07:33 - 03:07:35

way more profound if the child was

03:07:35 - 03:07:38

vaccinated. And this was taken over a 10 year period of

03:07:38 - 03:07:41

time. And I do feel that this is a subject

03:07:42 - 03:07:45

that deserves to be addressed in actual study

03:07:46 - 03:07:49

deserves to be done for these families, for these children, for the

03:07:49 - 03:07:52

health and welfare of them and to stop this epidemic. Thank you.

03:07:54 - 03:07:56

Dr. Mumper online.

03:07:58 - 03:08:01

I want to express appreciation for the amount of

03:08:02 - 03:08:05

suffering that was described today by

03:08:06 - 03:08:08

parents and clinicians with regards to profound

03:08:09 - 03:08:12

autism. Our chair

03:08:13 - 03:08:15

Dr. Foley has identified

03:08:16 - 03:08:19

this issue as something really significant for the committee and I hope

03:08:19 - 03:08:22

that by the end of the day today we can actually move

03:08:23 - 03:08:26

forward with some action so that these families

03:08:27 - 03:08:29

know that we have heard their concerns

03:08:30 - 03:08:33

and are going to address that as a high priority.

03:08:37 - 03:08:37

Thank you.

03:08:39 - 03:08:42

For Dr. Rawson and then Ginger Taylor.

03:08:44 - 03:08:47

S looking at the public comments. So 22% comments

03:08:48 - 03:08:52

talked about etiology causation. So I think one of the issues of autism

03:08:52 - 03:08:54

is because we don't know exactly what causes it. It makes it hard to

03:08:56 - 03:08:59

know what to do as far as treatments and testing and so forth. And

03:08:59 - 03:09:02

a lot of themes to the comments were calls for environmental immune

03:09:02 - 03:09:04

metabolic and gene environment

03:09:05 - 03:09:08

research. So I think that's a high priority. The second most common

03:09:09 - 03:09:12

comment was in 15% of cases was profound

03:09:12 - 03:09:15

high support autism. So I think that's very important because

03:09:16 - 03:09:19

I think a lot of people view autism is one disorder

03:09:19 - 03:09:23

where it's a spectrum of course, right where some people are very high functioning, some people have

03:09:23 - 03:09:25

profound autism and need the support that they

03:09:25 - 03:09:28

deserve. And the third most common comment was on adult

03:09:28 - 03:09:32

services housing long term care. So a lot of our kids are getting older

03:09:32 - 03:09:36

aging out of school. I see this all the time in practice for kids

03:09:36 - 03:09:39

after 22. There's nothing for them. The parents don't know what to do. There's no

03:09:40 - 03:09:43

really good support systems in place. I think that's the high priority as well.

03:09:44 - 03:09:44

Thank you.

03:09:48 - 03:09:50

I want to think this is Harris for her comments because she has

03:09:52 - 03:09:55

highlighted a kind of a glaring problem

03:09:56 - 03:09:59

in that we have described my

03:09:59 - 03:10:02

son's conditions were described in her list.

03:10:03 - 03:10:06

And she's looking at. It kind of backwards. Family said people

03:10:07 - 03:10:09

looking at it like here are causes of autism

03:10:10 - 03:10:13

if we treat these causes of autism the autism goes away. And

03:10:13 - 03:10:16

she's saying there were autism in the first place. They were sick.

03:10:17 - 03:10:20

They need to be treated. And part of that is that we've never defined

03:10:21 - 03:10:24

autism. 1943. We've gotten a scripture

03:10:24 - 03:10:24

behavior.

03:10:26 - 03:10:30

All efforts have been a quarter century, but we still not have

03:10:31 - 03:10:34

no biomarkers. We have no autism. There's no blood tests. There's no

03:10:35 - 03:10:38

it's not an objective physical thing. It's a description of

03:10:38 - 03:10:41

behavior which piggybacks on what Dr. Reznow

03:10:42 - 03:10:45

is saying that we need to actually know what's going on in biology of these kids

03:10:46 - 03:10:49

before we can. Move forward. And that has been done.

03:10:50 - 03:10:52

By parents and dissident doctors, but not by this committee.

03:10:54 - 03:10:55

John Rodakis.

03:10:58 - 03:11:02

Thank you to Ms. Harris to bring that up and earlier we heard from

03:11:02 - 03:11:05

two other parents Mr. Kalamajik and

03:11:05 - 03:11:08

Mr. Vinemiller who both described treatments that

03:11:09 - 03:11:11

profoundly help their significantly help their

03:11:12 - 03:11:15

children. What ginger says is right. Autism is a behavioral

03:11:15 - 03:11:18

description. It's not a description of underlying biology

03:11:18 - 03:11:21

condition. And so, you know from that perspective

03:11:22 - 03:11:25

a it's not surprising that parents over here or over there notice that this thing

03:11:25 - 03:11:28

helps their child. But secondly it really just underscores the

03:11:29 - 03:11:32

heterogeneity and the near impossibility of conducting valid

03:11:32 - 03:11:35

clinical trials when you have children with

03:11:35 - 03:11:38

vastly different biological underlying conditions

03:11:39 - 03:11:43

and you're lumping them together under a symptomatic label and

03:11:43 - 03:11:46

asking did it help redeem it help. So

03:11:46 - 03:11:49

we have a system that works well for some conditions but it's not working

03:11:49 - 03:11:53

for autism. So I'm encouraged to

03:11:53 - 03:11:55

continue to explore this with hopefully with the FDA. Thank you.

03:11:59 - 03:12:02

Dr. Rasan. A I want to follow up on the heterogeneity of

03:12:03 - 03:12:06

autism. It's very genius. And there's a wide spectrum of not

03:12:06 - 03:12:09

only symptoms but also medical problems. And that's why a lot of

03:12:09 - 03:12:13

autism studies looking at treatments have failed because they take all cambers of

03:12:13 - 03:12:16

autism and study particular treatment and say, saying let's study

03:12:17 - 03:12:20

the group of kids and see what the treatment does for speech or let's see what this does for this

03:12:21 - 03:12:24

underlying metabolic problem. As opposed to taking all comers. So I think

03:12:24 - 03:12:28

we need to be very careful research and make sure that you're studying the group that you want to

03:12:28 - 03:12:31

look at. If you just take all comers, that's very

03:12:31 - 03:12:34

heterogeneous and it sometimes makes it difficult to find what

03:12:35 - 03:12:38

treatments are going to work. And plus the testing is going to be a lot different

03:12:38 - 03:12:42

in different individuals as well because some kids will have a certain problem with other ones

03:12:42 - 03:12:45

don't. So that involves doing a lot of testing, laboratory testing

03:12:46 - 03:12:49

and so forth that I think a lot of kids don't really get at least in our healthcare system

03:12:49 - 03:12:50

at this point.

03:12:52 - 03:12:55

I'm going to just speak in my capacity also as a member briefly. I think we

03:12:56 - 03:12:59

hear over and over again both in this room and also in the written

03:12:59 - 03:13:02

comments that we received and also in our work as either clinicians or

03:13:02 - 03:13:06

advocates that autism is a whole body

03:13:06 - 03:13:09

disorder and we have evidence that has emerged

03:13:10 - 03:13:12

over the past few years that confirms that

03:13:14 - 03:13:17

we have immune system differences, mitochondrial functioning

03:13:18 - 03:13:20

differences, cellular metabolic

03:13:20 - 03:13:24

differences, increased rates of gastrointestinal disorders

03:13:24 - 03:13:28

and other comorbidities. We have a situation again where

03:13:28 - 03:13:31

autism as a whole body disorder. And I think our community is really

03:13:32 - 03:13:35

craving for our medical system to catch

03:13:35 - 03:13:38

up with that knowledge and to provide effective treatments

03:13:39 - 03:13:42

for co-occurring conditions. And with respect to research, I will also

03:13:42 - 03:13:45

add we need cohorts. We need sub

03:13:45 - 03:13:49

cohorts in research. The heterogeneity issue has been raised over

03:13:49 - 03:13:52

and over again today and in our community in

03:13:52 - 03:13:54

general. We need cohorts. We need

03:13:55 - 03:13:55

biomarkers

03:13:58 - 03:14:01

and we need to frame our research endeavors going forward

03:14:02 - 03:14:03

in that framework. Thank you.

03:14:06 - 03:14:07

So wider light.

03:14:09 - 03:14:13

I want to thank. Everyone who made comment public. It was

03:14:13 - 03:14:15

really incredible to hear and to read.

03:14:17 - 03:14:20

It was I've made public comment for many times here at the ICC before I was a member

03:14:21 - 03:14:25

and always wondered, I have to say if the IECC members read it.

03:14:25 - 03:14:28

I know from people who I've spoken with here and I can speak for

03:14:28 - 03:14:32

myself. It was enthralling and resonated with me as a

03:14:32 - 03:14:35

parent. And again, thank you for your thoughtfulness. I wanted to

03:14:35 - 03:14:39

comment specifically with Dr. Stahmer and

03:14:39 - 03:14:42

doctor I think and Dr. Gassner. I really

03:14:42 - 03:14:45

appreciated what you wrote specifically about research that also

03:14:45 - 03:14:48

examines the experiences of autistic families and individuals saying

03:14:49 - 03:14:52

to our extreme administrative burden in navigating systems without effective

03:14:52 - 03:14:53

or meaningful supports.

03:14:55 - 03:14:58

And what really resonated me was the part where you wrote requests for nonessential information

03:14:58 - 03:15:02

particularly where the condition does not change is important. Navigating these

03:15:02 - 03:15:05

systems pulse parents from the workforce and from this simple gift of

03:15:06 - 03:15:09

parenting. So many times I look at my son

03:15:09 - 03:15:12

and I think I just want to be his mother right now. And I have

03:15:13 - 03:15:16

so many other things to do and it breaks my heart. We should

03:15:16 - 03:15:20

not do that to parents and other caregivers. We deserve to be

03:15:20 - 03:15:23

parents and our children need us as parents, not just

03:15:23 - 03:15:26

administrators. So I want to thank you for

03:15:26 - 03:15:29

that. I just want to be joshua's mother and sit with him and watch

03:15:29 - 03:15:33

TV or play games or take him somewhere. And so many times these things get

03:15:33 - 03:15:36

in the way. I just also want to thank everyone who came here

03:15:36 - 03:15:39

today. Obviously there are things we need to discuss about

03:15:40 - 03:15:42

Maryland, but then also not Maryland. The rest of the country

03:15:43 - 03:15:47

that is experiencing issues with Medicaid and implementation. And

03:15:47 - 03:15:50

again also a person who spoke about seclusion and restraint.

03:15:51 - 03:15:55

That is something that I put under public safety. We will not only be

03:15:55 - 03:15:58

looking at wandering, which we should also look at, but also

03:15:59 - 03:16:02

a larger umbrella of public safety. I had a similar

03:16:02 - 03:16:02

situation

03:16:04 - 03:16:07

maybe not to the extent that you described, but that's not something I'm letting go as

03:16:07 - 03:16:10

well. So thank you everyone for your thoughtful comments. It means a lot.

03:16:12 - 03:16:14

Okay, that concludes our morning session.

03:16:16 - 03:16:19

We'll take a break for lunch until 1:15pm and then we'll come back and

03:16:19 - 03:16:22

have a series of presentations regarding the proposals

03:16:23 - 03:16:26

that were provided to the committee last week

03:16:26 - 03:16:28

and were made publicly available on the IACC

03:16:29 - 03:16:31

website. Please return promptly at

03:16:32 - 03:16:35

1:15pm. We have a lot of work to do for the

03:16:35 - 03:16:36

autism community. Thank you.

04:17:53 - 04:17:57

Thanks everyone. So, I'll hand it over to you to start the committee

04:17:57 - 04:17:57

business.

04:17:59 - 04:18:01

Okay. Thank you everyone for being here.

04:18:04 - 04:18:06

The working portion of the day is going to

04:18:06 - 04:18:10

begin. We have three topic presentations

04:18:10 - 04:18:13

this afternoon. The first on medical comorbidity

04:18:14 - 04:18:17

and addressing diagnostic overshadowing and diagnostic lumping.

04:18:18 - 04:18:21

Presented by Laura Solini. The second on a potential

04:18:21 - 04:18:25

recommendation to adopt profound autism as a designation for

04:18:25 - 04:18:28

policy and research across hhs presented by me.

04:18:30 - 04:18:33

And the final topic is a set of proposals to decrease the risk of death

04:18:33 - 04:18:37

in connection with wandering and elopement. And to decrease the

04:18:37 - 04:18:40

risk of those occurrences overall. Presented by

04:18:40 - 04:18:41

Crystal Higgins.

04:18:43 - 04:18:47

Each of these proposals was spearheaded by the individuals presenting them.

04:18:48 - 04:18:51

Laura saline created and wrote attachments a and b. I created

04:18:52 - 04:18:55

attachments C and D. Each topic presentation

04:18:55 - 04:18:59

will be followed by a discussion period. This will be

04:18:59 - 04:19:02

the work of the committee. To discuss and further explore

04:19:02 - 04:19:05

these proposals. With the opportunity to express

04:19:06 - 04:19:08

opinions and offer potential changes.

04:19:09 - 04:19:11

Robust debate and engagement is crucial.

04:19:13 - 04:19:16

To the federal members in particular. We need your

04:19:17 - 04:19:19

expertise and we want your feedback.

04:19:21 - 04:19:23

Not only today but going forward.

04:19:24 - 04:19:28

After each of the topic presentations we will vote together

04:19:29 - 04:19:32

and we will vote on each of the attachments separately.

04:19:34 - 04:19:37

And also depending on whatever additions or

04:19:37 - 04:19:38

changes were suggested by the committee.

04:19:41 - 04:19:41

After that period

04:19:43 - 04:19:46

in the afternoon of the voting, we will shift gears and we will

04:19:46 - 04:19:50

discuss the possible creation of working

04:19:50 - 04:19:50

groups.

04:19:52 - 04:19:55

So with that, I just want to check in and see if Laura Cellini

04:19:55 - 04:19:59

is ready virtually to begin the

04:19:59 - 04:19:59

presentation.

04:20:02 - 04:20:04

Sylvia, I am ready if you guys want to pull up the slides.

04:20:22 - 04:20:24

Okay. The first page please of the deck.

04:20:25 - 04:20:28

Great. Thank you. Good afternoon. Once again, my name is Laura

04:20:29 - 04:20:31

Saline. I'm a public member. Thank you for letting me join you

04:20:31 - 04:20:34

today. This presentation focuses on co

04:20:35 - 04:20:37

occurring medical conditions and autism and the need for more

04:20:38 - 04:20:40

consistent clinical recognition and follow through.

04:20:41 - 04:20:44

Especially for individuals with the highest support needs.

04:20:45 - 04:20:49

This theme was repeatedly mentioned in both public comments and during

04:20:49 - 04:20:52

introductory presentations by new members this morning.

04:20:53 - 04:20:56

In this presentation you will see three shared ideas.

04:20:57 - 04:21:00

First, the medical standard of care does not change

04:21:01 - 04:21:04

because a patient has autism. Second

04:21:05 - 04:21:08

diagnostic overshadowing is a real patient safety

04:21:09 - 04:21:11

and care quality problem. And third

04:21:12 - 04:21:15

certain clinical triggers may be more common in autism

04:21:16 - 04:21:17

and should reliably prompt further

04:21:18 - 04:21:21

evaluation. That is the framework for everything that is going to

04:21:21 - 04:21:25

follow in this presentation. The basic point is

04:21:25 - 04:21:28

straightforward. Autism can change how symptoms show

04:21:29 - 04:21:32

up, sometimes referred to as atypical.

04:21:33 - 04:21:36

But it should not change whether those symptoms are taken seriously

04:21:37 - 04:21:40

by clinicians. In actuality, if an individual

04:21:40 - 04:21:44

has autism, it should actually raise the threshold for

04:21:44 - 04:21:47

careful and structured evaluation. Having a

04:21:47 - 04:21:51

diagnosis of autism does not lower the standard for a

04:21:51 - 04:21:54

clinical response. The recommended action

04:21:54 - 04:21:57

under considerations in attachments a and B

04:21:58 - 04:22:01

lay out a practical response through two complementary

04:22:02 - 04:22:04

federal lanes. HRSA, which is the health

04:22:04 - 04:22:08

resources, health resources services

04:22:08 - 04:22:12

administration for clinician training workforce

04:22:12 - 04:22:14

development and EHR prompts

04:22:15 - 04:22:18

and CMS, the Centers for Medicaid and Medicare Services

04:22:19 - 04:22:22

for early and periodic screening, diagnostic and

04:22:22 - 04:22:25

treatment. Otherwise we will be referred to as

04:22:25 - 04:22:28

EPSD going forward, which is the

04:22:29 - 04:22:32

Medicaid and CHIP benefit for children that requires

04:22:33 - 04:22:36

comprehensive screening and medically necessary

04:22:36 - 04:22:39

treatment. Both are grounded in existing care

04:22:39 - 04:22:40

standards.

04:22:42 - 04:22:42

Next slide please.

04:22:50 - 04:22:53

The CDC data does not show a lack of

04:22:53 - 04:22:56

evidence. And as we see these lanes are going to

04:22:56 - 04:22:58

be color coded going

04:22:58 - 04:23:02

forward. This was developed by my son, who

04:23:02 - 04:23:04

is on the spectrum and digital media

04:23:05 - 04:23:08

designer. And so you can see as you follow through on the

04:23:08 - 04:23:12

deck, the HR lane will be in gold. CMS will be in

04:23:12 - 04:23:15

light blue and share foundation will be with dark blue and

04:23:15 - 04:23:18

gold. And so we can track which lane we are

04:23:18 - 04:23:20

following in the deck. Next slide.

04:23:23 - 04:23:26

These guidelines were developed and

04:23:26 - 04:23:30

they have existed for in sometimes many years. For example, the

04:23:30 - 04:23:33

buoy study on from the AAP dates back to

04:23:34 - 04:23:37

2,010 regarding GI evaluation autism

04:23:38 - 04:23:41

and that co occurring factors and those atypical

04:23:42 - 04:23:45

presentations. As you can see, some of the organizations

04:23:45 - 04:23:48

listed here for which these guidelines were drawn upon are the american academy

04:23:49 - 04:23:52

of pediatrics, jama, the american association of

04:23:52 - 04:23:55

neurology. Once again, the gi jump

04:23:56 - 04:23:59

domain from the aap and as well as the

04:23:59 - 04:24:02

joint commission, which recently stressed the importance of

04:24:03 - 04:24:05

cautioning against diagnostic

04:24:05 - 04:24:08

overshadowing. Much of the data, of course, is called

04:24:09 - 04:24:11

from the CDC. Next slide.

04:24:14 - 04:24:17

The standard of care does not change because the patient

04:24:17 - 04:24:20

has autism. Essentially, when we see

04:24:21 - 04:24:24

that there are physical symptoms such as pain

04:24:24 - 04:24:28

regression, sleep disturbances seizure like events, gi issues

04:24:28 - 04:24:32

or significant safety risks. These findings still require

04:24:33 - 04:24:36

a clinical attention. Put simply, the same

04:24:36 - 04:24:40

symptoms that would prompt evaluation in another patient

04:24:40 - 04:24:44

not diagnosed with autism should prompt evaluation here

04:24:44 - 04:24:47

too, especially when the change is new worsening,

04:24:47 - 04:24:50

fluctuating or otherwise unexplained. Next slide.

04:24:53 - 04:24:56

Diagnostic overshadowing. The main patient safety

04:24:56 - 04:24:59

failure we are addressing is diagnostic overshadowing. This

04:24:59 - 04:25:03

was mentioned this morning in particular by Kaden. And I think that was

04:25:04 - 04:25:07

really important to hear his account and how it was. It was very clear that

04:25:07 - 04:25:11

he needed detection. So thank you, Cayden, for

04:25:11 - 04:25:12

sharing that with us today.

04:25:14 - 04:25:18

Diagnostic overshadowing is attributing symptoms or meaningful clinical change

04:25:18 - 04:25:21

to autism itself rather than evaluating for a co

04:25:21 - 04:25:24

occurring medical condition. In autism

04:25:25 - 04:25:28

pain, GI disease, neurological changes, fatigue

04:25:28 - 04:25:31

allergies or acute illnesses may present as

04:25:31 - 04:25:34

aggression, withdrawal, self injury,

04:25:34 - 04:25:37

food, refuse food refusal, sleep

04:25:37 - 04:25:40

collapse, hyperactivity, irritability or

04:25:40 - 04:25:43

neurodevelopmental regression. The practical rule is simple.

04:25:45 - 04:25:48

Treat abrupt behavioral or physiological change as a possible

04:25:49 - 04:25:51

clinical sign until evaluation suggests

04:25:51 - 04:25:54

otherwise. This is a patient safety issue

04:25:55 - 04:25:57

associated with increased emergency care,

04:25:57 - 04:25:59

hospitalization, and sadly premature

04:26:00 - 04:26:03

mortality. Dismissing symptoms prior to

04:26:04 - 04:26:07

evaluation may represent a form of medical neglect.

04:26:08 - 04:26:08

Next slide.

04:26:10 - 04:26:11

The key clinical.

04:26:13 - 04:26:15

Signal in this population is deviation from

04:26:16 - 04:26:19

baseline. First established baseline function is clearly

04:26:20 - 04:26:23

as possible. Communication, motor function, sleep

04:26:23 - 04:26:27

patterns, eating behavior, seizure and illness history

04:26:27 - 04:26:31

in day to day functioning. From there three habits matter

04:26:32 - 04:26:35

document baseline, take caregiver report seriously and consider

04:26:36 - 04:26:39

competing medical neurological psychiatric and safety

04:26:39 - 04:26:42

explanations before defaulting to just autism.

04:26:44 - 04:26:47

Caregiver observed change is the primary clinically relevant

04:26:47 - 04:26:50

source of information, especially in non speaking or

04:26:51 - 04:26:54

minimally verbal individuals. Clinicians should not

04:26:54 - 04:26:56

discount it. Next slide.

04:26:59 - 04:27:03

HRSA, as I mentioned earlier, is the vehicle for which clinicians

04:27:03 - 04:27:06

receive training, direction workforce development and

04:27:07 - 04:27:10

is really the best track and most appropriate for this specific

04:27:11 - 04:27:12

initiative. Next slide.

04:27:15 - 04:27:18

As you can see there are multiple domains under

04:27:18 - 04:27:22

what is called a review of systems. A

04:27:22 - 04:27:25

structured review of systems is a standard clinical method for identifying

04:27:25 - 04:27:27

symptoms that may not be reported

04:27:27 - 04:27:30

directly. In autism, this is especially important

04:27:31 - 04:27:34

because symptoms are often expressed indirectly. Slides

04:27:35 - 04:27:38

8 and 9 show the domains were clinically meaningful signals

04:27:38 - 04:27:41

tend to cluster gastrointestinal and feeding issues

04:27:42 - 04:27:45

sleep disturbance neurological and seizure related concerns

04:27:46 - 04:27:49

function and regression safety risks immune patterns

04:27:50 - 04:27:53

metabolic considerations motor findings and psychiatric

04:27:53 - 04:27:54

symptoms. Next slide.

04:27:56 - 04:27:59

The practical value is consistency. Incorporate these domains into

04:27:59 - 04:28:03

previsit tools caregiver questionnaires templates and

04:28:03 - 04:28:07

EHR workflows so important signals are less likely to be

04:28:07 - 04:28:10

missed. This is not indiscriminate testing. It is

04:28:10 - 04:28:14

a structured approach to recognizing when further evaluation

04:28:14 - 04:28:16

is warranted and preventing misconditions from

04:28:17 - 04:28:20

escalating. I am not going to go into these specific in

04:28:21 - 04:28:24

depth domains. I believe that some of our clinicians

04:28:25 - 04:28:28

during the discussion period can do that. But if anyone is

04:28:28 - 04:28:31

interested, there is more information specifically in attachments

04:28:32 - 04:28:34

a and B. Next slide.

04:28:37 - 04:28:40

HRSA. Is the appropriate agency for training

04:28:40 - 04:28:44

side. The recommendation is to develop and disseminate CME

04:28:44 - 04:28:47

for structured clinical guidance and practical tools such as

04:28:48 - 04:28:51

EHR prompts that help frontline clinicians

04:28:51 - 04:28:54

recognize and respond to co occurring conditions. In

04:28:55 - 04:28:58

routine or emergency care especially, the framework

04:28:58 - 04:29:01

translate existing evidence into feasible scalable tools so

04:29:02 - 04:29:05

care becomes more proactive rather than reactive or

04:29:05 - 04:29:06

crisis driven. Next slide.

04:29:10 - 04:29:12

The CMS EPSDT track

04:29:14 - 04:29:17

you'll get the hang of it after a while just rolls off the tongue.

04:29:18 - 04:29:21

On the CMS side EPSDT already requires

04:29:22 - 04:29:24

comprehensive screening and medically necessary

04:29:24 - 04:29:27

treatment. Nothing we recommend here today is

04:29:27 - 04:29:30

new. These are currently in place. There are just gaps

04:29:31 - 04:29:33

and inconsistencies. The issue is

04:29:34 - 04:29:35

inconsistent implementation.

04:29:37 - 04:29:40

And diagnostic overshadowing. Managed care organizations

04:29:41 - 04:29:44

readily ration ready use of rationale to attribute symptoms

04:29:44 - 04:29:46

to autism rather than evaluate them.

04:29:48 - 04:29:50

CMS issued comprehensive edits

04:29:51 - 04:29:54

EPSDT best practice guidance in September of

04:29:54 - 04:29:58

2024. The recommendation is to build on that letter

04:29:58 - 04:30:01

by clarifying that autism cannot be used

04:30:02 - 04:30:04
to narrow EPSDT entitlement or

04:30:04 - 04:30:07
obligations. This is not a new mandate. It is

04:30:08 - 04:30:11
cleaner implementation of what the statute already requires.

04:30:12 - 04:30:12
Next slide.

04:30:16 - 04:30:18
A preexisting autism diagnosis should not be used to defer

04:30:19 - 04:30:22
truncate discourage or deny medically necessary

04:30:23 - 04:30:23
assessment.

04:30:24 - 04:30:28
Referral follow up or covered treatment. Co-occurring symptoms

04:30:28 - 04:30:30
and safety risks need to be documented independently.

04:30:32 - 04:30:33
Next slide.

04:30:35 - 04:30:38
Under APSD under EPSDT

04:30:39 - 04:30:42
clinical triggers that should prompt further evaluation include developmental

04:30:42 - 04:30:45
regression persistent GI symptoms or pain

04:30:45 - 04:30:48
behaviors, severe sleep disruption, seizure

04:30:48 - 04:30:52
like activity, abrupt behavioral change, wandering risk

04:30:52 - 04:30:55

psychiatric deterioration motor decline and other meaningful

04:30:56 - 04:30:59

changes in function or safety. These are common clinical

04:30:59 - 04:31:03

realities and should not be dismissed solely because the patient carries an

04:31:03 - 04:31:05

autism diagnosis. Next slide.

04:31:08 - 04:31:11

Managed care organizations should not use autism as a

04:31:11 - 04:31:14

basis to deny discourage or unduly delay medical

04:31:15 - 04:31:18

necessary evaluation referral or

04:31:18 - 04:31:21

covered follow up. Documentation of symptoms

04:31:22 - 04:31:25

caregiver observations functional decline and safety

04:31:25 - 04:31:28

concerns must support clinical reasoning, continuity of care

04:31:30 - 04:31:32

referrals and access to services.

04:31:33 - 04:31:36

As you'll notice the wonder enlobment coding is something that we particularly

04:31:37 - 04:31:40

wanted to highlight is this is an issue that sometimes

04:31:41 - 04:31:42

has sadly

04:31:44 - 04:31:47

resulted in a high loss of mortality. Next

04:31:47 - 04:31:47
slide.

04:31:50 - 04:31:53
The bottom line is simple. These recommendations ensure that

04:31:53 - 04:31:55
individuals with autism receive the same diagnostic

04:31:56 - 04:31:59
thoroughness, safety assessment and follow through that any

04:31:59 - 04:32:02
patient should receive for the same symptoms or

04:32:02 - 04:32:05
risks. They operationalize existing standards of

04:32:05 - 04:32:09
care. They do not invent a new one. PRUSAS role

04:32:09 - 04:32:11
is to equip clinicians with training and practical

04:32:11 - 04:32:14
tools. CMS's role is to make clear that autism cannot

04:32:14 - 04:32:17
be used to narrow existing

04:32:17 - 04:32:21
EPSDT obligations. Together those

04:32:21 - 04:32:24
two lanes address a correctable implementation

04:32:25 - 04:32:27
gap with real implications for health and

04:32:27 - 04:32:31
safety. The authority already exists. The

04:32:31 - 04:32:33

problem is uneven and inconsistent implementation

04:32:34 - 04:32:37

due to lack of clear federal guidance. Thank you.

04:32:40 - 04:32:40

I'm done.

04:32:41 - 04:32:42

Thank you Laura.

04:32:44 - 04:32:46

Impossible to bring Laura up on the screen. Thank you.

04:32:48 - 04:32:50

All right, I'd like to open up to the committee for

04:32:51 - 04:32:54

discussion questions. Observations.

04:32:55 - 04:32:58

Feedback. Again, we particularly want to hear from our federal colleagues

04:32:59 - 04:33:02

as well. And I will just say on that note, I can't see everyone's name.

04:33:04 - 04:33:08

So if I gesture to you, if you could also just say your name when you

04:33:08 - 04:33:08

speak. Thank you.

04:33:26 - 04:33:27

Margaret Bush virtually.

04:33:31 - 04:33:33

Thank you. Can you hear me okay? Yes.

04:33:34 - 04:33:38

Okay. Thank you, Laura, for that presentation.

04:33:38 - 04:33:41

Just, I am here representing HRSA. So thank you for sharing all

04:33:41 - 04:33:44

that. HRSA definitely recognizes that early

04:33:44 - 04:33:47

screening early diagnosis, these services, education

04:33:48 - 04:33:51

can improve child development and symptoms and daily functioning

04:33:52 - 04:33:55

and quality of life. And I wanted to mention and highlight

04:33:55 - 04:33:59

HRSA's leadership education and neurodevelopmental and other

04:33:59 - 04:34:01

related disabilities training program, the

04:34:01 - 04:34:05

lend. It has 60 training sites across

04:34:05 - 04:34:08

the country and very strong bipartisan

04:34:08 - 04:34:10

support. And I just want to update that

04:34:12 - 04:34:15

the land notice of funding opportunity is currently in

04:34:15 - 04:34:18

process. So we definitely support the

04:34:18 - 04:34:21

individual, the family, the clinicians, the

04:34:21 - 04:34:24

educators, and hopefully we'll have an update on that

04:34:25 - 04:34:25

process soon.

04:34:27 - 04:34:31

Thanks. Margaret, I have a follow up question on that

04:34:32 - 04:34:35

in your current clinical standards in your training

04:34:35 - 04:34:39

materials. Is there a training for

04:34:39 - 04:34:41

a lot of these co occurring medical based conditions?

04:34:44 - 04:34:48

I am not sure, but I will get the answer and I will follow up with you.

04:34:48 - 04:34:52

Okay. If not, take attachment B. Thank

04:34:52 - 04:34:53

you. Thank you.

04:35:01 - 04:35:04

Thanks. I think the diagnostic overshadowing is

04:35:05 - 04:35:08

really important. So my older kid with autism when he was

04:35:08 - 04:35:10

young, he was like three or four years old. He had chronic diarrhea.

04:35:11 - 04:35:14

Six, eight times a day run out of diaper. It was just

04:35:15 - 04:35:18

horrendous. And one saw GI doc. This is before I really knew much about autism.

04:35:19 - 04:35:23

And I remember talking to him and he said, you know, dysrrhea is just part of autism.

04:35:24 - 04:35:27

And I said, okay, well, do we need to do a stool test? He said no

04:35:28 - 04:35:31

doing his scope. Now. So we left and I kind of accepted because I

04:35:31 - 04:35:34

figured, well, I saw doctor. He was kind of one of the better ones in the state

04:35:34 - 04:35:37

supposedly. And he said, just part of autism is just what it is.

04:35:38 - 04:35:41

And so we later found out that my child had other GI problems

04:35:42 - 04:35:45

and so forth that we treated in the diary went away. But I still see

04:35:45 - 04:35:49

this in practice where patients come in and say that they're told by other

04:35:49 - 04:35:52

conditions that it's just part of autism. That whether it fill in the

04:35:52 - 04:35:55

blank, whatever problem you have. You know, rashes or

04:35:55 - 04:35:59

autism, GI issues, part of autism. Even

04:35:59 - 04:36:03

kids will have abnormal lab values or reports like abnormal

04:36:03 - 04:36:06

eg seminal blood tests. Oh, you don't need to treat it. You know,

04:36:06 - 04:36:09

you just have autism. So I think it's, I don't know how to get around it.

04:36:11 - 04:36:14

Because I think it still happens quite a bit that if a patient goes into

04:36:14 - 04:36:17

the ER and they don't have autism, they get kind of a full court

04:36:18 - 04:36:21

press, lots of treatments test. And if they have autism, it's

04:36:21 - 04:36:24

like, it's like flips a switch. And the doctor starts thinking

04:36:25 - 04:36:28

it's just part of autism. And these kids, I mentioned earlier, I had three kids that

04:36:28 - 04:36:31

had appendicitis. Sent home from the ER with constipation

04:36:31 - 04:36:35

diagnosis and one of them was died because of it. So I'm

04:36:35 - 04:36:35

not saying that

04:36:38 - 04:36:41

pick up every kid that has that problem because it's hard to diagnose sometimes. But I think

04:36:42 - 04:36:45

the diagnostic overshadowing is a big issue that I don't know what

04:36:45 - 04:36:46

the answer is for.

04:36:54 - 04:36:58

So I do see in, in my own personal experience that

04:36:58 - 04:37:01

there's, there's a huge. Issue

04:37:02 - 04:37:03

in regards to getting these kids

04:37:05 - 04:37:08

diagnosed early in intervention early because

04:37:08 - 04:37:12

early intervention is key. And then there is

04:37:13 - 04:37:15

the concern that it seems as though

04:37:16 - 04:37:17

unless a doctor falls under

04:37:19 - 04:37:22

these, you know, the broad spectrum of functional medicine alternative

04:37:22 - 04:37:26

integrative that they, they don't look at these

04:37:26 - 04:37:29

as underlying conditions as Dr.

04:37:30 - 04:37:33

Rasnal said is that it's just a part of,

04:37:33 - 04:37:36

of autism that these doctors need to be

04:37:37 - 04:37:40

properly trained, that they're not properly trained. They're not given this information

04:37:43 - 04:37:45

and I truly feel that

04:37:47 - 04:37:50

in my own experience, it took me two and a half years to get a

04:37:50 - 04:37:52

diagnosis. Or anything

04:37:54 - 04:37:57

for my son when my pediatrician just kept looking at me and saying all

04:37:57 - 04:38:00

that's normal. So we need to

04:38:01 - 04:38:04

establish some form of care here

04:38:05 - 04:38:06

in regards to getting them

04:38:08 - 04:38:11

diagnosed because regional centers, it's a year out for

04:38:12 - 04:38:14

any value, a full evaluation, at least in

04:38:14 - 04:38:16

California. And, and I believe

04:38:16 - 04:38:18

that's a little on the ridiculous

04:38:19 - 04:38:22

side. But first the diagnosis

04:38:23 - 04:38:26

and then established care for these underlying conditions, because some of

04:38:26 - 04:38:28

them are treatable.

04:38:30 - 04:38:30

Thank you.

04:38:33 - 04:38:36

Turn it over to Dr. Mumper, who's virtually joining us.

04:38:40 - 04:38:44

Thank you so much. First of all, I totally

04:38:44 - 04:38:47

second everything that my colleague Dan has said about

04:38:48 - 04:38:51

the diagnostic overshadowing we've been fighting

04:38:52 - 04:38:54

this battle for 25 years at least

04:38:54 - 04:38:57

now. And we do need doctors who can

04:38:58 - 04:39:01

think as systems biology. I am concerned that

04:39:02 - 04:39:05

for these guidelines to be implemented within a Medicaid

04:39:06 - 04:39:09

setting, we're going to have significant barriers about funding

04:39:09 - 04:39:12

for clinician time. The average

04:39:13 - 04:39:16

pediatrician and family physician is expected to spend about

04:39:16 - 04:39:20

seven or eight minutes with a patient. And these are not problems that can be

04:39:20 - 04:39:24

solved in short acute visits. They require

04:39:24 - 04:39:27

coordination of care over time. And when I was

04:39:27 - 04:39:30

providing care to children with autism in a Medicaid system

04:39:31 - 04:39:34

and got audited, I was told that I had too many level

04:39:35 - 04:39:37

four and level five visit

04:39:37 - 04:39:40

charges. And that's going to be a

04:39:40 - 04:39:44

barrier for a lot of pediatricians working within

04:39:45 - 04:39:48

government clinics. So I think that I

04:39:49 - 04:39:52

thought Laura did a spectacular job in laying

04:39:52 - 04:39:56

out very complex information. And I applaud her son

04:39:56 - 04:39:59

for doing the graphics in a way that was so easy to

04:39:59 - 04:40:03

understand, but to translate that into actual

04:40:03 - 04:40:06

action by clinicians is going to

04:40:07 - 04:40:09

require an awareness of the time that it takes

04:40:10 - 04:40:13

and it's going to require federal support to

04:40:14 - 04:40:17

change the pay structure so that those doctors

04:40:17 - 04:40:20

can do the kind of in depth analysis that these

04:40:20 - 04:40:24

patients have deserved for decades honestly. We

04:40:24 - 04:40:27

are decades behind on this and I hope that today we

04:40:28 - 04:40:31

can take positive action to move these suggestions

04:40:32 - 04:40:34

forward. So thank you so much,

04:40:34 - 04:40:36

Laura, for working on this.

04:40:40 - 04:40:43

Dr. Rawson. Doll. The other thing that comes to mind

04:40:43 - 04:40:46

would be failure to

04:40:46 - 04:40:49

refer. So parents will

04:40:49 - 04:40:51

hear, oh, your kid is a boy. Give them time.

04:40:53 - 04:40:56

And the diagnosis gets delayed. So the average age of diagnosed in Minnesota right now is five years

04:40:56 - 04:40:59

old. And we knew early intervention works best when you start young.

04:41:00 - 04:41:03

So that's another big area too is just failure to refer

04:41:03 - 04:41:07

and fail to get diagnoses. You mentioned the regional centers in California.

04:41:07 - 04:41:11

California is only state has regional centers I know of. So actually they have a better system

04:41:11 - 04:41:15

than almost every other state. And they're still what, a year behind it. But app

04:41:15 - 04:41:18

patients been on waiting list for over a year to get just not done diagnosis.

04:41:18 - 04:41:21

Done. And of course what we do is say we don't need the diagnosis. We're going to move forward

04:41:21 - 04:41:25

treating comorbidities and testing for those things. But

04:41:25 - 04:41:28

yeah, kids are just not getting diagnosed early enough so they can't get the early intervention they

04:41:28 - 04:41:28

need.

04:41:30 - 04:41:33

Dr. Fogle. We have one another online, Bill Oldham.

04:41:34 - 04:41:37

Okay, let's do Belgium and then we'll put it out in Diana Diaz Harris.

04:41:37 - 04:41:37

On.

04:41:39 - 04:41:42

Thank you. First of all, I'd like to say to Laura, thank you for that

04:41:43 - 04:41:47

amazing work that's fantastic and appreciate all the hard work that you

04:41:47 - 04:41:49

did. I think one of the perhaps

04:41:51 - 04:41:54

unrecognized or unapplauded benefits of

04:41:55 - 04:41:58

that kind of diagnostic clarity. Would apply in the

04:41:58 - 04:42:02

data side as well. Right. We would have much greater opportunity to actually

04:42:02 - 04:42:04

get to the phenotypes and actually get to

04:42:05 - 04:42:08

combinations of issues that we can actually do some work in the data field

04:42:09 - 04:42:09

on.

04:42:11 - 04:42:14

Second other comment I'd make is a

04:42:14 - 04:42:18

suggestion. There have been in the past

04:42:19 - 04:42:22

in work I've done with HRSA. Things called quality

04:42:22 - 04:42:25

collaboratives. Where those collaboratives are actual

04:42:26 - 04:42:29

representatives from a number of the clinics and organizations

04:42:29 - 04:42:32

that HRSA has around the country and they get together and they take

04:42:33 - 04:42:36

things like your document and figure out how to get that into

04:42:37 - 04:42:39

practice. So there are mechanisms within

04:42:40 - 04:42:43

these agencies that are on the healthcare delivery side in the federal

04:42:43 - 04:42:46

space, which I'd love to hear from our

04:42:47 - 04:42:50

federal members on how we can actually get some of those existing

04:42:50 - 04:42:54

mechanisms to help cross this kind of translational

04:42:54 - 04:42:57

gap that you so, so well enabling identified.

04:43:04 - 04:43:07

There. I just wanted to mention how difficult it is

04:43:07 - 04:43:07

to.

04:43:09 - 04:43:12

Get the testing and even get blood work for our

04:43:13 - 04:43:16

kids in order to find out if there are

04:43:16 - 04:43:18

true underlying co occurring

04:43:18 - 04:43:21

conditions. In my personal case

04:43:22 - 04:43:23

when my son got a little bigger

04:43:25 - 04:43:27

and it was, it was a little harder to get blood work.

04:43:28 - 04:43:32

We got kicked out of three Sonora labs. And so I had

04:43:32 - 04:43:35

to hire phlebotomist privately

04:43:35 - 04:43:37

to come and get his blood at home

04:43:39 - 04:43:42

because I really wanted to find out what the this underlying

04:43:44 - 04:43:47

new health concern was. And so we don't even get

04:43:47 - 04:43:50

as far as. Getting lab testing

04:43:51 - 04:43:54

or blood work because some practitioners will say

04:43:54 - 04:43:57

it's just too hard or it's too traumatic or you don't

04:43:58 - 04:44:01

want to hurt them or traumatize, you know, the

04:44:01 - 04:44:05

young adult or the teen. By getting this testing.

04:44:06 - 04:44:09

But then you have to do it when they end up in the er under

04:44:09 - 04:44:13

sedation. So it should be easier. There

04:44:13 - 04:44:16

should be appointments with accommodations. To

04:44:16 - 04:44:20

just be able to get that testing done and see what's really going on

04:44:20 - 04:44:22

and what that underlying condition is.

04:44:26 - 04:44:29

Yes. Hi, I'm Kirsten Jensen. I'm sitting in for

04:44:30 - 04:44:33

capri snapp from CMS. So we just wanted to convey thank

04:44:33 - 04:44:36

you for the proposal. We don't have an official response

04:44:37 - 04:44:40

at this point, but given that we received it so recently that we will

04:44:40 - 04:44:42

take. It under advisement.

04:44:47 - 04:44:47

Daniel?

04:44:51 - 04:44:54

I thought I might mention my mom tried taking me

04:44:54 - 04:44:57

to doctors when I was two years old and they could not get

04:44:58 - 04:45:01

anyone to help. My stomach issues or vision problems.

04:45:02 - 04:45:03

Because they said I was fine.

04:45:05 - 04:45:06

And that was a big, big problem.

04:45:09 - 04:45:10

And it still is.

04:45:18 - 04:45:18

Ginger tailor.

04:45:20 - 04:45:23

So there's a really good study that only 39%

04:45:24 - 04:45:26

of US pediatricians refer for an autism

04:45:26 - 04:45:27

diagnosis. Often parents

04:45:29 - 04:45:32

self prefer to get a diagnosis still waiting 12 to 48 months.

04:45:34 - 04:45:37

And besides to echo the comments and Laura, great job

04:45:38 - 04:45:42

families have to go to multiple physicians before they're

04:45:42 - 04:45:45

heard. So I just want to echo that if this training was

04:45:45 - 04:45:48

available and they could work to test and

04:45:48 - 04:45:52

normalize labs, that just could be a huge gift for so many

04:45:52 - 04:45:53

on the spectrum. Thank you.

04:45:59 - 04:45:59

Noticed very early on

04:46:02 - 04:46:05

the phenomenon it just autism coming from doctors

04:46:06 - 04:46:09

acts as a social contagion because the medical community

04:46:10 - 04:46:13

where you enter the autism world.

04:46:15 - 04:46:18

Their lack of curiosity about these cases, their lack of

04:46:19 - 04:46:22

investigation. Their acceptance of serious bowel

04:46:22 - 04:46:23

problems. It teaches

04:46:25 - 04:46:28

other other caregivers and other disciplines,

04:46:28 - 04:46:31

education, behaviorists that that's just autism

04:46:32 - 04:46:36

and it contributes to the less than aesthetic of

04:46:36 - 04:46:39

our kids that we've been fighting against for, you know, half century.

04:46:40 - 04:46:44

So if we can get doctors to start taking each case

04:46:44 - 04:46:46

seriously, that has downstream effects of

04:46:47 - 04:46:48

they will teach.

04:46:50 - 04:46:54

Just in their behavior taking these cases more seriously that everything needs

04:46:54 - 04:46:55

to be investigated properly.

04:46:57 - 04:47:00

I'm going to just make a comment in my role as a member as

04:47:00 - 04:47:03

well. You know Dr. Tim Bouey presented to the

04:47:03 - 04:47:05

IACC about this topic years

04:47:05 - 04:47:09

ago. And he over and over again

04:47:10 - 04:47:13

at conferences and in published literature

04:47:14 - 04:47:17

has really pointed out that gastrointestinal disorders are

04:47:17 - 04:47:21

underdiagnosed in the autism

04:47:21 - 04:47:23

population leading to preventable

04:47:25 - 04:47:25

pain and suffering

04:47:27 - 04:47:30

and behavioral manifestations of that pain and suffering

04:47:31 - 04:47:34

that are corrected with appropriate treatment. And he

04:47:34 - 04:47:36

presented to this committee years

04:47:36 - 04:47:39

ago. And I think we have an opportunity

04:47:40 - 04:47:40

today to

04:47:41 - 04:47:44

really, you know, put forth

04:47:45 - 04:47:48

some recommendations. These are just recommendations to

04:47:49 - 04:47:51

hhs and the secretary. We are not making

04:47:52 - 04:47:54

policy. We are just making

04:47:54 - 04:47:57

recommendations, but their recommendations that our federal

04:47:57 - 04:47:59

partners and federal agencies can then consider

04:48:01 - 04:48:04

in more depth. And I will say the issue of diagnostic overshadowing is

04:48:05 - 04:48:08

one I see as a clinician over and over again. I am treating

04:48:08 - 04:48:11

a 21 year old man with minimally verbal

04:48:12 - 04:48:12

autism

04:48:14 - 04:48:17

with, I mean gut wrenching years of constipation

04:48:19 - 04:48:21

who, you know, really, really needs a

04:48:21 - 04:48:24

colonoscopy. You know, I think like anyone would really agree with that

04:48:25 - 04:48:27

and was told by the gastroenterologist that he went to see

04:48:28 - 04:48:32

his parents were told. Yeah, that's, that's going to be, that's going to be kind of

04:48:32 - 04:48:32

difficult.

04:48:34 - 04:48:35

And that was a couple weeks ago.

04:48:38 - 04:48:41

So I really want to urge consideration of the

04:48:41 - 04:48:44

proposals in these amendments that we.

04:48:46 - 04:48:49

Could deliver to secretary kennedy and

04:48:49 - 04:48:50

hhs, you know, tomorrow.

04:48:53 - 04:48:54

So I just urge our federal partners

04:48:56 - 04:48:58

again, you know, this isn't policy. This is just

04:48:59 - 04:49:02

recommendations for consideration. I'm going to turn it over

04:49:02 - 04:49:05

to Laura. Thank you. And thank you everyone for

04:49:06 - 04:49:09

sharing your comments and your thoughts. I

04:49:09 - 04:49:12

just wanted to reiterate that these guidelines

04:49:13 - 04:49:15

that are in these documents are actually

04:49:17 - 04:49:20

taken from current peer reviewed

04:49:20 - 04:49:23

publications and consensus statements from major

04:49:23 - 04:49:25

medical organizations. None of these are

04:49:26 - 04:49:28

exotic. None of these are

04:49:28 - 04:49:31

new. These are things that are supposed to be

04:49:31 - 04:49:34

happening. And as and I appreciate Dr.

04:49:35 - 04:49:38

Momper's comments around reimbursement in the time that

04:49:38 - 04:49:41

clinicians will need to spend and maybe that is something that we can talk to

04:49:42 - 04:49:44

with our CMS partners because

04:49:45 - 04:49:48

EPSDT is currently in

04:49:48 - 04:49:51

place. It is a requirement. It is not

04:49:51 - 04:49:54

consistently being administered across the

04:49:54 - 04:49:58

states. And I want to clarify that it is the states

04:49:58 - 04:50:01

through their Medicaid waivers or Medicaid itself

04:50:02 - 04:50:04

or CHIP, which is the Children's Health Insurance program

04:50:06 - 04:50:08

that are responsible for the delivery of these

04:50:09 - 04:50:12

and for the implementation and

04:50:12 - 04:50:15

surveillance. So, you know, I'm hopeful that maybe we can

04:50:16 - 04:50:18

figure out some more ways that we can make this work for both

04:50:18 - 04:50:22

clinicians, our federal partners, our agencies

04:50:22 - 04:50:25

and the stakeholders as well. So thank you very much.

04:50:52 - 04:50:52

Denver Phillips.

04:50:55 - 04:50:58

So anecdotally and also just in the name of bringing

04:50:59 - 04:51:02

some of these clinical terms home and highlighting

04:51:02 - 04:51:04

the time sensitivity of all of this.

04:51:06 - 04:51:09

My daughter deteriorated very rapidly

04:51:10 - 04:51:12

at the age of two from happy and healthy.

04:51:14 - 04:51:15

To all of these conditions that we're talking about.

04:51:18 - 04:51:21

And the only recommendation we got from her pediatrician was behavioral

04:51:21 - 04:51:22

therapy.

04:51:24 - 04:51:27

After that, I took matters into my own hands.

04:51:29 - 04:51:29

And my daughter ended up with.

04:51:31 - 04:51:34

An in mitochondrial DNA depletion at only

04:51:34 - 04:51:36

30% and her muscle.

04:51:38 - 04:51:41

Hypothyroidism. Primary immune deficiency.

04:51:42 - 04:51:45

Chronic diarrhea and something called

04:51:45 - 04:51:49

pseudotumor cerebri, which caused intracranial

04:51:49 - 04:51:52

pressure so high that it permanently damaged her

04:51:52 - 04:51:53

optic nerves.

04:51:55 - 04:51:55

And so

04:51:57 - 04:51:59

I think that that just highlights Laura's statement that

04:52:00 - 04:52:03

this, you know, putting this off or not paying attention to this

04:52:04 - 04:52:04

can really

04:52:06 - 04:52:07

result in medical neglect.

04:52:09 - 04:52:12

In a really bad situation for some very deserving kids. So I hope

04:52:12 - 04:52:15

that that offers some context for our federal members to consider

04:52:16 - 04:52:19

the time sensitivity of all of this. Thank you.

04:52:20 - 04:52:23

Dr. Rosnia. Hopefully I'm not speaking too

04:52:23 - 04:52:26

much. The other thing I see in practice quite a bit is

04:52:27 - 04:52:30

kids come in with no tests ever done. You know, maybe a CDC

04:52:31 - 04:52:34

if you're lucky maybe with lead level, but that's about it. So people are not

04:52:35 - 04:52:38

testing for these things. They've been pretty well identified in autism the comorbidities and

04:52:38 - 04:52:41

lab tests that are out there available for these things. The other thing that

04:52:42 - 04:52:45

we know happens in some case autism is regression right loss of

04:52:45 - 04:52:48

skills. And so if an adult goes to ER

04:52:48 - 04:52:51

with loss of speech, they get a full court press to get spinal tap

04:52:52 - 04:52:55

MRIs, you get a whole camera testing. A kid

04:52:55 - 04:52:58

progressing and we call it autism. No one seems to really do

04:52:58 - 04:53:02

tests, try to figure out what's going on. Just, oh, it happens in cause autism needs to

04:53:02 - 04:53:05

grasp. So I think we need a paradigm shift in medicine too that if you don't

04:53:06 - 04:53:09

do a test, you can't find a problem. You don't find a problem. You can't treat it. You don't treat

04:53:09 - 04:53:12

it. You don't see an improvement. So if you're a doctor doesn't test and never sees

04:53:13 - 04:53:16

a treatment and notice the treatment overseas improvements. You're not going to test because you

04:53:16 - 04:53:19

just don't see that benefit. If you're someone like me, you test a lot of kids

04:53:19 - 04:53:23

and treats a lot and sees improvement, not of course in every kid, but some, then

04:53:23 - 04:53:26

you want just more kids. Right. So I think it's

04:53:27 - 04:53:30

a self fulfilling kind of thing where if you don't test, you just never test.

04:53:31 - 04:53:34

And so again educating doctors and providers

04:53:35 - 04:53:38

is going to take a long time. But something that we need to think about as well.

04:53:56 - 04:53:58

I'm just going to make another comment also just in like clinical

04:53:59 - 04:54:02

experience. You know, because of the communication challenges

04:54:03 - 04:54:06

and because many individuals on the spectrum, even those who have

04:54:07 - 04:54:10

more speech, more functional speech aren't able to communicate

04:54:11 - 04:54:14

their internal experiences. And so as

04:54:14 - 04:54:16

clinicians, we need to have a higher degree of

04:54:17 - 04:54:20

suspicion for the range of co occurring medical conditions

04:54:20 - 04:54:24

that are more common in autism, especially when

04:54:24 - 04:54:27

there are changes. Behavioral changes, pain

04:54:27 - 04:54:31

behaviors, sleep. I mean, Laura mentioned a lot of signs

04:54:31 - 04:54:32

and symptoms that need to be considered.

04:54:34 - 04:54:36

And I really feel like, you know, my medical colleagues.

04:54:40 - 04:54:44

At least in my training, you know, I really wasn't adequately trained to

04:54:45 - 04:54:48

think in terms of index of suspicion for co occurring

04:54:49 - 04:54:52

conditions in individuals with autism. And I think this is important

04:54:53 - 04:54:56

not just for our primary care physicians, our pediatricians and our family

04:54:56 - 04:54:59

practice docs. But all subspecialists

04:55:00 - 04:55:02

to really have a consideration for

04:55:04 - 04:55:06

the ways that various body systems

04:55:08 - 04:55:11

are mutually and reciprocally regulating

04:55:12 - 04:55:14

and can lead to behavioral

04:55:14 - 04:55:16

changes, psychiatric symptoms.

04:55:19 - 04:55:22

A whole host of sequelae. So I just wanted to

04:55:22 - 04:55:25

add that just in my clinical experience. I just don't think we

04:55:26 - 04:55:29

have a framework of having a higher index of

04:55:29 - 04:55:32

suspicion and sometimes just having to proceed with

04:55:33 - 04:55:34

a workup even if you're not sure.

04:55:36 - 04:55:37

Simply to rule it out.

04:55:42 - 04:55:45

Just a question is it's been really

04:55:46 - 04:55:48

a great discussion about this particular issue

04:55:49 - 04:55:53

and a lot of compelling examples of what's happening in the day

04:55:53 - 04:55:56

to day experiences of the individuals

04:55:56 - 04:55:59

and families. In terms of the

04:55:59 - 04:56:03

attachment that was included, and I think this applies to

04:56:03 - 04:56:04

attachment B potential

04:56:07 - 04:56:10

based on the conversation that we're having right now

04:56:11 - 04:56:14

and knowing that we have five minutes, I think, until we go into the next topic.

04:56:17 - 04:56:19

Do you get this feeling that or do you feel like

04:56:22 - 04:56:24

what's in this document does reflect what's been discussed

04:56:25 - 04:56:28

here. Anything that you wanted to particularly highlight

04:56:29 - 04:56:32

in the recommendations that address any of the

04:56:32 - 04:56:35

items have been brought up in this conversation or in the presentation.

04:56:43 - 04:56:46

I just want to kind of condense everything

04:56:47 - 04:56:50

that we've talked about here. To.

04:56:51 - 04:56:54

One talking point, which is autism should be

04:56:55 - 04:56:55

a launch point.

04:56:57 - 04:56:57

Not an end point.

04:57:03 - 04:57:04

Daniel.

04:57:06 - 04:57:07

I thought I also might mention.

04:57:11 - 04:57:14

Have you ever thought of implementing a reporting system for

04:57:14 - 04:57:17

caregivers when doctors do not listen?

04:57:20 - 04:57:22

Because a lot of non speakers.

04:57:25 - 04:57:29

Well I wasn't able to really advocate for myself in the

04:57:29 - 04:57:29

hospital.

04:57:31 - 04:57:31
Several months ago.

04:57:34 - 04:57:36
And that was an issue for me as well.

04:57:39 - 04:57:43
Thank you, Daniel. I want to just circle back to what

04:57:43 - 04:57:46
Jennifer Johnson raised, which is there any particular

04:57:47 - 04:57:50
comments about the attachments in the particular

04:57:50 - 04:57:54
proposals in the documents, which we will be voting on

04:57:54 - 04:57:58
whether or not to send to secretary kennedy and

04:57:58 - 04:58:01
HHS later this afternoon. Dr. Mumper, I see you have your hand raised.

04:58:03 - 04:58:06
So two quick things. Another is a payment issue and this

04:58:07 - 04:58:09
goes to my federal colleagues and I do not envy

04:58:10 - 04:58:14
your position having to deal with allocating funds. But

04:58:14 - 04:58:17
some of the lab tests that I found most helpful to help my

04:58:17 - 04:58:20
patients with autism included a sophisticated

04:58:20 - 04:58:23
organic acid test that detects all kinds of

04:58:24 - 04:58:27

metabolic abnormalities and the frat test, which is

04:58:27 - 04:58:30

the folate receptor antibody test, which is

04:58:31 - 04:58:34

if it's positive, that's an indication to use leucovorin, which can be life

04:58:34 - 04:58:38

changing for as many as 65 to 85% of

04:58:38 - 04:58:41

patients with autism. These are classically

04:58:41 - 04:58:45

not covered by most insurances, and families have to bear the

04:58:45 - 04:58:48

burden out of pocket. So any way to make these tests more

04:58:48 - 04:58:51

affordable or covered through insurance would be

04:58:51 - 04:58:54

awesome. Second thing is I volunteer myself

04:58:55 - 04:58:58

and I'm going to speak for many of my colleagues at the Medical Academy of

04:58:58 - 04:59:01

Pediatrics that we are very committed to

04:59:02 - 04:59:02

helping to train

04:59:05 - 04:59:08

pediatricians, family docs and specialists who take care of kids

04:59:09 - 04:59:12

in these medical issues. And so we

04:59:12 - 04:59:15

can work in the future on how to make that

04:59:15 - 04:59:16
happen. It's going to be

04:59:18 - 04:59:21
a long process, but I'm very committed to making that happen.

04:59:33 - 04:59:36
And I just make one comment. On that note that my son

04:59:37 - 04:59:40
that had these life threatening seizures, this is honey renicella. Sorry, I didn't have

04:59:40 - 04:59:43
you call my name. My son that had those life threatening seizures was

04:59:44 - 04:59:47
seen by the pediatric neurologist at our local

04:59:47 - 04:59:49
hospital at du pon. And he was chief of neurology.

04:59:50 - 04:59:52
And they dug and dug for the

04:59:53 - 04:59:57
root cause. And again, we were given the makE-A-Wish trips saying

04:59:57 - 04:59:58
good luck. God bless sometimes children

04:59:59 - 05:00:02
die. And it was that simplistic test

05:00:02 - 05:00:06
that she is suggesting to get covered to test

05:00:06 - 05:00:09
for cerebral folate deficiency in which we identified to a spinal tap.

05:00:11 - 05:00:14
That upon proper treatment with leucovorin stopped the seizures.

05:00:15 - 05:00:18
In their tracks. So simplistic covered by

05:00:19 - 05:00:19

insurance.

05:00:20 - 05:00:23

Not a very expensive test. However, so many of our families are

05:00:24 - 05:00:27

unable to obtain that so too, Liz's point. It's

05:00:27 - 05:00:31

something that definitely needs to be brought into consideration. So I appreciate

05:00:31 - 05:00:32

her mentioning that.

05:00:52 - 05:00:55

We need health equity for individuals with autism.

05:01:03 - 05:01:07

Yes. Thank you. I've been really moved by

05:01:07 - 05:01:10

all the comments as part of this

05:01:10 - 05:01:13

discussion. But, you know, to that important question about

05:01:14 - 05:01:17

costs and reimbursement, I think it would be

05:01:18 - 05:01:21

really powerful to understand the CMS response

05:01:22 - 05:01:25

to this proposal given that it directly impacts them

05:01:25 - 05:01:28

and their operations. So I wonder if there is an opportunity

05:01:30 - 05:01:33

to integrate that feedback when they've had a moment

05:01:34 - 05:01:36

to review the proposal

05:01:37 - 05:01:39

appropriately. I just wasn't sure

05:01:42 - 05:01:45

how the discussion could be complete

05:01:45 - 05:01:48

without that input given that they're a member of the

05:01:48 - 05:01:50

committee. So I just, I would like your to hear

05:01:51 - 05:01:53

an understanding of, of how we move forward. Thank you.

05:01:58 - 05:01:58

Respond to that.

05:02:01 - 05:02:04

I mean, I can respond that we would like to take some time to take a look at the

05:02:05 - 05:02:07

proposal we can provide a reaction. I don't know what the

05:02:08 - 05:02:11

committee's process is. For that.

05:02:13 - 05:02:13

Thank you.

05:02:17 - 05:02:19

My view on this and Laura have a chance is that

05:02:21 - 05:02:24

providing recommendations to the secretary and to hhs

05:02:25 - 05:02:28

is an opportunity for CMS to more fully engage with what

05:02:28 - 05:02:29

is in this

05:02:30 - 05:02:33

document. And, you know, I may have that wrong, but I also

05:02:34 - 05:02:34

feel like.

05:02:37 - 05:02:40

This is an issue that's plagued the autism community for a couple of

05:02:41 - 05:02:44

decades now. And we are not getting

05:02:44 - 05:02:47

adequate medical care and we want our federal

05:02:47 - 05:02:51

partners and agencies to engage

05:02:51 - 05:02:54

with common sense standard of care recommendations

05:02:55 - 05:02:56

and to provide guidance.

05:02:57 - 05:03:01

To clinicians around the importance of considering medical

05:03:01 - 05:03:04

comorbidities, especially in individuals who are

05:03:05 - 05:03:07

have communication challenges and behavioral challenges.

05:03:10 - 05:03:12

And my comments on CMS's comments are not

05:03:14 - 05:03:14

intended.

05:03:17 - 05:03:20

In any way. We recognize that the challenges

05:03:21 - 05:03:25

for this community and we are listening to the conversation

05:03:25 - 05:03:28

here. We've had representation on this group over the years.

05:03:30 - 05:03:32

I think the response that's being given

05:03:33 - 05:03:36

directly from caprice is that

05:03:37 - 05:03:38

we were given this proposal.

05:03:40 - 05:03:44

Last Thursday and is an agency. You know, we.

05:03:48 - 05:03:51

Don't have an official response to it. As

05:03:51 - 05:03:54

an aside, I am the person that led the EPSDT show that's

05:03:54 - 05:03:57

referenced about that project. I have worked

05:03:58 - 05:04:01

with CMS is doing extensive work in the CMS space.

05:04:04 - 05:04:05

And I mean in the EPSDT space.

05:04:07 - 05:04:11

Beyond that guidance. So I think

05:04:11 - 05:04:12

that's.

05:04:14 - 05:04:17

Where the direction that we've received is that we would just

05:04:17 - 05:04:20

like to take a little time to look at this more in depth given

05:04:21 - 05:04:23

the lateness. If

05:04:24 - 05:04:25

we're voting on this later.

05:04:27 - 05:04:27

So perhaps.

05:04:29 - 05:04:32

You know, that's where you follow your normal process.

05:04:34 - 05:04:37

And that's where we are. I don't, I don't have much more to say. Capri

05:04:37 - 05:04:41

said to leave to make a presentation. But we do

05:04:41 - 05:04:44

recognize the importance of autism. We recognize the

05:04:44 - 05:04:48

importance of EPSDT that has not lost on

05:04:48 - 05:04:51

us. You have the person that led the project here and has and led

05:04:51 - 05:04:53

the EPSDT work for five years.

05:04:59 - 05:05:03

Thank you. Laura. So I just want to clarify

05:05:04 - 05:05:07

once again. And it's wonderful. Thank you so much for your

05:05:07 - 05:05:10

work on epsdt.

05:05:10 - 05:05:13

Essentially, and I think everyone who's unfamiliar with

05:05:14 - 05:05:17

epsdt is we are not adding anything new

05:05:18 - 05:05:18
to

05:05:19 - 05:05:22
EPSDT. These are

05:05:22 - 05:05:24
medically necessary conditions.

05:05:26 - 05:05:29
That co-occur in autism, but they're being missed due to diagnostic

05:05:30 - 05:05:33
overshadowing or because there's an atypical

05:05:33 - 05:05:34
presentation.

05:05:35 - 05:05:37
So what we're really proposing

05:05:39 - 05:05:42
is clarification and a structured review of

05:05:42 - 05:05:45
systems so that clinicians don't miss

05:05:45 - 05:05:48
them. One of the things that I'm glad

05:05:49 - 05:05:52
Bill Oldham brought up, the ability to capture better data

05:05:52 - 05:05:55
with this. We know that in the last 20

05:05:55 - 05:05:58
years, there's been more mandates and coverage around things like

05:05:59 - 05:06:03
applied behavioral analysis. In my own

05:06:03 - 05:06:07
anecdotal experience, when we treated

05:06:07 - 05:06:10

underlying and co occurring conditions in our son,

05:06:10 - 05:06:14

we didn't need any services. So there may

05:06:14 - 05:06:14

be also

05:06:16 - 05:06:20

a cost shift that when we treat underlying and co

05:06:20 - 05:06:22

occurring medical conditions, we may see

05:06:23 - 05:06:26

symptoms, even though we're not treating autism per se with

05:06:26 - 05:06:30

those. We may see symptoms that are

05:06:30 - 05:06:33

associated with autism ameliorate or severity

05:06:34 - 05:06:37

reduction. So I just want to be clear to CMS and our other

05:06:37 - 05:06:40

federal partners. This is not a new

05:06:40 - 05:06:43

mandate. This should just, this is really just a clarification

05:06:44 - 05:06:46

of what already is required under

05:06:47 - 05:06:48

EPSDT. So thank you.

05:06:51 - 05:06:53

Okay, I think we do have to wrap up this topic

05:06:54 - 05:06:57

for now and move on to topic number

05:06:57 - 05:06:58

two, which is

05:06:59 - 05:07:03

consideration of a profound autism designation for

05:07:03 - 05:07:05

research and policy. And I will be

05:07:07 - 05:07:08

doing that presentation.

05:07:14 - 05:07:15

Thank you. Perfect.

05:07:22 - 05:07:25

So I first like to just start by saying that throughout this

05:07:25 - 05:07:28

presentation, I will be using the terms nonverbal and minimally verbal

05:07:29 - 05:07:32

interchangeably alongside the terms non speaking and minimally

05:07:33 - 05:07:36

speaking. I recognize that the latter terms are preferred by

05:07:36 - 05:07:40

some members of the autism community while the former terms

05:07:40 - 05:07:42

are found throughout the autism scientific literature.

05:07:44 - 05:07:47

And before I proceed, I would like to just add that the

05:07:48 - 05:07:50

word profound was used in roughly 90 of the

05:07:51 - 05:07:54

259 public written comments that were received by this

05:07:54 - 05:07:57

committee. So roughly 35% of

05:07:58 - 05:08:01

our written comments. So a large proportion of

05:08:02 - 05:08:05

the autism community and the autism

05:08:05 - 05:08:08

academic and research community are already using this term.

05:08:10 - 05:08:13

Many of the public comments share that use the term profound

05:08:13 - 05:08:16

autism or profoundly autistic share a theme of being

05:08:17 - 05:08:20

underrepresented in policy research

05:08:21 - 05:08:21

and the media.

05:08:23 - 05:08:25

So the term profound autism is relatively

05:08:26 - 05:08:29

new. It was introduced by Dr. Catherine Lord around

05:08:29 - 05:08:32

2021. And the term arose in response to

05:08:33 - 05:08:36

concerns from researchers and academic clinicians that

05:08:37 - 05:08:39

current diagnostic systems are incapable of accurately

05:08:40 - 05:08:43

capturing the functional needs of some individuals with

05:08:43 - 05:08:46

autism. Who require near constant support or

05:08:47 - 05:08:47
supervision

05:08:49 - 05:08:52
and most often include people with limited minimal or unreliable

05:08:52 - 05:08:52
speech.

05:08:54 - 05:08:57
Finding a term to distinguish this group of individuals from the wider

05:08:58 - 05:09:01
autism spectrum was seen as especially important as

05:09:01 - 05:09:04
diagnostic criteria have widened and individuals with

05:09:04 - 05:09:08
vastly different profiles, needs and abilities

05:09:09 - 05:09:11
were included under one diagnostic term autism.

05:09:13 - 05:09:16
The Lancet commission on the future of care and clinical research and autism

05:09:17 - 05:09:20
published in 2022 with Dr. Lord as the first author

05:09:21 - 05:09:24
addressed this fundamental gap in autism policy and diagnostics

05:09:25 - 05:09:28
that individuals with the highest support needs remained poorly

05:09:28 - 05:09:31
identified within existing classification

05:09:31 - 05:09:34
systems. They noted serious issues with both

05:09:34 - 05:09:37

DSM 5 and ICD 10, including that the

05:09:38 - 05:09:41

primary domains that form the basis of an autism spectrum

05:09:41 - 05:09:44

diagnosis, communication deficits and repetitive

05:09:44 - 05:09:47

or restrictive behaviors don't effectively capture

05:09:48 - 05:09:52

real world functional disability, including the

05:09:52 - 05:09:55

capacity to effectively advocate or communicate one's needs

05:09:55 - 05:09:58

or wishes. The commission noted that with the

05:09:58 - 05:10:01

expansion of diagnostic criteria, those

05:10:02 - 05:10:05

with the highest support needs were at risk of being marginalized by

05:10:06 - 05:10:09

a focus on more able individuals in media research

05:10:09 - 05:10:10

and policy.

05:10:12 - 05:10:15

They proposed the term profound autism to be an

05:10:15 - 05:10:18

administrative designation, not necessarily a formal

05:10:19 - 05:10:22

diagnostic subtype similar to what the proposal is before

05:10:22 - 05:10:23

you today.

05:10:25 - 05:10:28

The LANSA Commission proposed three criteria for the designation of profound

05:10:28 - 05:10:31

autism. Which were anchored in functional

05:10:31 - 05:10:34

needs. And those functional needs

05:10:35 - 05:10:39

requiring 24 access 24 hour access to an adult

05:10:39 - 05:10:41

who could care for them if concerns arose.

05:10:42 - 05:10:45

Being unable to be left completely alone in a residence.

05:10:46 - 05:10:49

And being unable to effectively take care of basic

05:10:50 - 05:10:53

daily adaptive needs like eating and hygiene. They

05:10:53 - 05:10:56

noted that in most cases those needs are associated with

05:10:57 - 05:10:59

very limited spoken language.

05:11:01 - 05:11:04

And or a substantial diagnosed intellectual

05:11:04 - 05:11:07

disability with an IQ below 50. The

05:11:08 - 05:11:11

speech criteria and the IQ criteria were

05:11:11 - 05:11:14

and/or designation with the primary focus being

05:11:15 - 05:11:15

on

05:11:17 - 05:11:18

functional support needs.

05:11:23 - 05:11:26

In parallel at around 2021 and 2022 in SAR, the

05:11:26 - 05:11:29

International Society for Autism Research developed a Delphi process that

05:11:30 - 05:11:33

culminated in a proposed framework for profound autism for individuals

05:11:33 - 05:11:36

with the highest support needs. Again, their

05:11:37 - 05:11:40

central and core anchoring criterion was profound functional

05:11:40 - 05:11:43

dependence. That the person required adult supervision to ensure

05:11:44 - 05:11:47

physical and mental health, safety and wellbeing

05:11:48 - 05:11:51

due to risks such as elopement, injury or lack of environmental

05:11:51 - 05:11:54

awareness. And that their adaptive functional skills

05:11:55 - 05:11:58

led to an inability to perform most activities of daily living

05:11:59 - 05:12:02

independently. They noted that these individuals also

05:12:02 - 05:12:06

tend to have marked communication disabilities

05:12:06 - 05:12:07

and limitations

05:12:08 - 05:12:11

and also had that same and or criteria with significant

05:12:12 - 05:12:14
cognitive impairment.

05:12:22 - 05:12:25
About a year after the Landsu Commission administrative framework for profound autism

05:12:25 - 05:12:28
was proposed, the CDC via the autism and developmental

05:12:29 - 05:12:32
disabilities monitoring network published surveillance data from

05:12:34 - 05:12:36
2000 covered the years 2000 to 2016.

05:12:38 - 05:12:41
And they found that roughly 26% of individuals

05:12:42 - 05:12:44
met criteria for profound autism.

05:12:46 - 05:12:50
Interestingly, the CDC criteria operationalized primarily

05:12:50 - 05:12:53
around speech and an IQ less than

05:12:53 - 05:12:56
50. However, the speech criteria used were

05:12:56 - 05:12:59
very, very narrow in that study and we can get back to this later

05:12:59 - 05:13:03
if there are questions. But notably, even in

05:13:03 - 05:13:07
this study where IQ was a criterion for the profound

05:13:07 - 05:13:09
designation. Profound autism

05:13:09 - 05:13:12

designation, almost 20% of their sample

05:13:13 - 05:13:15

did not have IQ data available

05:13:16 - 05:13:18

and IQs were imputed using other

05:13:19 - 05:13:22

criteria, many of which were functional criteria

05:13:22 - 05:13:25

such as adaptive functional scores, aggressive behavior

05:13:26 - 05:13:27

or self injury.

05:13:32 - 05:13:35

Sorry, I'm going to go back. So why is this

05:13:35 - 05:13:38

designation important? I mean obviously we're talking about that those

05:13:38 - 05:13:41

with the highest support needs really have fundamental differences

05:13:42 - 05:13:45

in terms of what they require across the

05:13:45 - 05:13:48

lifespan in terms of services and supports. But it's also

05:13:49 - 05:13:52

really important from the idea of really being better able

05:13:52 - 05:13:53

to understand.

05:13:55 - 05:13:58

Risk factors or biological risk factors

05:13:59 - 05:13:59

and underpinnings for this particular

05:14:01 - 05:14:02
cohort.

05:14:03 - 05:14:07
Those with profound autism or the highest support needs have

05:14:07 - 05:14:08
elevated mortality.

05:14:10 - 05:14:14
Those with autism in general have slightly elevated mortality, perhaps

05:14:14 - 05:14:16
maybe one 1.3 to 1.5 times the general

05:14:16 - 05:14:19
population. But those with the highest support needs

05:14:20 - 05:14:23
have roughly 2.8 to 5 times mortality risk

05:14:23 - 05:14:26
compared to the general population and reduce life

05:14:26 - 05:14:30
expectancy. 7 years for men and 15 years

05:14:30 - 05:14:33
less for women. And certainly this group, as we'll hear from

05:14:34 - 05:14:36
later, has elevated safety risks from a range of

05:14:36 - 05:14:40
issues, including wandering and elopement.

05:14:46 - 05:14:50
This cohort also has higher rates of co occurring medical

05:14:50 - 05:14:53
conditions. Epilepsy, which is found at

05:14:54 - 05:14:57

roughly 1% in the general population and is present about

05:14:57 - 05:15:00

in about 8% of autistic individuals with lower support needs

05:15:01 - 05:15:04

is present at a much higher rate, 21% in those with the highest

05:15:05 - 05:15:07

support needs. Likewise

05:15:08 - 05:15:11

gastrointestinal disorders are significantly more common in those with

05:15:12 - 05:15:15

autism and the highest support needs and symptoms

05:15:15 - 05:15:16

are also more severe.

05:15:18 - 05:15:21

And interestingly in terms of motor impairments and this body of research

05:15:22 - 05:15:25

is very exciting to me. Because I think there's an emerging

05:15:26 - 05:15:29

conception in the scientific literature of autism as a

05:15:29 - 05:15:33

motor disorder, as a motor movement disorder. We know that

05:15:33 - 05:15:37

motor differences in autism spectrum as

05:15:37 - 05:15:40

a whole are 22 times greater than in the general population.

05:15:41 - 05:15:44

But the risk of motor differences and motor challenges

05:15:45 - 05:15:48

and disabilities is even higher for those with the highest support needs

05:15:50 - 05:15:53

roughly a four to six times higher compared to the autism spectrum

05:15:53 - 05:15:54

overall.

05:15:57 - 05:15:59

There's research that shows that those who have autism spectrum

05:15:59 - 05:16:03

disorder plus a diagnosed intellectual disability also have

05:16:03 - 05:16:05

significantly greater motor incoordination.

05:16:07 - 05:16:10

And certainly this group, there's a robust data that they have

05:16:10 - 05:16:13

elevated rates of sleep disorders, feeding difficulties

05:16:14 - 05:16:15

and self injuries behavior.

05:16:21 - 05:16:24

So here is the central paradox. The individuals with the

05:16:25 - 05:16:28

greatest medical complexity and functional support needs

05:16:28 - 05:16:32

are the most excluded from the research designed to help

05:16:32 - 05:16:35

them. Despite higher rates of epilepsy,

05:16:35 - 05:16:38

gastrointestinal disease sleep disorders, self

05:16:38 - 05:16:41

injury, 94% of autism spectrum

05:16:41 - 05:16:44

disorder research participants have lower support needs.

05:16:45 - 05:16:48

This is not a random gap. Studies show deliberate

05:16:49 - 05:16:52

or implicit selection bias against those with higher support

05:16:52 - 05:16:56

needs in eight out of 10 studies. And the trend is

05:16:56 - 05:16:59

moving in the wrong direction. Those with

05:16:59 - 05:17:03

arguably the greatest need are the least represented in

05:17:03 - 05:17:04

the research that could help them.

05:17:10 - 05:17:13

Existing systems do not reliably capture individuals with the

05:17:13 - 05:17:16

highest support needs. And it's why a functional

05:17:17 - 05:17:20

designation of profound autism, in my opinion, is needed.

05:17:23 - 05:17:26

There have been many criticisms of the dsm5 diagnostic framework for

05:17:26 - 05:17:29

autism, and the framework is largely based on social

05:17:29 - 05:17:33

communication and restricted behaviors, not overall

05:17:33 - 05:17:36

functioning. The severity levels level

05:17:36 - 05:17:40

one, two or three were designed to reflect the level of support

05:17:40 - 05:17:40

needed

05:17:42 - 05:17:45

in those domains, again with respect to social communication or restricted

05:17:46 - 05:17:49

repetitive behaviors. Yet Mazarach and colleagues found

05:17:49 - 05:17:52

in 2019 that clinician severity ratings.

05:17:53 - 05:17:56

Were strongly associated with measured IQ, suggesting that

05:17:57 - 05:18:00

measured cognitive function was being folded into severity determinations

05:18:01 - 05:18:04

contrary to DSM-5 intent. Other

05:18:04 - 05:18:07

criticisms of our current diagnostic framework include the idea that

05:18:08 - 05:18:11

autism is not a single spectrum running from mild to

05:18:11 - 05:18:14

severe in a straight line. It is highly

05:18:14 - 05:18:17

heterogeneous condition along multiple dimensions

05:18:18 - 05:18:22

social communication, language, motor functioning,

05:18:22 - 05:18:25

sensory processing, adaptive functioning, and co-occurring condition.

05:18:27 - 05:18:30

And these domains do not necessarily neatly correlate with each

05:18:30 - 05:18:34

other. A person can be severely affected in one

05:18:34 - 05:18:35

dimension and not in another.

05:18:37 - 05:18:40

The issue of co-occurring conditions such as anxiety,

05:18:40 - 05:18:44

ADHD, epilepsy, and other medical conditions deserve special

05:18:44 - 05:18:47

mention as they can have a tremendous impact on the daily

05:18:47 - 05:18:51

functioning of autistic individuals. Yet

05:18:51 - 05:18:53

as ways barred and bartab and colleagues noted in

05:18:53 - 05:18:56

2023, there is currently no formal way to designate

05:18:56 - 05:18:59

the combined effect of these aspects of autism on a

05:18:59 - 05:19:02

person's capacity to function in day to day life.

05:19:04 - 05:19:07

That gap is precisely what a profound autism designation

05:19:08 - 05:19:11

grounded in functional capacity and functional language would

05:19:11 - 05:19:12

begin to address.

05:19:14 - 05:19:16

If autism is not a single linear

05:19:16 - 05:19:19

continuum, but a multidimensional heterogeneous condition

05:19:21 - 05:19:24

than treating everyone under one label for research and policy

05:19:24 - 05:19:28

purposes is simply inadequate. And those

05:19:28 - 05:19:30

with the greatest support needs risk being invisible

05:19:31 - 05:19:34

within the very category meant to represent them.

05:19:37 - 05:19:41

So what are the proposals and attachments see they're really pretty

05:19:41 - 05:19:41

simple.

05:19:44 - 05:19:46

The proposals are minimally speaking or non speaking

05:19:47 - 05:19:50

and the requirement for continuous or near continuous supervision.

05:19:51 - 05:19:54

This would apply similar to the LANSAs commission and in

05:19:55 - 05:19:58

SAR to individuals over the age of eight, eight years or older.

05:19:58 - 05:20:01

This would be for research policy and program

05:20:01 - 05:20:04

planning. And it does not in any way affect

05:20:04 - 05:20:08

dsm or in eligibility determinations

05:20:08 - 05:20:10

for programs either at the state or federal level.

05:20:13 - 05:20:17

And notably in the proposal before the committee. Minimally speaking

05:20:17 - 05:20:20

is really aligned with a functional communication definition.

05:20:24 - 05:20:25

So at the most basic level.

05:20:29 - 05:20:32

The designation proposed an attachment C is

05:20:32 - 05:20:33

really framed around

05:20:35 - 05:20:38

is the person's communication ability enough to

05:20:38 - 05:20:41

assure safety and get basic needs met.

05:20:42 - 05:20:45

The functional definition is crucial because the term

05:20:46 - 05:20:49

minimally verbal or minimally speaking has very different meanings across

05:20:50 - 05:20:53

different research studies and context. Including

05:20:53 - 05:20:55

in the CDC surveillance data that I mentioned

05:20:56 - 05:20:59

earlier. It's not word counts that matter

05:20:59 - 05:21:03

or whether a phrase has two words or three words. It's

05:21:03 - 05:21:06

whether speech can be used to convey someone's internal state.

05:21:08 - 05:21:09

Their needs or their wants.

05:21:11 - 05:21:14

Can a person express pain, a medical issue or

05:21:14 - 05:21:17

a direct need? Many individuals with autism

05:21:18 - 05:21:21

even who have many words or even two to three word phrases

05:21:22 - 05:21:22

can't do that.

05:21:24 - 05:21:27

I think from a practical level, I think about can an individual

05:21:28 - 05:21:30

call 911 and get help.

05:21:31 - 05:21:35

Not necessarily explain the whole situation, but say enough to get

05:21:35 - 05:21:38

a first responder to come to their home or wherever they are.

05:21:39 - 05:21:42

Can they tell a medical provider that they have a headache? Or

05:21:42 - 05:21:46

abdominal pain? Or a toothache? We need

05:21:46 - 05:21:49

to focus on functional criteria because that's what really matters

05:21:50 - 05:21:52

for individuals and their families.

05:21:56 - 05:21:59

Sorry, I was on the wrong slide. Okay. Sorry.

05:22:00 - 05:22:02

Here are the criteria.

05:22:08 - 05:22:09

Our proposal for the profound autism

05:22:10 - 05:22:12

designation. We are specifically

05:22:14 - 05:22:16

recommending that the criterion of intellectual

05:22:17 - 05:22:20

disability not be used in this functional

05:22:20 - 05:22:22

definition of profound autism as it is

05:22:22 - 05:22:26

unreliable, unnecessary and potentially

05:22:26 - 05:22:29

exclusionary. The lancet and ins are

05:22:29 - 05:22:32

proposed frameworks that included id

05:22:33 - 05:22:36

used it, as I mentioned earlier, in an and or

05:22:38 - 05:22:42

option with speech disability. The primary focus was

05:22:42 - 05:22:45

on continuous support needs and 247 care.

05:22:46 - 05:22:49

IQ was used as an and/or criteria with being minimally speaking

05:22:50 - 05:22:53

or non speaking, but notably again in those models

05:22:54 - 05:22:57

used very narrow criteria of what was meant by non speaking.

05:22:58 - 05:23:00

Or minimally speaking or minimally verbal.

05:23:02 - 05:23:06

IQ testing is a resource intensive and not always

05:23:06 - 05:23:09

available. Indeed, in the CDC surveillance

05:23:09 - 05:23:12

study, as I mentioned, roughly 20% of children did not have

05:23:13 - 05:23:13

measured IQ.

05:23:15 - 05:23:18

And as I mentioned before, the method used to estimate IQ included a number of

05:23:19 - 05:23:22

behavioral and functional factors. We know that

05:23:23 - 05:23:26

IQ is unreliable. There is a large body of

05:23:26 - 05:23:28

published research that supports that idea.

05:23:30 - 05:23:33

And references are noted in attachment C. Answering

05:23:33 - 05:23:36

an IQ question requires speech or

05:23:37 - 05:23:40

reliable and consistent motor functioning and motor

05:23:40 - 05:23:43

planning, including initiation. And yet

05:23:43 - 05:23:46

motor impairments motor impairments are well described in

05:23:46 - 05:23:50

autism, again a growing body of literature, an interest in this

05:23:50 - 05:23:50

idea.

05:23:53 - 05:23:56

And crucially, some non speaking or minimally speaking individuals

05:23:56 - 05:23:59

demonstrate average or above average intelligence with appropriate

05:24:00 - 05:24:04

assistive and augmentative communication and yet may still require

05:24:04 - 05:24:05

continuous support.

05:24:07 - 05:24:10

Having reliance on IQ as a criterion for profound

05:24:11 - 05:24:14

autism might exclude individuals who meet functional or

05:24:14 - 05:24:17

communication criteria but lack of formal intellectual disability

05:24:18 - 05:24:21

diagnosis. It may misclassify individuals due to known

05:24:22 - 05:24:24

assessment limitations and it reinforces

05:24:25 - 05:24:28

systematic underestimation of cognitive potential.

05:24:38 - 05:24:42

As I mentioned functional criteria are central to many

05:24:42 - 05:24:45

policy proposals and supports the core

05:24:45 - 05:24:48

criterion of the Lancet and INSAR proposals for profound autism

05:24:49 - 05:24:52

were functional. The requirement for continuous support for safety

05:24:52 - 05:24:55

and wellbeing. We need this designation so we can have

05:24:56 - 05:24:57

consistent identification across

05:24:59 - 05:25:02

system systems, improved research designs and

05:25:02 - 05:25:03

planning. This is crucial

05:25:05 - 05:25:08

that are resource planning. I think having a term for individual with the highest

05:25:08 - 05:25:09

support needs

05:25:11 - 05:25:14

more descriptive, I think supports interagency coordination

05:25:15 - 05:25:18

and it aligns with the autism cares act priorities.

05:25:19 - 05:25:23

We need to recognize those with the highest support needs and begin to

05:25:23 - 05:25:26

correct the systematic and unequivocal exclusion from research

05:25:26 - 05:25:30

and design policy with their lifelong continuous support

05:25:30 - 05:25:33

needs in mind. The term is already being widely

05:25:33 - 05:25:36

used. Let's operationalize it

05:25:37 - 05:25:40

along functional criteria around speech and support needs so that

05:25:40 - 05:25:43

we capture the lived and clinical experience of this cohort

05:25:44 - 05:25:47

and correct the underrepresentation in research and policy.

05:25:48 - 05:25:48

Thank you.

05:25:52 - 05:25:54

So I'll turn my hat over now as chair Dr.

05:25:54 - 05:25:56

Rosnell. I saw your hand first.

05:25:58 - 05:26:00

Yeah, so in clinical studies

05:26:01 - 05:26:05

generally you try to pick kids that you think are going to do well. So you exclude

05:26:05 - 05:26:07

high functioning kids because maybe they don't have as much room to improve.

05:26:08 - 05:26:12

And you exclude low function kids because they are

05:26:12 - 05:26:15

severely affected may not prove much. You try to get the medium affected kids. And so

05:26:15 - 05:26:19

a lot of studies are doing that. And even going further and selecting out like, okay, let's take

05:26:19 - 05:26:22

kids just with speech delay. Who meet this criteria model he affected

05:26:23 - 05:26:26

and so forth. So I don't know how you fix that in research

05:26:26 - 05:26:29

because there's no incentive to have profound autism in your research study

05:26:30 - 05:26:33

because it might screw your so to say. For

05:26:33 - 05:26:36

example, we oftentimes exclude kids with seizures from the studies

05:26:36 - 05:26:40

because if a kid has a seizure, that's an adverse event. And you don't want

05:26:40 - 05:26:43

adverse events in your studies. You're trying to prevent those sort of things. So there need to be

05:26:43 - 05:26:46

research set aside for we're actually going to study for on autism.

05:26:47 - 05:26:50

Or maybe they're in the study, but they're kind of analyzed a bit separately

05:26:50 - 05:26:53

or if they have a seizure, it doesn't ding your whole

05:26:53 - 05:26:56

study. That makes sense. So it's a big problem in research because

05:26:57 - 05:26:59

the clinicians don't want to put on kids in the studies.

05:27:01 - 05:27:05

We got a collaboration with our FDA partner is in our

05:27:05 - 05:27:07

future. Dr. Beckel Mitchner.

05:27:08 - 05:27:11

Thank you. I also, I first want to applaud you for highlighting this

05:27:12 - 05:27:15

community. And we heard many comments around the table early on

05:27:15 - 05:27:19

that there's a really a great need to to do more

05:27:19 - 05:27:22

research and provide more services. I just want to, from a research

05:27:23 - 05:27:26

perspective representing one of the NIH institutes that supports

05:27:27 - 05:27:30

a large number of autism studies. I just want to

05:27:30 - 05:27:34

raise a couple of items for consideration and I would

05:27:34 - 05:27:37

appreciate hearing from my other NIH colleagues as well.

05:27:39 - 05:27:43

Definitions matter. We've heard a lot about the heterogeneity

05:27:43 - 05:27:47

of autism and autism spectrum disorders over

05:27:47 - 05:27:50

today and for our lifetimes. I do

05:27:50 - 05:27:53

have a concern that if we too narrowly

05:27:54 - 05:27:57

define profound autism, we will end up excluding

05:27:58 - 05:28:02

unintentionally a number of individuals from studies

05:28:02 - 05:28:05

as well. So it can actually potentially backfire and have the opposite

05:28:06 - 05:28:09

effect on our research portfolios. Dr.

05:28:10 - 05:28:13

Rassan's comments are well taken. This really comes down

05:28:13 - 05:28:16

to sort of an inclusion exclusion criteria

05:28:17 - 05:28:20

as researchers are determining what their clinical

05:28:20 - 05:28:21

endpoints might

05:28:21 - 05:28:24

be. So I do have some

05:28:24 - 05:28:28

concerns that we may not be seeing the full picture with the

05:28:28 - 05:28:30

definition that has been

05:28:30 - 05:28:33

proposed. I would love to see more

05:28:34 - 05:28:37

expert opinion on this and to raise with other subject matter experts.

05:28:38 - 05:28:41

So from my perspective, I would support additional information

05:28:42 - 05:28:45

gathering and people like Dr. Lord and many

05:28:46 - 05:28:49

others who have experience in this to really understand the full

05:28:49 - 05:28:52

spectrum of what we might be voting on and

05:28:52 - 05:28:55

what would be best for the research

05:28:56 - 05:28:57

opportunities that lay in front of us.

05:29:06 - 05:29:08

Dr. Alan monarch.

05:29:10 - 05:29:12

With regard to what Dr. Rawson brought up about

05:29:14 - 05:29:17

the highest functioning and the lowest functioning. Those would be important

05:29:18 - 05:29:21

for outcome studies. We were doing interventions. We have a lot

05:29:21 - 05:29:25

of other research to do for people with autism. We need to figure out

05:29:25 - 05:29:28

what is causing autism. We need to understand their bodies

05:29:28 - 05:29:31

better. Their GI systems, their immune functioning. There are many, many

05:29:31 - 05:29:35

studies to do. And I would argue that we need the

05:29:35 - 05:29:38

profound group. In order to understand

05:29:38 - 05:29:40

that. Because they may

05:29:42 - 05:29:45

their gap in their health markers may be wider.

05:29:46 - 05:29:47

And more easily detected.

05:29:52 - 05:29:53

Caitlin.

05:29:57 - 05:29:59

I want to start by saying that I support the intent of this

05:29:59 - 05:30:03

proposal. It matters to me that people with the highest support

05:30:04 - 05:30:07

needs, especially my non speaking peers are

05:30:07 - 05:30:09

even better supported. That is important to me.

05:30:11 - 05:30:13

At the same time, I have some important concerns.

05:30:15 - 05:30:17

The term profound autism does not come from a neutral place.

05:30:19 - 05:30:22

It was originally used to describe people like me with the assumption that we also

05:30:23 - 05:30:26

had intellectual disability that profound men low cognitive

05:30:26 - 05:30:29

ability. Many of us were also labeled nonverbal.

05:30:30 - 05:30:33

But that is not accurate. Schellers are not

05:30:33 - 05:30:36

nonverbal. We are not speaking. We have language.

05:30:37 - 05:30:41

We have thoughts. The issue is not a lack of understanding.

05:30:42 - 05:30:43

The issue is getting our words out.

05:30:44 - 05:30:48

So I don't identify with the term profound autism as it is commonly

05:30:48 - 05:30:48

understood.

05:30:50 - 05:30:53

I do have profound motor challenges including apraxia

05:30:53 - 05:30:57

and those affected by ability to speak. But that is different

05:30:57 - 05:31:00

from having a low IQ. When people could use these

05:31:00 - 05:31:04

concepts, we are underestimated. I also want

05:31:04 - 05:31:07

to speak for my brothers and sisters in the autism community who have

05:31:07 - 05:31:11

fluent speech. Some of them have high support needs and profound

05:31:11 - 05:31:14

challenges in daily life. I don't support the definition of

05:31:14 - 05:31:18

profound autism that leaves the malder makes their needs less visible.

05:31:19 - 05:31:22

Another concern I have is about how this term is already understood by the public.

05:31:24 - 05:31:26

Profound autism has been widely used to mean low intelligence.

05:31:28 - 05:31:31

That perception is out there and will be hard to change. I worry

05:31:32 - 05:31:34

that adopting this term even with a more careful definition

05:31:36 - 05:31:39

may reinforce those negative assumptions rather than correct them. So

05:31:39 - 05:31:42

while I support the goals of this proposal, I want to be

05:31:42 - 05:31:45

clear. I support it to help my non speaking peers get the recognition

05:31:46 - 05:31:48

and support they deserve. But the term

05:31:49 - 05:31:52

itself, as it is commonly used and understood, does not represent

05:31:53 - 05:31:54

me and my non speaking community.

05:32:01 - 05:32:01

Thank you, Laura.

05:32:04 - 05:32:06

Couple things. I just want to reiterate

05:32:08 - 05:32:11

we are highlighting the need for profound, which is

05:32:11 - 05:32:14

exceptional. There is still level three.

05:32:16 - 05:32:19

So what we've come to realize, and I think this was expressed

05:32:19 - 05:32:23

in public comments and in comments today. And I know many people in the

05:32:23 - 05:32:24

committee do live with this reality.

05:32:26 - 05:32:28

There is an exceptional population for which

05:32:30 - 05:32:33

there they cannot be left alone for any amount of time

05:32:34 - 05:32:35

because safety is a very serious

05:32:36 - 05:32:39

risk. So we haven't really captured

05:32:39 - 05:32:43

that in our current descriptions under the DSM for levels

05:32:43 - 05:32:46

one, two and three. So there has been a momentum

05:32:47 - 05:32:51

to adopt this. And this is actually being currently used now

05:32:51 - 05:32:54

in research papers. And I believe in SAR just had

05:32:54 - 05:32:55

this focus

05:32:57 - 05:33:00

regarding about getting input from experts

05:33:01 - 05:33:04

outside of the committee. Of course, that is something that the

05:33:05 - 05:33:09

federal members can do. But at this stage

05:33:10 - 05:33:13

for this committee, these are recommendations. These are

05:33:13 - 05:33:16

not the same as like a federal register rule that

05:33:17 - 05:33:19

is being finalized in which we are soliciting outside

05:33:20 - 05:33:23

comments to make a final rule. So I just want to make sure

05:33:24 - 05:33:27

that we're clarifying that this is only a

05:33:27 - 05:33:30

recommendation that would go to Secretary Kennedy

05:33:31 - 05:33:33

and that that would then be determined by him.

05:33:34 - 05:33:35

So thank you.

05:33:37 - 05:33:38

And if I.

05:33:39 - 05:33:42

Might ask Andrea and asking that question or

05:33:43 - 05:33:43

suggesting

05:33:45 - 05:33:47

in additional experts to speak to

05:33:47 - 05:33:50

this, I took it as part of

05:33:51 - 05:33:54

a deliberative process that the committee would engage in to

05:33:54 - 05:33:57

consider whether this is a recommendation

05:33:58 - 05:34:01

that the committee would vote on to move

05:34:01 - 05:34:04

forward to the secretary. Is that part of

05:34:06 - 05:34:07

where were you seeking something different?

05:34:09 - 05:34:12

I think the language of the recommendation

05:34:12 - 05:34:16

really matters in terms of how constraining it might be

05:34:16 - 05:34:17

for future research.

05:34:19 - 05:34:23

I don't know if it's appropriate to actually propose a change

05:34:23 - 05:34:26

in the language for us to consider. But I would suggest

05:34:28 - 05:34:31

Diana maybe in your role as neck, for example,

05:34:31 - 05:34:35

convening experts to include members of this committee, I think

05:34:35 - 05:34:37

also, because I think that

05:34:38 - 05:34:40

the perspectives that we've heard today

05:34:42 - 05:34:45

are really important. I'm just not sure if

05:34:46 - 05:34:50

me personally representing my agency right now would be comfortable voting

05:34:50 - 05:34:53

for this definition in, in this form, even as

05:34:53 - 05:34:56

a recommendation to the secretary at this

05:34:56 - 05:34:59

point. I feel like I need more information to be able to

05:34:59 - 05:35:00

vote on that.

05:35:03 - 05:35:07

I would like to, because we do have, and

05:35:07 - 05:35:09

I, you know, take this recommendation is one that's directed

05:35:10 - 05:35:14

specifically at hhs agencies. And we do have a number

05:35:14 - 05:35:14

of

05:35:16 - 05:35:19

federal partners on the committee who are from different parts of

05:35:20 - 05:35:23

hhs. And as I read the

05:35:23 - 05:35:26

recommendation, it would apply

05:35:26 - 05:35:29

both to research and policy

05:35:30 - 05:35:32

and that if I'm following the recommendation

05:35:32 - 05:35:35

correctly, HHS agencies

05:35:37 - 05:35:40

could potentially be asked to follow this definition

05:35:41 - 05:35:44

when considering any policy or research

05:35:45 - 05:35:48

is that I just want to make sure that the committee understands the

05:35:48 - 05:35:49

recommendation

05:35:51 - 05:35:53

and what, you know, for their federal agency, they would

05:35:53 - 05:35:56

be, I guess, voting for

05:35:56 - 05:35:59

in terms of the recommendation and moving that forward.

05:36:00 - 05:36:02

And if there's questions from any of our

05:36:04 - 05:36:05

HHS representatives on that.

05:36:07 - 05:36:10

So actually, I'm sorry if we could just get the clarification that I

05:36:11 - 05:36:14

asked about in terms of the recommendation for both research and policy

05:36:15 - 05:36:18

in that HHS agencies would be asked to apply. So this is a

05:36:18 - 05:36:21

recommendation for HHS to consider.

05:36:22 - 05:36:25

We are not a policy making body. We are a body that can make

05:36:26 - 05:36:28

recommendations to HHS for consideration

05:36:29 - 05:36:33

that then our national autism coordinator can follow up with and

05:36:33 - 05:36:36

HHS is free to come back to this committee and tell us, you know, if

05:36:36 - 05:36:40

what works and what doesn't. But how

05:36:40 - 05:36:42

I see these committee's role and particularly the public members

05:36:43 - 05:36:46

is taking the lived experience and the

05:36:47 - 05:36:50

urgent concerns of the autism community and

05:36:50 - 05:36:54

translating them into policy for HHS to

05:36:54 - 05:36:56

consider. We are in no way

05:36:59 - 05:37:02

charged with creating policy that is mandated to adopt.

05:37:06 - 05:37:10

Thank you. Good afternoon everyone. I wasn't here in the

05:37:10 - 05:37:13

morning of Judas Cooper. I'm the deputy director

05:37:13 - 05:37:16

at deafness and communication disorders institute.

05:37:19 - 05:37:20

I have to say that both

05:37:22 - 05:37:25

my director and myself were thrilled to see the focus on

05:37:26 - 05:37:28

non speaking because our institute has tried to be

05:37:31 - 05:37:34

a small leader in bringing attention to non

05:37:34 - 05:37:36

speaking we've, we've done workshops, we've done

05:37:37 - 05:37:38

initiatives, we've encouraged research.

05:37:42 - 05:37:46

And so I think shining the spotlight on the needs of

05:37:46 - 05:37:49

this population and the research needs. We are very

05:37:50 - 05:37:50

supportive of that.

05:37:52 - 05:37:55

I for one know I'm concerned about this controversy.

05:37:58 - 05:38:01

And the voting. But I will say that the

05:38:02 - 05:38:04

applications that might come in that are focused on.

05:38:06 - 05:38:09

Non speaking individuals. They'll go through peer review.

05:38:12 - 05:38:13

The science will be judged.

05:38:16 - 05:38:16

And so

05:38:18 - 05:38:21

I think there's a spotlight and then there's the process

05:38:21 - 05:38:24

of the impact of the spotlight on.

05:38:27 - 05:38:30

How we define a profound will

05:38:30 - 05:38:30

be

05:38:32 - 05:38:34

viewed in the applications that come

05:38:34 - 05:38:37

in. So I think we are

05:38:38 - 05:38:40

very supportive of anything that can.

05:38:42 - 05:38:46

Encourage research with this population. We've been trying to do

05:38:46 - 05:38:47

that for many years.

05:38:51 - 05:38:52

So thank you for the document

05:38:54 - 05:38:57

and I'm hoping that, Scott, yeah, some of us have

05:38:57 - 05:38:59

been on the panel and have talked about this before.

05:39:01 - 05:39:05

Yeah. So thank you. Thank you very much. We'll take

05:39:05 - 05:39:08

just three more comments. Dr.

05:39:08 - 05:39:12

Elaine Hubel online and then Bill Oldham and then

05:39:12 - 05:39:15

Cayden and CD Sweeney. So we'll, we'll go

05:39:16 - 05:39:19

in that order. And Lane, Bill

05:39:19 - 05:39:22

Oldham, Caden and then CD. And then we'll have to move

05:39:23 - 05:39:26

on. Oh, okay. And then Elizabeth. Okay. And then we'll have to move on. Okay.

05:39:27 - 05:39:28

Okay. So can you hear me?

05:39:30 - 05:39:32

Yes. Okay. I was going to say you might not have to take my

05:39:33 - 05:39:36

comment. Okay. So I would just say because I

05:39:36 - 05:39:39

this topic has come up before and it is beyond

05:39:40 - 05:39:40

critically important

05:39:42 - 05:39:44

and sort of I've been hearing

05:39:46 - 05:39:49

and really taking heart to heart the comments that come sort of

05:39:49 - 05:39:50

from people who

05:39:52 - 05:39:53

appreciate the

05:39:55 - 05:39:55

really.

05:39:58 - 05:40:01

Extreme needs of this, you know, of this population

05:40:02 - 05:40:04

and the caregivers and then people who

05:40:06 - 05:40:10

have important concerns. So I would just say from like the

05:40:10 - 05:40:11

perspective of an agency outside

05:40:13 - 05:40:15

HHS, so environmental protection agency

05:40:16 - 05:40:18

and sort of understanding the importance of having

05:40:21 - 05:40:24

categories based knowing the complexity of the

05:40:24 - 05:40:27

factors that we're trying to incorporate into

05:40:28 - 05:40:31

classifications that are going to be meaningful for making

05:40:32 - 05:40:33

decisions that are most.

05:40:35 - 05:40:37

Health protective health promoting

05:40:39 - 05:40:43

of the most vulnerable groups, whatever those may be in

05:40:43 - 05:40:46

whatever context. I would just say that I think.

05:40:48 - 05:40:51

It would be important to really take

05:40:51 - 05:40:52

advantage of newer

05:40:54 - 05:40:57

more recent methodologies for evidence based synthesis and data

05:40:58 - 05:41:01

driven classifications that that could help us.

05:41:04 - 05:41:07

Protect and the intent of this

05:41:07 - 05:41:11

recommendation. So maybe alter the recommendations of what we're wanting

05:41:11 - 05:41:14

is really evidence

05:41:15 - 05:41:18

based data driven classifications. That will

05:41:18 - 05:41:21

meet the needs of the most vulnerable

05:41:22 - 05:41:24

in a really, in a way that.

05:41:26 - 05:41:30

Helps both on support and on research and

05:41:30 - 05:41:32

on regulatory actions.

05:41:34 - 05:41:38

I'll leave it at that, but that would, that to me is

05:41:38 - 05:41:40

something that takes some real good

05:41:41 - 05:41:45

work. And I, and I think I would love to see a working group

05:41:45 - 05:41:46

focus on that.

05:41:48 - 05:41:51

Thank you, Yes, thank you. First of

05:41:51 - 05:41:54

all, I'd say I applaud you for the for a couple of things. One is

05:41:55 - 05:41:55

that

05:41:57 - 05:41:59

as I understand our responsibilities as a

05:41:59 - 05:42:02

committee, we're looking to suggest

05:42:03 - 05:42:06

exploration for the general direction of travel for our

05:42:06 - 05:42:10

community. And I'd encourage us all to

05:42:12 - 05:42:15

not make the perfect the enemy of the good. We need

05:42:15 - 05:42:18

to advance, I think if for all of us who

05:42:20 - 05:42:23

took the time and the energy and I hope it was all of us to read the public

05:42:24 - 05:42:27

comments, this is clearly an issue that

05:42:27 - 05:42:30

needs action. So we're not here to make

05:42:30 - 05:42:32

policy. We're here to suggest a direction to

05:42:32 - 05:42:36

travel. And I applaud you for what you what you've got

05:42:36 - 05:42:39

in this document. I think it advances us down the path that

05:42:39 - 05:42:42

we need to go. There was a particular comment

05:42:43 - 05:42:44

in the public comments on there are different

05:42:45 - 05:42:48

autisms. And I agree wholeheartedly the

05:42:48 - 05:42:52

definitions matter. But we have to start making progress

05:42:52 - 05:42:55

towards what some of those new definitions actually are

05:42:56 - 05:42:57

rather than

05:42:58 - 05:43:00

debating because the time and the struggle is

05:43:00 - 05:43:04

now. I'd also applaud

05:43:04 - 05:43:07

you for one more thing. The differentiation

05:43:09 - 05:43:10

in the document about intellectual

05:43:10 - 05:43:14

disability. As the father of two

05:43:15 - 05:43:18

minimally verbal and nonverbal boys.

05:43:20 - 05:43:22

There's a lot going on in their head every

05:43:22 - 05:43:26

day. They're a real human being with a

05:43:26 - 05:43:29

brain and capability and they deserve this kind of

05:43:29 - 05:43:31

distinction. So thank you for your good work.

05:43:33 - 05:43:34

Thank you. Caitlin.

05:43:41 - 05:43:44

I'm going to ask you to restart that and put the microphone closer, please, if you can

05:43:45 - 05:43:45

take your time.

05:43:52 - 05:43:55

I want to be clear. I will vote yes but want to speak my mind on it.

05:43:57 - 05:44:00

Thank you, Kane. Let's do Katy Sweeney and then

05:44:00 - 05:44:03

Elizabeth and then we're going to move on to our next topic. Thank

05:44:03 - 05:44:07

you. I heard in this discussion in the last

05:44:07 - 05:44:09

phrases like want more time to review.

05:44:11 - 05:44:14

Leading the project for five years. This is not new.

05:44:15 - 05:44:18

Languages concerning for future

05:44:18 - 05:44:18

research.

05:44:20 - 05:44:24

Convening experts. I need more info. From

05:44:24 - 05:44:26

reviewing the 25 year history of

05:44:27 - 05:44:30

IAC, I think this committee is notorious for kicking

05:44:30 - 05:44:31

the can down the road.

05:44:33 - 05:44:36

That diminishes the lived experience. Of

05:44:36 - 05:44:39

both families and individuals affected.

05:44:42 - 05:44:45

And the reality of our autism

05:44:45 - 05:44:47

children, young adults families and caregivers.

05:44:49 - 05:44:52

I ask as a parent how much more

05:44:52 - 05:44:54

time and info do you need?

05:45:02 - 05:45:06

This recommendation impacts me and the millions of non-speakers

05:45:06 - 05:45:09

in America. I wish that non speakers didn't have to

05:45:09 - 05:45:12

contend with another label. But I appreciate that this definition

05:45:13 - 05:45:15

explicitly excludes intellectual disability.

05:45:17 - 05:45:20

Tens of thousands of non speakers now type to communicate, the

05:45:20 - 05:45:23

vast majority are like me. Diagnosed with an intellectual

05:45:24 - 05:45:26

disability before being able to show how capable we are.

05:45:28 - 05:45:31

I would prefer not to use the term profound autism because

05:45:31 - 05:45:34

its definition has historically conflated non speaking with intellectual

05:45:35 - 05:45:38

disability. An assumption that is harmful to understanding our

05:45:38 - 05:45:41

capabilities. With this recommendation, I hope

05:45:42 - 05:45:45

the autism community can come together and presume competence for

05:45:45 - 05:45:48

non speakers. I am generally supportive of this

05:45:49 - 05:45:52

recommendation because it will focus research and policy on helping

05:45:52 - 05:45:54

families that have the greatest support and aids.

05:45:55 - 05:45:59

However, I would highly recommend one sentence be added to

05:45:59 - 05:46:01

section 6 person centered considerations.

05:46:02 - 05:46:06

The sentences providing services and supports for robust

05:46:06 - 05:46:10

alternative and augmentative communication are essential for maximizing

05:46:10 - 05:46:13

the health. Safety and potential of individuals with

05:46:13 - 05:46:13

autism.

05:46:15 - 05:46:18

And one final thought my sincere hope is that these efforts will help

05:46:18 - 05:46:21

change the way the world sees non speaking autism.

05:46:22 - 05:46:25

Our support needs may be high. Our thoughts are profound.

05:46:27 - 05:46:27

Thank you.

05:46:30 - 05:46:33

Thank you. Would it be possible to read again

05:46:34 - 05:46:34

the sentence.

05:46:37 - 05:46:38

For the proposed addition?

05:46:40 - 05:46:44

Sorry, I'm going to just try to take the sentence reads

05:46:45 - 05:46:48

providing services and supports for robust

05:46:49 - 05:46:51

alternative and augmentative communication.

05:46:52 - 05:46:55

Are essential for maximizing the

05:46:55 - 05:46:58

health, safety and potential of

05:46:58 - 05:46:59

individuals with autism.

05:47:04 - 05:47:07

I want to read it back to you. Providing services and supports for robust

05:47:09 - 05:47:11

assistive and automatic communication are essential to

05:47:12 - 05:47:15

essential for maximizing the health, safety

05:47:17 - 05:47:17

and potential

05:47:19 - 05:47:22

of individuals with autism. And it's aac

05:47:22 - 05:47:24

alternative and augmentative communication.

05:47:32 - 05:47:35

So we have to move on. I'm going to propose that we

05:47:35 - 05:47:38

add that sentence to attachment C

05:47:40 - 05:47:43

and later in the afternoon. That will be added to that

05:47:44 - 05:47:44

proposal.

05:47:46 - 05:47:48

So we are going to move on now. We're a little bit behind

05:47:49 - 05:47:52

schedule. Yeah, sorry. I think because

05:47:53 - 05:47:55

you've made that proposed on looking to my colleagues

05:47:56 - 05:47:59

to the right that we might need to as a committee vote

05:47:59 - 05:48:03

on making that change to this document.

05:48:07 - 05:48:08

Protocol or.

05:48:12 - 05:48:14

We could potentially vote to accept a document

05:48:15 - 05:48:18

including the proposed change. Okay. Okay.

05:48:19 - 05:48:22

But we would need to, we would probably need to send that exact language out

05:48:23 - 05:48:26

just so everybody's clear on what it is. Okay. Can we do that during the

05:48:26 - 05:48:29

break, which is now shortened? Yes. Thank you.

05:48:30 - 05:48:33

Okay, I'm going to turn it over to Crystal Higgins. We're going to start

05:48:34 - 05:48:37

at topic three wandering and elopement. In

05:48:37 - 05:48:38

autism. Thank you.

05:48:41 - 05:48:43

Sarah Klicker for the presentation.

05:48:58 - 05:49:01

Thank you for your attention to this issue. I know several of you here

05:49:02 - 05:49:05

have lived experience with this and I'm grateful to be able to

05:49:05 - 05:49:08

present on the topic. And possible solutions today.

05:49:09 - 05:49:12

I will say this is one of many urgency topics.

05:49:13 - 05:49:16

And my hope is that we can continue to bring additional safety issues to the table

05:49:16 - 05:49:18

as we work together in the future.

05:49:24 - 05:49:28

Nearly half of children with autism will wander a bolt from a safe environment.

05:49:28 - 05:49:31

When we use the CDC's most recent autism prevalence

05:49:32 - 05:49:35

estimates based on the 2014 birth cohort and u. S.

05:49:35 - 05:49:38

Census information. That means we're looking at over 1.1

05:49:39 - 05:49:41

million families in the u. S affected.

05:49:43 - 05:49:46

These families are living with a level of risk most people could never imagine.

05:49:48 - 05:49:48

We.

05:49:52 - 05:49:52

Sure.

05:49:54 - 05:49:57

We have several peer-reviewed studies on this issue. This problem

05:49:58 - 05:50:01

in supporting data have been presented at previous IAC meetings many

05:50:01 - 05:50:04

times, including in 2010, 2013

05:50:04 - 05:50:08

2016 and 2017. This has been an ongoing and

05:50:08 - 05:50:11

consistent crisis that has not been adequately addressed.

05:50:12 - 05:50:15

Right now we're experiencing an average of eight fatalities per month

05:50:15 - 05:50:18

in the u. S. And lori mce at the national

05:50:18 - 05:50:22

autism safety council recently reported that in 2026

05:50:22 - 05:50:25

we are already outpacing last year's fatalities by

05:50:26 - 05:50:26

30%

05:50:29 - 05:50:32

As I mentioned, the data has been comprehensively presented at previous

05:50:33 - 05:50:36

IAC meetings. So I'm just going to briefly summarize the main trends here

05:50:36 - 05:50:39

that demonstrate the pathways to effective prevention.

05:50:40 - 05:50:43

On the left are causes of fatalities in a five year study that analyzed

05:50:43 - 05:50:46

over 800 media reported wandering and elopement cases

05:50:47 - 05:50:50

from 2011 to 2016. On the right is an

05:50:51 - 05:50:54

analysis from media reported instances in 2025 that

05:50:54 - 05:50:56

show the trends have not changed.

05:50:57 - 05:51:00

By and large, these individuals are going to water with traffic

05:51:01 - 05:51:04

fatalities coming in second. It's important to note that in the

05:51:04 - 05:51:08

five year study, 76% of drownings were

05:51:08 - 05:51:11

in natural bodies of water or drainage waters. This is unique to this

05:51:12 - 05:51:15

population and responses should be appropriate and specific to address

05:51:15 - 05:51:16

this pattern.

05:51:20 - 05:51:24

Fatalities happen fast. You can see on the left here the lighter blue

05:51:24 - 05:51:27

represents fatal incidents in the same five year study. The highest

05:51:27 - 05:51:31

amount in an hour or less. Every case is critical.

05:51:32 - 05:51:34

You can see the majority of rescue components were first responders

05:51:35 - 05:51:38

in Good Samaritans. This underscores the need for consistent

05:51:39 - 05:51:42

first responder training and for the public to be immediately notified

05:51:42 - 05:51:45

and directed to search nearby water when a person with autism

05:51:46 - 05:51:46

goes missing.

05:51:49 - 05:51:52

This graph is from the 2025 review by nasc.

05:51:53 - 05:51:56

Fatality spike in warmer months. We've seen this consistently for over

05:51:56 - 05:51:59

15 years. Recommendations to combat this issue should be

05:51:59 - 05:52:02

urgently adopted and implemented.

05:52:04 - 05:52:06

Multi-layered preventative measures are most successful.

05:52:08 - 05:52:11

Home safeguards like alarms, fencing and locks, personal safeguards

05:52:11 - 05:52:15

such as tracking devices and personal identification are prudent measures

05:52:16 - 05:52:19

swimming lessons are critical and clinical counseling should include

05:52:19 - 05:52:23

risk education and options for families to consider. As well as

05:52:23 - 05:52:26

informing families on trends such as heightened risks during times of

05:52:27 - 05:52:30

transition family gatherings, warmer months and increased

05:52:30 - 05:52:33

risk overnight. Most families report they were never

05:52:33 - 05:52:37

canceled about wandering at the time of diagnosis. We

05:52:37 - 05:52:40

would never, for example send a patient with epilepsy home without

05:52:40 - 05:52:44

medication or a seizure safety plan. Why have we

05:52:44 - 05:52:47

continued to leave autism families to learn about wandering risk

05:52:47 - 05:52:49

through a close call? Or worse a tragedy?

05:52:51 - 05:52:54

Safety counseling should be standard at the time of suspected or official

05:52:54 - 05:52:55

diagnosis?

05:52:57 - 05:53:01

These are the most common barriers to preventative measures cited by

05:53:01 - 05:53:04

parents. Many families living in this constant heightened state of

05:53:04 - 05:53:07

alert and experiencing persistent traumatic events

05:53:08 - 05:53:10

face barriers that limit their ability to keep their loved ones safe.

05:53:11 - 05:53:15

It's possible to eliminate most if not all of these barriers with

05:53:15 - 05:53:15

sufficient support.

05:53:19 - 05:53:21

Parents noted that the number one barrier was lack of funding.

05:53:22 - 05:53:25

Right now Medicaid coverage remains uneven where it does exist

05:53:26 - 05:53:28

and it's still completely non-existent in many states.

05:53:29 - 05:53:32

Medicaid routinely covers nonmedical preventative

05:53:33 - 05:53:36

interventions across multiple conditions including home

05:53:36 - 05:53:40

modifications and monitoring systems where they reduce risk

05:53:40 - 05:53:43

of serious harm. Autism related wandering and

05:53:43 - 05:53:46

elopement meets the same thresholds of risk and should be treated consistently.

05:53:47 - 05:53:48

Within this framework.

05:53:54 - 05:53:57

The most recognized similar alert system to

05:53:58 - 05:54:01

Missing an endangered person or MEP alerts are the amber alerts or silver

05:54:02 - 05:54:05

alerts. We're talking about immediate notification of a missing

05:54:05 - 05:54:08

person via wireless emergency alerts including descriptions

05:54:09 - 05:54:12

and specific directives to the public within geographic proximity.

05:54:14 - 05:54:17

MEP alerts already exist and autism fits squarely into

05:54:17 - 05:54:20

this category. No new legislation is required.

05:54:21 - 05:54:24

Some states are adopting their own alert systems to address these incidents.

05:54:25 - 05:54:28

But there is no consistent framework that states can readily adapt to capture

05:54:29 - 05:54:30

each missing person with autism.

05:54:34 - 05:54:36

As we've seen, time is critical in these incidents.

05:54:37 - 05:54:40

Drowning accounts for the vast majority of wandering fatalities

05:54:41 - 05:54:44

and most of those are happening close to home or the last known location

05:54:45 - 05:54:48

ends in natural bodies of water. Alerts must be issued

05:54:48 - 05:54:51

immediately upon report without delay, eligibility

05:54:51 - 05:54:55

barriers or waiting periods. Any delay in public

05:54:55 - 05:54:58

notification reduces the likelihood of rapid recovery

05:54:58 - 05:55:00

and increases the probability of a fatal outcome.

05:55:02 - 05:55:05

Every reported incident should be presumptively classified as critical from the

05:55:06 - 05:55:09

outset. Triggering immediate activation of MEP alerts.

05:55:10 - 05:55:12

It's simply a very effective way to trigger an appropriate

05:55:13 - 05:55:15

response, reduce search times and save lives.

05:55:19 - 05:55:22

Responses and directives should reflect the known risk patterns, search water

05:55:22 - 05:55:26

first in traffic corridors, known behavioral attractors

05:55:26 - 05:55:27

and nearby terrain.

05:55:30 - 05:55:33

Even in states where autism training is required for first

05:55:33 - 05:55:36

responders, it doesn't always specifically include training on missing persons

05:55:37 - 05:55:40

with autism or wandering and elopement prevention. These

05:55:40 - 05:55:44

are key critical things for responder awareness that

05:55:44 - 05:55:47

individuals may not respond to their name, may flee or hide from

05:55:47 - 05:55:50

responders may not recognize danger, they may be

05:55:50 - 05:55:53

silent, not splashing or calling for help. The drowning can look very different

05:55:54 - 05:55:57

than typical drownings and they may not be aware

05:55:58 - 05:55:59

or be able to control their body.

05:56:00 - 05:56:01

In traffic risks.

05:56:07 - 05:56:10

We can take action now. We can standardize MEP alerts to

05:56:10 - 05:56:13

expedite proper search responses with autism specific criteria

05:56:14 - 05:56:17

and guidance. We can expand first responder training that

05:56:17 - 05:56:20

specifically includes unique risks and appropriate response to missing

05:56:21 - 05:56:24

individuals with autism. We can support coverage under

05:56:25 - 05:56:28

EPSDT. As well as home and community based

05:56:28 - 05:56:31

services, and we utilize HRSA and

05:56:31 - 05:56:34

EPSDT standardized safety counseling for families.

05:56:37 - 05:56:40

Last, as an additional consideration, we must

05:56:40 - 05:56:44

address a gap in our understanding and research.

05:56:44 - 05:56:47

And, Amy, I really appreciated your comments earlier on this.

05:56:47 - 05:56:50

What's happening biologically to our loved ones in these moments.

05:56:52 - 05:56:55

For some bolting may reflect an acute neurological stress response

05:56:55 - 05:56:59

rather than intentional behavior. Differences in

05:56:59 - 05:57:02

autonomic regulation, sensory processing and threat

05:57:02 - 05:57:04

perception can push the nervous system into fight or flight.

05:57:06 - 05:57:09

Or impulsive motor, during which inhibition or stopping the body

05:57:09 - 05:57:13

is challenging. If we expand our understanding, we can assign

05:57:13 - 05:57:16

effective treatment, trauma informs care in response to stressors.

05:57:17 - 05:57:20

This is essential to providing what could be one of the most useful pathways

05:57:21 - 05:57:24

to reducing wandering cases, as well as other critical

05:57:24 - 05:57:25

safety issues.

05:57:27 - 05:57:30

The next slide is a video because I really want

05:57:30 - 05:57:32

everybody to see what this looks like in real life.

05:57:35 - 05:57:36

This incident in the video will show you

05:57:38 - 05:57:41

how the trends that we just highlighted elopement under supervision

05:57:42 - 05:57:45

repeated instance tendency to go quickly to a natural nearby body of

05:57:46 - 05:57:48

water. And most importantly, how critical

05:57:49 - 05:57:51

immediate and informed responses.

05:59:14 - 05:59:14

We get that back up.

05:59:18 - 05:59:18

Sorry guys.

05:59:38 - 05:59:41

In the interruption, we still can't hear that online. Or

05:59:42 - 05:59:42

through the video cast.

05:59:50 - 05:59:53

I will highlight what happens in a moment. For those who can't hear online.

06:01:09 - 06:01:12

Guide families and first responders with the tools they need to keep these

06:01:12 - 06:01:13

individuals safe.

06:01:17 - 06:01:20

Every single time. There we go some families

06:01:20 - 06:01:24

are not as lucky just as we were

06:01:24 - 06:01:25

preparing to finalize this presentation.

06:01:27 - 06:01:30

These are four of several fatalities that

06:01:31 - 06:01:31

occurred

06:01:33 - 06:01:36

Alex 32 had some independence and enjoyed cleaning the trash

06:01:36 - 06:01:39

out of the canal behind his home. He went missing

06:01:40 - 06:01:43

for an unusually long period of time and his family mistakenly

06:01:43 - 06:01:47

believed they had to wait 72 hours before filing a

06:01:47 - 06:01:50

missing persons reports. The investigation still ongoing

06:01:50 - 06:01:52

but his body was found in the canal.

06:01:54 - 06:01:57

25 year old Dustin and his twin brother were both diagnosed

06:01:57 - 06:02:01

with autism this month Dustin opened a window despite the

06:02:01 - 06:02:04

furniture in front of it left home and in the very early morning hours

06:02:04 - 06:02:05

was hit by a bus on the highway.

06:02:07 - 06:02:11

Matthew who was nine years old got through three different types of locks.

06:02:11 - 06:02:15

One of which was a mechanical lock that according to his father was difficult to figure

06:02:15 - 06:02:18

out. But Matthew did and he was quickly killed by a car.

06:02:19 - 06:02:22

And Maddie 13 years old wandered from home in the dark and fog in the

06:02:22 - 06:02:26

middle of the night and was walking down the highway when she was hit and killed

06:02:26 - 06:02:27

by a dump truck.

06:02:29 - 06:02:32

After submitting these slides a 55 year olds a voted father Juan Andre

06:02:32 - 06:02:36

drowns in LA after jumping in the lake to save his 14 year old son

06:02:37 - 06:02:37

who had wandered into the water.

06:02:39 - 06:02:42

This is a public health crisis and it is preventable.

06:02:43 - 06:02:46

Thank you to the full committee and to the department of hhs for hearing this

06:02:46 - 06:02:49

issue. I am so hopeful that we can support meaningful

06:02:50 - 06:02:53

life saving resources becoming readily available to our community

06:02:53 - 06:02:53

together.

06:02:56 - 06:02:56

Thank you.

06:02:58 - 06:03:00

Thank you Crystal. So I'm just going to go through.

06:03:03 - 06:03:05

Well first I just wanted to say as noted in attachment

06:03:06 - 06:03:09

D, the IACC sent a letter to

06:03:09 - 06:03:12

then Secretary Kathleen civilius about this issue

06:03:12 - 06:03:13
in2011.

06:03:17 - 06:03:17
There's more to do

06:03:19 - 06:03:22
and this is a public health crisis with seven to eight

06:03:23 - 06:03:27
just based on media reports seven to eight deaths per month

06:03:27 - 06:03:31
in the autism community and that's not with active surveillance. Those are simply

06:03:31 - 06:03:34
advocacy organizations. Following media

06:03:34 - 06:03:37
reports. So just to review the recommendations

06:03:39 - 06:03:42
in attachment D, which I hope you all had a chance to

06:03:42 - 06:03:44
review. The first one is to

06:03:46 - 06:03:49
for Secretary Kennedy HHS to clarify and promote

06:03:49 - 06:03:52
consistent use of the missing and endangered persons alert

06:03:52 - 06:03:55
category within the integrated public alert and warning system

06:03:56 - 06:03:59
I pause for autism related wandering and elopement

06:03:59 - 06:04:03
incidents. I listed

06:04:03 - 06:04:06

with Crystal's input a number of operational

06:04:09 - 06:04:11

guidance implementation considerations for the

06:04:11 - 06:04:15

secretary. The second proposal is for the CDC to update

06:04:15 - 06:04:18

its wandering and elopement webpage to emphasize drowning

06:04:18 - 06:04:21

risk and the prioritization of searching nearby water sources

06:04:22 - 06:04:25

and high traffic areas that is not currently clear on the

06:04:25 - 06:04:28

CDC CDC allotment and wandering webpage.

06:04:30 - 06:04:30

And we

06:04:32 - 06:04:35

if the committee adopts would recommend also creating

06:04:35 - 06:04:38

downloadable safety information sheets for first responders

06:04:38 - 06:04:41

and for providers and caregivers directly from the CDC website.

06:04:43 - 06:04:45

The third proposal is to reevaluate and expand ICD

06:04:47 - 06:04:50

10 coding for wandering to potentially capture

06:04:50 - 06:04:52

clinically assessed prospective

06:04:52 - 06:04:56

risk. Because right now the code is typically only used for

06:04:57 - 06:05:00

a history of wandering and we are proposing that if this

06:05:04 - 06:05:06

either well we would need evaluation from

06:05:08 - 06:05:12

the national center for health statistics, but the recommendation is really for them to look

06:05:12 - 06:05:15

at this issue and see if a prospective

06:05:16 - 06:05:17

wandering code risk would be appropriate.

06:05:19 - 06:05:22

The second would be update early

06:05:23 - 06:05:27

EPSDT and bright futures guidance to include

06:05:27 - 06:05:30

risks of wandering elopement. And the fifth would be to

06:05:30 - 06:05:31

encourage consistent

06:05:33 - 06:05:36

coverage of safety supports under hcds waiver

06:05:37 - 06:05:40

programs. So things like locks, door alarms, fencing related

06:05:40 - 06:05:41

safety equipment.

06:05:43 - 06:05:46

And the sixth is to promote clinical adoption of wandering and elopement risk

06:05:46 - 06:05:49

guidance. Again through

06:05:51 - 06:05:54

the CDC in conjunction with updating their web page and

06:05:54 - 06:05:56

providing downloadable materials.

06:05:58 - 06:05:59

I believe these are common sense

06:06:01 - 06:06:04

actionable easily implementable

06:06:05 - 06:06:08

recommendations. And again, they are recommendations to

06:06:08 - 06:06:11

the secretary and to HHS for consideration.

06:06:12 - 06:06:13

I open the floor to discussion.

06:06:15 - 06:06:15

Tracy.

06:06:18 - 06:06:22

So this is an issue that is very near and dear

06:06:22 - 06:06:22

to me.

06:06:24 - 06:06:26

At the age of five my son in

06:06:26 - 06:06:30

kindergarten, he had a one on one aid.

06:06:30 - 06:06:33

After school program in which I was arguing with the regional center

06:06:34 - 06:06:37

or your developmental disability systems, whichever

06:06:38 - 06:06:41

that may apply to in your state and getting him

06:06:42 - 06:06:43

an aid as they drug their feet.

06:06:45 - 06:06:48

They lost my son. So when I went to go pick him up, I was told

06:06:48 - 06:06:51

that my son was not a good boy today.

06:06:56 - 06:06:59

And when I asked the caregiver what had happened.

06:07:01 - 06:07:01

Sorry.

06:07:03 - 06:07:03

He had told me that

06:07:05 - 06:07:08

he didn't contact you. I said, no.

06:07:09 - 06:07:10

They said we lost your son.

06:07:13 - 06:07:15

And I said, what do you mean you lost my son? I said, yes. He was

06:07:16 - 06:07:19

gone for two hours. And we had every known adult

06:07:19 - 06:07:22

looking for him. As they went to the playground.

06:07:24 - 06:07:27

My son went to the adjacent park. And was there

06:07:28 - 06:07:28

by himself.

06:07:30 - 06:07:34

Severe at the time. With his symptoms and playing on

06:07:34 - 06:07:37

a hillside where he could have fell off. Near a busy street

06:07:38 - 06:07:40

where he got hit. Like I said, I feel very

06:07:41 - 06:07:42

blessed and very lucky.

06:07:45 - 06:07:47

And I was told. That my son wasn't a good boy today.

06:07:50 - 06:07:50

So.

06:07:52 - 06:07:53

There were many levels in which

06:07:55 - 06:07:56

this deserves to be addressed.

06:07:58 - 06:08:01

Also where my son's paraeducator was constantly

06:08:02 - 06:08:05

pulled away from him. And luckily one day I just happened to be

06:08:05 - 06:08:08

volunteering in the classroom. And no.

06:08:09 - 06:08:10

Walked out of the room.

06:08:11 - 06:08:12

Headed towards park again.

06:08:15 - 06:08:18

And I brought him back as his paraeducator was passing out

06:08:18 - 06:08:18

papers.

06:08:20 - 06:08:23

And I believe, I truly believe that paraeducators

06:08:24 - 06:08:27

and most aides, most of them just having high school

06:08:27 - 06:08:31

diplomas are not educated on how to care for an individual

06:08:31 - 06:08:33

autism, especially one that elopes.

06:08:36 - 06:08:39

And a teacher who told me I could never volunteer in her classroom again.

06:08:41 - 06:08:43

So this is definitely an issue.

06:08:45 - 06:08:49

I feel very blessed and very lucky. I had to resign

06:08:49 - 06:08:50

from working.

06:08:53 - 06:08:56

Us in financial bind. But for the

06:08:57 - 06:08:58

health, welfare and safety of my son.

06:09:00 - 06:09:03

And thank you. I'm sorry. I want to just make sure we're a little bit behind

06:09:03 - 06:09:06

time. So I want to make sure other people have a chance. Lisa waiter light.

06:09:08 - 06:09:08

Thank you.

06:09:10 - 06:09:14

When Kevin Devonte's law passed and we have a committee member, I think who can

06:09:14 - 06:09:17

speak to this, who I think is virtual. Shortly after

06:09:18 - 06:09:21

one life was saved. Like shortly after, you may know

06:09:22 - 06:09:25

like almost, I don't know how many days. This is a problem

06:09:26 - 06:09:29

with easy answers than other problems that

06:09:29 - 06:09:33

can save lives. This is a discussion that should have happened years ago

06:09:34 - 06:09:37

that could have saved lives years ago. And we have a chance to do

06:09:37 - 06:09:40

it now. We're all in this committee because we want to make

06:09:41 - 06:09:44

a difference. And this is an easier decision than others to

06:09:44 - 06:09:48

make, in my opinion. We don't really have a choice.

06:09:49 - 06:09:53

And we've got subject matter experts here. We've got parents here,

06:09:53 - 06:09:56

parents of children with autism and parents with neurotypical children.

06:09:57 - 06:09:59

Nobody wants this to happen. Nobody wants to be looking for their

06:09:59 - 06:10:03

child. Nobody wants, God forbid, find their child

06:10:04 - 06:10:07

no longer around. This is an easy one. I hope we don't

06:10:07 - 06:10:10

have much discussion and we can vote for this and move on. Thank you.

06:10:17 - 06:10:19

Okay. Matthew Maynard from the CDC.

06:10:24 - 06:10:27

Thank you. So thank you for the presentation. Obviously there's an incredibly

06:10:27 - 06:10:28
important topic.

06:10:30 - 06:10:33
I just wanted to comment that after reviewing the CDC

06:10:34 - 06:10:34
specific

06:10:36 - 06:10:39
recommendations with looking into including

06:10:40 - 06:10:43
ICD codes into surveillance systems, if we're talking about autism

06:10:43 - 06:10:46
surveillance, that's, you know, within our within our grasp.

06:10:47 - 06:10:51
Updating websites and disseminating guidance is all seem like practical things that

06:10:51 - 06:10:54
are worth exploring and considering. So thank you.

06:10:56 - 06:10:56
Thank you.

06:11:09 - 06:11:13
I'm concerned that the current language references surveillance, but doesn't

06:11:13 - 06:11:16
specify who is responsible, what exactly is monitored and

06:11:16 - 06:11:19
how accountability is enforced. Given the

06:11:19 - 06:11:22
seriousness, including preventable deaths, I would ask

06:11:23 - 06:11:24
for ownership and clear lines of reporting.

06:11:29 - 06:11:32
Thank you so much. Just for

06:11:33 - 06:11:36

clarity, I think our CDC member brought up

06:11:36 - 06:11:40

the possibility. I think that they would explore more active surveillance, although that is not a

06:11:40 - 06:11:43

proposal in this attachment

06:11:43 - 06:11:46

or one that we will be voting on today. But I'm glad to hear

06:11:47 - 06:11:50

that that potentially could be a consideration. Crystal.

06:11:52 - 06:11:54

Yes. Also, if MEP alerts were to be

06:11:55 - 06:11:58

autism specific as other similar alert systems

06:11:58 - 06:12:02

operate, there is a surveillance component there. Again, we're not writing the

06:12:02 - 06:12:05

policy, but I, my hope would be that there would be similar

06:12:06 - 06:12:09

surveillance to capturing these incidents through that means.

06:12:11 - 06:12:14

Thank you, Laura Sweeney. I just want to also

06:12:14 - 06:12:17

stress that absent any

06:12:17 - 06:12:20

alert system specifically. We do have

06:12:21 - 06:12:24

currently the missing endangered persons, which is what we are

06:12:25 - 06:12:27

leveraging here. However, police

06:12:27 - 06:12:31

departments, first responders are taking this on themselves

06:12:32 - 06:12:33

and some are trying to access

06:12:34 - 06:12:37

training. So I think that they are

06:12:37 - 06:12:40

actively looking for this kind of direction

06:12:41 - 06:12:44

and that many would appreciate it. So I think this will definitely help

06:12:45 - 06:12:48

them. And just what I've seen on social media, many

06:12:48 - 06:12:51

are trying themselves to seek it out

06:12:52 - 06:12:55

and are anxious for this. So I hope we support this. Thank you.

06:12:59 - 06:13:02

So much. Sorry, I just wanted to add, you know, some states are taking this on

06:13:02 - 06:13:03

as initiatives.

06:13:05 - 06:13:09

In the public private partnership that we have in Maryland. It's called the Maryland

06:13:09 - 06:13:12

autism coalition. I encourage everyone who's interested to Google

06:13:13 - 06:13:16

this information. We have pscs about

06:13:16 - 06:13:19

wandering to search water first call 91

06:13:19 - 06:13:23

immediately. So there wouldn't be these miscommunication. And it's

06:13:23 - 06:13:26

really very good information we have worked with and we've worked with

06:13:26 - 06:13:28

Laurie McAlane's new new

06:13:28 - 06:13:30

organization. There are

06:13:31 - 06:13:34

examples, but I think we've got to lead the way in saying that this is something

06:13:34 - 06:13:37

that needs to be national, not an state by state basis. This is a national

06:13:38 - 06:13:39

initiative. Thank you.

06:13:52 - 06:13:55

Dr. Rosnow. I think it's been brought up before, but just to reiterate

06:13:56 - 06:13:59

that the mortality rate in autism is about three times higher.

06:13:59 - 06:14:02

Than drone population. A lot is related to johnny

06:14:02 - 06:14:06

accidents, car wrecks, you know, getting money from a car and so forth. So

06:14:06 - 06:14:09

I think that we can reduce mortality risk hopefully.

06:14:09 - 06:14:12

By having this system. So.

06:14:19 - 06:14:22

We are a little bit behind schedule, so I'm going to just sort of make one last

06:14:22 - 06:14:25

call for comments, debates,

06:14:25 - 06:14:29

opinions. I would love to hear from our

06:14:29 - 06:14:29

federal members

06:14:31 - 06:14:34

as well. Thank you to Matt from the CDC for commenting.

06:14:43 - 06:14:46

Hi. Christina Chacon from

06:14:46 - 06:14:50

AHRQ. I know you said you wanted to hear from the federal side, so I will

06:14:50 - 06:14:53

be brief because I know we're running up on time. But I

06:14:53 - 06:14:56

think all of us here recognize them for

06:14:57 - 06:14:57

this.

06:14:59 - 06:15:02

And I think Matt really answered my question because my biggest thing was confirming.

06:15:04 - 06:15:07

I think from the federal side, just making sure that we're promoting

06:15:07 - 06:15:11

accurate information because we want to do our best to help the

06:15:11 - 06:15:12

community and help the caregivers

06:15:14 - 06:15:14

and also help.

06:15:16 - 06:15:20

The not just the caregivers, but the family members and your friends

06:15:20 - 06:15:22

that are also, it takes a

06:15:22 - 06:15:25

village. And so just ensuring that the information

06:15:26 - 06:15:29

that we're going to be creating as a federal government

06:15:30 - 06:15:32

is accurate is very important. And I think

06:15:34 - 06:15:37

Matt confirmed that. So I think from a federal standpoint, that is something that was very important

06:15:38 - 06:15:40

on our end. And so thank you Matt for doing that.

06:15:48 - 06:15:50

So again from the CMS side,

06:15:52 - 06:15:55

We appreciate these recommendations and we'll need some more time to take a look at

06:15:56 - 06:15:58

them internally given that we just received them.

06:16:07 - 06:16:10

Okay, so we're going to adjourn for a break

06:16:12 - 06:16:14

now. We're going to have our break be slightly

06:16:14 - 06:16:18

shorter. This was originally scheduled for 15 minutes. We'll take a 10

06:16:18 - 06:16:18

minute break.

06:16:21 - 06:16:24

And return at 325 for

06:16:24 - 06:16:27

brief further discussion and then voting. Thank you.

06:28:03 - 06:28:06

To federal official. The products that come out of this committee are really meant

06:28:06 - 06:28:10

to be deliberative, which means that they should have the participation of the federal

06:28:10 - 06:28:11

members as well as the public members.

06:28:13 - 06:28:16

So when we talk about having conversation and when our

06:28:16 - 06:28:19

friend from the CMS says that they need to go back to their federal

06:28:19 - 06:28:23

agency, I think a lot of people in the room would also say that they would

06:28:23 - 06:28:27

need to go back to their agency that they can't speak for their full agency.

06:28:28 - 06:28:31

So that puts the federal members in a slightly challenging situation

06:28:31 - 06:28:34

in that they also recognize the urgency. And I think many

06:28:35 - 06:28:38

of the people around the table would say that they feel even more

06:28:38 - 06:28:40

urgency because we're responsible for all of these

06:28:43 - 06:28:46

laws, not the laws, but the ways that things get put into place.

06:28:47 - 06:28:50

And everyone in this room is just as passionate as each other.

06:28:50 - 06:28:54

And really wants to see change. So I just wanted to put this out there

06:28:55 - 06:28:58

that if we go forward with a vote

06:28:59 - 06:29:03

as is presented now, there's a good chance that the federal

06:29:03 - 06:29:06

members will have to abstain and that might not look great. From the

06:29:06 - 06:29:08

public. It may also

06:29:09 - 06:29:13

cause some FACA issues because there hasn't been the deliberation

06:29:13 - 06:29:14

that's required to come out of this committee.

06:29:16 - 06:29:18

So I just wanted to put that out there.

06:29:20 - 06:29:21

Any, is there anything else?

06:29:24 - 06:29:26

Is there a way to take a vote between meetings.

06:29:28 - 06:29:29

To expedite things?

06:29:31 - 06:29:34

Like if they've had, if we determine that they need six

06:29:35 - 06:29:37

weeks or whatever for discovery or to gather

06:29:37 - 06:29:41

information, can we hop online? And take a

06:29:41 - 06:29:44

boat? I think the votes would need to happen out in the

06:29:44 - 06:29:47

open. We could potentially schedule a brief zoom

06:29:47 - 06:29:50

meeting or something like one hour meeting. Yeah. Okay.

06:29:51 - 06:29:53

Thank you. And we are also looking to have the next

06:29:54 - 06:29:57

IACC meeting probably before the end of the fiscal year. So we're not

06:29:58 - 06:30:01

talking, you know, early next year.

06:30:01 - 06:30:04

That's a really fairly quick timeline. But yeah, I mean,

06:30:04 - 06:30:07

again, I don't I think it was Katie made the point that we don't

06:30:07 - 06:30:10

want to not be a productive body. Just want to make sure that

06:30:10 - 06:30:14

we're not getting in trouble with the law or on the front page of the

06:30:14 - 06:30:17

Washington Post because we haven't done things the proper way. And

06:30:17 - 06:30:21

have to go back and redo them again. Right. So are

06:30:21 - 06:30:24

there any questions about that in the federal role on the FACA?

06:30:25 - 06:30:28

Question about that? I think we've had ample time for deliberation in a public

06:30:28 - 06:30:31

setting today and all the members have had the material since

06:30:32 - 06:30:35

Thursday. And I think the suggestion that this is not somehow compliant

06:30:35 - 06:30:36

with FACA is not accurate.

06:30:39 - 06:30:41

And I reject that.

06:30:45 - 06:30:49

Ginger. I also wanted to say kind of thinking about

06:30:49 - 06:30:52

this, how to say this while I my comments

06:30:52 - 06:30:56

date back to the times and the years that the things

06:30:56 - 06:30:59

should have been done. Everything considered at this meeting

06:30:59 - 06:31:02

done. I should have been done. And the first ICC meeting

06:31:03 - 06:31:06

in 2006. And the fact that

06:31:06 - 06:31:09

we're still having people say. Even if you're a

06:31:09 - 06:31:12

substitute, even if why did Capri

06:31:12 - 06:31:16

sleep? What's so important? Our community, the parents are like, we are

06:31:16 - 06:31:19

in crisis to ever hear 26 years

06:31:19 - 06:31:22

later, we haven't had enough time to deliver every

06:31:22 - 06:31:25

all the parents on this committee have

06:31:25 - 06:31:28

deliberated. We've lived it. We have decades of

06:31:29 - 06:31:32

experience and knowing the value. Of what we vote on here.

06:31:33 - 06:31:36

So I just don't want to hear that anymore. For federal

06:31:36 - 06:31:39

members. Because if you're a federal member, this should be your

06:31:39 - 06:31:42

specialty within your agency. And you should already know

06:31:43 - 06:31:46

what these issues are. So I also reject the.

06:31:49 - 06:31:52

Ethos if we hadn't had enough time. It's been two days. It's been two decades.

06:31:54 - 06:31:57

I'm just making the point that the product that goes forward from this committee

06:31:58 - 06:32:02

per facca rules has to be a deliberative product that is

06:32:02 - 06:32:04

deliberated by this body. So it shouldn't have been written

06:32:05 - 06:32:09

really before coming to this body and without any chance to edit

06:32:09 - 06:32:12

based on the feedback from other federal

06:32:13 - 06:32:15

sorry from the agencies that these federal members are

06:32:15 - 06:32:19

representing. I can promise you that at my

06:32:19 - 06:32:22

institute, I might be able to get my, the director of the institute to review it

06:32:22 - 06:32:26

within three days, but I couldn't get mat probably to redo it

06:32:26 - 06:32:29

within three days. So I'm not just making the point about the product. I'm not arguing about

06:32:30 - 06:32:31

the signs or about

06:32:32 - 06:32:35

the situation. I'm just saying that per facca

06:32:35 - 06:32:39

rules, that's my job here, is to talk about the factor rules.

06:32:39 - 06:32:43

That's what is required. Just and then that to

06:32:43 - 06:32:46

me that says that the agencies need to figure out how to

06:32:47 - 06:32:48

fix that problem.

06:32:50 - 06:32:51

For clarification.

06:32:52 - 06:32:55

Can you repeat what you said about the paper shouldn't have been presented. I

06:32:55 - 06:32:58

mean, I've been to IACC meetings for a very long time.

06:32:59 - 06:33:03

There were always presentations made specifically on wandering and elopement.

06:33:03 - 06:33:06

For years. I mean, that's what got me to know about the

06:33:06 - 06:33:08

ICC and the importance of what we do here.

06:33:09 - 06:33:13

I didn't even hear anything from the CDC saying that they were asking for

06:33:13 - 06:33:13

an extension.

06:33:15 - 06:33:18

So I don't a. I don't know that the

06:33:18 - 06:33:21

presentations shouldn't have been given before. Like there would be work

06:33:21 - 06:33:25

group to put that together. This time there was no work group because this is our first meeting.

06:33:25 - 06:33:29

So I'm just trying to get clarification like would we have just talked about it and then put

06:33:29 - 06:33:31

together like who would have put together a document beforehand number

06:33:31 - 06:33:34

one. And then number two, if there's no disagreement about a

06:33:35 - 06:33:38

specific, let's call it recommendation or what was provided in the

06:33:38 - 06:33:40

papers, can we at least go.

06:33:41 - 06:33:45

Paper by paper or like recommendation by recommendation and see if there

06:33:45 - 06:33:48

has been enough deliberation that we can vote on it. I don't know

06:33:49 - 06:33:52

FACA, but it seems to me at least on one of these, there's no

06:33:52 - 06:33:55

deliberation that needs to be taken further than we've or we've already talked about

06:33:55 - 06:33:57

it. And frankly, this organization has talked about it for years.

06:33:58 - 06:33:59

So that's my point of clarification.

06:34:02 - 06:34:02

So

06:34:04 - 06:34:07

it's not speaking in an official capacity as a designated

06:34:07 - 06:34:11

federal official for the IAC. But

06:34:11 - 06:34:14

because the this committee has as

06:34:14 - 06:34:15

voting members

06:34:16 - 06:34:19

federal representatives from the different federal

06:34:19 - 06:34:20

agencies, it's that

06:34:22 - 06:34:25

deliberative process that they need to also be part

06:34:25 - 06:34:28

of. So it is really

06:34:28 - 06:34:31

remarkable. You know, the documents that were prepared for

06:34:32 - 06:34:34

today and the amount of work that went into the

06:34:35 - 06:34:38

documents. And I think what's being

06:34:38 - 06:34:41

suggested, if I could go that far, is to give the

06:34:42 - 06:34:45

federal agencies an opportunity to review these before

06:34:46 - 06:34:49

they're voted on. Because as written, the letter does say that the

06:34:50 - 06:34:53

committee is putting forward these recommendations, which

06:34:54 - 06:34:55

to for federal

06:34:57 - 06:34:59

for the federal staff, that means that they are

06:35:01 - 06:35:03

among those that are making these recommendations for these specific

06:35:04 - 06:35:07

actions. And while it might not appear

06:35:07 - 06:35:10

as if it's making policy, it is in a way

06:35:11 - 06:35:14

putting the agency in a position to, to do

06:35:14 - 06:35:18

that. And so they just need to, in their role, do their

06:35:18 - 06:35:21

due diligence to have the time to review

06:35:22 - 06:35:25

what has been proposed here. I would also suggest that there's probably some things in here

06:35:25 - 06:35:29

that may not be considered in terms of

06:35:29 - 06:35:32

other agencies that might have equities in them

06:35:33 - 06:35:36

and that can also be identified and some other things clarified

06:35:37 - 06:35:40

if they are able to have the time to review them before

06:35:40 - 06:35:41

voting on anything.

06:35:49 - 06:35:51

So thank you for the opportunity to comment. I mean, I guess this.

06:35:54 - 06:35:57

Directed towards the, towards the federal leadership.

06:36:01 - 06:36:03

I've been doing work with the federal government off and on for three decades.

06:36:06 - 06:36:09

And generally speaking, when there's a deliberative body, there's kind of a

06:36:09 - 06:36:12

rules of engagement process. That was not

06:36:13 - 06:36:15

included for any of the public members. In

06:36:17 - 06:36:20

our onboarding beyond just a cursory powerpoint

06:36:20 - 06:36:21

presentation

06:36:23 - 06:36:26

that, you know, in spite of all best intentions got, you

06:36:26 - 06:36:29

know, still got press coverage. So from my

06:36:29 - 06:36:32

perspective, when we put a kind of a

06:36:32 - 06:36:36

dialogue in place, we ought to at least know as public

06:36:36 - 06:36:38

members what the actual process is

06:36:39 - 06:36:43

so that our voices are not stifled by

06:36:43 - 06:36:45

delay and a desire for further

06:36:46 - 06:36:47

deliberation

06:36:48 - 06:36:52

that may or may not be necessary. So, you know, for my

06:36:52 - 06:36:55

perspective, I just kind of like to know what the rules of the road are

06:36:55 - 06:36:58

and get proper direction on that so we can make sure

06:36:59 - 06:36:59

we're as constructive as possible.

06:37:05 - 06:37:05

Dr. Member.

06:37:13 - 06:37:15

I wonder. Sorry, let me get my video up.

06:37:18 - 06:37:21

I wonder if the public members, and I know that many of

06:37:21 - 06:37:23

my colleagues have studied these

06:37:23 - 06:37:26

issues, are able to vote today

06:37:27 - 06:37:31

so that our voices aren't delayed and the autism community

06:37:31 - 06:37:34

understands that we are working actively for them. And then

06:37:34 - 06:37:38

if the federal agencies by, you know, for legal

06:37:38 - 06:37:40

reasons need more time, that could be

06:37:41 - 06:37:44

facilitated later. But I would hate to leave this meeting today

06:37:45 - 06:37:48

without being able to vote on these

06:37:48 - 06:37:51

issues, especially the wandering issue. Thank you.

06:37:55 - 06:37:56

Dawn Kilmore.

06:38:03 - 06:38:03

This is my first day here.

06:38:05 - 06:38:08

And we did not, at least I didn't receive any

06:38:09 - 06:38:12

statements information about what the decision making

06:38:12 - 06:38:15

policy is within. The committee here.

06:38:17 - 06:38:21

So, and I find it hard to believe that there isn't a standard operating

06:38:21 - 06:38:24

procedure for doing this kind of thing. Is there a standard operating

06:38:24 - 06:38:25

procedure for doing this kind of thing?

06:38:27 - 06:38:27

And if there is.

06:38:30 - 06:38:33

I would assume we should follow it. And if there isn't, I don't see why we can't go ahead

06:38:34 - 06:38:38

and vote. And if federal members. Think believe

06:38:38 - 06:38:39

that they should abstain. That's fine.

06:38:44 - 06:38:47

My understanding is, and I have not run this type of faculty committee

06:38:47 - 06:38:51

before. I've run review meetings in the past, so, but my

06:38:51 - 06:38:54

understanding is that generally the fact that meeting back a

06:38:54 - 06:38:58

committee would meet and come up with, for instance, a topic that they're

06:38:58 - 06:39:01

interested in, like wandering former work group and then come up

06:39:01 - 06:39:04

with recommendations during that work group that includes the federal

06:39:04 - 06:39:07

members. In this case, the federal members were not included

06:39:08 - 06:39:11

in that deliberation like Jennifer pointed out. And so it makes

06:39:11 - 06:39:14

it challenging for the federal federal members to vote on something that

06:39:15 - 06:39:19

they haven't had a chance to fully consider in terms of

06:39:19 - 06:39:20

going up their, their ranks

06:39:22 - 06:39:25

and then will be responsible for. So, I

06:39:25 - 06:39:28

mean, if it were me, I would recommend

06:39:29 - 06:39:30

tabling this until the very beginning of the

06:39:31 - 06:39:34

next, I don't think we can take two

06:39:34 - 06:39:36

votes, two separate votes on the same issue.

06:39:40 - 06:39:43

I'm not really sure how we would have half of the members vote on

06:39:43 - 06:39:44

a particular topic.

06:39:46 - 06:39:47

And then the other half vote later.

06:39:50 - 06:39:53

We can check with our office of committee management. Why don't we have

06:39:53 - 06:39:55

a vote on whether or not on each specific

06:39:56 - 06:39:59

issue, we should take a vote, because at least

06:39:59 - 06:40:02

on one, there doesn't seem to be much disagreement, especially by the agency

06:40:03 - 06:40:04

who would be tasked to do it.

06:40:08 - 06:40:08

Laura.

06:40:11 - 06:40:15

I just want to clarify that under FACA, there is no minimal

06:40:15 - 06:40:17

time period for

06:40:17 - 06:40:20

deliberation. Basically, the requirement is that we publicly

06:40:21 - 06:40:24

deliberate and we consider these things, which I agree with,

06:40:24 - 06:40:28

Sylvia. We have done here today. And yeah,

06:40:28 - 06:40:31

as John Gilmore said, if the federal members need more time, they need more

06:40:31 - 06:40:34

time. But I propose we vote.

06:40:37 - 06:40:38

I second that.

06:40:41 - 06:40:42

Lisa Ackerman.

06:40:44 - 06:40:48

I agree and wish we could vote on these very

06:40:48 - 06:40:51

important issues and show the community we mean business

06:40:51 - 06:40:55

to move forward for the community. And these issues have

06:40:55 - 06:40:58

been discussed. I watch them. And have thrown things at

06:40:58 - 06:40:58

my computer.

06:41:05 - 06:41:06

So I'm speaking now as a member.

06:41:09 - 06:41:12

I understand if federal members feel they need more

06:41:12 - 06:41:13

time.

06:41:14 - 06:41:17

And they should either abstain or vote no. In that case.

06:41:20 - 06:41:23

My hope is after this voting process, we're going to turn

06:41:25 - 06:41:28

to hopefully the formation of several working groups that will include

06:41:30 - 06:41:32

federal members is my strong hope

06:41:34 - 06:41:34

so that

06:41:36 - 06:41:38

we can have a process of working together

06:41:39 - 06:41:42

for the future. And if these

06:41:43 - 06:41:46

particular attachments or particular proposals don't pass

06:41:46 - 06:41:49

today, we can take them potentially to working groups that we form

06:41:50 - 06:41:51

and bring them up as.

06:41:53 - 06:41:55

You know, kind of a first order of business at the next meeting.

06:41:57 - 06:41:59

Again, I do understand that our federal

06:42:01 - 06:42:03

colleagues are in potentially a different

06:42:04 - 06:42:06

position. But I also agree with my public

06:42:07 - 06:42:10

colleagues that we represent the

06:42:10 - 06:42:13

larger autism community and this community has weighted

06:42:15 - 06:42:18

two decades for action. And I think we have a responsibility

06:42:18 - 06:42:19

to that

06:42:20 - 06:42:23

community. And that's my thought. Thank you.

06:42:31 - 06:42:34

Yeah. Can someone explain to me how the process

06:42:34 - 06:42:37

works? I'm under the impression that

06:42:39 - 06:42:41

all the deliberation is supposed to happen basically

06:42:42 - 06:42:45

in the committee meeting here or in a working group.

06:42:47 - 06:42:48

Yet if I understand correctly.

06:42:51 - 06:42:51

Discussions.

06:42:52 - 06:42:55

The federal agencies are essentially requesting to

06:42:57 - 06:42:57

deliberate.

06:42:59 - 06:43:01

Committee work in their agencies outside

06:43:02 - 06:43:05

the bounds of where we're supposed to be doing this. Do I have

06:43:06 - 06:43:06

that correct?

06:43:10 - 06:43:13

I think the point is that the federal members that are in this room

06:43:14 - 06:43:18

don't, I'm protecting, don't feel like they've had a

06:43:18 - 06:43:21

chance to take the information back up to their leadership

06:43:22 - 06:43:24

and so they don't feel like as individuals representing their

06:43:24 - 06:43:27

agency, they have the correct information. So they haven't come

06:43:27 - 06:43:28

to the table.

06:43:29 - 06:43:30

With adequate.

06:43:31 - 06:43:35

Representation. Yeah, if I could offer in terms of

06:43:37 - 06:43:40

federal advisory committee that we administer

06:43:40 - 06:43:43

and oversee and support in the administration for community

06:43:43 - 06:43:45

living. That committee does not have federal members

06:43:46 - 06:43:49

that vote. But in the deliberative process

06:43:52 - 06:43:55

there, as Megan mentioned, there are topics that are proposed

06:43:56 - 06:43:58

and the committee decides what topics they're going to focus

06:43:58 - 06:44:01

on. And then they work with the

06:44:02 - 06:44:02

federal members.

06:44:04 - 06:44:05

On proposed recommendations

06:44:07 - 06:44:10

and it allows time for the federal members to take a

06:44:10 - 06:44:13

recommendation and then give their feedback until they're

06:44:14 - 06:44:17

and that feedback is discussed in the public setting. So that

06:44:17 - 06:44:20

it is a deliberative as part of a committee business

06:44:22 - 06:44:24

until the committee decides to ultimately vote on

06:44:25 - 06:44:28

recommendations. Just so an example of how that works.

06:44:32 - 06:44:35

Dr. Marcella Rogniac. Sorry, I don't have the full name in front of

06:44:35 - 06:44:36

me. Thank you.

06:44:40 - 06:44:43

I appreciate that. Yes, and it's Dr. Ranjan, but it's

06:44:43 - 06:44:46

fine. I just wanted to say that

06:44:47 - 06:44:50

I am kind of dual role because I am here representing

06:44:51 - 06:44:54

our agency. And I do understand that it's a very frustrating process

06:44:55 - 06:44:58

in regards to what the federal agencies can and can't do

06:44:59 - 06:45:02

and what kind of decisions can be made for those of us that are at the

06:45:02 - 06:45:05

table. But I also understand from the

06:45:05 - 06:45:09

private sector as a parent who would want to ensure

06:45:09 - 06:45:12

that there are pieces that we are looking for for our children

06:45:13 - 06:45:15

and for safety within our communities.

06:45:16 - 06:45:20

So I would like to just also propose, is there

06:45:20 - 06:45:23

a possibility of walking through the recommended

06:45:24 - 06:45:27

sample proposed letter and maybe

06:45:27 - 06:45:28

identifying as a group

06:45:30 - 06:45:33

which items that federal partners and our public

06:45:33 - 06:45:33

sector

06:45:35 - 06:45:39

feel ready to vote on because there could be some pieces that we

06:45:39 - 06:45:42

could vote on and others we would put

06:45:42 - 06:45:45

in another bucket, if you will, because I work in bucket. Sorry about that.

06:45:46 - 06:45:49

We would put those that have other federal

06:45:49 - 06:45:53

implications. And so part of the reason we need to go back

06:45:53 - 06:45:56

to our leadership within our agencies are that

06:45:56 - 06:45:59

there are policy implications that may need to be changed.

06:46:01 - 06:46:01

There are

06:46:03 - 06:46:06

funding implications that may need to be

06:46:07 - 06:46:10

changed or adapted. And in the presentations that

06:46:10 - 06:46:12

we've had this

06:46:12 - 06:46:15

today, there are also other

06:46:15 - 06:46:18

implications within each agency. That may be

06:46:19 - 06:46:23

impeded by some of the workforce changes that we have gone through

06:46:24 - 06:46:27

recently. Some of our agencies are running even

06:46:27 - 06:46:31

slimmer than before. So ensuring that we have

06:46:31 - 06:46:32

somebody that could do the work.

06:46:34 - 06:46:37

And you know, I'm going to kind of call out our last one with attachment.

06:46:39 - 06:46:41

Three. A lot of that is

06:46:42 - 06:46:45

internal work within an agency. That could possibly be done.

06:46:47 - 06:46:47

But it would be

06:46:48 - 06:46:52

who us to allow that agency to go back and look at their

06:46:52 - 06:46:55

workflow process and develop a timeline of when

06:46:55 - 06:46:59

those guidelines could be updated. What's reasonable?

06:46:59 - 06:47:03

To have that action done? Those are the kinds of things that

06:47:03 - 06:47:07

happen in the work groups. Like if we normally would have

06:47:07 - 06:47:09

a work group and we would deliberate the work group

06:47:09 - 06:47:13

members, including the federal members would come up with a

06:47:13 - 06:47:16

strategic action plan and a time plan for the timelines

06:47:17 - 06:47:19

of deliverables. We kind of are missing that piece

06:47:20 - 06:47:23

since we are kind of going from presentations today

06:47:24 - 06:47:27

and wanting to do a vote. So maybe there's something that we could

06:47:27 - 06:47:30

do to kind of find ourselves in the middle so we can make

06:47:31 - 06:47:33

some positive movement today and have a vote

06:47:35 - 06:47:38

and also be able to then move things into the other bucket as to

06:47:39 - 06:47:42

here are priorities for work groups in the next meeting. Thank

06:47:43 - 06:47:43

you. Appreciate it.

06:47:46 - 06:47:49

Thank you, Laura Selin. I. Yeah, I just want to clarify

06:47:50 - 06:47:53

some things here. Thank you so much for that previous

06:47:53 - 06:47:56

comment. Couple things. Number one, we are a little bit

06:47:57 - 06:47:59

different than some advisory councils because we do have the

06:48:00 - 06:48:03

autism cares act. The autism cares act

06:48:05 - 06:48:08

specifically directs us to take action in recommendations

06:48:09 - 06:48:11

to the secretary of hhs on certain

06:48:11 - 06:48:15

topics. So that is all of these that are

06:48:15 - 06:48:18

being considered here today are directly tied to the

06:48:18 - 06:48:21

authority in the CARES act. The other thing I

06:48:22 - 06:48:25

want to point out is, you know, as our federal

06:48:25 - 06:48:28

members, you guys have different processes and different stages

06:48:29 - 06:48:31

of policy development in which you are

06:48:32 - 06:48:35

soliciting public advice or hardening things for

06:48:36 - 06:48:38

final drafts. This is not that

06:48:39 - 06:48:42

stage. So what we are attempting to do is

06:48:42 - 06:48:46

we are attempting to fulfill some of the directives

06:48:46 - 06:48:49

in the CARES act by making urgent recommendations

06:48:50 - 06:48:52

around issues that are particularly

06:48:53 - 06:48:57

concerning for clinical care or safety needs

06:48:57 - 06:49:01

to the secretary. That does not mean that

06:49:01 - 06:49:04

these are going to necessarily be implemented. And these are

06:49:04 - 06:49:07

nonbinding. So also for a public that is

06:49:07 - 06:49:11

listening, what we do and recommend here does not necessarily

06:49:11 - 06:49:15

mean that these will be incorporated or adopted

06:49:15 - 06:49:18

by the federal government. For those federal

06:49:18 - 06:49:21

partners, I understand my husband

06:49:22 - 06:49:25

is a bureaucrat in the state, and so I completely understand the

06:49:25 - 06:49:29

need to go back to your agencies

06:49:29 - 06:49:32

to get other consideration that can also

06:49:33 - 06:49:36

happen if the secretary receives our

06:49:36 - 06:49:39

recommendation, you can go back and let him know if you have

06:49:39 - 06:49:43

workforce shortages, if there are other agencies that you think that

06:49:43 - 06:49:46

this can be applicable to all of that can happen

06:49:47 - 06:49:49

after we make these recommendations or

06:49:50 - 06:49:53

not. Actually, it might even give you more flexibility

06:49:53 - 06:49:55

to have those conversations outside of

06:49:57 - 06:50:00

the FAQ requirements for this

06:50:00 - 06:50:03

body. So I just want to make those clear. Thank you.

06:50:06 - 06:50:09

Just one quick point that. Although they

06:50:10 - 06:50:13

may first of all again, that would not necessarily represent the

06:50:13 - 06:50:16

federal worker sorry, the federal member.

06:50:19 - 06:50:22

Thoughts on the proposed text, which is the product

06:50:22 - 06:50:25

of the, of the committee. I just also want to point out that

06:50:26 - 06:50:29

HHS will likely make likely be required by

06:50:29 - 06:50:33

GAO to indicate how they respond to these

06:50:33 - 06:50:36

recommendations. So it would end up likely being

06:50:36 - 06:50:39

binding for the federal members.

06:50:44 - 06:50:46

I'm sorry, Megan, are you.

06:50:49 - 06:50:52

One of the IACC makes recommendations GAO asks us

06:50:53 - 06:50:56

as HHS how we are implementing these recommendations.

06:50:57 - 06:50:59

So they are not exactly nonbinding.

06:51:05 - 06:51:05

Tracy.

06:51:07 - 06:51:11

So first of all there's a huge divide here. Between

06:51:11 - 06:51:15

the public members and the federal members. And that's been like

06:51:15 - 06:51:15

that for a while.

06:51:17 - 06:51:20

And secondly, Sylvia stated as earlier she

06:51:20 - 06:51:24

sent these documents out. And if you are going to

06:51:24 - 06:51:27

go over them, take them back to your departments and vote on

06:51:28 - 06:51:31

it that way or make your decisions. When will that be? Do

06:51:31 - 06:51:34

we get a solid date? Do we do we get an answer

06:51:35 - 06:51:36

or do we have to wait another 10 years?

06:51:40 - 06:51:40

Ginger.

06:51:43 - 06:51:46

I understand again that we are the autism community has been

06:51:46 - 06:51:50

sitting on these recommendations for decades. So this

06:51:50 - 06:51:53

committee is finally taking them to the secretary and say, this is what

06:51:54 - 06:51:55

we recommend. I don't understand.

06:51:58 - 06:51:59

Your explanation that you would have to

06:52:01 - 06:52:04

justify that to DAO because we're not making policy.

06:52:05 - 06:52:09

We're just saying this is policy that we would like you to start on the journey

06:52:09 - 06:52:12

to becoming reality. So I don't think you're accountable to

06:52:12 - 06:52:16

GIO because it's not the secretary's policy.

06:52:16 - 06:52:16

Yet.

06:52:18 - 06:52:20

Wouldn't that be the stage where you would go back and go.

06:52:22 - 06:52:25

We've got a funding problem here. We got a staffing problem here. We want to change

06:52:26 - 06:52:28

these three words around why this is a blanket recommendation.

06:52:30 - 06:52:31

To send us along the road.

06:52:32 - 06:52:32

And if

06:52:34 - 06:52:36

the fact that the wandering pieces involved in this.

06:52:38 - 06:52:40

I think it is dark if there's anyone in this

06:52:40 - 06:52:44

room, in this building who would have a problem

06:52:44 - 06:52:47

with it. My family is affected by this. My son is

06:52:48 - 06:52:51

in first grade. He was an autism classroom of three that was two by the end of

06:52:51 - 06:52:55

the year because the only girl in the class. Lost her life to

06:52:55 - 06:52:58

drowning. So it is baffling to me that people wouldn't be

06:52:58 - 06:53:02

rushing to summer's coming. This is the drowning

06:53:02 - 06:53:02

season.

06:53:04 - 06:53:07

What's going to change between now and then about these

06:53:07 - 06:53:10

recommendations that you can go back and go, oh, we have a new consideration.

06:53:11 - 06:53:14

We would like you to change that tree to a seven. We can

06:53:15 - 06:53:17

amend this. At the policy making

06:53:17 - 06:53:20

level. This is the beginning stage of here's the

06:53:20 - 06:53:22

problem. Here's the needs of the community.

06:53:24 - 06:53:27

Please secretary, let's start fixing these problems.

06:53:29 - 06:53:32

Thank you, Deirdre. I say I'm virtual. Thank

06:53:32 - 06:53:35

you. So I just want to flag that many of us do not have

06:53:37 - 06:53:40

where the sole representative from our department. And we do not

06:53:41 - 06:53:44

necessarily have the autonomy to move without.

06:53:47 - 06:53:48

Approval from

06:53:50 - 06:53:53

our secretary or our leadership or the immediate

06:53:53 - 06:53:57

deputy under that person. Three days is not enough to get.

06:53:58 - 06:54:00

Eyes on something that I would need to vote on.

06:54:03 - 06:54:06

In all cases. Like there are some things that I feel like I can, but they're not all

06:54:06 - 06:54:09

things. If there's going to be conflict within my

06:54:09 - 06:54:12

agency, I will not be able in three working days to

06:54:13 - 06:54:16

get eyes on it from anyone outside of my building, let alone

06:54:16 - 06:54:19

the number two in my department. And

06:54:20 - 06:54:23

it is unfortunate. This is a new scenario for many of

06:54:23 - 06:54:27

us where there is a lot more oversight for federal workers

06:54:27 - 06:54:31

and a lot less autonomy than for those of us who have been on

06:54:31 - 06:54:31

previous

06:54:33 - 06:54:35

had served previously that we had at that time.

06:54:37 - 06:54:38

Unfortunately, that's the reality.

06:54:41 - 06:54:44

Is represented in some of those very little.

06:54:47 - 06:54:51

We're not charging my department. If this moves forward, my

06:54:51 - 06:54:54

department would be on the receiving end of the secretary's action

06:54:54 - 06:54:57

if the secretary of HSS chose to take our

06:54:57 - 06:54:59

recommendations. I feel really confident in doing that

06:55:00 - 06:55:04

today, but I just want to voice what some other people may be

06:55:04 - 06:55:07

experiencing that they are not showing up here today with a level of

06:55:07 - 06:55:11

autonomy that they may have been able to show up within years past.

06:55:13 - 06:55:16

Thank you. Laura Sellaney. I just want to make sure

06:55:17 - 06:55:19

we're not conflating for clarification and I appreciate

06:55:20 - 06:55:23

Megan and on his comments around the GAO that's really good to

06:55:23 - 06:55:27

know. However, the request from the

06:55:27 - 06:55:30

GAO to answer is not the same as

06:55:31 - 06:55:34

a binding requirement legally. So I just want to make sure

06:55:34 - 06:55:37

we're not conflating things with, you know, you got to

06:55:37 - 06:55:40

justify a reason for GAO as opposed to

06:55:41 - 06:55:44

this was a shell and you have to do it. So just

06:55:45 - 06:55:47

legal clarification there on wording. Thank you.

06:55:50 - 06:55:52

Bill Oldham online and then lease a lighter light.

06:55:57 - 06:55:59

So I have a great degree of confusion as to what the

06:56:00 - 06:56:03

process actually is because it sounds like.

06:56:06 - 06:56:09

Public and federal are talking past each

06:56:09 - 06:56:12

other. And if there is a process, then the public

06:56:12 - 06:56:15

members need to be informed on what that process actually is

06:56:17 - 06:56:21

so that we can actually begin to move forward. I would like for us to move

06:56:21 - 06:56:24

to a vote on these issues. And if federal members have to

06:56:24 - 06:56:27

abstain, then abstain and we can come back to

06:56:27 - 06:56:30

it. As Sylvia suggested in working group sessions to make

06:56:30 - 06:56:33

these documents better. None of these documents are intended to be perfect

06:56:34 - 06:56:37

today. We need to make steps forward

06:56:38 - 06:56:41

or else we're not doing our jobs as committee members from my perspective, let alone

06:56:41 - 06:56:42

honoring our community.

06:56:47 - 06:56:51

I'm going to apologize if I seem gruff right now. I don't mean this. I'm very frustrated

06:56:51 - 06:56:55

to be honest with you. None of us here who are parents have time

06:56:55 - 06:56:56

for this sort of thing.

06:56:58 - 06:57:02

Our children in our community need us to protect

06:57:02 - 06:57:06

them. I'm looking at this agenda. And

06:57:06 - 06:57:08

mind you, I've seen agendas for 30 years in my

06:57:08 - 06:57:11

career. And it clearly says public

06:57:11 - 06:57:14

comment section done. All of this done lunch break community business.

06:57:15 - 06:57:18

And we talk about all of these things that we've been talking about for hours.

06:57:19 - 06:57:21

And it brings us to a vote.

06:57:23 - 06:57:26

Did no one see this prior to this that we were going to vote?

06:57:28 - 06:57:32

I know again, I apologize. But I work two jobs. I've got

06:57:32 - 06:57:35

a kid who won 247. I'm up 18

06:57:35 - 06:57:39

hours a day. And I was up till 2:00 in the morning reading these things.

06:57:40 - 06:57:43

And I understand that the federal agencies may need to go back and I respect

06:57:43 - 06:57:46

that. I work for a federal government for a while. So I understand that.

06:57:47 - 06:57:51

What are we talking about right now? Are we refusing to have the vote? I'm trying

06:57:51 - 06:57:54

to understand what this conversation is about.

06:57:55 - 06:57:58

Is it about stymieing what we're trying to do? Do we have to

06:57:59 - 06:58:02

wait? Can someone move to have a vote anyway? And the federal

06:58:02 - 06:58:05

agencies can choose to abstain because we keep

06:58:05 - 06:58:08

talking, but we're not doing. And this IAC

06:58:08 - 06:58:09

committee is going to do things.

06:58:11 - 06:58:14

And good things that we're going to protect people. We're going to make a difference and we're going

06:58:14 - 06:58:17

to be effective. That's why we're here. That's what we lose sleep.

06:58:21 - 06:58:23

I think there's a call for a vote. There's been a second.

06:58:24 - 06:58:28

If you would like to call for a vote, I'll second it again and we can proceed

06:58:28 - 06:58:31

and try to move this forward. But I just don't understand what we're doing.

06:58:34 - 06:58:37

So, I mean, I would like to call a vote if we could on piece by

06:58:37 - 06:58:40

piece. Because again, it appears that we could pass at least one of these things.

06:58:42 - 06:58:45

But we have to do something because I see the agenda and I saw the agenda

06:58:45 - 06:58:48

and I read the agenda and I look at all these things and I don't understand what's happening.

06:58:50 - 06:58:52

Caden and then I'll make a comment.

06:58:56 - 06:58:58

I want to vote plus why we're here.

06:59:05 - 06:59:09

Tracy, and that'll be the last comment. Just real quick. So

06:59:09 - 06:59:11

the public members are very clear that.

06:59:12 - 06:59:15

For the most of us who have spoke up that we want to vote

06:59:15 - 06:59:17

today. If the government

06:59:18 - 06:59:21

members cannot vote at this point, can you give us

06:59:22 - 06:59:24

a timeline as to when you will get

06:59:26 - 06:59:27

those votes back to us? Please?

06:59:30 - 06:59:33

My understanding is that we're going to vote today and if the federal members or anyone

06:59:34 - 06:59:37

wants to abstain or vote no or vote yes, whatever it is, it will. It

06:59:38 - 06:59:38

will stand for today

06:59:40 - 06:59:40

and potentially.

06:59:43 - 06:59:46

We can bring proposals to working groups, which we also still have to discuss

06:59:46 - 06:59:47

and vote on.

06:59:50 - 06:59:53

I'm going to make the difficult choice to have us move on

06:59:54 - 06:59:55

vote on all the proposals.

06:59:58 - 06:59:59

As written except with the

07:00:02 - 07:00:02

addition that was provided

07:00:04 - 07:00:07

by Elizabeth Banker earlier. I understand

07:00:09 - 07:00:10

again if the federal members need to

07:00:10 - 07:00:13

abstain. We get

07:00:13 - 07:00:16

it. But then let's come together in the working groups.

07:00:17 - 07:00:20

And revise and move forward. This is, this is opening a

07:00:20 - 07:00:24

door. This is not final policy. We are making broad

07:00:24 - 07:00:27

recommendations for HHS to consider.

07:00:29 - 07:00:30

They are not binding.

07:00:32 - 07:00:36

And I'd like to, do I have a motion to take a vote

07:00:36 - 07:00:38

and we're going to vote in reverse order.

07:00:41 - 07:00:44

With voting on attachment D first, which is the

07:00:45 - 07:00:48

wandering and elopement. Do I have a motion for a vote?

07:00:50 - 07:00:52

I motion to make that vote. Do I have a second?

07:00:54 - 07:00:54

A second.

07:01:03 - 07:01:05

Believe the voting is going to occur through

07:01:06 - 07:01:07

zoom links that were sent

07:01:09 - 07:01:09

the other day.

07:01:11 - 07:01:14

So sorry. Yes. So.

07:01:20 - 07:01:22

There was an email sent from.

07:01:25 - 07:01:28

It's actually, the link is from.

07:01:30 - 07:01:33

It's from one source of one sourcevents. Com.

07:01:34 - 07:01:37

I received my link on April 24 at

07:01:37 - 07:01:40

5:14 p.m. In case that helps.

07:01:42 - 07:01:45

So mine popped up in in the meeting. Is that

07:01:46 - 07:01:49

mine? Yes. Yes.

07:01:53 - 07:01:53

So.

07:01:56 - 07:01:56

Yeah.

07:01:58 - 07:02:01

No, everyone has their own unique link. Well, so you have to

07:02:01 - 07:02:04

find it in your emails. I'm sorry. That was it came from

07:02:05 - 07:02:09

amyloski. So what we're going to try to do

07:02:09 - 07:02:13

is to the public the votes in the room for people that don't have access to

07:02:13 - 07:02:16

the zoom, but you're going to need to give us some time to make

07:02:17 - 07:02:20

a note because we need to record who voted.

07:02:21 - 07:02:21

For and against

07:02:23 - 07:02:25

for anybody who wants to use the zoom. You're welcome to do that

07:02:26 - 07:02:29

if you're not using the zoom. We'll count you in the room. Please don't vote

07:02:30 - 07:02:31

in vote place in both places.

07:02:32 - 07:02:35

And also if you are a federal member

07:02:37 - 07:02:40

and there's a member and an alternate here.

07:02:48 - 07:02:51

If you are a federal member and there's both a member and an alternate

07:02:52 - 07:02:55

here, please make sure only one of you is voting. It's one vote per agency

07:02:56 - 07:02:56

please.

07:02:59 - 07:03:01

Dr. Hines, you will be the member. Yes.

07:03:08 - 07:03:11

Margaret Bush virtually has her hand up.

07:03:12 - 07:03:15

It popped up on my screen. So is that my vote or

07:03:15 - 07:03:19

do I need to go into the other link. That you were referencing?

07:03:22 - 07:03:25

Same with me if it popped up on your screen you can use the zoom to vote.

07:03:26 - 07:03:27

Okay, thank you.

07:03:30 - 07:03:32

Excuse me. What do I do if I can't find it?

07:03:35 - 07:03:38

If if you can't find it will get votes in the room.

07:03:40 - 07:03:43

So I guess anybody who hasn't voted in the zoom already

07:03:44 - 07:03:47

raise your hands and we'll just get a yes or no or abstain

07:03:48 - 07:03:50

from you. So we can vote now if we do have

07:03:51 - 07:03:54

it. If you do. If you do see it in zoom. Yes, you can vote now.

07:03:58 - 07:04:01

This is yes on attachment D and this is

07:04:02 - 07:04:04

to adopt all nine recommendations within that attachment.

07:04:07 - 07:04:10

This is Amy from tech support. If it's not popping up on your screen

07:04:11 - 07:04:14

you can look in the more under polls and see if it's there.

07:04:15 - 07:04:16

On zoom.

07:04:21 - 07:04:21

If you have a question.

07:04:23 - 07:04:23

Okay.

07:04:26 - 07:04:29

Just give us a couple seconds to make sure the people who are trying to access it on

07:04:29 - 07:04:32

zoom are able to and then we'll see. Who else

07:04:33 - 07:04:33

needs to vote.

07:04:47 - 07:04:50

All right. If you're in the room and you did not vote on zoom already please raise your

07:04:50 - 07:04:51

hand and we'll record your vote.

07:04:53 - 07:04:54

Elizabeth bunker.

07:04:59 - 07:04:59

Yes.

07:05:02 - 07:05:02

Ginger Taylor.

07:05:04 - 07:05:04

John Gilmore.

07:05:07 - 07:05:08

Do with Cooper.

07:05:10 - 07:05:11

Honey Renicello.

07:05:13 - 07:05:13

Loo call.

07:05:15 - 07:05:16

Anybody that I missed in the room.

07:05:18 - 07:05:20

Rick Lambert? Ah yes. Yes

07:05:21 - 07:05:23

I can't tell who's down at the end. I'm sorry.

07:05:26 - 07:05:29

Dr. Rodney. Yes. Daniel

07:05:30 - 07:05:30

Keeley.

07:05:32 - 07:05:35

You put it in the zoo. Okay. Anybody that

07:05:35 - 07:05:39

I missed anybody on zoom who did not see the poll come

07:05:39 - 07:05:39

up for them.

07:05:50 - 07:05:53

Say something. No okay all right it looks like we have

07:05:55 - 07:05:55

seven abstain

07:05:57 - 07:05:58

and 26.

07:06:01 - 07:06:05

34 yes and zero nos. Will need to

07:06:05 - 07:06:08

go back and confirm that everybody who voted in the zoom

07:06:09 - 07:06:12

is appropriately voting. But I think the yeses have it.

07:06:16 - 07:06:20

Thank you to have a motion to vote on attachment see the profound

07:06:20 - 07:06:22

autism designation on motion to vote.

07:06:24 - 07:06:24

This second.

07:06:33 - 07:06:36

Okay, so there should be a new poll that launched in zoom for those of you who

07:06:36 - 07:06:39

are able to access it. Will give people a few minutes.

07:06:42 - 07:06:44

Or a few seconds to vote and then we'll go around the room again.

07:07:13 - 07:07:16

Others in the room ginger tailor. Yes.

07:07:19 - 07:07:22

In the room Judith Cooper? Yes. Honey

07:07:22 - 07:07:23

Renicella yes.

07:07:26 - 07:07:27

Rick yes.

07:07:31 - 07:07:32

Any others in the room?

07:07:33 - 07:07:34

Or on zoom.

07:07:36 - 07:07:36

I did.

07:07:40 - 07:07:43

Okay so we have 13 abstain.

07:07:46 - 07:07:47

26 yes and one no.

07:08:04 - 07:08:07

Proceeding in reverse order do I have a motion for a vote

07:08:07 - 07:08:11

for attachment B propose her clinical guidance on structured review of systems

07:08:12 - 07:08:15

reduction of diagnostic overshadowing and clinical safety assessment for individuals with

07:08:15 - 07:08:16

autism spectrum disorder.

07:08:18 - 07:08:21

I make emotions about. I second.

07:08:25 - 07:08:27

Give me one second I'm sorry I'm trying to pull it up and zoom.

07:08:37 - 07:08:40

This is just for attachment B regarding

07:08:41 - 07:08:42

HRSA.

07:09:02 - 07:09:03

Is that rec 5.

07:09:05 - 07:09:08

Should be attachment B adopt all I don't see it.

07:09:12 - 07:09:13

So what we're going to do is.

07:09:17 - 07:09:20

Let me could we go to attachment a while

07:09:21 - 07:09:24

I modify the poll for attachment B sylvia is that all right?

07:09:27 - 07:09:28

A motion to vote on attachment

07:09:30 - 07:09:31

a sorry I just want to read it out.

07:09:35 - 07:09:38

Proposed CMS guidance EPSD T clarification regarding

07:09:38 - 07:09:41

clinical assessment co occurring conditions and safety risks

07:09:42 - 07:09:44

risks for children with autism spectrum disorder.

07:09:49 - 07:09:52

We're saying be for now we have a technical issue and we're going to go to

07:09:53 - 07:09:56

a and then we'll come back to B so this is for attachment a do I have

07:09:56 - 07:09:59

a motion to take a vote yes I have motion for vote.

07:10:01 - 07:10:01

The second.

07:10:12 - 07:10:14

I apologize my zoom seems to have.

07:10:17 - 07:10:17

Okay let me go back.

07:10:19 - 07:10:22

Okay attaching. A.

07:10:32 - 07:10:33

Right you should see it now.

07:10:59 - 07:10:59

We can go around the room.

07:11:01 - 07:11:01

Was with bonker.

07:11:08 - 07:11:08

Yes.

07:11:10 - 07:11:12

Others in a room ginger Taylor yes.

07:11:14 - 07:11:17

Judith Cooper. Abstain. Honey

07:11:18 - 07:11:20

Renicella yes any others in the room.

07:11:22 - 07:11:24

Rick Lambert yes all right.

07:11:30 - 07:11:33

So we have 12 abstain. And 27

07:11:34 - 07:11:34

yes.

07:11:38 - 07:11:41

Right and you'll have to give me one minute I'm sorry to fix the

07:11:41 - 07:11:43
poll for attachment B.

07:13:02 - 07:13:04
Achelor launched for you all for attachment B.

07:13:10 - 07:13:14
I'm just going to clarify that attachment B didn't

07:13:14 - 07:13:17
contain EPSD T guidance so I'm fine

07:13:18 - 07:13:21
voting the way it is but I just want to be clear for all the members

07:13:21 - 07:13:23
that attachment be

07:13:25 - 07:13:29
was proposed HRSA clinical guidance on structured review of

07:13:29 - 07:13:32
systems reduction of diagnostic overshadowing and clinical safety assessment

07:13:32 - 07:13:34
for individuals with autism spectrum disorder

07:13:36 - 07:13:39
this attachment did not contain EPSD T

07:13:39 - 07:13:43
recommendations I apologize for that. Are you

07:13:43 - 07:13:43
okay

07:13:45 - 07:13:48
just continuing the vote yeah that's fine as long as everybody's clear everyone

07:13:49 - 07:13:51
attachment B. I can rename it later.

07:14:02 - 07:14:03

In the room Elizabeth Bonker.

07:14:06 - 07:14:06

Yes.

07:14:07 - 07:14:11

Ginger Taylor yes. Judith Cooper

07:14:12 - 07:14:15

abstain honey Renisella yes Rick

07:14:15 - 07:14:18

Lambert yes yes anybody else in the room I missed?

07:14:25 - 07:14:28

Right we have 13 abstain 27 yeses

07:14:29 - 07:14:31

and zero nos I should have said that for the others.

07:14:38 - 07:14:41

Okay so that concludes this portion of our afternoon

07:14:43 - 07:14:46

thank you to everyone who expressed their opinions

07:14:47 - 07:14:48

and participated obviously

07:14:50 - 07:14:51

and I'd like to move on now to

07:14:53 - 07:14:57

working group proposals and discussions to shape the strategic plan

07:14:59 - 07:15:01

I think is has been obvious here today

07:15:03 - 07:15:06

I think. Many members here have expressed an interest and the

07:15:06 - 07:15:07

importance of having working groups.

07:15:09 - 07:15:13

What I imagine is that our working groups would be able to function

07:15:14 - 07:15:16

as many FACA working groups do.

07:15:19 - 07:15:22

Outside of a public meeting so that individuals could

07:15:22 - 07:15:23

collaborate with each other

07:15:25 - 07:15:25

ask questions

07:15:27 - 07:15:28

work on proposals

07:15:30 - 07:15:33

engage subject matter experts. My hope is

07:15:34 - 07:15:38

and this has been in discussion with Diana Diaz Harrison

07:15:38 - 07:15:39

our national autism coordinator.

07:15:41 - 07:15:45

That perhaps we could have some also some

07:15:45 - 07:15:45

public

07:15:47 - 07:15:50

virtual meetings that the working groups would sponsor from

07:15:51 - 07:15:53

time to time, especially if we wanted to engage

07:15:54 - 07:15:57

multiple subject matter experts in

07:15:57 - 07:15:59

discussion. And I would also

07:16:01 - 07:16:04

envision that perhaps those public forums could also

07:16:05 - 07:16:08

include listening sessions that would allow our public to

07:16:08 - 07:16:10

engage with this committee more.

07:16:13 - 07:16:16

I think, you know, I think there are many more people who would like to engage with this

07:16:17 - 07:16:19

committee. I think especially that they

07:16:21 - 07:16:23

understand that we see their lived experience

07:16:25 - 07:16:25

and are responsive to that.

07:16:28 - 07:16:28

So

07:16:29 - 07:16:32

I first would like to just open up some general comments

07:16:33 - 07:16:36

to just the ideas of working groups and what people are interested

07:16:36 - 07:16:38

in. I have some ideas that I'd like to

07:16:39 - 07:16:42

share, but this is, you know, a participatory

07:16:42 - 07:16:45

process. So I'm just going to open the floor for discussion

07:16:45 - 07:16:45

initially.

07:16:53 - 07:16:53

Crystal.

07:16:55 - 07:16:58

I think one of the resounding topics we heard today throughout

07:16:59 - 07:17:02

public comments in person and here on the committee

07:17:03 - 07:17:05

was about communication rights and

07:17:05 - 07:17:08

access. I would love to suggest a

07:17:08 - 07:17:11

communication working group. And as I mentioned in my

07:17:11 - 07:17:15

presentation. There is an array of safety

07:17:15 - 07:17:18

needs that are really critical to address

07:17:19 - 07:17:21

wandering alone is one of them. So I would love to see

07:17:22 - 07:17:26

those topics addressed. Consistently in this

07:17:26 - 07:17:26

committee. Thank you.

07:17:30 - 07:17:33

John. I'd like to propose a working group that

07:17:34 - 07:17:36

focuses on epidemiology and also perhaps

07:17:37 - 07:17:40

definition of autism. You can't do one without the other.

07:17:45 - 07:17:46

Hand online. Bill Oldham.

07:17:53 - 07:17:55

Couple of comments one is I think if

07:17:56 - 07:17:59

if our session today proves anything that proves that there is a

07:17:59 - 07:18:03

passion for making progress, I think that is shared by the

07:18:04 - 07:18:06

federal members. I don't discount that for a

07:18:06 - 07:18:09

moment. I think that if.

07:18:10 - 07:18:13

We can't if we don't have working groups I don't understand how we

07:18:13 - 07:18:17

make the substantive progress that we need to make. So I think to

07:18:17 - 07:18:20

me this is a critical evolution for the work of both

07:18:20 - 07:18:23

public and federal members. And welcome

07:18:24 - 07:18:27

participation across a range. Of working groups. Thank you.

07:18:37 - 07:18:41

I'm just going to make a quick comment that I'm excited to

07:18:41 - 07:18:43

support the working groups and facilitate

07:18:44 - 07:18:47

conversations between public and federal members to make the

07:18:48 - 07:18:51

working groups robust actionable and will really be

07:18:51 - 07:18:54

the meat of our work together.

07:18:58 - 07:18:59

I'm just going to make a brief comment

07:19:01 - 07:19:04

in your packet of proposals. This is getting back to the vote. There was also

07:19:04 - 07:19:07

a proposed sample letter to the secretary. I do

07:19:07 - 07:19:09

think we should go back and vote to

07:19:11 - 07:19:13

see if the committee.

07:19:15 - 07:19:17

Votes to send that

07:19:17 - 07:19:20

letter. Hopefully if you take a quick

07:19:20 - 07:19:23

minute to review it, I think oni will work on

07:19:24 - 07:19:27

setting up that vote. But in the meantime we can continue our

07:19:28 - 07:19:31

working group discussion. Dr. Mumper online.

07:19:38 - 07:19:41

Would like to propose a working group addressing underlying

07:19:42 - 07:19:44

comorbid conditions associated with autism.

07:19:48 - 07:19:50

Thanks Tracy. I'm Dr. Mumper online.

07:19:53 - 07:19:56

I just don't have video. I was going to propose a working group on

07:19:56 - 07:19:59
the medical evaluation

07:19:59 - 07:20:03
workup treatment with the goal of getting those guidelines

07:20:04 - 07:20:07
to providers of medical care. So essentially

07:20:08 - 07:20:08
ditto. Thank you.

07:20:14 - 07:20:15
Sorry Scott Robertson.

07:20:21 - 07:20:24
I think it would be good to explore the possibility of something on

07:20:25 - 07:20:28
adult life issues. It was emphasized heavily today at times

07:20:29 - 07:20:32
that folks spend the majority of their time in adult life

07:20:33 - 07:20:36
and so issues around housing have come up today employment

07:20:36 - 07:20:37
on our end

07:20:38 - 07:20:41
transportation. So maybe work group that can explore

07:20:42 - 07:20:46
and a lot of those issues touch upon each other too. I know for instance

07:20:46 - 07:20:49
us at the office of disability employment policy. I also work on transportation

07:20:50 - 07:20:53
to work issues. And and we look at housing because these things

07:20:53 - 07:20:57
intersect together. So maybe I could explore these big picture

07:20:57 - 07:21:00

issues that where you have, you see a lot of.

07:21:02 - 07:21:05

Major barriers and challenges for autistic adults

07:21:06 - 07:21:08

and autistic youth as they're transitioning into adult life.

07:21:11 - 07:21:15

Lisa Ackerman. Thank you everyone for this

07:21:15 - 07:21:18

discussion. I would love to have a work group for wait lists

07:21:18 - 07:21:20

for diagnoses and waivers.

07:21:25 - 07:21:26

Yeah just to build on

07:21:27 - 07:21:31

your comments. I'm sorry. I don't remember your name. Robert

07:21:31 - 07:21:34

Scott's comments just I was going to say something similar

07:21:35 - 07:21:37

but I would like to make sure it includes adult

07:21:37 - 07:21:40

services, safety and supportive housing.

07:21:42 - 07:21:45

Because the house part, the, the physical structure

07:21:46 - 07:21:50

doesn't speak to the comprehensive needs

07:21:50 - 07:21:53

that our adults have. So adult services safety and

07:21:53 - 07:21:54

supportive housing. Thank you.

07:21:57 - 07:22:00

Just quick yeah when I say housing we mean like

07:22:01 - 07:22:05

full connection to services. So we have regular that's one of the reason

07:22:05 - 07:22:09

I wanted to sit next to the outer is where there's

07:22:09 - 07:22:10

a like a housing interagency

07:22:12 - 07:22:15

initiative called the housing services resource center

07:22:16 - 07:22:19

that looks at these types of focuses. So yes, we are thinking of

07:22:21 - 07:22:24

like focus supports and services. I don't mean just housing

07:22:25 - 07:22:28

like just like folks who have an apartment and everything's wonderful. I mean and the same for

07:22:28 - 07:22:32

transportation too like transportation would be travel trading

07:22:32 - 07:22:35

right it would be so all these focuses

07:22:36 - 07:22:39

obviously would come with the support needs for folks

07:22:39 - 07:22:42

with the major challenges to address and you need better services for

07:22:42 - 07:22:43

that. So I agree.

07:22:45 - 07:22:48

Thank you Dan online. Sorry

07:22:49 - 07:22:49

I had to go to zoom

07:22:50 - 07:22:53

so medical corn embitties and potential treatments

07:22:54 - 07:22:57

and some of the combinities are things like mitochondrial dysfunction and

07:22:58 - 07:23:00

folate metabolism and stuff including also seizures.

07:23:06 - 07:23:08

This may encompass what Dan was suggesting but I'd like

07:23:10 - 07:23:12

a working group or at least a subgroup of a working group around biomedical

07:23:13 - 07:23:17

research priorities. So from primary research we saw

07:23:17 - 07:23:19

etiology was the number one most common

07:23:21 - 07:23:24

in the public comments. So

07:23:25 - 07:23:28

the kinds of things that NIH is allocating its vast

07:23:28 - 07:23:29

budget towards.

07:23:31 - 07:23:35

So I'd like to as chair I'd like to make a proposal that I think

07:23:35 - 07:23:37

would encompass a lot of the topics that are brought up

07:23:37 - 07:23:40

today. So I would propose

07:23:41 - 07:23:44

three broad working groups. One would be a

07:23:44 - 07:23:47

working group dedicated to issues around communication and safety.

07:23:49 - 07:23:52

The second would be to medical care and research.

07:23:54 - 07:23:55

And the third would be

07:23:57 - 07:23:59

kind of broadly speaking lifespan issues.

07:24:01 - 07:24:04

But you know from suspicion to.

07:24:05 - 07:24:08

Geriatric concerns sort of across the

07:24:08 - 07:24:11

lifespan that would focus on services and supports

07:24:12 - 07:24:12

access.

07:24:14 - 07:24:17

I think there would potentially be overlap and some concerns

07:24:18 - 07:24:21

in different working groups. My only concern about having too many working groups

07:24:21 - 07:24:25

is that people are busy and not everyone

07:24:25 - 07:24:28

can dedicate a lot of time. In terms of those

07:24:30 - 07:24:33

three working groups, my proposal would be that they

07:24:33 - 07:24:36

be chaired by our public

07:24:36 - 07:24:39

members. And so for the communication and safety working

07:24:39 - 07:24:43

group, I would propose Elizabeth Bonker and

07:24:43 - 07:24:47

Crystal Higgins as co chairs for the

07:24:47 - 07:24:48

medical and research

07:24:49 - 07:24:50

working group.

07:24:51 - 07:24:55

I would propose Dr. Zerodni and Laura Sellini as co

07:24:55 - 07:24:57

chairs. And for the. I'm going to just call it

07:24:58 - 07:25:01

lifespan supports for lack of a better word. Maybe we could come up with

07:25:01 - 07:25:05

a better title. But for that I was going to propose

07:25:06 - 07:25:08

Lisa Akerman and Lisa Widerlet as co chairs.

07:25:10 - 07:25:13

And as I said, I think it's incredibly important that we have

07:25:14 - 07:25:18

robust collaboration between public and federal members

07:25:18 - 07:25:22

in these working groups. And I'm so thrilled that

07:25:23 - 07:25:26

Diana that you are intending to actively support

07:25:27 - 07:25:30

that process. I welcome comments or other suggestions.

07:25:38 - 07:25:42

Is it possible perhaps to split the adoption

07:25:42 - 07:25:45

of the worker groups into three separate votes? I think we could be

07:25:45 - 07:25:47

supportive of the one that pertains to our agency

07:25:48 - 07:25:51

mission. But I didn't have a prior access

07:25:51 - 07:25:55

to know whether that you know there was no way of knowing because this comes up dynamically

07:25:56 - 07:25:59

like the other two. So I can only, I think I may be

07:25:59 - 07:26:03

only able to focus in terms of our ability to engage on the one

07:26:03 - 07:26:07

that pertains to the agency mission. I'm sorry if to put the

07:26:07 - 07:26:10

complexity but. Yeah. Thanks I didn't consider

07:26:10 - 07:26:14

that to do other federal members have

07:26:14 - 07:26:16

that concern about voting for a working group.

07:26:17 - 07:26:20

That doesn't pertain to them or that they may not participate on.

07:26:25 - 07:26:27

I think we could just abstain from that.

07:26:28 - 07:26:31

Yeah, I think CMS would have the same. Position.

07:26:33 - 07:26:36

I think the question would just be would that impact if we abstain

07:26:36 - 07:26:37

the votes?

07:26:43 - 07:26:46

Maybe we could just take up what the concern would be for voting

07:26:47 - 07:26:50

for a working group that you wouldn't necessarily participate

07:26:50 - 07:26:53

in. Well maybe I could understand that. Further.

07:26:55 - 07:26:58

I know on my end, so I'm not the decider

07:26:59 - 07:27:02

at the at the at the agency like leadership is above me

07:27:03 - 07:27:06

and I just don't want to make a decision that they haven't had the knowledge to

07:27:06 - 07:27:06

be able to

07:27:10 - 07:27:13

since on the alternate and there's an I'm standing in for

07:27:15 - 07:27:18

our assistant secretary and leadership at the at the agency. It doesn't mean I have

07:27:19 - 07:27:22

it doesn't mean any focus on it. I just.

07:27:23 - 07:27:26

You know it. S just better for me to be able to inform

07:27:27 - 07:27:30

leadership on things so I don't like go back to the office and our

07:27:30 - 07:27:34

leadership doesn't like surprises. So yeah. Thank you

07:27:34 - 07:27:38

Dr. Beckel Michner. Yeah I think that the breadth of

07:27:38 - 07:27:41

the working groups just makes it really hard to know what specificity, what will

07:27:41 - 07:27:44

be covered based on some of the specific ideas that came

07:27:44 - 07:27:47

up. So from my perspective abstention

07:27:48 - 07:27:51

is not a no. I want to be supportive. I just

07:27:51 - 07:27:54

don't know. You know it's hard to vote for something when you don't have

07:27:55 - 07:27:56

firm definition of what it is.

07:28:02 - 07:28:05

Possible that I know in previous discussion as we were talking about

07:28:05 - 07:28:08

voting earlier is this one of the things that we can vote on

07:28:09 - 07:28:12

maybe online via zoom where we have a proposal of the

07:28:13 - 07:28:16

working groups and maybe a brief description who the chairs would be

07:28:17 - 07:28:20

and a brief description. And then maybe we could meet via zoom all together

07:28:20 - 07:28:23

and vote on it. Is that possible? So that way we have enough time.

07:28:24 - 07:28:26

Would that seem like a fair compromise?

07:28:37 - 07:28:38

I just want to say that.

07:28:40 - 07:28:42

We are all very anxious to get to work.

07:28:43 - 07:28:47

And so to once again kick it down the road for another vote.

07:28:48 - 07:28:49

Impedes progress.

07:28:52 - 07:28:55

I mean my conception was like whoever wanted

07:28:56 - 07:28:59

to be on a particular working group that that working group could decide

07:28:59 - 07:29:03

what they take up. For example the medical and research

07:29:03 - 07:29:06

group could decide to take up things related to NIH

07:29:06 - 07:29:10

funding or FDA drug trials. I mean that the working group

07:29:10 - 07:29:13

itself would decide what order and what

07:29:13 - 07:29:16

the primary topics would be and then bring that

07:29:16 - 07:29:20

information. Obviously all working groups bring

07:29:21 - 07:29:24

their information and recommendations back to this primary

07:29:24 - 07:29:26

committee. So for example

07:29:28 - 07:29:31

medical evaluation and co-occurring medical conditions could be taken up in the

07:29:31 - 07:29:35

medical and research working group should that working group

07:29:35 - 07:29:35

decide.

07:29:37 - 07:29:39

That was what they wanted to prioritize at that moment or

07:29:39 - 07:29:42

epidemiology. I would imagine would be, you know, in that

07:29:43 - 07:29:44

research group. So I know it's a little.

07:29:46 - 07:29:49

Fluid, but I think that's okay. The working

07:29:49 - 07:29:52

groups themselves, if they are adopted.

07:29:54 - 07:29:57

Could decide what their primary focus would be in

07:29:57 - 07:29:59

collaboration, you know, public and federal partners.

07:30:03 - 07:30:06

So a quick question can you explain your rationale around having

07:30:06 - 07:30:10

public members share the working groups as opposed to having federal

07:30:10 - 07:30:13

members having the opportunity to co-chair with a public member?

07:30:16 - 07:30:20

I feel like, you know, we could explore that. I think if

07:30:20 - 07:30:23

federal members wanted to chair a particular working

07:30:23 - 07:30:26

group, you know, I didn't mean that to be

07:30:27 - 07:30:30

in a negative way. I feel like

07:30:30 - 07:30:33

the passion and lived experience

07:30:34 - 07:30:37

to the IACC is, you know, being provided

07:30:38 - 07:30:39

primarily by the public members.

07:30:41 - 07:30:45

And I know we are all eager to get to work and don't have

07:30:45 - 07:30:48

the opportunity to influence the federal response in our daily

07:30:50 - 07:30:50

jobs and life.

07:30:52 - 07:30:52

But certainly.

07:30:55 - 07:30:58

You know, I apologize. I didn't mean that to be offensive to any of

07:30:59 - 07:31:01

the federal members. And if there's a federal member who wants to co-chair

07:31:02 - 07:31:03

a working group.

07:31:05 - 07:31:08

Of any kind doesn't have to be the ones that I proposed.

07:31:11 - 07:31:11

Sure.

07:31:13 - 07:31:17

I think it's a good plan to have the public members share the groups because they

07:31:17 - 07:31:20

have the urgency and the understanding. The federal members

07:31:21 - 07:31:24

are working for institutions who could have done any of this

07:31:24 - 07:31:28

at any time. This legislation didn't need to be passed for you to

07:31:28 - 07:31:30

do these things. This committee doesn't have to exist

07:31:31 - 07:31:35

and you haven't. Not you personally, but your, you

07:31:35 - 07:31:38

know, CMA has not done. Their due diligence in seeing what we

07:31:38 - 07:31:38

need.

07:31:41 - 07:31:44

And doesn't have a decision maker and nothing against

07:31:44 - 07:31:47

you. But you know, I invite Dr. Ross to come and sit with us so he

07:31:47 - 07:31:51

can make a decision so we can advance. The Trump

07:31:51 - 07:31:53

administration is behind this. Bobby has been.

07:31:54 - 07:31:58

Advocating for our kids four decades. What

07:31:58 - 07:32:00

is happening here is really important and oppressive.

07:32:02 - 07:32:02

So

07:32:04 - 07:32:07

with respect to the federal members, I'm glad you're

07:32:07 - 07:32:10

here, but you're not the leader in these topics. You're

07:32:10 - 07:32:14

not, you know, you're not looking

07:32:14 - 07:32:17

at your mortality saying how is my children going to

07:32:17 - 07:32:21

be my child going to be taken care of. And you live in

07:32:21 - 07:32:24

bureaucracy. Everything has a great decision. And so I

07:32:24 - 07:32:28

don't want that to be the guiding principle of the way this committee

07:32:28 - 07:32:31

works. We have the urgency and we have the experience and with knowledge.

07:32:32 - 07:32:35

We have the resources. We have the kids who have recovered.

07:32:36 - 07:32:39

We have the kids who have died. We have. We're

07:32:39 - 07:32:41

the story. The federal government has sit by.

07:32:43 - 07:32:45

Since 1943 and let this be.

07:32:47 - 07:32:50

Whatever. So I don't have the trust there. And if we are trying to

07:32:51 - 07:32:54

rebuild the trust with the community to serve the

07:32:54 - 07:32:54

community.

07:32:56 - 07:32:59

I want to support sylvia's idea to have the

07:32:59 - 07:33:01
speak community led.

07:33:02 - 07:33:03
Thank you, ginger and laura.

07:33:06 - 07:33:08
I think one of the advantages of having

07:33:10 - 07:33:13
a public members direct the committee is actually related

07:33:13 - 07:33:16
more to FACA. While we do need

07:33:17 - 07:33:20
and want and really will benefit from having

07:33:21 - 07:33:25
federal and public members both serve,

07:33:25 - 07:33:27
FACA does, there is

07:33:29 - 07:33:32
a line for which we want to make sure that it doesn't look like there's too much

07:33:33 - 07:33:36
federal influence on any sort of decision making

07:33:37 - 07:33:40
from a public body. So I just

07:33:40 - 07:33:43
wanted to put that out there as a consideration. Thank you.

07:33:49 - 07:33:53
Hi, it's Dr. Becky Holland. I just, I just wanted to

07:33:53 - 07:33:53
acknowledge that.

07:33:57 - 07:33:59
As a new person in the federal government.

07:34:02 - 07:34:06

I feel, and what I've learned, is there a lot of people from the

07:34:06 - 07:34:09

federal government here who do care and who are here

07:34:10 - 07:34:13

spending their day working on this. So it feels a bit dismissive.

07:34:16 - 07:34:19

And a bit of an attack because many of us have never, some

07:34:19 - 07:34:23

of us at least haven't been here before. So I

07:34:23 - 07:34:26

don't, I think that the way forward for us all is to think of

07:34:26 - 07:34:30

this as a true collaboration and try to resist

07:34:31 - 07:34:34

the urge of dismissing either, either group.

07:34:36 - 07:34:36

Thank you.

07:34:38 - 07:34:41

Katie. Sweeney based on that.

07:34:43 - 07:34:45

Could we or could I propose or we propose

07:34:46 - 07:34:50

that they are co chaired by a public member and a federal

07:34:50 - 07:34:53

member that each of the three working groups? Is that a fair

07:34:54 - 07:34:54

proposal?

07:34:55 - 07:34:56

I like that idea. And

07:34:57 - 07:35:00
again,

07:35:00 - 07:35:03
I didn't think that through. I wasn't sure that federal members would want

07:35:04 - 07:35:07
co chair. And I think that's a great, that's a great

07:35:07 - 07:35:10
idea. So I think as we move forward, maybe

07:35:10 - 07:35:11
we can.

07:35:13 - 07:35:16
Hone in a little bit on whether these three working

07:35:17 - 07:35:17
groups.

07:35:18 - 07:35:20
Kind of capture the issues that have been raised

07:35:23 - 07:35:26
and then would love to hear from federal members who may want to

07:35:26 - 07:35:27
co-chair

07:35:28 - 07:35:32
a committee. It's not a committee. It's a working group.

07:35:32 - 07:35:33
Sorry, a working group.

07:35:44 - 07:35:47
I like that idea. So can we move forward with

07:35:47 - 07:35:49
what, what would be the next step of vote? On those

07:35:51 - 07:35:54

three committees? Well, maybe what we could do is have

07:35:54 - 07:35:57

a vote on three proposed committees.

07:35:57 - 07:36:01

Again, broad topics that encompass a lot of what has been

07:36:02 - 07:36:03

raised here today

07:36:04 - 07:36:07

with the specific agenda of those working groups

07:36:08 - 07:36:12

being determined by the co chairs and members

07:36:13 - 07:36:15

at this juncture. Scott.

07:36:17 - 07:36:20

And did you say, can you clarify whether you'll be able to split that

07:36:21 - 07:36:24

into three separate, both of it up? Because I checked with my

07:36:25 - 07:36:27

manager and he said that would be

07:36:29 - 07:36:31

our preference so that it would make it

07:36:31 - 07:36:34

easier, the one that's related to our agency

07:36:35 - 07:36:38

mission being the one that's easier for us. Yeah.

07:36:38 - 07:36:41

Yeah. So I have three different votes, three separate boats prepared. Thank you.

07:36:43 - 07:36:46

Okay, let's try that. But I think if your federal role

07:36:47 - 07:36:50

doesn't particularly conflict or with

07:36:50 - 07:36:54

the possibility of a working group in which you won't participate.

07:36:59 - 07:37:02

However you want to. Okay.

07:37:06 - 07:37:10

Do we have a motion to vote for a communication and safety working group

07:37:10 - 07:37:13

with the co chairs to be termed a bit later?

07:37:15 - 07:37:16

For that vote.

07:37:38 - 07:37:39

S in the room, Elizabeth Bonker.

07:37:43 - 07:37:43

Yes.

07:37:45 - 07:37:47

Ginger Taylor. Yes.

07:37:49 - 07:37:52

Judith Cooper. Yes, honey Renicella. Yes.

07:37:53 - 07:37:56

I forgot my last person. Rick Lambert. Class yes.

07:38:06 - 07:38:08

We have 35 yeses and three abstains

07:38:09 - 07:38:10

zero no's.

07:38:13 - 07:38:16

Thank you. Do I have a motion to vote on a proposed

07:38:17 - 07:38:20

combined medical and research working group?

07:38:25 - 07:38:26

Hi, Lisa again. Yes.

07:38:54 - 07:38:54

Yes.

07:38:56 - 07:38:59

Ginger Taylor. Yes. Judith Cooper.

07:38:59 - 07:39:02

Yes. Honey Renicella.

07:39:02 - 07:39:05

Yes, Rick Lambert. Yes. Yes.

07:39:06 - 07:39:09

All right, so 36 yes for

07:39:09 - 07:39:11

abstains. Zero nos.

07:39:15 - 07:39:18

Okay, do I have a motion to vote on

07:39:19 - 07:39:22

a working group that would encompass lifespan

07:39:22 - 07:39:23

issues motion?

07:39:51 - 07:39:53

In the room? Elizabeth bonker.

07:39:55 - 07:39:57

Yes. Ginger taylor. Yes.

07:39:58 - 07:40:01

Judith cooper. Yes, honey Renisella. Yes.

07:40:02 - 07:40:05

Rick Lambert. Yes. Yes. All right. 37

07:40:05 - 07:40:06

yeses.

07:40:08 - 07:40:10

Three abstentions. Zero no's.

07:40:14 - 07:40:16

Before we continue our discussion on.

07:40:19 - 07:40:23

Working group working groups. And cochain. Well, I don't know. Should we go back and try

07:40:23 - 07:40:26

to vote on the letter or should we, are you ready for that?

07:40:27 - 07:40:30

Oni? Okay. I just want to go back. So in the packet

07:40:30 - 07:40:33

that you received was a proposed sample letter to the secretary

07:40:36 - 07:40:39

with all of the proposals that we voted on today. If they, if

07:40:39 - 07:40:41

they hadn't moved forward, we would have amended the

07:40:41 - 07:40:44

letter. But given that all of the proposals

07:40:45 - 07:40:47

moved forward or were voted yes.

07:40:49 - 07:40:50

The question would be

07:40:52 - 07:40:55

to vote to send this letter to the secretary.

07:40:59 - 07:41:02

Do I have a motion to send this motion?

07:41:03 - 07:41:03

Second?

07:41:28 - 07:41:28

Elizabeth bonker.

07:41:31 - 07:41:31

Yes.

07:41:33 - 07:41:36

Ginger tailor. Yes. Judith cooper.

07:41:37 - 07:41:39

Abstain honey renicella. Yes

07:41:40 - 07:41:41

remember? Yes.

07:41:44 - 07:41:48

All right, we have 13 abstentions. Two

07:41:48 - 07:41:49

no's and 24 yeses.

07:41:55 - 07:41:58

Okay, thank you. So looks like we've adopted

07:41:58 - 07:42:01

three working groups again communication and safety.

07:42:03 - 07:42:05

Medical research and lifespan supports.

07:42:08 - 07:42:11

So I open the floor for discussion about

07:42:11 - 07:42:14

those who would like to. Either propose or

07:42:15 - 07:42:17

themselves or propose someone else as

07:42:19 - 07:42:21

a potential co chair of each of those committees.

07:42:29 - 07:42:33

Scott, just a question on logistics. Are we going to have to vote

07:42:33 - 07:42:36

on the, on the co-chairs or is that, does that not need

07:42:37 - 07:42:37

a vote?

07:42:41 - 07:42:44

That I don't know? Okay, I just wanted to fill, I

07:42:44 - 07:42:47

filled in my, I can't do anything without dynamic about my

07:42:47 - 07:42:48

boss. Sorry.

07:42:52 - 07:42:55

I'm in favor of voting for that, but Lisa waiter light

07:42:56 - 07:42:59

on a similar type of committee. We had people pick their

07:42:59 - 07:43:03

committees that they wanted to be on and the committee chose the chairs

07:43:03 - 07:43:06

and the co chairs. I would suggest that as a good thing because

07:43:07 - 07:43:11

great. Okay, so let's do it that way. Maybe

07:43:11 - 07:43:11

we could

07:43:13 - 07:43:16

start with the communication and safety working group. You can be

07:43:16 - 07:43:19

on more than one. Working group if you want to be.

07:43:23 - 07:43:24

I don't know, should we do that by.

07:43:26 - 07:43:28

Show of hands, like who wants to be on each working group?

07:43:30 - 07:43:33

Logistically what can I make another suggestion that can we

07:43:33 - 07:43:33

actually

07:43:35 - 07:43:38

go back and consider and send you, you give us a date

07:43:39 - 07:43:42

like a week from Friday or something? Because yeah, we may

07:43:43 - 07:43:46

be able to find really enthusiastic experts

07:43:47 - 07:43:51

and people that will want to serve on those committees. Outside

07:43:51 - 07:43:53

of the members of the committees that would be

07:43:53 - 07:43:55

representing, you know, broader interests.

07:43:58 - 07:44:01

I can do that on a working group. Is that correct? I'm going to look at

07:44:02 - 07:44:05

our federal partners. Yes, we can have outside

07:44:05 - 07:44:08

members. Yeah. On working groups. Or

07:44:09 - 07:44:12

working group members do not have to be members of the full committee.

07:44:13 - 07:44:16

Oh, okay, great. I didn't realize that. So that's

07:44:16 - 07:44:20

perfect. So maybe we could just, okay. Ginger.

07:44:21 - 07:44:24

Is that true of the private members as well.

07:44:25 - 07:44:27

We have experts on all of this.

07:44:29 - 07:44:29

Okay.

07:44:31 - 07:44:34

I mean, one thought would be that the public members today could declare

07:44:35 - 07:44:38

which working groups they would like to be on, and then we would

07:44:39 - 07:44:39

await.

07:44:45 - 07:44:48

Follow up from our federal partners

07:44:49 - 07:44:52

about who might be. I just don't know what how we would do that sort of

07:44:52 - 07:44:53

publicly.

07:44:57 - 07:44:58

Publicly in terms of

07:44:59 - 07:45:02

like just finalizing do we need to finalize the

07:45:02 - 07:45:06

members of the working group in this public forum? Or could that be

07:45:06 - 07:45:07

done outside? No, we don't need.

07:45:09 - 07:45:12

So what I would propose is that the public members today

07:45:15 - 07:45:17

indicate which working groups they would like to be on.

07:45:21 - 07:45:23

So we're going to start with the communication. Sorry. Okay.

07:45:24 - 07:45:28

Can we establish a target size

07:45:28 - 07:45:29

of these working groups?

07:45:31 - 07:45:32

Because if we're going to open it up to public.

07:45:34 - 07:45:37

And federal, they could get very large and

07:45:37 - 07:45:38

unmanageable.

07:45:41 - 07:45:43

John. Continuing on CD's

07:45:43 - 07:45:46

point. There's what 43,

07:45:47 - 07:45:50

46 total public and private. Members sent to

07:45:50 - 07:45:53

somebody know there's 40 43 children members of the writing.

07:45:54 - 07:45:54

So.

07:45:56 - 07:45:59

Maybe we should limit the total pool of people who can be

07:45:59 - 07:46:03

at 43 so federal member

07:46:04 - 07:46:06

doesn't want to be on their spot could be taken by somebody within

07:46:08 - 07:46:11

their organization who would they would feel more comfortable with it.

07:46:12 - 07:46:15

But not necessarily have 10 people show up from that same organization

07:46:16 - 07:46:18

representing that one voting spot.

07:46:24 - 07:46:28

I'm sorry just to content from that standpoint, maybe a federal

07:46:28 - 07:46:31

member could or would like to go ahead and commit, you

07:46:31 - 07:46:35

know, they feel empowered to do so here. But

07:46:35 - 07:46:39

there's still open period where they can be swapped out or

07:46:39 - 07:46:42

that role could still be filled by somebody just as a process point.

07:46:43 - 07:46:46

Thank you, John. Amy Adams online. Thank you.

07:46:49 - 07:46:49

You know, I just want to.

07:46:51 - 07:46:52

Acknowledge that there's a lot of.

07:46:54 - 07:46:57

Ways to manage a federal advisory committee and and

07:46:57 - 07:47:01

its working groups. So we've seen a lot of variations on that

07:47:01 - 07:47:03

theme. But I do just want to reiterate.

07:47:05 - 07:47:08

My understanding that the public members and the federal members

07:47:08 - 07:47:12

could potentially suggest experts who could participate

07:47:12 - 07:47:15

in working groups. And I could imagine

07:47:16 - 07:47:18

that there are. Members who might.

07:47:21 - 07:47:23

Have important perspectives to add to more than one working

07:47:24 - 07:47:27

group. But I appreciate the point about the slides. I do.

07:47:30 - 07:47:33

But I feel for example my colleagues at the deafness

07:47:34 - 07:47:37

institute would be relevant both to the medical research and to

07:47:37 - 07:47:41

the communication working groups right in really substantive core

07:47:41 - 07:47:41

ways.

07:47:44 - 07:47:44

So I do think.

07:47:47 - 07:47:50

You know, giving folks like a week not that long. I appreciate the

07:47:50 - 07:47:53

urgency. But just to let people really think about.

07:47:54 - 07:47:57

The right expert voices that they want to include in these discussions

07:47:59 - 07:48:01

and think through sort of the right

07:48:04 - 07:48:06

collection there. And then the public piece would be

07:48:07 - 07:48:10

once the working groups are decided, then you would publish the

07:48:11 - 07:48:14

rosters of those just so that there's transparency on

07:48:15 - 07:48:16

who would be on each working group.

07:48:19 - 07:48:23

Laura. So I'm just double checking FACA

07:48:23 - 07:48:26

and maybe some of the federal members. So I

07:48:26 - 07:48:29

understand that with our working groups, we can

07:48:30 - 07:48:33

solicit membership that are not appointed to the

07:48:33 - 07:48:37

committee. However, I believe that

07:48:37 - 07:48:40

they cannot act as voting members in the

07:48:40 - 07:48:43

working group if I read the act correctly.

07:48:45 - 07:48:46

Does someone have clarification on that?

07:48:49 - 07:48:52

So I'm hearing from our committee management office that that is correct.

07:48:55 - 07:48:55

Thank you.

07:49:01 - 07:49:04

Is there a way also for the federal members you could when you send out the request.

07:49:05 - 07:49:09

For the membership? Can you put something in around depth and breadth of

07:49:09 - 07:49:12

what that group might represent from your perspective? So we have

07:49:12 - 07:49:15

a little more information around it. To make it to make choices.

07:49:17 - 07:49:18

That'd be helpful. Thank you.

07:49:28 - 07:49:30

With that clarification from Laura Sellini that.

07:49:32 - 07:49:35

Non IACC members would not be voting members of working

07:49:35 - 07:49:36

groups.

07:49:38 - 07:49:41

Does that change anyone's perspective about having

07:49:43 - 07:49:46

non IACC members named as part of working groups

07:49:47 - 07:49:50

rather than. Being able to simply

07:49:50 - 07:49:50

solicit

07:49:52 - 07:49:55

their input. During the working group process?

07:49:58 - 07:49:58

Scott.

07:50:00 - 07:50:03

I was just going to say that we didn't use working groups in the

07:50:03 - 07:50:07

last duration, but when I, so I was on the committee

07:50:07 - 07:50:10

a long time ago as a public member back in 2012 to

07:50:10 - 07:50:14

2014. And we did have working groups then and we had somewhere when I called

07:50:14 - 07:50:17

it and folks were there just for their expertise

07:50:18 - 07:50:21

basically like it was researchers and service folks etc that had

07:50:21 - 07:50:24

a lot of expertise in that specific area.

07:50:24 - 07:50:27

Right. So I think I just want to say this aligns with

07:50:28 - 07:50:31

historically what the committee has often done with having

07:50:31 - 07:50:34

work groups having SMEs would be similar to what it's done

07:50:35 - 07:50:38

in the in the past who aren't on the, I mean that's one of the purposes

07:50:38 - 07:50:41

of having them right is there may be expertise beyond

07:50:42 - 07:50:45

the books here. Right. There's a lot of folks out there beyond who's in this room.

07:50:46 - 07:50:46

Yeah.

07:50:47 - 07:50:51

Dr. Becket mentioned yes my experience with working groups similar to Scott's is that they are

07:50:51 - 07:50:55

there as getting information together so that they bring it

07:50:55 - 07:50:58

to the full committee and the committee votes. There's not that many votes that happen

07:50:59 - 07:51:02

in a working group, but maybe an informal vote, but it's non binding because

07:51:02 - 07:51:05

it's the work of the committee and the committee members where the votes

07:51:06 - 07:51:06

happen.

07:51:08 - 07:51:11

Laura Sellaney. I personally think that maybe

07:51:11 - 07:51:12

for clarity

07:51:13 - 07:51:16

because I can imagine that there will be a lot of interest from

07:51:17 - 07:51:20

non appointed members to serve in working groups. As we know there's no shortage of

07:51:21 - 07:51:22

stakeholders and

07:51:22 - 07:51:24

opinions. So

07:51:26 - 07:51:29

I personally would prefer that we solicit

07:51:31 - 07:51:34

stakeholder input from various experts. I agree. I think

07:51:34 - 07:51:37

that is absolutely necessary to bring in researchers, people

07:51:38 - 07:51:41

in the not for profit sector, other areas that can be very helpful

07:51:42 - 07:51:44

to us. But I want to make sure that

07:51:46 - 07:51:49

it is actually in understanding what FACA does

07:51:49 - 07:51:52

state. It is actually the members that are appointed on this committee

07:51:54 - 07:51:56

who are the ones driving these

07:51:57 - 07:51:59

decisions. So just for clarification I wanted that to also be

07:52:00 - 07:52:04

a consideration that even if we didn't have them as official working

07:52:04 - 07:52:07

group members that they could maybe just come and

07:52:07 - 07:52:07

present

07:52:09 - 07:52:13

and you know ad hoc information from them and we could solicit

07:52:13 - 07:52:15

their advice and input. Thank you.

07:52:24 - 07:52:27

Waiter light. I just wanted to add, I mean I know it's been a long

07:52:27 - 07:52:30

day, but as a parent who's seen many iterations of

07:52:30 - 07:52:33

the IACC like it's heartening to see this level of interest from

07:52:34 - 07:52:37

federal partners who not only want to participate but lead

07:52:38 - 07:52:42

in not only lead but bring subject matter experts. It means

07:52:42 - 07:52:45

a lot. So thank you and I hope this is the beginning of like a

07:52:45 - 07:52:48

really, really good sign for all of us to make urgent change

07:52:49 - 07:52:52

very quickly. That's really great and maybe some innovations that haven't been thought

07:52:52 - 07:52:54

of before. So thank you.

07:52:56 - 07:52:58

I would just like to make a comment as a

07:52:58 - 07:53:01

member. I appreciate Dr.

07:53:01 - 07:53:04

Beckel mentioned earlier your proposal about having non

07:53:05 - 07:53:08

IACC members on the working group. I think my preference and the way

07:53:08 - 07:53:11

that I personally had envisioned them is that they would be

07:53:11 - 07:53:14

IACC members and that we would solicit input from

07:53:15 - 07:53:17

subject, even regular input from subject matter

07:53:17 - 07:53:19

experts, researchers,

07:53:19 - 07:53:22

academics, stakeholders.

07:53:25 - 07:53:28

So maybe what I would propose is for us to take a vote

07:53:29 - 07:53:32

now about whether we want non

07:53:32 - 07:53:35

IACC members to be officially part of working groups.

07:53:37 - 07:53:40

And then I think in terms of just committee

07:53:40 - 07:53:43

business, I will provide the federal

07:53:44 - 07:53:47

members, all the members with a sort of an outline of

07:53:48 - 07:53:51

what the committees might take up and then we could receive a

07:53:51 - 07:53:55

response within one week about which federal

07:53:55 - 07:53:58

members would like to be on which committees. And I would also like to

07:53:59 - 07:54:02

proceed today in the few minutes we have left with identifying

07:54:02 - 07:54:06

which public members would like to serve on which committee. So

07:54:06 - 07:54:09

do I have a motion to vote on whether or not we would

07:54:10 - 07:54:13

include non IACC members in the working groups.

07:54:15 - 07:54:16

I make a motion to vote.

07:54:30 - 07:54:31

So, but all in favor of which one?

07:54:33 - 07:54:36

Okay. All in favor of including non IACC

07:54:36 - 07:54:39

members on working groups. Please raise your hands.

07:54:41 - 07:54:41

And.

07:54:45 - 07:54:49

As official members versus bringing in people as

07:54:49 - 07:54:51

needed. There's a difference. This is as official members.

07:54:58 - 07:55:01

Of non IACC members as official members of the working group

07:55:02 - 07:55:05

rather than just being brought in for subject matter expertise from time to time.

07:55:07 - 07:55:10

If you're on zoom, you can I mean if you're attending virtually you can

07:55:10 - 07:55:12

raise your hand in zoom as well and we will count you.

07:55:21 - 07:55:22

No hands virtual.

07:55:29 - 07:55:31

Dann Rosnoll and Bill Oldham, are you voting to

07:55:33 - 07:55:36

allow non IACC members and working groups? Are you raising your

07:55:37 - 07:55:39

hand to make a comment? I'm okay to have them as

07:55:40 - 07:55:41

members, but not as

07:55:43 - 07:55:45

witnesses as how I think of them rather an expert

07:55:46 - 07:55:47

guidance, but not full members.

07:55:49 - 07:55:51

Okay, so this is full members of working group.

07:55:53 - 07:55:55

So so is your no. Okay

07:55:57 - 07:55:57

Dawn Rosanna.

07:56:01 - 07:56:04

Okay everybody else in the room who vote no please

07:56:04 - 07:56:04

raise your hand.

07:56:09 - 07:56:12

I was online who are voting no you also need to raise your hands.

07:56:32 - 07:56:35

Christina Chacon are you voting yes for or

07:56:36 - 07:56:38

no. Everybody know okay.

07:56:40 - 07:56:41

Yes okay.

07:56:47 - 07:56:50

And you had expressed that you were a no Dawn Rawson

07:56:51 - 07:56:54

can you just officially vote if you can if you're not going

07:56:54 - 07:56:55

through security or something.

07:56:57 - 07:56:59

I'm sitting outside of security so now okay okay

07:57:00 - 07:57:04

I think I just need a clarity on official versus unofficial because they have no

07:57:04 - 07:57:06

voting power. So I'm trying to understand that

07:57:07 - 07:57:10

I think that they would be you know sort of regular

07:57:11 - 07:57:14

attendees at. All working group meetings

07:57:15 - 07:57:15

as opposed to

07:57:17 - 07:57:20

coming in from time to time. Or even from periods of time

07:57:21 - 07:57:24

to give subject matter expertise that they would be kind

07:57:24 - 07:57:27

of full members of the group and that they're, you know, availability would be

07:57:28 - 07:57:29

taken into consideration that kind of thing.

07:57:31 - 07:57:33

All right then I would vote now. Misunderstood.

07:57:35 - 07:57:35

Any abstentions?

07:57:45 - 07:57:48

Okay it's it seems like there's a little bit of confusion here and we do

07:57:48 - 07:57:51

need to get out right at five o'clock or else they will kick us out

07:57:52 - 07:57:55

so maybe we should try to sort some of this out by email

07:57:55 - 07:57:55

or something.

07:57:57 - 07:58:01

Let's try one more time we have a couple more minutes okay we are now

07:58:01 - 07:58:04

voting for whether you want non

07:58:05 - 07:58:07
IACC members to be full

07:58:08 - 07:58:10
members of working groups.

07:58:12 - 07:58:13
Rather than just occasional participants.

07:58:15 - 07:58:19
For subject matter expertise that non IACC members would be full

07:58:19 - 07:58:22
members of working groups. So everyone who votes

07:58:23 - 07:58:27
full non voting members right full non voting members.

07:58:28 - 07:58:32
But as was pointed out there aren't probably going to be very many modes but we will be voting on

07:58:32 - 07:58:35
who's co-chair for example so

07:58:36 - 07:58:39
so everyone in favor of

07:58:39 - 07:58:43
allowing non IACC members to be part of working

07:58:43 - 07:58:46
groups. Please raise your hands now.

07:58:51 - 07:58:52
Including those online.

07:58:57 - 07:58:59
Anybody online? In favor.

07:59:02 - 07:59:04
Looks like no so 10 in favor.

07:59:10 - 07:59:13

Everyone who is voting know who is not in favor of having

07:59:14 - 07:59:17

non IACC members as a full members of working

07:59:17 - 07:59:18

groups please raise your hand.

07:59:34 - 07:59:37

17 in the room plus 8 online so 25.

07:59:39 - 07:59:43

25 opposed. Okay, so since we

07:59:43 - 07:59:46

were out of time for today I think what we

07:59:46 - 07:59:49

should do is that we should follow up with each other

07:59:51 - 07:59:52

in a group email

07:59:55 - 07:59:57

about who would like to be on which working groups

07:59:58 - 08:00:01

both public members and federal members

08:00:02 - 08:00:05

and we could do that it's going to be a big long email chain

08:00:07 - 08:00:10

but we'll do it that way and I would like to propose a deadline for

08:00:10 - 08:00:10

that.

08:00:15 - 08:00:17

Tuesday May 5 by 5 p.m.

08:00:19 - 08:00:22

The federal members are going to get a breakdown correct

08:00:22 - 08:00:24

beforehand yes I will send that out

08:00:25 - 08:00:26

by start of day tomorrow thank you.

08:00:29 - 08:00:32

Thank you to everyone who made the trip here who participated

08:00:34 - 08:00:37

and look forward to working collaboratively with all of the

08:00:38 - 08:00:41

members and and all of our federal partners and thank you

08:00:41 - 08:00:44

to all those who participated with public comments

08:00:46 - 08:00:48

our our day today is adjourned. Thank you.