INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

THURSDAY, JULY 14, 2022

The full Interagency Autism Coordinating Committee (IACC) convened virtually, at 1:00 p.m., Susan Daniels, Ph.D., Executive Secretary, presiding.

PRESENT:

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

MITCHELL BERGER, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA)(representing Anita Everett, M.D., D.F.A.P.A

SAMANTHA CRANE, J.D., Quality Trust for Individuals with Disabilities

DAYANA J. GARCIA, M.Ed., Administration for Children and Families (ACF)

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

ALYCIA HALLADAY, Ph.D., Autism Science Foundation

ELAINE COHEN HUBAL, Ph.D., U.S. Environmental Protection Agency (EPA)

JENNIFER JOHNSON, Ed.D., Deputy Commissioner, Administration on Disabilities, Administration for Community Living

<u>PRESENT: (continued)</u>

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

CINDY LAWLER, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Rick Woychik, Ph.D.)

YETTA MYRICK, B.A., DC Autism Parents

LINDSEY NEBEKER, B.A., Freelance Presenter/Trainer

JENNY MAI PHAN, Ph.D., University of Wisconsin-Madison

JOSEPH PIVEN, M.D., University of North Carolina-Chapel Hill

JALYNN R. PRINCE, B.F.A., Madison House Autism Foundation

SCOTT MICHAEL ROBERTSON, Ph.D., Senior Policy Advisor, Office of Disability Employment Policy, U.S. Department of Labor

SUSAN RIVERA, Ph.D., University of California, Davis

STUART SHAPIRA, M.D., Ph.D., Centers for Disease Control and Prevention (CDC) (representing Georgina Peacock, M.D., M.P.H., F.A.A.P.)

MATTHEW SIEGEL, M.D., Tufts University

IVANOVA SMITH, B.A., University of Washington

PRESENT: (continued)

MARTINE SOLAGES, M.D., Medical Officer, Division of Psychiatry, Center for Drug Evaluation and Research, U.S. Food and Drug Administration

HARI SRINIVASAN, University of California, Berkeley

JULIE LOUNDS TAYLOR, Ph.D., Vanderbilt University

ANNA E. TSCHIFFELY, Ph.D., U.S. Department of Defense (DoD)

PAUL WANG, M.D., Simons Foundation

STEPHEN WHITLOW, J.D. Merakey

TARYN MACKENZIE WILLIAMS, M.A., U.S. Department of Labor

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PROCEEDINGS

DR. SUSAN DANIELS: Hi Good afternoon, everyone. Welcome to this meeting of the Interagency Autism Coordinating Committee Strategic Plan working group. And we're welcoming you back for a second day of this meeting. Welcome to our online audience who may be viewing through NIH videocast. And to members of the committee and alternates who are serving with the committee today. We went through a list of people who were present yesterday. We're not going to do that again today. But the slides that will be posted that will show that and you will see people as they come in and out as they comment on various discussion topics today.

So, in terms of the housekeeping items, again, as a reminder, in case there's anybody here who wasn't here yesterday. We will have a person who is designated from our office, Steven Isaacson, who will be able to read comments for anybody who wants to submit their comments in writing. And he has his name labeled as send comments here in the Zoom chat, so that you can send your comments to him, and he'll be happy to read them. And everyone, you can keep your camera's off unless you're speaking. And if you want to speak and you don't want to turn your camera on, that's fine, too. We don't want anybody to get camera fatigue. And we will be going through today's meeting agenda.

I published a new meeting agenda that is online on the IACC website to adjust for some things that we changed as of the meeting yesterday. So, wanted to make sure that is all worked out. And I worked in just one break for today. Because yesterday, it seemed like one break was enough. So, if you want to follow along with the agenda, check the link on the IACC website for this meeting. But again, I'll go over a recap of yesterday's meeting.

So, we had a great meeting yesterday, lots of wonderful feedback shared by our members about different sections of the strategic plan. So, we went over questions 1, 2, 3, and 4 of the IACC strategic plan and out of the seven question areas. Plus, there are some other areas we're going to talk about today. We discussed the purpose of the IACC strategic plan. We reviewed the process and the timeline. And we did collect that feedback from you all, which was so helpful. So, today, what has changed on the agenda is we're going to go through questions 5, 6, and 7. And then with the cross-cutting objectives, sex, gender and disparities, we've added more time to be able to talk about those in a little more detail. And we have COVID-19, and then we will close out today's meeting. So, with that, I'm ready to jump right into question 5, unless there are any questions from the committee.

All right, so we're going to start with question 5, which is on Services and Supports. So, the proposed question 5 text is, “What Services and Supports Are Needed to Maximize Health and Well-Being?” And we change that over from quality of life, because we heard yesterday that that would maybe be a better way to word that. And so, that is how we have it now. But you'll also have an opportunity on the survey after the meeting, if you have any other suggestions about the wording of the question. But we're trying to keep them short and readable.

So, the topics that are included in this question include education, health care, child safety, including issues like wandering. And we can also add something about water safety, as I know, that's an issue Congress is interested in. And I know Scott Robertson and some others on the committee have mentioned this before as well. Systems navigation, ensuring individualization, choice, person centered planning and self-direction. Caregiver and family supports, outcomes, quality of services and service's needs. The training and development of the services workforce, and coordination of services. So, that's a general overview of what's in question 5. And so, I'm going to ask the same discussion questions I've been using throughout this meeting -- throughout the meeting yesterday, and we'll use them today. Are there any other important topics or points that we need to include in question 5? And have there been any significant recent changes in whether it's in policy, in research or services that could impact the direction that we want the strategic plan to take in this area? So, I have a question or a comment from Ivanova Smith.

MS. IVANOVA SMITH: Hello, this is Ivanova Smith. My comment is I think we could add transition to adulthood. Because that definitely supports the services that are needed to transition to adulthood and helping a person be supported and doing adult activities. Thank you.

DR. DANIELS: Thank you, Ivanova. So, transition to adulthood is actually the first item in question 6, which is all about adulthood and serving. That's not a problem at all. So, yeah, so we will definitely cover that in question 6. Very important topic.

Julie Taylor.

DR. JULIE LOUNDS TAYLOR: You probably want to put that in, question 5, or a piece of that, I think sort of the continuity of services between sort of school-based services and adult services is a real challenge. And maybe that fits best in only question 6, but it kind of is almost a sub bullet in this coordination of services piece. To kind of work towards some sort of better continuity there than what we typically see.

DR. DANIELS: Okay. Thank you. Jalynn R. Prince, did you have a comment? I saw you turn on your camera.

MS. JALYNN R. PRINCE: Yes. There's something we hit on a little bit yesterday about the number of people that are being diagnosed as adults. And how do we put that in here and maybe in two places? Because the thing I keep hearing is, now that I have a diagnosis, and I know that I need some assistance. How do I get that if I've not been able to hold a job because of some of the things I've discovered about myself that has kept me from employment? How do I access those things, so I can be more productive? So, I can learn more about myself. And the term yesterday or talking about things yesterday about services for adults. Meanings or somebody being low support needs doesn't mean no support needs. And I think that's something that we need to take into consideration very seriously. And looking at what those services and supports are, whether it comes in number 5, or it comes in number 6, or both.

DR. DANIELS: Thank you. So, with adult services related to diagnosis and post diagnosis, we do have that in question 6. But something that you just mentioned about describing the range of what can be covered with high support needs versus low support needs, which none of this terminology is perfect. But we definitely recognized from previous discussions with the committee that intellectual disability language and communication disabilities are one form. But there are mental health, co-occurring conditions and other kinds of conditions and disabilities that can lead to having higher support needs. It's not just one specific definition. So, I think, question 5 might be a good place to describe that as a preamble to going into what the different supports are. So, we could try to do that.

MS. PRINCE: Thank you.

DR. DANIELS: Sam Crane.

MS. SAM CRANE: Hi, everyone. This is a sort of a -- it sounds like a minor point, but I just want to be careful on it a bit. Right now, we have on page four a statement that individuals with ASD are at increased risk for drowning and I checked the site for it. I'm not sure that it necessarily says what were -- that actually supports that statement. I'm not aware of any really, really good evidence. Given that drowning is, I believe, for some age groups, the number one cause of unintentional death in children overall. Frequently, if we see frequent drowning deaths in kids with ASD that's consistent with the fact that we see frequent drowning deaths in all children. So, I think that we could safely say that there is concern that drowning is a common cause of death in kids who wander but not necessarily that it's unusually common for kids with ASD.

In addition, I think I'm skeptical of citing DNA because I've had similar concerns about their research, which generally is very focused on reviewing news articles, and sort of anecdotal reports on safety issues that haven't -- aren't what I would consider particularly epidemiologically sound. I think it actually highlights a really pressing need for rigorous epidemiological research on accidental and drowning deaths in kids with ASD because we really just don't actually have very good research on that at all.

DR. DANIELS: Thank you. I don't know if we have anyone from Department of Justice on the call today. Do we have anybody from DOJ? I know in speaking with DOJ that there's a high proportion of wandering cases that end in accidental death or drowning. And that might be part of what the water safety concern is. But we can look at references. I know that DOJ has a report, but I don't know if it's a public report about that. But I can check in with our contacts there.

MS. CRANE: Yeah, I think it would be safe to say that of wandering deaths. Drowning is a very common one, I think that would be a very safe thing to say. I just don't know if there's necessarily evidence that kids with ASD, compared with kids who don't have ASD are more likely to die by drowning. Because it's such a incredibly -- like I said, I can go on about this. But drowning is just a really, really common cause of death in children across the country. So, I think that's one of my concerns. And I think that it's important that we do some really good research on -- that actually compares apples for apples. Kids with ASD versus kids without ASD because I haven't seen a very good comparison.

DR. DANIELS: Yeah. And the data that DOJ has perhaps I don't know if they're going -- if they have anything that they will be publishing formally or if they can cite any actual data. I know that they do have some because they've shown it to me. So, we can look into that further but appreciate that comment. Scott, do you have some additional comments?

DR. SCOTT MICHAEL ROBERTSON: Yeah, thanks, Susan. So, I concur that for that area as far as water safety and some other areas that it's helpful to have higher quality evidence and statistical significance on these things. Because sometimes assertions are made in somebody's areas related autism based on smaller sample sizes or evidence that may not be generalizable. And it's good to have scrutiny in terms of think really critically about what the evidence is presented by either journal articles or reports out in that space. I just want to add on the water safety before I just had a few other ones just to mention briefly. The water safety is equal access to swimming skills too, is something that is completely under studied in resources as far as supports and services. I grew up on a lake, my parents still own it. So, I learned swimming skills, relatively young and used to sometimes go to the ocean, etcetera for an undersea shore, but a lot of other folks who are autistic lack full access to equal access to instruction in swimming skills, water safety, etcetera. Which I think parallel some other diverse underrepresented population groups where there's marginalization, including, for instance, Black Americans have historically been very marginalized in terms of full equal access to swimming safety and equal access to pools etcetera, over time in along with other areas in terms of discrimination that has happened historically here in the United States. And I think it's something that if we're going to have water safety in here that the swimming instruction is really helpful to have. I have a few other things that I wanted to add on here, the transportation section should have a little bit more on travel training for children and youth who are autistic.

As far as learning to use transportation systems and the barriers folks have as far as in adolescence on learning to obtain a driver's license and barriers, they're in and how to access public transportation. There's some studies I can send you that you could site quickly in there and easily. And including also report from New Jersey that's very extensive on this space. That was published out Rutgers University. I feel like I should cover a transportation especially since the DOT does not happen to be on this committee. And because that's a major focus as far as here in this space. And then just a couple of other things that I wanted to call out was the housing area on here does not mention the high rate of homelessness, this been found by research out in the United Kingdom, and across like Europe. But we need more research on that homelessness focus here, in the United States. It's a major gap as far as that housing and it seems like there's a really high rate of homelessness among autistic people. But we need a lot more research in that space on housing, access and various folks experience and how that relates back to quality of life. And then just a couple other things that I wanted to highlight were the education system.

That full continuum of access for education that helps folks develop their skills and talents through education in K to 12. And then the cross connection on that for transitioning over to higher education, and post-secondary education and training. That a lot of folks don't have equal access, including, especially autistic people, other folks with disabilities to education across the board, as they're growing up. And fitting us having receiving accommodation supports they need to be successful in school. Again, in K to 12 and beyond and having full transition supports that are consistently able to empower folks to have equal access to education. And the other element that I wanted to touch upon was including here in the education system, the workplace, Workforce Training and other areas. That there should be partnerships of autistic people on educating service providers about autism, the lived experience, how to empower folks, best practices, promising practices. I think it should be weaved into here throughout this action and other aspects of the strategic plan is that partnership, collaboration with autistic people.

It's very under emphasizing research and practice. And this fits into the other areas we touched upon, for instance, yesterday, like peer supports, where that collaboration with autistic people is immensely important and having training for autistic people to help empower for autistic people and families. And to access supports and services in that systems navigation piece that was also mentioned yesterday as far as access to supports and services.

DR. DANIELS: Thank you so much, Scott, for those comments. And we will take those down. On homelessness, we did talk about homelessness at our last IACC meeting. And that is indeed on the federal agenda. And we will want to make mention of that in the strategic plan. So, appreciate hearing about that. I saw that Alycia Halladay, you had a reference to share? Do you mind just hopping on and mentioning what that is?

DR. ALYCIA HALLADAY: Oh, hi, everybody. I so sorry. I sent it to Susan for a point of clarification. But in fact, there are a number of epidemiological studies using different designs that show that drowning is at an increased risk for kids. And I mean, the study was in children, but are the studies have been in children's but there is evidence to say that drowning is one of the leading cause of death. Some studies are showing that epilepsy has a higher mortality rate than drowning. But I think that there is scientific evidence for us to be very, very concerned about drowning. And I won't pretend to know what in fact, the solution should be, whether it's swimming lessons, whether its kids wearing these water, these things that tell whether they're in contact with water, there's some of these water bracelets. I think mechanisms to alleviate wandering or a high, high priority, but I wanted to send some of that evidence to Susan just for her information.

DR. DANIELS: I appreciate that. And Alycia, if you wouldn't mind sending it to IACC team to make sure it doesn't get lost from the chat here. I'd love to have those references.

DR. HALLADAY: Okay. Should I email them or send them to -- okay, okay.

DR. DANIELS: Yeah, if you could just email them that would be great. Or if you put them in the chat to everybody, then our team can just grab them off the chat.

DR. HALLADAY: I'll just email them to save time.

DR. DANIELS: All right, thank you. All right. I'm going to go to Steven for written comment.

MR. STEVEN ISAACSON: Good afternoon, everyone. Nicole Williams sent me a comment asking, "Do we need to specifically mention the training of first responders when we speak about training and development on the second to last bullet?"

DR. DANIELS: That is a great comment. We can certainly make sure that we pull out training of first responders there is something more about that in question 6. Especially with regard to state law enforcement but I think that would be appropriate to put in here too.

DR. NICOLE WILLIAMS Thanks, Susan. Yeah, I just wasn't sure. Especially if the DOJ is not here. I didn't know whether would fit with question 5 or 6. So, I just thought I'd bring it up now.

DR. DANIELS: I appreciate that. Thank you to you and Scott both for trying to step in for agencies that might not be represented here today. And transportation is on the federal interagency workgroup for autism, but they're not on the committee. So, thanks, Scott, for representing them. Ivanova Smith, do you have another comment?

MS. SMITH: Hello, this is Ivanova Smith, I just want to comment about wandering. I think it's really important that autistic children get support in their exploration. And is there a way that we could have partners with the service providers, we have partnerships with, like hiking groups, and different group that allows people to go long walks. And helping providers support autistic people in exploring the environment. And I also really want to emphasize the importance in swimming lessons. It's really important that autistic people practice swimming. And because we need to get the practice with our fine motor skills, and we may have struggles with motor planning and things like that. And so, so try to get swimming lessons as soon as possible. And it should probably be part of the early intervention strategies. If they could show that autistic children or any children that needs extra support, get swimming lessons, as part of the early intervention programs.

DR. DANIELS: Thank you. And yes, and we also can be thinking about physical activity as a health promotion activity as well. And not just the safety side. So, that's another thing that we can probably put in. Dena?

MS. DENA GASSNER: Good afternoon, everybody. I just, I apologize for jumping on late. And if these things have been addressed, just dismiss it. But in terms of health care, and I don't know, maybe under mental health, there's a slide somewhere else. But suicide prevention services, accommodated suicide prevention services are not noted here. Also, workforce training on health care delivery, is really important, from the ER system to any other medical system we have to navigate.

In terms of supports and services, the barriers we face in navigating Social Security are significant. I mean, individuals on SSI, are making far below the federal poverty level. And housing in New York is average, this was in the New York Times at $5,000 a month now in New York City. And a lot of people who are disabled in New York try to live in the city because of the access to transportation. But clearly things are not equitable in terms of that need for a living wage. We have issues with the marriage penalty, limiting the amount of money a couple can have.

So, I mean, I think people having something that looks closer to a living wage is critical, because poverty is another form of trauma, right? And we just talked about people who are without housing. So, it's not just limited to that people who are trying to live on $800 a month and then the penalties for inadvertently overstepping in those systems are really abusive. And I also don't see anything here that offers an option for adults other than employment. We have this mystical thinking that if someone has a job, that that will solve all the issues and we see the rates of unemployment in our population. And while again, part of that is because of service deficits. Part of it is due to workplace discrimination. Part of it is that not all autistic people can work full time and not having something in between. Something where people can go to quality, recreational programs or day programs, or volunteerism, with support to still have a full and enriching life is really a huge gap in terms of service delivery.

So, I just wanted to add those things there. Okay, I'm going to wait for disparities later. Thanks.

DR. DANIELS: Okay, thanks. Yeah, since some of those issues are in questions 6. I know, it's a little confusing for the way the plan historically was set up. There was a question 5 first, and then question 6 came a year later, because they wanted to pull out more about adulthood. And we've kept that structure over the years. So, some of these issues are in question 6. These are helpful comments. So, I appreciate that.

MS. GASSNER: Thank you.

DR. DANIELS: Thank you, Dena. Sam.

MS. CRANE: Yeah, it's just a very short comment, but I was really liked Ivanova's recommendation about outdoor programs. And it reminded me of non-autism specific research showing that when children have, I believe the term that they often use is risky. No risky activities versus dangerous activities, riskier playgrounds, riskier activities, where kids can sort of safely explore the boundary between safety and risk. They are actually far less likely to die from accidental injury. So, I think that that would be a really fruitful area to explore, is the extent to which that principle plays out among autistic children. Many of whom I think people might undervalue risky activities, thinking like, oh, autistic children are so much higher risk of accidental death. Might paradoxically exacerbate that risk to not offer safe opportunities to engage in risk.

DR. DANIELS: Thank you, Sam. I know I've read that research too. It wasn't autism specific. But that's a that's a good point. Thank you for raising that. Scott Robertson.

DR. ROBERTSON: Yep. Thanks, Susan. I wanted to concur with what Sam just shared as far as the dignity of risk principle, and equal access for autistic people to have that parallel that non-autistic people have as far as being able to pursue opportunities of life that fit folks, interests and strengths. And that may have some slight challenge at times, because sometimes folks are so over protected because of beliefs about their -- and this is not just specific to autism. This is a challenge that we've seen historically, for instance, in development disabilities more broadly, and some other types of significant disabilities.

But I definitely concur that folks should be able to have different opportunities to experience different elements in life and not be segregated or separated away from opportunities to pursue in childhood, and adolescence and adult life. That means that folks should also have the supports and accommodations they need to mitigate difficulties and challenges as they occur. So, I think there's that balance point kind of on that. And that's what the dignity of risk philosophy and the development disability community and self-determination for folks who are with disabilities. In terms of children, adolescents and adults is so important. And I also wanted to concur with emphasizing more here in the chapter on the community living aspect for children, adolescents and adults. Again, folks are sometimes separated away from having that full access, equal access to community living across many different activities, not just a school, not just healthcare, but all the other activities, leisure activities, recreation, that non-autistic people experience. We do have a dearth of research on that and a dearth in some cases of promising and best practices. And policy is on this as far as the subject area as far as the huge area of community living, and the equal access for autistic people throughout all these different areas. Including, as I say, leisure and recreation, and independent living skill development for folks and community living skill development in childhood and adolescent and an adult life.

That non-autistic people are developing these skills. And so,metimes folks, again, because of beliefs about autism or beliefs about capability, or other concerns may not be receiving the supports and services they need. And the ability to pursue opportunities and have that full access to community life that they want and fits their interests and skills. And helps them also with pursuing opportunities as they grow older and age again into adolescence and adult life and later adult life. So, I don't know maybe ACL is on here if they wanted to speak more on that community living element.

DR. DANIELS: Thank you, Scott, for those comments. Do we have any additional comments about education like anything that is an important need? Maybe that might have emerged in the last few years. I know that with COVID, of course, there's something in the COVID section that is about some educational issues that were raised during the pandemic. But Dena, you have a comment?

MS. GASSNER: Just the inadequacy of the transitional support services continues to plague our population. A lack of meaningful post-secondary programs. They either want the twice exceptional, gifted and talented, formally AS profile students, or they have special programs for people with intellectual disabilities. Both which are doing wonderful things. But there's a huge array of people who need much more intensive support but are capable of academics services. And there are very few programs that do that. Also, the inordinately high workload for disability support personnel at all university settings, but particularly at community colleges. Many parents send their kids to community college to keep them close to home, not realizing how many kids with IEPs or students who needed IEPs that never received them are part of that community college profile, and the caseload there are astronomical.

So, I think anything we can mention about the needs for lower ratios for those disability support people would be really helpful.

DR. DANIELS: Thank you, Dena. Mitchell, on behalf of SamHSA. Do you have any comments, or you have some comments, I see that your hand is raised.

DR. MITCHELL BERGER: Yes, I was just going to suggest that in addition to public schools and private schools, charter schools and homeschools be touched on. I'm looking at the NCES statistics report from 2019. And it looks like traditional public schools have about 47 million students, but charter schools now have 3 million. Home schools or 1.7 million, and private schools are about 5.8 million. So, that's still a potentially substantial number of those with ASD who are being educated in non-public school settings that may have challenges that might be worth discussing, if possible.

DR. DANIELS: Do we have anybody from Department of Ed on today? I don't think so. What are the particular issues that relate to private schools, charter schools and homeschools that we would want to mention in the plan? I am not 100 percent aware of what is needed there.

DR. BERGER: I'd might just mentioned that those are -- if there wasn't a lot of research, just if those are settings where maybe some people with ASD are receiving their education. I'm not I'm not an expert on that topic, either. I would defer to others. But I just thought because there was this discussion of public schools. And without getting into too much of some of the politics and stuff, just it might be good to have discussion on the other options, too, if there's research on it.

DR. DANIELS: Okay, thank you. I can always check in with Department of Education too about that. Thank you. Paul.

DR. PAUL WANG: Yes, a small comment was I'm just thinking it might be worth touching on. AAC, Augmentative and Alternative Communication modalities in this section. If it doesn't already touch on that. Other people on the committee will have thought much more deeply about this. If I recall, also, one or two committee meetings go I think we received a number of public comments about AAC. And I think it's important that these kinds of modalities be made available, are accepted. That the support for sometimes expensive equipment is available.

DR. DANIELS: Right, thank you. Yes, and we touched on like development of AAC in the intervention section, but deployment and having adequate training for people to be able to use ACC, getting access to things can be a part of chapter 5. So, thank you for that. Dena, do you have another comment?

MS. GASSNER: Yeah. I don't know if it appears somewhere else. But reproductive health care. I know we have like LGBTQ stuff coming up in terms of disparities, but reproductive health care, and particularly health care that specializes in treatment for sexual assault. I think there's a huge void there. And given the high frequency of sexual abuse in our community, having people that are highly qualified to address those things for this population is really important.

DR. DANIELS: Thank you. I think that there are probably maybe more than one place that we could fit something in about that. And that has come to my attention to in, especially with regard to say online victimization. That there's a need for professionals who understand how to work with people on the autism spectrum to help them through situations where they may have been victimized in various ways. Scott, do you have another comment?

DR. ROBERTSON: Yeah, first, I wanted to concur with the mention of AAC, that I think there's a place for that in here on service supports to for Augmented Alternative Communication, as well as access to for instance, supports like captioning that can be helpful for folks is complementing processing of information. And when you may experience auditory processing issues. There's almost no research at all, on captioning access by autistic children, adolescents and adults and the AAC use as far as supporting good access to tools and technologies. And, frankly, part time AAC use too That AAC use would be of benefit, I think, to millions more autistic people in United States, worldwide. Sometimes even on an occasional basis, where I think folks don't understand that we have part time and full-time users. I use AAC sometimes myself and I think that we need more research on that. And we need to embed that more in practices and policies. That AAC, there's a spectrum of, if you will, of AAC tools and supports and access high tech and low tech. And that it can be of great benefit to many autistic people, including folks who are who otherwise are often speaking. Would find better access days again, training on AAC tools and technologies to be able to be and systems to help them and support better communication access and schoolwork, community living, healthcare. I also forgot to mention, and you don't have this in here. Probably partly because you may not be aware of the research that's being published right now recently, is we're starting to now have data on the services cliff, and I think it fits well into the educational system mentioned here.

For instance, in K to 12 is the services cliff is the drop off on access for autistic people as kids and adolescents to occupational therapy. And speech and language therapy and learning supports and other supports like that. There is a huge, huge drop off after primary school is that many of us and this was the case for me, I received occupational therapy as a kid in primary school from fifth grade all the way through -- sorry, from first grade, first grade all the way through fifth grade and did not receive it in middle school or high school and have not received it as an adult as well.

We don't have good training for OTs and speech and language therapists and other human services specialists on autism as much in terms of the emergence of what we've had in the research literature and keeping pace with that. And empowering folks for access to the best practices for supports and strategies. And making sure that it's being funded.

I think is really important and the service systems are prioritizing that because I think the specialist SLPs and speech and language pathologist. And occupational therapy practitioners and other, social workers, other human services specialists should be supporting autistic people, throughout K to 12 and beyond. And that should be part of folk's IEPs and Rehab Act 504 plans. And it's just not happening. Because we see that drop off in the numbers. And I believe that the article has been just recently published. I'll see if I can get you the articles that actually show the data on the cliff in terms of showing how much the numbers decrease substantially by the time you get to secondary school. And then when you hit adult life, the access to OT and speech and language therapy is almost non-existent at that point. So, it's something that really needs to be addressed and would make a huge difference, I think in quality of life and health and wellness for folks. And it is supported by insurance as well.

But often, there's a dearth of service providers at times for outside private access to occupational therapy and speech and language therapy. And some metro areas may in the end, rural and suburban areas may not have good access to providers. I know for instance here in the D.C. metro area, there's only like I think like four or five OTs, for instance, to take my health insurance. And most of them and I know some of this may end up fitting into question 6 instead of 5. But some of them don't specialize in cognitive disabilities and executive functioning and only do more motor things and may not be able to help with sensory and executive function and communication and independent living kind of aspects that OTs really should be able to help out with, as the field. And then for instance, SLPs is with communication access, including AAC use. There's a lot of OTs that are really extensively trained in AAC use and should be supporting empowerment and access AAC use for autistic people from different backgrounds across the lifespan, including childhood.

DR. DANIELS: That would be great if you want to send that reference. I know that the services cliff was a topic of a Drexel autism indicators report a few years ago that was quite significant and brought that to a lot of people's attention. But it would be great to hear the latest on this. So, that would be very helpful. Thank you. JULIE, do you have some comments?

DR. TAYLOR: Just a quick comment to piggyback on what Scott was just saying. I'll send you a paper that came out last year that shows that the service clip looks pretty different for autistic people who do and do not have an intellectual disability actually. And for people who do have an intellectual disability, it looks sort of like the service cliff that we tend to think of with the big drop off. But when people don't have an intellectual disability, we think of it as kind of like a service slope, where they start losing access to services year by year while they're in high school. And then that drop off doesn't look as distinct when they leave high school because they've already lost quite a few of the services that they had been getting earlier. So, I don't know how that factors into this. But Scott's experienced and what he's seen as similar to what we've seen, as well. I'd be happy to send that along.

DR. DANIELS: Great, that would be really helpful. Thanks, Julie. Ivanova.

MS. SMITH: Hello, this is Ivan Nova. And

I just wanted to check the dentistry under healthcare systems because there's a lot of autistic people that don't have access to dentistry and good dental care. And that that does affect all health. I just want make sure that's being looked at under the health care systems, thank you.

DR. DANIELS: Thank you actually, in the IACC, we included dental health in one of the objectives of an early strategic plan. Thanks to one of our members who was a champion of that. And actually, there are programs now to train dentists and how to help people on the autism spectrum. I think the IACC deserves some credit for having helped with that, but it's certainly good to mention in the context of health care. So, thank you, Dena.

MS. GASSNER: To piggyback on what Ivanova just said, I'd like to point out that even where there is dental care, it usually doesn't include cosmetic dentistry. And for people who are already struggling with social engagement, just keeping teeth healthy, may not be sufficient. My son's missing 13 permanent teeth and if we had not been able to afford cosmetic dentistry for him, he would have looked very, I don't know. People treat people with bad dentistry inhumanely. And it's a very huge social thing. I did also want to, what was the other thing I wanted to bring up? I wanted to also talk about in the education system, and this may belong somewhere else. I was shocked to find out that under 504 plans, they don't necessarily acknowledge the diagnosis. So, when you're doing a school-based count, for the number of students who have educational plans for autism. It will usually only include kids with IEPs. And that means we're missing a huge number of people. And not too much of a fine point on what Julie Scott have already said. But, you know, people who have intellectual disabilities usually have incorporated into their school days very specific times to acquire those independent living skills. They actually have higher rates of at least part time employment than people without intellectual disability. Because people without ID are in academics all day long, and they get no opportunity to learn any independent living skills. We've even gotten rid of home economics.

So, there's really like no place for it to happen. So, if I were the queen of everything, they would have longer school lifetime, they would be in until 21. And half of the day would be spent on work skills and independent living skills. But that's not how things are structured. That's not what the unions will allow. But that's just a huge gap. That's part of why we see so many kids not make it past their freshman year, even in a part time post-secondary program, because they don't have the skills to function without prompting, constant prompting. So, I just wanted to add that to the list.

DR. DANIELS: Thank you. Thank you for bringing that up. And I'm going to make a smooth transition into question 6, as we've already been talking about some things that are covered in question 6.

So, question 6 is the lifespan issues question. And the way the question is worded currently is, “How Can We Meet the Needs of People on the Autism Spectrum Throughout the Lifespan?” And the topics that are in this question our transition to adulthood, adult services and supports, including post-secondary education, employment, housing, transportation and other services. Adult diagnosis, adult health and well-being, service delivery for adults, community integration, services and supports for adults with high support needs. Older adulthood in autism, justice, safety, emergency preparedness and premature mortality and inclusion of lived experiences in research services and policy. So, those are some of the topics that are included in this question. But like all the others, are there other topics that we want to include here, anything that you want to highlight, under some of the topics I've just mentioned, or have the there have been some recent significant changes in the field, that should be reflected in the strategic plan in terms of shaping our direction? So, I will go to Ivanova Smith.

MS. SMITH: I think it would be good to have autistic parenting supporting parents that are autistic parents, or supportive family autistic families. Like if the father is autistic, and then the kids autistic but maybe the mom isn't. Or like that kind of situation where like, it's a mostly autistic family and supporting those families.

DR. DANIELS: Thank you. Yeah. So, we do have something about caregiving in question 5. But the thought about parents that may be on the spectrum or have other kinds of challenges is not specifically mentioned right now. So, that could be added into that. We'll go to Jennifer Johnson next.

And, Jennifer, it looks like you're unmuted, but I don't know if you might be having some sort of computer issue.

Why don't I come back to you. And if you need help, you can text our team and people can try to help you out. Alycia.

DR. HALLADAY: Sorry, I didn't know I was next. So, I would like to highlight something that I think we mentioned on section three, but I have a question for you. But I think it belongs in both places. And I'm flexible in how it gets included is that we need to continue to support and develop and to refine longitudinal studies.

So, these are studies that can start anytime in a person's life but follows them across time. So, you take that same person, and you're following them across time until way into adulthood. And I think some of these studies have been very fruitful and not just looking at cross sectional analyses, but actually these prospective longitudinal analyses. The problem I want them and the reason I want them mentioned in those places is because traditional funding models don't necessarily accommodate them. Traditional NIH and other mechanisms are from four to five years, even ASF only funds for a couple of years. And so, they don't really fit into traditional models. And so, I think we need to ensure that these studies continue to get supported. And I know that there's a number of different ways that they can.

For example, the SEED Study is funded in increments, but they just got funded for their next set of incremental studies for the next four years to follow those kids in the first couple of SEED phases up. So, that's one particular example but I just want to put a plug in for the importance of longitudinal assessment.

DR. DANIELS: Thank you. And I believe that we do have something in question 6 about longitudinal studies in adults and cohorts that go into adulthood. But I don't think there's a problem with mentioning it in more than one place. And I don't know if Elaine may have a follow up to that. Do you want to go ahead Elaine?

I think Elaine's hand disappeared, so maybe she might be having some problems too. So, next, I'll go to Jalynn Prince.

Now, Jalynn has disappeared. So, Steven, do you have some comments in writing?

MR. ISAACSON: Hi, there. This is Steven, I'll be addressing a question from Lindsey Nebeker. Question is under which question; would we be addressing services and supports for adults who are veterans or serving in the military?

DR. DANIELS: They could be addressed in this question that's on adulthood. Are there specific issues related to being in the military that you're concerned about? So, maybe Lindsey might have to come back with further clarification about that.

MS. LINDSEY NEBEKER: This is Lindsey, I'll just pop in. The only thing -- the reason I was asking this question is that I was trying to read through, and I was trying to locate any references to it. And I may have missed it if there was mention of it in the documents. But--

DR. DANIELS: No, the VA is a member of the committee. But we don't really have a lot of information about veterans. One of the issues is I think that sometimes -- they do have veterans who are getting diagnosed. But if you're active duty, there can be problems with mentioning that you may be on the spectrum or even getting evaluated as far as I understand. But some people who are veterans do go on to get diagnoses. So, we could get some information from the VA about that. But it sounded -- the last time I talked with them; it sounded like it wasn't very documented. So, we could see if there's anything more that they might have to add. Is that what you're talking about?

MS. NEBEKER: Yeah, I think I was more concerned or wanting to focus on because of the complexity of the services and supports that veterans and people in the military already have. Combine that with if they happen to be autistic. And just recognizing and acknowledging the complexity of the services and supports that would need to address both things.

DR. DANIELS: So, we can check in with the VA about that, and see if they have anything that they would want us to mention in the plan. So, I'll go back to Elaine, to see if you might be able to give your comment.

DR. ELAINE COHEN HUBAL: I don't know why everything froze up. Following up from yesterday, on oversampling. So, this is on this topic of longitudinal studies. So, not just individual, not just studies focused specifically on autism. But the federal government is doing, we should really be advocating for oversampling of this population. And the thing that actually was just going to call the other day. And there's maybe somebody on the call, who knows more about this, but Bureau of Labor Statistics is very specifically in the process of planning, a longitudinal study that covers specifically this transition period from into adulthood. And so, it just seems to me that this is like a perfect time to get in and there probably other things. And so, if anybody knows more about that, or I can send the contact of the people that were looking for input on that study.

DR. DANIELS: Oh, thanks. Is that something that's a part of Department of Labor?

DR. HUBAL: I know nothing about it. It's Bureau of Labor Statistics. Scott, do you know?

DR. ROBERTSON: So, I'll have to cross check on that. I know, we are running a research project at OARC on autistic youth and young adults. It's a three-year research project on access to employment. We've been running listening sessions, etcetera. But I hadn't heard anything about our sister agency, BLS running something, but I can check with our counterparts there after this session to cross connect and ask about that.

DR. DANIELS: I'll just go ahead and email the contacts I have.

DR. ROBERTSON: Yeah, if you could, if you heard that from BLS, if you could email to us too, including myself too, let me know about that. So, I can talk to them and get on the same page. Because I'd be definitely of interest in that focal point.

DR. HUBAL: It seems like a good window. Okay. Thank you.

DR. DANIELS: Thank you. And Jennifer Johnson, did you ever get your system working? Because I know I skipped over you because you were having some kind of difficulties?

DR. JENNIFER JOHNSON: Can you hear me now?

DR. DANIELS: Yes, I can hear you.

DR. JOHNSON: All right, great. I just had a couple of things some of which may overlap with question 5. But I think one important policy, I guess development we could call it is that the HCBS Settings Rule will be the state transition plans. We'll be completing their process by next year. And so, I just looking at the plan and what they are related to the Settings Rule and where it might need to be updated, given where things are with that will be important. And then another thing that I think was the development. Since the last time the strategic plan was updated was the release of the OIG report on Critical Incident Monitoring systems. And big gaps in those monitoring systems.

So, I think generally just health monitoring for health and safety in home and community-based services, is another important area that we want to make sure is incorporated into the plan. And then the last is just on a related note to that. We don't have a really good system for tracking, abuse and neglect and victimization of individuals with disabilities generally, but autistic people specifically.

And so, I don't know if there's anything in the plan right now around that. We do support what is called the National Adult Maltreatment Reporting system. So, this is a system that Adult Protective Service Providers will use, or agencies will use to track allegations of abuse or neglect. So, that's maybe something to highlight in the plan. And of course, DOJ does have the work that it's doing related to this. Individuals with disabilities and crime and be victims of crime. So, I just again, want to make sure that that kind of issue is incorporated into the plan.

DR. DANIELS: Okay, thank you. And we can also talk with DOJ about anything they might know about that as well.

DR. DANIELS: Okay, next, we'll take a comment from Joe Piven.

DR. JOSPH PIVEN: Great, thanks. Can you hear me okay, Susan? Okay, good. Well, I think you're aware, other people are aware that I've had sort of an academic research interest in older age. This is a bullet point in this whole section on lifespan. But I think it requires a lot more.

I think that just as an example, Autism Speak, just voted two days to starting to try and understand the breadth and depth of this area. And I'm a little worried that it's kind of beyond the scope of the conversation that we're having this afternoon, to just throw out a few ideas for a strategic plan. When there are in other fields, whether it's psychiatry or medicine, there are a whole textbooks written about older age. And I think maybe you heard me say, a few weeks ago, on the Autism Speaks workshop.

I, for one, think we have almost no knowledge base about this whole area. And I don't know that we can just extrapolate from what we know, is a disorder that's mostly been viewed as a disorder of childhood into older age. So, I think that this just requires a lot more thought. And I don't know what you're thinking about in this regard. I know we've kicked around some ideas about bringing a session into this meeting. But I'm just wondering about a separate working group or something that would give this a little bit more attention. I mean, granted, I'm biased about this. I have spent some time thinking about this maybe more than other people. But I don't think people quite appreciate how much is there that we're not thinking about. I was thinking about.

DR. DANIELS: Thank you, Joe. So, we were intentional about trying to create something mentioning older adulthood in autism in the plan. And the plan is a guiding document, it's not going to be a full literature review on any one topic. It's already with, as you've all seen, how many different topics we're trying to cover. The plan will probably end up being about 100 pages or so it's going to be a big document, but it'll have a little bit about a lot of things. And so, it will have a little bit about older adulthood, it won't necessarily be the textbook on older adulthood. But we certainly can fit in a few paragraphs about it if we have some good information. And it's really meant to be a guide to the agencies about, hey, this is an important issue.

We would like to see more action in this area and giving them some thoughts about what kinds of things people think are important priorities and not getting into minutiae and little details. That those agencies that give out funding or that are providing programs for people will probably lift something from whatever language we put there and be able to shape it their own way, using consultations with experts in those fields.

So, we don't have to feel like we need to be comprehensive. But we do want to mention every important topic, and I agree that older adulthood and autism is important, and we definitely want to include it in the plan. So, thank you. I will go to Alisha Halladay next.

DR. HALLADAY: Sorry to ask a quick

question. Lifespan is really from birth to death. But we really seem to be talking about issues that and as we should I'm just outwardly questioning the title of this particular chapter or question. We're really talking about anything between things that we need to prepare children and young adults for but we're really talking about things may start at adolescence to adulthood. So, should we keep it as lifespan? To me that seems that it's too broad, whereas I'm just thinking that it may not accurately represent the lifespan. And that kind of occurred to me when we talked about longitudinal studies and how they should be focused on adults.

MS. GASSNER: Just jumping in, I think that Drexel, and a couple of other transition groups have used life course. I don't know if that's helpful or not.

DR. HALLADAY: Yeah, I can't really speak to how other people use it. I just wanted us to think about whether or not we're really talking about the lifespan in this particular chapter.

DR. DANIELS: So, some of that is historical. And we have question 5, as I said, it was there before question 6 came along, because the committee in 2010, decided they really wanted to focus on adulthood. And we started with adulthood with transition and younger adulthood, early adulthood. And that whole area has expanded a lot over the last more than a decade. And so, there's more to talk about now than there was back in 2010. But some of the childhood issues are in question 5, more like early education and issues like that. And so, that's a historical distinction. These chapters are not perfect. However, we're trying to keep some of it the same, because we've been tracking data on research since 2008. And if we start mixing things around, then we won't be able to keep tracking. So, that's the purpose of keeping them in their bins, so that we--

DR. HALLADAY: That's good enough for me. No, that's good enough for me.

DR. DANIELS: I know that for people like you do want to know how things have changed since 2008. And so, are our offices keeping track of that, but if we start kind of messing around with the definitions too much, then those data will no longer be meaningful. So, that's the reason, it's not perfect.

I know we're trying to be super accurate and representative about each particular question titles so that's where I'm coming from. However, I completely agree with you. If it's for the purposes of tracking and making sure we look at things across the lifespan, so to speak of the IACC, then that's completely rational.

Yeah, we might be able to address some of that in just how we talk about it. But I agree it's a little bit it, might be slightly confusing.

Next. Let's see, we've got about five minutes left. I think we can get through for more questions, and then we will take a break. So, Dena.

MS. GASSNER: Just real quickly, I just wanted to say that there are -- like I'm in the state of New York. And if you don't have a diagnosis before the age of 18, in the state of New York. You experience huge administrative burden in trying to prove that you are autistic before the age of 18. And for many of us there, there was no diagnosis available, when we were that age. There is very little in regard to record keeping about those things. And that means an entire segment of our population is denied access to services. And in order to get those services and to create that case file to prove evidence of need. You have to basically be non-autistic, like you have to have huge executive function, you have to be able to track down records. It's an undue burden. And I would project that we should assert that if a person successfully obtains a developmental assessment, which is another barrier in itself. But if they have one, they have confirmation of a diagnosis, they should be eligible for at least some basic services 10 hours a week to 10 hours a month. Like something should be available. I think eliminating people based on a lack of records or based on IQ alone, is just untenable.

DR. DANIELS: Thank you, Dena and that that is an important issue. It came up in the context of housing when we talked about homelessness, and it was brought to our attention when we discussed homelessness. That some individuals who are adults have difficulty connecting back to the service system if they didn't have the diagnosis previously, or they weren't connected to services. So, we will make sure that we say something about that in the plan.

MS. GASSNER: Thank you.

DR. DANIELS: We'll take a comment from Hari.

MR. ISAACSON: Either I received some comments from Hari, I don't know if Hari wants to speak, or I'll read the comments.

He says on aging, we don't have enough

information. But we can expect all the long-term effects of the psychotropic medications that many are on since childhood to address behaviors. These include liver issues, memory issues, movement issues, and compounding aging issues faced by the non-autistic population.

DR. DANIELS: Thank you, thank you for that Hari. And yes, there are a lot of different issues related to age, and we'll try to distill out some in the section that we'll have on older adulthood. But if you have other comments about it, you can feel free to send them. So, we'll take a couple more comments, and then I will give a last chance to anybody who has not spoken so far in the session. So, Scott.

DR. ROBERTSON: Yeah, thanks, Susan. So, firstly, the employment section could be bolstered as far as putting more in there on Access to Work Based Learning and internships, apprenticeships, etcetera. For supporting employment access and career pursuits. The word career should be in there for autistic adolescents in middle school, high school and autistic adults throughout the life course. So, like that should start and I don't know if some of that would fit into Q 5 versus Q 6. I know this stage together is that better access to work opportunities in high school has made the major difference.

What Drexel is finding in this research, that there's a huge disparity in folks who can access internships and other forms of work-based learning in youth and young adulthood that leads to better opportunities for employment across the lifespan. And so, you see that disparity for a lot of autistic people who have access to employment and some who don't. And I can send you the studies on that, that backup as far as the need for supporting better access for workplace learning, employment access. And frankly, more research on best practices that are evidence base that can help entire folks to access supports they need to thrive in gainful employment and career paths across adolescence and adult life. There have been some recent literature reviews that have been released in the last several years that are very disappointing that show that basically, the research literature needs to be expanded and enhanced significantly on employment for autistic people across the lifespan that we just don't have as much quality there, as we showed in the research. And it is not covering focuses like apprenticeships and internships and matching employment to fit folks' interests, skills and talents with targeted supports and services that can help address barriers and difficulties folks experience. As well as partnering with autistic people just like we see with community based participatory research and participatory action research in that space. I also wanted to mention just a couple of other things on some other topics that were mentioned as far as the parenting and veteran's issues.

I know that on the veterans and for context, is sort of like almost like a Don't Ask, Don't Tell type of a thing with lots of [inaudible] people that folks are afraid to talk about their autism because technically, there's a medical rollout in the handbook for the military, as far as serving an active duty is parallel to a lot of other disabilities have that complexity to all of that. Starting to potentially change over time, there's now been some discussions about having a better waiver process potentially, for some of the agencies in the Department of Defense for folks to who can serve who are able to serve and want to serve. And then you have some veterans who may or may not have known about their autism, or just didn't talk about it for these complexities. Who now are talking about their autism, you know, after they've left service in the military.

So, that I think that's something maybe they have in there. If only just briefly to mention that autistic people have served in our armed forces in America. And there are autistic people who are veterans, and they're autistic people who are veterans who've experienced trauma, and PTSD, etcetera. And then -- can someone go on mute if they're -- so and also the parenting aspect is far as I agree as far as parenting, marriage, like romantic relationships, like full access for folks and more research kind of in that space. This fits into what we have with this Q 6 area is that Peter Pan phenomenon honestly, with research on autism and practices, supports and policies.

We see such a drop off, because historically, people believe that I guess autistic people disappeared or something like that, after early childhood. And it's changed somewhat over time, it's gotten better in research practices and policy, but we have a ways to go in that space. And I think people don't realize that autistic people are parents, want to raise families and need supports and services to be able to do so and have equal access in that space. Equal access to marry etcetera and not be discriminated against. And that NCD report from 2012 was really helpful for framing that issue as far as cross disability and giving us a hint of what should be supported for autistic people. But we just we don't have research literature on that, probably because of biases. And people also just don't know that, like, it's important to address in terms of ensuring autistic people can have the supported needed to raise families as folks want to and be able to participate in relationships and social relationships. And it's part of quality of life and health and wellness is that humans are our social beings and autistic people often thrive just as much as non-autistic people. But may need supports and services that are tailored to be able to help folks access opportunities for social life, including, again, relationships, families, being able to participate as a parent. And be able to participate also, as uncles, aunts, etcetera in terms of immediate family, extended family, too. We have no research literature on that either as how autistic people in adult life, cross connect to their families overall and how it can enhance their social life with supports and the richness as far as quality of life.

DR. DANIELS: Thank you, Scott, for all those comments. Very helpful. And we'll take a comment from Ivanova Smith.

MS. SMITH: This is Ivanova Smith and my comments around that justice [inaudible] emergency preparedness and premature mortality. And what supports and research is helping autistic people who are struggling with the justice system and criminal justice system and making sure that they're getting a fair trial and that being supportive if they are having to be incarcerated. Thank you.

DR. DANIELS: Thank you very much, Ivanova, and I'll just give one last chance to anybody that has not had a chance to speak so far. If you have anything on Question 6.

DR. TAYLOR: Yes.

DR. DANIELS: So, for people who have not spoken so far, yes.

DR. TAYLOR: Yes

DR. DANIELS: Who's speaking?

DR. TAYLOR: Hi, can you hear me? Can you hear me now?

DR. DANIELS: I can hear you, I thought that you would give in comments already. But I'll go ahead and then we'll go to break.

DR. TAYLOR: I haven't done this section. In fact, I was trying to get in on the last section, I've had technical difficulties for the last half hour. There were several comments that I would like to make. I appreciate so very much Scott's insights into all of this and some of the other comments. And I do need to take a moment because this is our entire field. And we started in on this area 15 years ago. And so, many of the things that you are mentioning, have been ongoing, including the lack of research and trying to get data.

It's been challenging, and I think this would be something that others that are listening could relate to as well. It is hard for autism organizations to get and to get funding, because there's not the research to warrant getting in and getting grants. And I think that is hampering greatly. The things that are happening in the lifespan issues in 21 and over. And that is has been our target group from the onset. In fact, we were one of the first in the country to look at what we deem as lifespan. And we've looked at that, because lifespan after high school, that's when surfaces and that's the way we have looked at it. I think there are a number of points, I will consolidate because there were several comments here. And Scott, you happen to bring a lot of these things to the forefront. I think funding for research so we can get into these questions so we can get the support.

So, we can get additional information is kind of a cycle in there. But we need to break through with that. I think there's a number of other things that we can work on, there's a couple of things that are a little bit more superficial. Although Scott was mentioning some aspects of things with transportation, I do think we need to encourage public spaces, including businesses to have better signage that is less confusing. We've worked with airlines and airports, for this particular reason and working with some of the airlines and helping adults learn how to fly. And signage is going to be very important. I'm just hitting on a few things.

I think there is something too, that has come up again and again in conversation about some of the services that are provided with government agencies or through states, utilizing demeaning language like Voc Rehab. When our folks are being trained and worked with in job readiness, or in jobs, to assume that they need to be rehabilitated as someone

-- that came about because of war injuries. And we are still utilizing it in many situations. And I think it is very misleading. Rather than giving education and guidance and with the dignity that comes along with those terminologies. And comments with things with Autism Speaks, I'm glad that Autism Speaks is coming on board. Because when we talked with them 14 years ago, they didn't want to have anything to do with adulthood.

I am delighted that they're in the field. But we all need to pull together and if we can look at this thing holistically, maybe we can get the research done that needs to be done to help individuals. And to also get funding for us to get in deeper and take care of many, many of the details that we were talking about today. And I know I made comments, but that was the handout for the last half hour or 45 minutes trying to get on. Thank you.

DR. DANIELS: Thank you so much, Julie,

for sharing your comments. So, thank you, everyone, for all of this useful discussion. Very helpful to hear about all of your comments.

We will take a 15 minute, or we'll take a 11-minute break and come back at 2:30 I don't want to give short shrift to sex and gender equity and disparities and COVID. So, I'll ask you to come back at 2:30 and if you need a couple of extra minutes, just pop on when you can, and we'll start discussing sex and gender next. Thank you so much.

(Whereupon, the Subcommittee members took a brief break starting 2:19 p.m. and reconvening at 2:30 p.m.)

DR. DANIELS: Welcome back, everyone. And let's see, we're on Question 7. So, we will go to question 7 next. So, question seven is research infrastructure and prevalence. And the proposed question 7 text is How Do We Expand and Enhance Research Infrastructure Systems to Meet the Needs of the Autism Community.

And the topics that are included here are bio repositories, data infrastructure, the research workforce, now the services workforce is in question 5. So, we've already covered that for today. Although if you have a comment about it, you can comment on it. And in the research workforce, there are mentions about the diversity of the workforce in autistic researchers, among other things. The epidemiological data gathering systems and surveys that help us gain data on autism, and the life course of people on the spectrum, and outreach and dissemination of research findings.

So, these are some of the bigger subsections of this question. And as before, are there any other important topics or points to consider regarding research infrastructure and prevalence studies? And have there been significant changes that have happened since the last strategic plan that could impact the direction of this field? So, happy to take some comments on this?

I'm not seeing anything so far. I'll ask CDC, if you have any -- Scott has a comment. But I will ask CDC too if you can think about whether you have anything to say about prevalence studies and anything that we need to be including. But first comment to Scott.

DR. ROBERTSON: Yeah, Susan, thanks. I think for this question 7 that I know this is also an area and I know some of this is history where things have been listed on here. But if this is research infrastructure and data infrastructure, maybe I would put things like for instance, the tissue banking for instance farther down, because that tends to maybe oriented toward more of the physical sciences. Where my interpretation of this section of the research infrastructure is for research, including like social science, etcetera and data sharing, there in. I don't know whether there could be more expanded content on supporting better communities of practice on here for researchers and researchers connections with practitioners and policymakers.

We really have a lack of that in autism research is very siloed at times and separated. And I think we need that more bolster among researchers themselves, sharing studies sharing findings, sharing approaches and strategies. And connecting researchers with practitioners out there and service providers, et cetera. The cross connect and how of information sharing so that it can inform what gets done in research, and bolster enthusiasm for putting out research in infrastructure. In the research infrastructure for these gaps that we see, because we've been constantly talking about the gaps in strategic plan and other areas for many years and some of the discussion today I think we have that challenge that I think sometimes researchers aren't pursuing things at times, both because of maybe there's not a lack of funding, but also some of these grant opportunities, like at NIH, you all have, and otherwise, they're very wide open, they offer a lot of flexibility on studies. But I think some researchers who are not aware of the importance of addressing the gaps. And I think that connection with more committees of practice with fellow researchers and practitioners, and frankly, autistic people, ourselves and family members.

I think would be helpful I think for addressing in that space. I know, there's a mention already of community based participatory research, but I think if we could bolster that language a little bit more too is that we need more of that, to connect back out at the community. I think, historically, and this still continues to be the case. A lot of awesome researchers just very disconnected from stakeholders out there and not as well informed, I think, especially by autistic people ourselves. In terms of what should be driven as far as on research priorities out there. And just one quick thing that I wanted to know, and then I'll throw it back to I think it was what Jennifer?

I know, the other hands to go to, is the I think, I don't know, whether it's this this question could be, again, put in there. Is that it's been a need for a really long time to have needs assessments and prevalence in terms of what it looks like this space for like older adolescents, and adults. I know that like the SEED project, etcetera. That you have at HSS, in terms of CDC and other areas are starting -- have been starting to get into adolescence life. But I think we need a lot more of that in adult life. The data tracking and these others research tend to be often limited historically to kids. And again, this is the Peter Pan phenomenon, again, that we did this question should be adjusting research infrastructure across the lifespan, honestly. And the gap exists mostly for adults, as far as getting data on where the needs and gaps are. And we've had a better progress for that internationally. And we're really far behind here in the United States. And we should be looking to our collaborators, and international and other countries to see where they've made progress on this and what we should be doing here in the United States to frankly catch up. Because I think it is really hindering us as far as making progress on these areas by not having as much priority on research infrastructure that has a greater focus on adults and older adolescents. We need extensively more commitment there and I think it's something that should be addressed more in language in this in this section. Which has historically not been as priority to this section, partly because of the adult focus in Q 6, even though again, this research infrastructure should apply to research on autism across the life course in alignment with the priorities under the Autism Cares Act and quality of life across the lifespan.

DR. DANIELS: Thank you, Scott. And those are good comments with the history of this section to when we started out with this plan in 2009. Some of the tissue banking and so forth was new. And so, there was a lot of interest in getting that up and running. But now it is up and running. And so, it seems like there is more emphasis on the connections between researchers and how we can really support the research community holistically. So, appreciate that. Next, we'll take a comment from Jennifer Johnson.

DR. JOHNSON: [inaudible]

DR. DANIELS: Yes. Just heard you.

DR. JOHNSON: You can hear me? Okay. I'm having a hard time figuring out this audio here.

So, just a couple of things I think that have developed since we last updated the strategic plan. Under the patient centered outcomes research authorization. The last reauthorization identified the IDD population is a priority for research that's authorized under that act. And although obviously, it doesn't point out, or call out specifically autism. Given that IDD is the population that's identified and many people who are autistic fall within that category. That might be something to reference or highlight as a potential resource for building more infrastructure and generating some research on individuals with autism. The other thing I was going to mention here is, as it relates to COVID. And I'm actually kind of surprised that COVID hasn't come up more frequently in our conversations today. But we certainly know from COVID, that we didn't have good data on people with disabilities in general, but autistic individuals. And obviously, there's a lot of research that needs to be done to understand the impact of COVID on autistic individuals in many different ways.

On their health or mental health, did it impact them differently, both physically and just in terms of -- we know it did in terms of community living, and just life in general. But we need to kind of be looking at, again, the impact of COVID, and what research we're supporting there. But also, we saw in the pandemic, that we didn't have the data to know what was happening to people with disabilities, including autistic individuals. So, just reinforcing the need for more of that administrative type of data. And being able to identify people with autism in data sets and being able to use that to better understand their outcomes.

DR. DANIELS: Thank you, Jennifer, for those comments. And we do have a section on COVID that we're going to be talking about soon. So, we can revisit that when we get there. But appreciate all of that. So, thank you. Next, we'll take a comment from Joe Piven.

DR. PIVEN: Thank you, Susan. I see that the bullet for the research workforce highlights diversity and artistic researchers. And I don't know if -- I don't want to detract from that. But I think we need more emphasis on developing the research workforce. And I say that apart, anecdotally, based on my position is directing a postdoctoral research, training and IH teacher to over the last 20 years. And we've always had a lot of applicants. And the field has been kind of burgeoning. Over the last cycle, I think we and other people around the country have just experienced a dramatic decrease in applicants. There are a lot of people that are going into industry and out to the clinical world and not going into research for a variety of reasons. And I think this is a place where we should be emphasizing novel approaches to training and just bolstering training in general.

I think the other piece of this is that we talk a lot about translational and interdisciplinary research. But in point of fact, doing that pulling that off, getting that funded, getting training in that area is really difficult, it's really a challenge. And I think we need to think about novel ways to train our young researchers that cross disciplinary boundaries, that cross institutions. And really just kind of work more creative ways to do this. So, that's just one plug for expanding that research workforce bullet point.

DR. DANIELS: Thank you. So, the chapter was reduced to a slide. So, it's certainly not everything but diversity and autistic researchers or new things that came up with research workforce. Of course, expanding the research workforce and supporting it has always been a part of the strategic plan. But appreciate that and if you have any suggestions on what kinds of things would be creative, new ways to inspire people to join the field or stay in the field. Things that could really help people. Please email us if you have thoughts about things that could be mentioned. And next we'll go to Matthew Siegel. Although your name on screen is Karen Vincent.

[01:44:46]

DR. MATTHEW SIEGEL: Thank you, Susan. I am still Matthew Siegel.

So, I would like to suggest we could add a bullet under this because it is part of research infrastructure, I believe, which is research access. And what I'm thinking about there is two pieces. One is accessibility for the general autism population that making research opportunities known to people such as innovative things like the EM platform and that was some of the work Safari has done in creating access to research studies. And just as importantly, a second part is facilitating access to research for people who have high support needs, whether that is people with autism who have intellectual disability, high sensory issues, interfering or severe behaviors, such as self-injury or aggression, who still need and deserve study and research. And yet, though the very things that they need researched, can prevent them from accessing research studies. And of course, key reference on this is Alisha Haliday and others published an article, I believe, last year on ways to increase access to research for individuals with autism who have high support needs or fit into these other areas of the spectrum that I've mentioned. So, thank you.

DR. DANIELS: Thank you, Matthew. And those things do fit in. So, what you're calling access is what we've included under dissemination. But we could use other terminology there as well. And in terms of inclusion of people with high support needs in research, I think that we have that in the upcoming equity and disparities section, but we can always put it in more than one place as well, as we've recognized that that's come up a few times in our conversation. So, thank you. Paul Wang.

DR. WANG: Yeah, Thank you Susan. I wanted to speak to the second bullet, the data infrastructure point. It's fantastic. I think that NIH has created and maintains and are the database where I think all federally funded researchers are mandated to deposit their research data findings so that they can be used as secondary sources for future researchers who might want to access that. Here though, I want to convey secondhand comments because I don't have first-hand experience in pulling data from NDAR. I have heard from many researchers, that it is very difficult, too difficult to get data out of NDAR. Others who are on this call may be able to speak to this from firsthand experience. But I think it's imperative that we make this resource as easily accessible as possible so that its full value can be realized. It's fantastic that it exists, that researchers are required to put their data in there. Let's make sure that the data can be used by other researchers, rather than going in and never coming out.

DR. DANIELS: Thank you. Thank you so much for those comments. And we can be sure to pass that on to staff at NIMH that are involved in that system to ask them about accessibility. Do you have any comments, Paul, in terms of what are the newer frontiers that we need to be addressing in terms of some of this type of infrastructure for researchers? As I know, Simon's has been involved a lot in creating infrastructure as well.

DR. WANG: Yeah, some of the other speakers have already touched on that issue. The last comment from Dr. Siegel about making sure that the individuals with autism who have high support needs can participate in research, that researchers can find them and recruit them without excessive barriers. It's important to include that population in research. There are of course, more and more different types of data that are being generated, sometimes in enormous volume. Obviously, there's what we think of as cognitive, behavioral or other kinds of data. There's genetic data, which we know are voluminous, imaging data, EEG electrophysiological and other kinds of neurophysiologic data. So, there are many different data types. And I think there's going to be great potential in looking across these data types. So, we just have to make sure that the ability to do that is there.

DR. DANIELS: Thank you. Do you see any further needs for linking any of these datasets or anything else that we would want to mention in the plan? We have several things in play is now.

DR. WANG: Yeah, I'm sorry that I don't have expertise to comment really specifically on that. But for sure, we want to be able to link across those different data types. Well, of course respecting subject privacy confidentiality issues, that's paramount. But when subjects consent or when it's possible to do that kind of linkage while preserving the privacy, it's an absolute must.

DR. DANIELS: Great, thank you. And we will consult with some of the experts that we know in that area to make sure that we include whatever is the latest there. So, thank you. Next, we'll go to Dena Gassner.

MS. GASSNER: Thanks, Susan. I'm grateful that Dr. Pittman brought up increasing the research community. I wanted to mention as a subset to that, the lack of workplace accommodations for autistic researchers and other disabled researchers, especially around the gatekeeping in terms of like entrance exams or interviews, things that are not going to demonstrate our relative strengths, and also the inordinately high number of hours a competitive researcher is expected to put in.

Also, there's a lot of privilege involved with who gets internships and postdoc settings, and low wages in regard to that. So, I did want to bring that up. And I also wanted to mention here, again, under epidemiological gathering, the 504 data that's being missed. And lastly, I wanted to talk about the inaccessibility of research data with Social Security. My dissertation is on a Social Security topic. I submitted a request for specific information. It was denied as not being beneficial to the department.

And so, in addition to my $30,000 a year in tuition, they wanted me to pay them nearly $1,000, for the data that I was requesting. I submitted an appeal for that, articulated some of the barriers that were unique to my situation, including being on Social Security myself, and was denied again. And so, we're not really going to be able to determine the outcomes people are experiencing in any other way the qualitative research as long as we do not have the funding or the access to Social Security data. So, I'm hoping we can do something in terms of improving that access.

DR. DANIELS: Thank you for those comments, Dena. We appreciate that. So, we'll go to Steven Isaacson next for comments that may have been written in.

MR. ISAACSON: Hi there. I have two comments, one from the [inaudible] and the other is from Jenny [inaudible]. The first one is from Yetta. I love the idea of community of practice. I would like to see, not only researchers, but other stakeholders, specifically autistic individuals, family members, and community providers. We need to bridge gaps. Additionally, I would like to see every state and territory to have access to funding to figure out prevalence data across the lifespan. We are trying to figure this out in DC. It is a challenge due to lack of funding. And there's a question from Jenny for objective three, strengthening statistical data gathering systems to advance understanding of the artistic population, while allowing comparisons and linkages across systems as much as possible. The question is, can we spell out what we mean by diverse samples?

DR. DANIELS: So, to answer that question with the objectives or recommendations as they're worded, we're trying to be brief, because if they're very lengthy, it's going to be hard for people to understand them. So, in the text, it should be clear what we're talking about when we're talking about including people with a lot of different diverse backgrounds and samples. We all are aware that samples, historically, have not been all that diverse in terms of gender and race and ethnicity and a lot of other factors. So, that's what we're talking about, but we probably won't want to lengthen the objective itself, but we can include something in the chapter that will make it clear that that's what we're talking about. Just to keep things clear and easy to read.

MR. ISAACSON: Susan, there's also a second one from Jenny. Under the objective two, expanding and enhancing the research workforce with attention to diversity and inclusion and accelerate the pipeline from research to practice. The question is, would we be able to include interdisciplinary and transdisciplinary research, especially for those who are switching into autism research from a different discipline? For example, those who come from humanities, arts, linguistics. I bring this up, because as an early career researcher, I find it a bit difficult to find where I fit when applying to jobs/funding as an interdisciplinary autistic researcher. Thank you.

DR. DANIELS: Thank you. And that actually was in a previous strategic plan. So, that is something that has been there. They wanted to encourage people to join from other fields and to do interdisciplinary work. And certainly, we'll include that in the chapter, we might not be able to include all the words in the exact recommendation because it would become too long, but it's an important point. And there are a lot of people in the autism field that do cross disciplines. And that's a really valuable feature in this field. So, we want to encourage people to do that. So, thank you. Joe Piven.

DR. PIVEN: I just wanted to echo and maybe build on what Paul Wang just said, which I thought was a really great point.

And, frankly, I thought about this for many years, and I've sort of forgotten about it. But I want to weigh in as someone who has some first-hand knowledge about NDAR. This is an incredible resource and a huge investment. It has remarkable potential. But there's been remarkably little productivity that's come out of this. I think it's an issue. I'm not sure if this is the forum to discuss this.

It's a very complicated issue. But since it's been raised, I just wanted to say first that I kind of resonate with what Paul's saying. If there is a role for this strategic plan to comment on this, I think it's a good idea. If you can do it in a way that's sort of appropriate and constructive. I think there is a role for rethinking and reassessing what is happening with NDAR because of these observations that we're all having. It's been many years. It's not a short-term experience. So, anyway, I just thought I should weigh in and say something about that.

DR. DANIELS: Thank you, Joe. And we probably won't be able to get into a lot of specifics about any one resource. But there are probably general recommendations that we can make, for example, talking about increasing accessibility to researchers that probably apply to multiple different resources that are out there. But if you have very specific comments to share with NDAR probably be best to contact NIMH, and we can connect you with the people that manage and are. So, thank you. Jalynn Prince.

MS. PRINCE: Thank you. I have been led to believe by several different sources that the CDC has more of a mandate to look at resources or research directed toward children than to adults. And if that is the case, do we need to make a recommendation? Or do we as individuals need to make certain that we could get language into Congress that would open the door for greater research for adults and adult issues and prevalence out of the CDC? Because as I understand it, the research about adults, as far as prevalence goes, the CDC had been able to get in on was not necessarily primary sources, but it was compiled by other sources to get an estimate of the prevalence out there. So, are there actions that either we can recommend in a strategic plan or that we should maybe look at within our congressional or legislative districts?

DR. DANIELS: Thank you, Jalyn. And I'll give Stuart the floor in case he has some comments from CDC about that.

DR. STUART SHAPIRA: So, great. Thank you very much, Susan. So, I don't know the exact language and the appropriations with regard to what CDC is being directed to do, whether it's specifies children.

DR. DANIELS: I know that CDC is moving towards doing more activities in the adult lane for both seed with the research study to understand aspects of autism and both risks for autism in the genetic as well as the non-genetic areas, and also in the prevalence monitoring that's done through the atom network.

So, both of these are expanding into the adolescent and adult lanes. And we wouldn't be able to do that if specifically it said in the appropriations, that we could only restrict our work to children. So, I would be surprised if there was such specificity that restricted the work to the childhood lane. But we can look into that further. Susan had brought up earlier that I may have thoughts on the section on prevalence monitoring in the strategic plan. I think it's very well written. It lays out the areas where prevalence monitoring has been occurring, such as in obtaining survey data, obtaining administrative prevalence using such datasets as healthcare claims data or active monitoring through direct examination of individuals and including them if they have the autism spectrum disorder diagnosis. The section very well lays out some of the limitations with various approaches to obtaining a prevalence value, including uncertainty of the diagnosis, whether the approach can provide a regional or national representative number, the participation in various approaches, as well as the cost of various approaches. And I think that in thinking about various approaches, it's also important to realize that the number or the prevalence number is important, but it's only partly helpful for the autism community. Because what really is important to know are the needs and the characteristics of people with autism in the general community, and are those needs being fulfilled.

So, certain prevalence monitoring approaches don't necessarily get at those questions. So, that needs to be considered in developing prevalence monitoring approaches. But I think what should be added to the prevalence monitoring section, focuses on the way that data are obtained because -- not only obtained and evaluated. Because that's been changing with time, that there have been much more of a focus on big data and data linkages.

DR. DANIELS: And it's through these types of approaches that more information that can be useful for prevalence monitoring can be collected. And so, subsequently data science approaches to evaluate ways to improve on the quality of the data and the information within the data are important to consider to obtain a prevalence number in a timely and efficient and a valid fashion. So, I think the main point is that there are currently a number of approaches that have been used to obtain a prevalence number, but data are changing, and the way data are obtained, and the way data are evaluated. So, some considerations to these changes in the environment and how data science can help improve prevalence estimates and the timely and efficient manner of obtaining those prevalence estimates and also obtaining more than just a number. Learning more about the needs of individuals in their communities, and how their needs can best be addressed should be a critical component of obtaining the prevalence. Thank you so much, Stuart, for those comments. That will be very helpful to us as we refine that section of this question. And I will give the last comment on question seven to Joe Piven.

DR. PIVEN: I'm sorry. I forgot to--

DR. DANIELS: Your hand is just left.

DR. PIVEN: Sorry, my apologies.

DR. DANIELS: That's not a problem. So, then, thank you so much for these comments. And we will move on to the next section, which is the cross-cutting theme of sex and gender. And want to get your thoughts about anything that we should include here. And again, this slide is an attempt to just summarize a few things that are in the chapter so far. But we can refine it based on the discussion here. So, some of the topics included are sex and gender disparities in diagnosis and diagnostic criteria, biological differences between sex and gender, differences in socialization of different sex and genders, differences across the lifespan including for older women, and differences in sexuality. I believe that reproductive health is in this section as well. But we will open this up for any other important topics that we need to include in this section, or if there have been some changes in the field in the past few years, since the last strategic plan that could impact the direction that we should take with this topic.

Dena.

MS. GASSNER: My video was turned off, but anyway. I do believe that there are some research looking at the male female ratio in adulthood, finding that it pretty much disappears in adulthood. And I know that people who are working in the field as social workers and therapists are also finding a closer to at least two to one ratio of male to female. So, I just want to make sure that's addressed. Again, touching base on trauma care, maternity care, there's a lot of good research out about the differences in pre-partum, partum, and postpartum care, and labor and delivery for autistic adult women and others who have uteruses. So, I would think that we might want to touch base on those issues.

DR. DANIELS: Thank you, Dena. We'll take note of that. Next, we'll take a comment from Jennifer Johnson.

DR. JOHNSON: Are you able to hear me?

DR. DANIELS: Yes.

DR. JOHNSON: So, I just kind of build off of what Dena was saying. But I think just generally getting access to training about sexuality and sex education in general is really important. And there's been a lot of that that actually happens and goes on. And so, I think that we need to make sure that that's in the strategic plan. And then we also probably want to make sure that there's information in there about recognizing sexual abuse and being able to report that because again, there's not a lot of training that goes on there either. And so, I think that's important to include, but also just want to support the comments about access to maternal health care and the importance of accessibility and culturally competent care.

DR. DANIELS: Thank you, Jennifer, for those comments. That's helpful and we didn't say anything specific on the slide about anything that would be male specific, but if there is, the title is sex and gender so it could include anything that might be male specific also.

DR. DANIELS: So, any other thoughts that you all have been having about this this topic? Yetta.

MS. YETTA MYRICK: Okay, I hope you can hear me. Just want to piggyback about the sexuality education, making sure that there's something of consent and teaching consent. So, it's one thing, obviously, to report about abuse. But another piece that I've been learning because I'm working with someone locally in DC who does do sexuality and education training, is really teaching about consent early on. So, I just wanted to throw that into the mix as something we should maybe be considering. Thanks.

DR. DANIELS: Thank you.

DR. DANIELS: Susan Rivera.

DR. SUSAN RIVERA: Hey, thanks, Susan. I'm not seeing anything in the report that mentions nonbinary or transsexual. And so, I think we need to be attentive to that. And make sure that we say something about that in this chapter. Because I think that's going to be really heavily on the minds of some of our stakeholders.

DR. DANIELS: Yes, there is an intent for that. And if it's not included, it probably was that we were running a little short of time as we were trying to get this first draft ready. But thank you for mentioning that. I know of issues I've heard about, but from your perspective, are there particular ones that you would like to bring to our attention?

DR. RIVERA: Not more specific than this. It's just been very underreported and under studied. The prevalence of non-binary and transgender individuals on the autism spectrum. And so, as I hear it talked about in the autism communities, there's an anger about that, and a feeling that there's a lack of research about that.

DR. DANIELS: Thank you. That's very helpful. And we'll be sure to have some information on it but would welcome any input from the committee on it if you run across something that would be helpful for that. Ivanova.

MS. SMITH: Hello, this is Ivanova, and my question is what reason to the lookup service providers and making sure [baby crying]-- Sorry about that. Is there any look at [inaudible] that autistic that are not speaking that have high support needs can get access to sex education, and to get support to be able to have the -- to be supported in being able to school that well supported living [inaudible] facilities. [Inaudible]

Sorry about [inaudible] background.

DR. DANIELS: Sorry, I forgot to unmute myself. I was also trying to just make sure there's not background noise going on from my computer because it makes the little ding sound sometimes. It sounded like you were talking about exploration of sexuality and concern about making sure that people who are nonspeaking are included in sex education, but I think some of us broke up a little.

MS. SMITH: I can repeat myself if you need me to. I just want to make sure that those people that have high support needs and are in residential facilities on residential support programs, that they're being given the access to this too, to the education. Because the is sexual assault that happens in those places and people not being given a support to be able to experience those adults things when they are adults. They are being restricted from that and that kind of thing. That's what I'm concerned about, is how do we make sure that people with the highest support needs that need the most support, they'll get to also have access to this education. Thank you.

DR. DANIELS: Thank you, Ivanova. Next, we'll take a comment from Jenny Mai Phan.

DR. JENNY MAI PHAN: Hello, can you hear me, okay? I was looking through the cross-cutting objectives, draft chapter. And I was looking for any language about sexual reproductive health outcomes. But I was not seeing that anywhere. Would that be something that could be added as a text within the chapter?

DR. DANIELS: Yes, we can include something on reproductive health in this area if it's not already there.

DR. MAI PHAN: Thank you.

DR. DANIELS: Are there any specific points that you were interested in?

DR. MAI PHAN: The paragraph that talks about looking at gender and sex as a cross cutting objective in a lot of the autism research focuses more on physical health or gynecological health but not necessarily on reproductive or sexual health. And this kind of ties into other earlier comments about sexual health education, too. I just want to make sure that language is included in the chapter.

DR. DANIELS: Thank you. Yes, we will make sure that we add some information about that. And if you have anything in terms of references that would be helpful to us feel free to send that along.

DR. MAI PHAN: Absolutely, I will. Thank you.

DR. DANIELS: Thank you. Dena.

MS. GASSNER: I'm sending you two authors, who've done a considerable amount of work on gender, non-binary and trans. We found out through their research that the frequency is higher in the field of autism for those gender diversities than in the non-disabled community. And they've tested that by examining populations of transgender people for autism, and evaluating autistic people for gender fluidity, gender diversity, and transgender status. So, I sent you two authors that I've done a lot of work on that. I want to go back to reproductive health care and talk about that again as another place for workforce development training, providing reproductive health care to people who have inordinately higher sensory management issues, who may have enteroception issues and difficulty reporting, pain in terms of intensity, kind, location, frequency. All of those are difficulties for people on the autism spectrum. And, again, not having a workforce that's a quick to address that can be very problematic for our group. And menopause. I hope when we're talking about the lifespan and older women, we get a lot of information as women. We've talked a lot about this in the node that I'm working with AARP. We get all this information about what to expect transitioning into puberty. But that's where our reproductive healthcare education tends to stop. We assume that women will figure it out from other people that they socialize with. We have limited social networks. And so, we're really in a void there.

And then lastly, the implications of late diagnoses or missed diagnoses as it applies to sexual vulnerability. So, to give you a real-life example, my son was diagnosed at three. We knew that because of his autism there were certain factors we had to consider. We provided him very intense, very structured information on sexuality, on relationships, on touch, on consent, primarily because we understood that he needed a different kind of intensive and intentional instruction. That looked quite differently for someone like me who wasn't diagnosed until 40, who is presumed by the family system, presumed by my social networks, presumed by even myself that I know enough to get by. And it led to a tremendous amount of victimization, repeated victimization.

So, I think the intersectionality of late diagnoses and inherently different kinds of vulnerability is something that needs to be addressed.

DR. DANIELS: Thank you. So, we'll take note of that. Thank you for sharing that. Next Scott Robertson.

DR. ROBERTSON: Yeah, thanks, Susan. I just wanted to concur with the emphasis on sexual education on sexuality and sexual education as far as equal access, that I think folks often don't have access to because of the fact of stereotypes and misbeliefs. And basically, often sometimes treating autistic kids and adolescents like they're younger children. And the term used out there sometimes this infantilizing comes up very often. And you've seen that and some of the literature talks about the problem there with treating autistic people who, in some cases may need an extensive array of certain supports for living but are adolescents or are adults and should have that equal access to education about sexuality and what that means across the lifespan. And I think that that cross connects with some of these other biases that were raised earlier, as far as you know, having kids, raising a family, being able to become a parent, getting married.

All that is cross connected together in terms of lifespan areas for autistic people that a lot of that is biases in the system and historically, where folks just are not treating autistic people respectfully, as human beings who should be able to have the same access to information and knowledge in that space. With support. The supports may need to be different, more targeted focus in some ways to help folks have equal access on that. But I think folks should not be because of their service and access needs. That should not be a reason for denying folks access to education and sexuality as they grew up just like other non-autistic kids and adolescents and adults have access to the information knowledge and resources. I think also too, and I think we've touched upon this a little bit, but the LGBTQIA plus focus on here, to expand a little also on the greater needs for that in research that we have so many gaps with inclusion of LGBTQIA plus folks in research samples. Very frequently, researchers are not even collecting data on gender identity and sexual orientation. In studies, I've noticed that myself, sometimes when we have looked at literature, it's just often just not collected at all. And there's not an emphasis on inclusion of folks in studies and also emphasis on how folks who identify as LGBTQIA plus can participate as researchers in this space and other spaces of awesome research.

So, I think we have a ways to go to make some progress in that area. And as was mentioned earlier, it does mention here that the rate of LGBTQIA plus is higher among autistic people. A lot of that is the rate of transgender as was mentioned earlier, and I can send you some research studies also on that where they have confirmed that high rate as high as potentially 10 percent maybe higher among autistic people who are folks who identify as transgender.

I agree also, with what was mentioned earlier about nonbinary too, is making sure gender fluidity is included on here and the medical care for autistic people who are LGBTQIA plus and other folks as far as that they need for having their needs met, including, for instance, if folks may need to transition between genders, as far as the medical care, or surgeries, et cetera, that are needed for that, that autistic people have equal access in that space, I think is paramount. I don't think that's been studied at all really in research literature.

DR. DANIELS: Thank you, Scott. Those are helpful comments. When people are talking about sex education, are you envisioning that coming through the educational system, through healthcare providers, or through toolkits that are put out by advocacy organizations, or I was just curious about whether anyone on the committee has a thought about where would be a good source for that information? I don't specify but just to know what people are thinking.

DR. ROBERTSON: I just meant on mine for all systems as far as education and healthcare and other aspects. It should be included especially where it's included already for non-autistic people, but I'll defer to the other folks on the committee for their thoughts.

DR. DANIELS: So, we don't have to be very specific about that in the plan. I was just curious about what people thought, and we do sometimes see organizations come up with toolkits that people can use. But there may be opportunities in established systems that are already, like you said, Scott, providing information on sexuality that could have perhaps update their offerings.

So, we're going to move right into equity and disparities to make sure that we have enough time to talk about that. And again, a lot of these overlap with each other. And so, there is some overlap with sex and gender here. But we have a new cross cutting theme that the committee wanted to add to the plan on equity and disparities. And this would include racial and ethnic, geographic, and socio-economic disparities, as well as sex and gender and other types of disparities. And also recognizing disability as a disparity group and autism within that as a subsection and intersectionality, between autism and all of these other areas that create disparities.

In addition, culturally competent and sensitive interventions and services and providers, disparities in age of diagnosis and access to services and supports, balanced and representative research samples, representation within the workforce, and inclusion accessibility accommodations and universal design are some of the things that potentially can be included in this chapter. And in the draft, maybe universal design, I don't think is mentioned. But I think it should be mentioned in this section. And we can expand a little bit on accessibility as a theme.

But I'd like to hear from you about any other important topics or points that we might want to include in the section. And what are some of the recent changes? And obviously, for those of us who work in the federal government, there have been a lot of major changes in the past year or two in this area. And every federal agency is working on diversity, equity, inclusion, and accessibility issues within our agencies and within programming from our agencies. And there's a lot going on with private organizations as well. But we'd love to hear some of your thoughts about this and how we can make this new section inclusive of everything that the committee might want to recommend.

DR. DANIELS: Dena.

MS. GASSNER: I know these events in the last day and today were optional. And as a result, I think some of our usual participants may not be here. So, I would recommend that there's a couple of people who have inordinately deep knowledge and lived experience around racial and ethnic disparities that we might want to schedule a separate call with just to pick their brain a little bit. In terms of disparities, I again want to bring up IQ as in and of itself, a factor that creates disparity. Either your IQ is too high, and as a result, you're not deemed worthy of services. If your IQ is high, they want you to settle for less challenging work in order to get accommodated instead of supporting you working at your potential.

If your IQ is too low, you're deemed ineligible for some research and some opportunities for independent living. So, I think using intellectual quotient that's not even designed to measure intelligence for this population creates in and of itself, multiple disparities that interfere with service delivery and accessibility.

DR. DANIELS: Thank you for those comments. The definitely helpful, and we have been hearing about some of those kinds of issues and can try to make a mention of that in the plan. Jenny Mai Phan.

DR. MAI PHAN: Hey Susan, I think it's also necessary to perhaps add in language in the chapter about this aggregating racial data. Because there are some racial groups that represent multiple countries as countries of origin, languages, and various backgrounds. And this is intersectionality aside. It's just the people who live here in the US, who may identify as, for example, Asian, but not ethnically representing one country of origin and does not really relate to experiences related to a different Asian country. So, in order to help ensure that everyone in our community are getting access to care and services and support, it is important to increase representation of historically underrepresented racial ethnic groups by disaggregating data.

DR. DANIELS: Thank you, for those clarifications and some finer points about that. We can try to make a mention of language. And if you have any references that you want to send to us, feel free to send that to IACC team.

DR. MAI PHAN: I do, and I will, thank you.

DR. DANIELS: Thank you. Jennifer Johnson.

DR. JOHNSON: It takes me a moment to get myself off mute here. So, one of the things I [inaudible] sure if the strategic plan incorporates anything related to how different cultures might view autism within their culture and whether they would recognize it as a disability or whether they recognize disabilities at all, and how that interplays with services and supports and also service delivery. So, again, I'm not sure if that's already in the plan, but if not, I think that's important to make sure it's included.

DR. DANIELS: Thank you. And if you have any references, I can think of one that I just saw within the last week. But if you have any references about that, that would be helpful.

DR. JOHNSON: Okay, yeah.

DR. DANIELS: Thank you. Scott.

DR. ROBERTSON: Yeah, thanks, Susan. I think there's a few suggestions that I had in here. And I can send you some literature too. I know that I have definitely have some literature on disparities that you may be able to cite in here as far as age of diagnosis, et cetera, and culturally competent. And I would add, in addition to culturally competent, linguistically competent too, as far as barriers that maybe autistic folks may experience from communities that may speak Spanish, or other languages here in the United States. Because not everybody, even beyond disability has English as their first language here in the United States. And that's one of the biases we sometimes have had historically. I wanted to call the emphasis here on socio economic disparities, as mentioned here. The resource literature, for instance, unemployment committee living has not collected data generally on economic prosperity and income, and wages, salaries among autistic people.

So, we don't even know what that gap looks like, let alone what that gap looks like for subgroups among autistic people as far as autistic people from diverse races, ethnicities, gender, sexual orientation, et cetera. So, we need more data on that. I'd emphasize it should be required on there is, especially with federally funded research, we should have more requirements, I think where possible to be collecting data on if you do an employment study, you should be collecting data on economic status. And you should be having diverse samples to is where possible to have diversity of autistic people from different backgrounds. Now, I know that's easier said than done. Because I am aware as a researcher by training in my own background, that it's especially with [inaudible] research, particularly around adults and adolescents. It's really hard sometimes to connect with folks and to achieve diverse samples. But I think we need to make stronger efforts in that space. Researchers need to have that priority.

I think from the plan here on the utmost importance to where possible to having as diverse of sample as possible, and maybe oversample at times, as was mentioned, I think earlier, sometimes oversample folks from diverse underrepresented backgrounds intentionally, just to make sure that you have that fully represented. Because it's been so underrepresented in the option research literature overall, because it tends to be I hate to say but I'm reflective of the stereotype out there of white male.

If you like computer geek kind of a thing is embodied in autism research. Autism practice and policy is kind of at times is so heavily biased and slanted and has not looked extensively at that intersection piece. I would add in geography too, urban, rural type of the thing is that often studies have not asked about geography. And then I can send you, if you want, citations for things like universal design. I'm glad you have that focus on here for empowerment of access. You mentioned one of the executive orders in the description there, I think it'd be helpful to mention just briefly, even if it's just the citations for in them a few of the other executive orders and the policy, including DEIA in the federal workforce where it spells out the abbreviation DEIA in that executive order. And I think the priority of folks understanding disability from the accessibility standpoint, and that intersectionality piece too is disability as part of diversity. And that autistic folks, just like other folks to disabilities, come from these other diverse backgrounds too is, I think something, this extra emphasis here is really needed. And I would say, I know this is not unique to autism. But that accessibility piece of DEIA that we have in diversity, equity, inclusion, and accessibility here in the government is not making its way outside of the governments.

Even sometimes not to our sister agencies, we have an issue there. I know that's not unique to autism. But we need to make more headway there. Because a lot of folks don't even know what the A is. And they don't know what accessibility even is at the bare minimum level. And it's hard to imagine that making inroads, I think [inaudible] specifically with the barriers that we have across the board on that focus for DEIA, but I'm glad you have a start by having the citation for the racial equity and underserved communities as one of the executive orders [inaudible] here.

And as you mentioned, and then I'll throw it back to others is, It's of utmost importance to us as federal agencies right now in the last couple of years is we've heavily expanded our focus. It's one of the top I'd say, two or three priorities I know for us here at DOL, is that diversity, equity, inclusion, accessibility piece. So, I think anything we can do to strengthen the language on that, and to make sure that it percolates into resource practices and policy, and that it should be influencing everything that we do in that space, including when we talk about workforces that should make sure not only that autistic people are able to participate in some of these workforce needs that we've been talking about us service provision and as researchers, but diverse autistic people who come from again, diversity of race, ethnicity, gender, gender identity, sexual orientation, veteran status, et cetera, socioeconomic status.

DR. DANIELS: Yes, certainly those are really important. And with accessibility, you're correct that a lot of people, it sort of drops off the end, or I find that with accessibility, that sometimes people are only thinking about physical disabilities, blindness or deafness, and they are not thinking about the broader range of disabilities. So, that is really important. And we do have neurodiverse Federal workforce initiatives going on in the government as well, that could be mentioned, and the executive order you mentioned as well. So, that could be built out a little bit more. But we also will try to, I don't know if this is in there already or not. But there's an intention to mention that there is something new that has come along since the last strategic plan is now that there's more focus on neurodiversity. And there are many conferences, et cetera, that are happening on this topic, and bringing people together to talk about this in a broader context. So, thank you for that comment. Sam Crane.

MS. CRANE: I want to quickly talk about bias in addition to access, but I think that we've talked about access, but bias can be a big barrier to diagnosis. And it's not just about cultural competence. One very common example is that African American people, especially children are differentially diagnosed, usually as having either a standalone ID or emotional disturbance or oppositional defiant disorder, which often can be a barrier to care. So, these are kids who are getting an evaluation. And the evaluator might believe that they're culturally competent, but they're often viewing behavior through a lens that is racially biased and tends to attribute behavior to, for example, intentional misconduct rather than autism or attribute difficulties to lower IQ rather than autism.

Another example that I've seen is that

sometimes people will get cultural competency training in a way that actually increases bias. So, I I've seen situations where Asian children have been dismissed because even if the parent who is also Asian mentions that they've noticed differences in eye contact and social engagement, the evaluator will say, well, I've learned that Asian cultures are less likely to make eye contact and are less likely to spontaneously interact with adults. And it's normal and this is all completely fine. And therefore, we're not going to recognize this child is autistic, even when the parents themselves are saying this is not actually normal for our culture. And this kid has siblings who are completely different. I think that we need to specifically call out bias in addition to cultural competency.

DR. DANIELS: Thank you, that is helpful. And if you have any recent references on that, we were looking up a few references, but there were some older ones. But if you have anything a bit newer, that would be great.

MS. CRANE: And unfortunately, a lot of these cases came to me as legal referrals. And so, I can't name names or provide data. Just something to add in the field.

DR. DANIELS: Not a problem, just if you have say, journal articles. But it's definitely an important issue. So, thank you. So, I'm going to go Steven. Do you have some written comments?

MR. ISAACSON: Hi, there. Yes, I have one comment from Yetta Myrick. Question is, is there anything about utilizing cultural brokers and or community liaisons? Anything about how to engage these communities? This is key information to include, and yet also concurred with that bias is a huge issue.

DR. DANIELS: Great, that's helpful. We don't have anything about that right now. But again, if you have any references, you might be able to send us whether it's a website or journal article, that would be helpful or even at this point, if there's not a lot in journals, if there's anything popular that we can refer to, just to understand a little bit more of that background, it would be helpful.

MS. MYRICK: Okay, I can do that. Thanks, Susan.

DR. DANIELS: No problem. Ivanova.

MS. SMITH: Hello, this is Ivanova. And my question is, is there anything to address the disparities for adoptees and adoptive parents, in getting support for the artistic adoptee children, and whether they're a transnational adoptee or transracial adoptee, if that looks in getting education to adopt an agency, that resources can be given to families that have adopted autistic kids, and they may need support. Thank you.

DR. DANIELS: Thank you. And I know that we don't have anything on that either. So, if you happen to know of any references, that would be helpful.

DR. DANIELS: So, do we have any other comments in this area? And do you have more

Ivanova, or I don't know if you might have left your hand up?

MS. SMITH: I'm sorry, I just left my hand up.

DR. DANIELS: It's okay. Dena.

MS. GASSNER: Just one comment. Part of the reason why we don't have a lot of information on this is that we're not recognizing the value of qualitative research. Because that's where some of these more marginalized populations are reporting out, when we can't get them in bigger datasets because we've done such an inadequate job of breaking down diverse populations. So, I guess I just want to point out the value of those lived experiences in that qualitative research. It listed above the status of an anecdotal report and provides true themes and thematic analysis that can inform this. So, I just wanted to put a shout out for qualitative, I guess.

DR. DANIELS: Thank you. And there is an intention, social determinants of health is in here in this strategic plan in the new plan. And it includes some social sciences research, but one of our limitations is we don't have access to a social sciences database. So, it's harder for us to find that. So, I know you're doing research in that area or anybody on the committee who might be doing research in that area, and if you see things that are coming out of social science journals that you want us to include, if you could send it our way that would be helpful, especially since I don't know that we can always find those. Scott.

DR. ROBERTSON: Yeah. Hi, Susan. I also have access to the database [inaudible] databases. So, I'd be happy to send you any articles you want. As far as including on that social science. And I concur also with not only qualitative research but mixed methods where it's qualitative and quantitative. I think especially for emergent areas that qualitative research is needed. And I hate to say it like this, but a lot of the areas that we talked about a lot, especially for adults and older adolescents have limited research in just key areas of the life experience, right? Where there would be a major benefit from having more qualitative research and mixed methods research in those areas. And it's complimentary to the quantitative research. And just so folks know for context, some of the issue also is because in Europe and other parts of the world, there's sort of more of the value for qualitative research. And historically, here in America, there hasn't been as much value placed on qualitative research which is why we don't see it funded sometimes as often as quantitative research. There's sort of a bias inclination toward quantitative research, even though they're complementary to each other.

So, I think if there's ways to call that out about a greater need for qualitative research and mixed methods research in these emerging areas that would be helpful. And again, happy on the social science and to help support in terms of the full text PDFs for what you want to read on these things and be able to cite and then any literature that's outside of academic too, that might be report sometimes for some of these emerging areas at times where it hasn't been published in peer reviewed scholarly journals, but may still be of interest because it's outside done by practitioners or whatever, but it might still be potentially citable.

DR. DANIELS: Thank you. That would be great if you have references, or we certainly can reach out if there are ones, we hear about that we're not able to easily access. So, any other comments on this topic?

Thank you so much for the helpful feedback. We got quite a bit on this that will help us to build it out a bit more.

So, I'm going to move us into the COVID section. That was the original break, but I moved it to just being one break if that's okay with everyone to just keep us moving.

So, we'll get out on time. Or if we happen to get out early, that would be great, too, if that works out. So, we'll move into COVID-19. So, we have a chapter on this. And the committee wanted this area to be forward facing to look to what we've learned from the COVID-19 experience, what we've learned about the vulnerabilities of the autism community, the needs for additional services, and assistance in various ways, and what the impact has been on the research community. So, we've included the topic so far of COVID-19 and physical health, including heightened risk of COVID-19 in the autism community, and the impact of say congregate care, impact of COVID-19 on maternal health and prenatal and postnatal development, impact of COVID-19 mitigation efforts including vaccines, distribution and uptake, sensory and communication issues that are associated with preventive efforts or interventions, services disruptions, and including educational disruptions and mental health impacts of physical distancing, the impact of COVID-19 on autism research and researchers, and what have we learned and how we can prepare better for the future, and including infectious disease preparedness types of activities.

So, those are some of the things we've included here. With regard to COVID-19, if any of you have thoughts about other topics that should be mentioned, with regard to COVID-19 and autism, we'd be interested in hearing your feedback.

Ivanova.

MS. SMITH: I will just say personally as an autistic person that COVID-19 protocols have been very inaccessible, and it's really affected my mental health and it's really affected a mental health and many autistic like me that have sensory issues about touching things around the face. And having trauma about being institutionalized. It made me feel like the community had become an institution. I was always terrified if I ended up in the hospital and not being able to have support. And I think that the protocols need to have understanding that not all Autistics can do the same thing. And I think that they had this belief that we all can just do the same thing. And that's not true. And it's caused a lot of distress for the community. And especially for Autistics who have high support needs and restrictive environments. They had fought decades to get freedom in those environments. And these protocols made that go backwards a lot and restricted people's rights to the community, to go on walks, to do sports, to do recreation, to be with the families, to do the daily routine. When an autistic person's routine is disruptive, that causes a lot of mental distress. And it can cause meltdowns. And if providers are not understanding, it can cause a lot of people to be abused in care facilities. And I worry that a lot of that happened.

My peers and I, we tried to set up zooms to support each other and to talk with each other. But not all autistic people can access zoom and can access video conferencing. There are many facilities that don't even allow people to have Wi Fi. They don't even allow people to access the virtual community. And so, many people were cut off from the community because of these protocols. And I want to make sure that if another pandemic was to happen, that we would make sure that there are exemptions and that care facilities are not restricting people from the rights to have virtual connection with the friends and family, and that they're not being denied access to technology and not being denied medical care because they can't wear a mask or follow certain protocols, or they need several people to support them in getting medical appointments.

I've had peers who they needed two people to support them in medical appointments. And they were denied access to the medical care and denied surgery that they needed because they weren't allowed to have two people supporting that person. So, this is something that it's really traumatic, and it's really had a negative impact on a lot of autistic people, including myself. And I really want to make sure that the CDC recognizes that, and they make sure that the protocols are more understanding of the needs of autistic people. Thank you.

DR. DANIELS: Thank you so much for sharing that detail about the experiences you and others have had with regard to some of these protocols. And so, we appreciate that information. And we'll be sure to include something about increasing accessibility and not infringing on people's rights as people try to put together protocols to keep people safe during a pandemic. Dena.

MS. SMITH: Thank you.

DR. DANIELS: You're welcome.

MS. GASSNER: I wanted to bring up the number of forward-facing personnel in multiple Human Services offices who have just simply left the industry, who have unfortunately died prematurely. So, there's a real deficit. We've had many Social Security offices that are closed or remain closed for in person visits, which can be very critical for communication. And then related, it's kind of a clash of the disabilities. The flip side of Ivanova's story is the number of autistic people with autoimmune issues who are equally trapped at home because we have decided to open up the community.

So, people don't have to comply with mask orders. And so, there's challenges on both sides of that argument, I guess, is all I want to say. But I think addressing the workforce shortages in Social Security and voc-rehab, in employment training protocols in in-home support service personnel, direct support staff personnel, who are, by the way, also massively underpaid. All of those have been amplified by COVID-19.

DR. DANIELS: Thank you, Dena, for that information and background. That's certainly an area that we could cover in the plan.

Next, I'm going to go to Steven to see if we have some written comments.

MR. ISAACSON: Hi, there. This comment is from Alisha Halliday. She says we need to look at the efficacy of online diagnoses and intervention. During the pandemic, we were thrown into just using it without being tested. We also need to look at comparative efficacy across different uses, such as medical and educational in symptoms like mental health or other core features.

DR. DANIELS: Thank you, Alisha, for those comments. That's definitely helpful with regard to remote services that people have been getting and health care. So, we'll be sure to include that. Jennifer Johnson.

DR. DANIELS: It looks like you're unmuted Jennifer, are you able to speak?

DR. DANIELS: I know it might be challenging if you're on a remote device.

MR. ISAACSON: Yes, she's on a phone, I think it looks like based on the participant list. I don't know if she has to hit something to unmute on the phone.

DR. DANIELS: Probably, and it's a little hard to see on a small device.

DR. DANIELS: There you are.

DR. JOHNSON: I thought I had unmuted myself on the phone, but I guess I hadn't. So, I think what I'm going to say has been said a little bit already by several folks. But one of the things that certainly came to the forefront with COVID was just overall access to care and qualities that are used in making medical decisions. And so, I think there's a lot of emerging work that's going on around the use of quality-of-life indicators, as it relates to medical decision making, and the discrimination and ableism that occurs within all of that. So, I think it's important that the strategic plan includes those kinds of issues. And Dena was talking a little bit about just the home and community-based service system and how it was really impacted by the pandemic. And it was an infrastructure that already had some issues, but certainly COVID really, truly impacted all parts of HCBS. But we've also seen some really good things emerging from the pandemic as a result of the impact that it had on home and community-based services. So, for example, we saw providers completely transform the way that they're providing services and support.

And so, I think it's worth looking at not only the impact of COVID on the HCBS infrastructure, but also what has been emerging, as more efficient and better ways of doing services and support. The other thing I think it's important to look at is we certainly knew that people with disabilities were at greater risk of being institutionalized for a variety of reasons as a result of the pandemic.

I think it's important to know where folks are, and if we saw increases and institutional settings for people, or whether it's slowed. We think it slowed the movement of people out of institutional settings but understanding that I think is important as well. And then the last thing is just that we know that all disasters and emergencies require local responses and state responses and it's all going to vary based on that local system and state system, and we also know that it really requires a lot of partnerships to address the needs of people with disabilities.

So, the extent to which we can incorporate those kinds of things and highlight that, highlight where it was working or the need for that, or any support that we can give for the partnerships to be there at the local and state level, to make sure that people with disabilities are included in any kind of disaster. We saw that where those relationships existed, either at the local or the state level really helped either that local area or the state overall to better respond to the needs of people with disabilities.

DR. DANIELS: Thank you, Jennifer. And I

know that we also have some federal coordination around disaster planning and people with disabilities as well, that will mention. We're going to add a section that will be about coordination efforts. Because there as we know, from our IACC meetings, and I've been trying to give out reports on all the different FACA committees that are meeting that we also have some work being done on preparedness. So, we certainly can add that into this section. So, thank you for that. Next, I'll go to Lindsey Nebeker.

MS. NEBEKER: Hi, yes, I think this was actually starting to be brought up already. But I was taking a look at this document here, and there's very little mention or emphasis that talks about accessibility to COVID vaccines and treatment, as well as vaccine education. I think that started to be brushed on and I would support the idea of including a part in it about collaborative efforts that are being made to improve those efforts. I see more emphasis in here about how we need to address the long-term effects of the pandemic on mental health and loneliness and depression and so forth. But I also wish that we can see an additional mention of how can we make the experience of getting treatment for COVID or getting a COVID vaccine more accessible or more accommodating for the individual. And then also addressing how there are individuals with higher support needs who are community based living programs, who might be considered on the first category of being able to qualify to get a booster vaccine, but the accessibility to making those appointments, there's so many loopholes that are involved with that to make an appointment with, to go into a pharmacy, get it.

They have to actually schedule time where they can actually go outside to do it. And so, it makes it more difficult for a group which has high vulnerability that should have easier access to it. So, that was just kind of my point I wanted to bring up. I know that the Autism Society of America has put out the Vaccine Education Initiative. And some of that facility affiliates have hosted sensory friendly vaccine clinics for kids and their families. And then we've also created some resource materials like health care communication boards and social stories that are related to learning about COVID and the vaccine safety as well as the experience and access to it.

DR. DANIELS: Thank you, Lindsey. That is great that we could mention that. I think it was meant to be a part of vaccine distribution and uptake. Certainly there are a lot of organizations that tried to create sensory friendly vaccination and so forth. And there are learnings from that, and I believe ASAN also put out some pretty useful information for people with disabilities about getting vaccinated and COVID-19 mitigation.

So, thank you. We can certainly increase the information that we have about that in the plan. So, I will go to Sam next in case ASAN have anything else to say about that or anything else that you wanted to mention.

MS. CRANE: I'm not at ASAN anymore.

DR. DANIELS: I know you are. But I know that you know all about what they're doing.

MS. CRANE: They're doing some really great work. And I absolutely recommend that people check out their resources, many of which are in plain language on the importance of vaccination. I sent this into the text comment too. So, please feel free to just not read that aloud. But I want to talk about the effects of long COVID and long term COVID on our population.

Especially because our population tends to have a lot of co-occurring diagnoses, I really think it would be worth researching whether or not we're more likely to experience long COVID. And also whether or not there are differences and how long COVID manifests in autistic people. There might also be differences in how to detect long

COVID, especially in people who are non-speaking and might not necessarily be able to describe their symptoms. I know anecdotally, there seems to be a pretty significant long COVID sort of outbreak among autistic people, many of whom already struggled with chronic fatigue and chronic pain. So, I think it's really worth researching.

DR. DANIELS: Thank you, Sam, for those comments. That's great to think about that too, with long COVID. And I think we had a brief mention but could certainly encourage research in that area. Ivanova.

MS. SMITH: I don't know why that happened. I apologize.

DR. DANIELS: It's okay. Not a problem. Scott.

DR. ROBERTSON: I'm glad that Sam brought up long COVID. Because I think we should have extensive mention on that because it's a major priority as you're in the federal government. Long COVID is now recognized as a disability under the ADA and other laws.

Federal agencies and the White House have emphasized long COVID in the last year, year and a half. And we have discussed it extensively here, for instance, at the Department of Labor. And I think if we could expose to that a little bit. I can get you some citations if that would be helpful,

Susan, as far as the focus here across the government for long COVID. I know you probably already have some citations also at NIH or HSS, overall. And I think trauma on here, too. There's trauma and burnout and just exhaustion. I know among the general population in America and worldwide. But I think it's been even greater in terms of impact for folks who say that they get disabilities, including autistic people, and the transition back to quote unquote, normal life or something has been hard for a lot of us, given that emotional impact over the last couple of years. It's been very difficult on our systems, as far as neurological cognitive, transitioning back to general social life, whatever that is.

I know it's still going to be different than 2019. But I think that's really important that transition process for folks and what it means for future health emergencies. And we should have accessibility and resources on disability more broadly. And maybe for autistic people on preparation for health emergencies and including future potential. I hate to say this, but potential future pandemics beyond COVID. This might happen again, and If so, we should be prepared for that and more ready than we were in 2020 in terms of not ready at all, and certainly not ready at on disability. And what was mentioned, on access to vaccines, just other outreach for COVID. I think we've had a lot of misses for that. I know, even just receiving the vaccines was hard for folks, transportation access at times during the course of the pandemic.

I mean, there's a lot of lessons learned on there. And a lot of people with disability, we don't drive. So, getting out to someplace that's really far away in the middle of the day or whatever was just hard to do at times. And I don't think that folks running the systems, I know they meant well, but didn't understand there's barriers at times. And the hotlines were not really well trained on disability and clinics specifically with disabilities like autism.

So, I think it's something utmost importance and I think just the lessons learned on COVID-19, post COVID-19. The research literature has some literature on autism and COVID, but not as much as you would have expected, given how much has impacted us in American worldwide over the last two and a half years. The research literature is not nearly as extensive as it should be. I don't know whether NIH has any space to prioritize that as something. I don't know if that could be put in the plan as far as a priority thread, if you will, for post COVID and for future health emergencies, is more research in that area, the impact on lived experience. And the positive impacts to as was mentioned by Jennifer. In some cases is open doors too.

So, I think there should be a balance that at times, teleworking has been helpful folks for the workplace, telehealth. So, I think some autistic people prefer things virtually or prefer hybrid. Some folks thrive a lot better by in person. So, I think that's something that we've also learned and are learning through the pandemic, that technology can be more empowering to folks, especially since they don't have to deal sometimes with a sensor environment of the physical space at times and other barriers, where you can control things sometimes at home or on your own online technology. But that doesn't work for some other folks as much, right?

So, I think keeping that in mind for autistic people, what we're learning on the balance point for COVID-19, on how much things have changed, and the impact that autistic people. And that's not been researched really at all, is the in terms of the benefits during this period, and what we've learned and how empowering it should be from the [inaudible] for autistic people, and more on these barriers, as they say, on mental health long term, what it's going to mean for the impact, how to support folks when they have traumatic memories from this period, and things like that, and how to treat folks respectfully with the impact it's had on disrupting, lives disrupting services access, as was mentioned, on Medicaid, home and community based services.

I forgot to mention that in the earlier services sections, but I think if you can have a little bit, it brings to mind a little bit expansion in terms of on Medicaid HCBS, for that plan anyway, and there's some other citations I could send. But I think that impact for autistic people on access to HCBS and other supports in the community and what that's meant, is really important to have in there. That's really critically an emotional focus in terms of that disruption on supports and disruption on just as much as disruption on education is important for the pandemic.

But I think it's a good start from what's in here. I think they're just going to be expanded a little bit. And I think we do have citations for some of these focuses, at least. I know that burnout trauma kind of area, that's going to be a place where, I don't even know whether I can get you a report on that online. I'll see if there's anything that we can cite down there. And some of those are just gaps that have just been missed by researchers.

DR. DANIELS: Especially if you have anything on the benefits of say, remote work or remote communication, that would be great. And I know that we asked earlier for any citations that have to do with telehealth and how that's been utilized. But that's a good point to bring up the positives. I know that the Simons Foundation, the spark report, one of their reports mentioned some of the positive.

DR. ROBERTSON: Can it be cross disability? At times if we don't have autism, are you able to sometimes cite cross disability ones?

DR. DANIELS: We can cite things that go across disabilities and that applies to autism as well. So, Steven, do you have a written comment?

MR. ISAACSON: Good afternoon. This is a comment question from Yetta Myrick. The first one is, is there anything about the loss of caregivers due to COVID-19 as it relates to supports of autistic individuals? Next comment is asking about anything about how school closures have impacted autistic students' progress. And then the last question is anything on telehealth?

DR. DANIELS: So, I know we had plans to include things about telehealth and the impact of what's happened with schools and access to education. But I don't think we have any information about the loss of caregivers. If you have any resources on that, send it to us. But I'm sure that that has had an impact on many people. Dena, do you have a comment?

MS. GASSNER: I was just going to bring up the loss of special education services throughout the lockdown. And the students who because of co-occurring conditions can still not return to school because we lifted the mask mandate, how we're going to address their last educational opportunities.

DR. DANIELS: Definitely, that is an important one that we will be sure to address. So, any other final comments, or is there anybody that has not spoken so far? And Scott, I don't know if your hand is still up, or I think your hand was still up. Is there anybody who has not had a chance to talk today or talk yesterday, that has a comment about any of these topics?

DR. DANIELS: Anything else on COVID-19

or any other topics?

DR. DANIELS: So, it sounds like we've probably covered it. Was there something else that someone wants to share?

MS. SMITH: It had a little thing that's told me to unmute. I don't know, if somebody wanted me to unmute or not, maybe? I will say that I just am really passionate about making so that we don't read traumatize people. And we help people heal from this traumatic experience.

DR. DANIELS: Thank you, Ivanova. So, that's a good note to end on with COVID-19.

DR. DANIELS: Scott, do you have another comment?

DR. ROBERTSON: Just briefly, when you asked that about anything else that just also brought to mind to for me -- sorry, I don't have my camera -- I think it relates to COVID-19 but maybe some of these other areas, is cognitive accessibility of information resources too. That it's written in a way where it makes sense to folks in more plain

English, direct English, the direct language. It's an issue for COVID-19. And it's an issue for some of these other focuses is that a lot of materials, frankly, are not accessible to autistic people and folks with other cognitive disabilities. And I think if we could put that in here, or maybe also other parts, a plan that needs to be more focused on that cognitive accessibility area for materials and lay summaries and things like that, in research. And when we engage in projects, I think it's sometimes this extra barrier as far as access, and then folks just don't, they don't get the big picture kind of on that. And then they're confused why they can't get diverse samples, or folks are just not understanding things. And they don't realize that sometimes they're writing these 90-word sentences that are full of complex lingo that just create extra challenges for folks to access. That we need to make more strides on that as far as making sure when we write material, so documents are accessible to folks.

That we distill things down and add in the layer place language summaries to make sure that folks can have equal access to information. That's been under studied too, as far as the autism research community. And they've made a lot of assumptions about how they present information at times. And there's almost like a, I hate to say it like this, like gatekeeping kind of ailment type too. But I don't think it's always intentionally, but it comes out like that, that by use of, of certain forms of complex language, they're sort of restricting the ability for folks to have access to information and resources. And I think sometimes folks just need to have more awareness and understanding that that's an issue out there and make some strides on that for, again, lay summaries, plainer language, and supporting that cognitive access for folks who may think differently, learn differently versus for folks with intellectual disability, especially having equal access to information materials.

DR. DANIELS: Thank you, that's very important point and a cross cutting point that has gone through various aspects of what we've discussed today. And now our team's job to try to distill some of this information and get it into a format that's readable and understandable. And as you can tell, those of you who've been with us these past two days, we've covered a lot of territory and there was already quite a bit in the plan. But we're going to be able to try to distill some of it down so that it can be presented in an understandable way for people to access. So, thank you for bringing that up. And Steven, I saw you had a hand raised but did that get resolved or is there anything else?

MR. ISAACSON: I just want to make note of a couple of references that Mitchell Berger put in the chat.

DR. DANIELS: Thank you. Do you want to mention what the topics are?

MR. ISAACSON: If Mitchell is still on, he can, but there's one from Autism Speaks about a survey that reveals widespread challenges in the autism community and water disparities. And then there is a journal article from Springer that talks about autism and caregiver impact from COVID-19.

DR. DANIELS: Thank you. So, Great work everyone on sharing all this feedback. This is really helpful to hear from you about this. And it will give us a lot of additional information that we can try to work into the draft. So, as you know, the strategic plan is an advisory document. And we are going to be using the feedback that you've shared today to help us revise it. So, the next steps are feedback that we've collected, we will try to incorporate that into what we have and revise it and also make it into more of a plain language format. And IACC members after today, are going to receive a survey that we'll share with you some of the wording for the mission and vision statement. We combine that into one because the separate mission and vision sounded like they overlapped. And so, they were just combined into one. And a revised set of core values that reflect some of the kinds of things that we've talked about over the last year as a committee trying to capture some of the ethos of this committee and what you'd like to see.

I think that we hadn't actually revised the core values in quite a few years. So, we have a revised set of those. And we will provide the question text and the aspirational goal text and give you an opportunity to review those and make any comments. And you can also provide us comments on the drafts that are out there, if you have any. We didn't provide Word documents for everybody to do line edits because getting line edits from 44 people would just be a little bit overwhelming and perhaps not a productive way to go. But you've all had an opportunity to share some of your most important areas today and yesterday in our meetings.

So, a lot of the points that you wanted to make you've made. But if you see additional things that you would like to point out, or if you want to send us references, you'll have a space in the survey that you can send those to us. And we'll use it to revise the draft so that it's even more reflective of the thoughts and ideas of this committee. And we will send it to you at the beginning of October in preparation for our meeting on October 26, which will be either a hybrid meeting where the committee will be in person and our audience will be on virtual or it will be all virtual. And we're just not really sure what space might be available and what kinds of restrictions there might be.

So, we can't say yet as to whether it's going to be in person or virtual. But if it is in person, only the committee will be in the room because the committee is already large. And there are some space restrictions now due to COVID. And we will discuss the plan in October. And we hope that it's in shape that perhaps the committee might be able to approve it with some changes. And if for some reason it's not, we will plan from there how to get it approved. We would love to get it out this calendar year so that it can be completed by then. But at the latest, we want to get it out at the very beginning of 2023. Because we want it to be out there and effective and being used by the agencies and other organizations.

MS. GASSNER: I just want to thank you, Susan and your team. This was a very productive process. And I appreciated the support and the organization. Thanks.

DR. DANIELS: Thank you. I feel like it's been a great meeting in terms of your participation. Everybody has been very forthcoming with your thoughts and ideas and helpful with references. And I appreciate that everyone's been really respectful of time and trying to take turns so that we can hear from everyone that wanted to speak. But of course, we will have a written opportunity. I know some people like to reflect a little bit more.

So, we'll be sending you that survey. I also will be sending you information about the 2021 summary of advances which at the April meeting, we didn't get through talking about all the submitted nominations and whether you had any feedback on them. So, we're going to take those via email and put them into a format so you can see them when you vote. And we will also share those documents on our website so that the public has access because we didn't really want to wait until the October meeting to move forward on it. So, you'll be receiving that as well to fill out.

So, with that I'd also like to say thank you to the OARC staff for all their help in putting this meeting together. There was a lot of work behind the scenes preparing the drafts, preparing the slides, and just sitting and discussing all of these issues in a lot of detail to try to capture what we think is new, based on some of the discussions that we've had with you and discussions we've had with federal agencies. And so, I really appreciate all the work that's gone into all of this -- and the website. So, thank you to the staff, thank you to the Rose Lee and Associates team that is our new contractor that will be supporting IACC meetings, and to NIH videocast, for helping us with broadcasting this so people in the public could access it, and it'll be recorded and put up on the web for everyone to access.

So, I am wishing everyone a great summer. I hope everyone is able to get a little bit of rest and relaxation over the summer, although I know that we're all very busy and working on a lot of important issues. But I hope that people will take time for your family, friends, and some time for yourself. And are there any last comments before we complete our meeting for today?

Scott.

DR. ROBERTSON: Yeah, I just want to say, Susan, thank you all, at NIH for spearheading the work of the committee and this workgroup session over yesterday, and today. I know it's very complex, as far as a lot of different diverse thoughts and ideas. And you all do amazing job of putting this all together and taking input from different diverse viewpoints and bring that together to help enhance the strategic plan. So, I hope you all know -- I don't want to speak for others, but I know my end we've definitely very value you all as a sister agency and the work you all do for the coordination here of the committee and how important it is to our stakeholders out there. The work that we do with the IACC and the effort that's put into helping shape this strategic plan, and the impact it has for folks. I'm not sure if everyone always understands that when they see the plan and then some other documents come out that the tremendous work that goes into this and the work that you all do behind the scenes to make all this happen and to make the trains run, if you will, run smoothly for this process. And I'm very glad that this has worked so well and appreciate the opportunity to give input. And I'll be sending you some, as I say some more citations and literature. And feel free, especially on the social science end, I've pretty extensive academic access. So, I'd be happy to -- anything you need a full text for, we'll get you.

DR. DANIELS: Thank you so much. And we really appreciate the partnership of all our sister agencies and all the members of our committee, people in the stakeholder community that have been really thoughtful about sharing input with us and every single member of the committee who's spoken the last couple of days and shared your thoughts, we really value and appreciate everything you shared. It was all very important. And we hope to do justice to your ideas and get them included in the plan. So, thank you so much for your attendance and patience and participation. We just really applaud you for your work. So, thank you and have a wonderful afternoon. Goodbye, everybody.

DR. RIVERA: Thank you, Susan. Thanks, everyone.

DR. ROBERTSON: Thanks everyone. Have a good summer and see all hybrid or in person, whatever the October session looks like.

DR. DANIELS: We will let you know for sure. We'll reach out in the fall with instructions.

DR. DANIELS: Thanks, everyone. Goodbye.

DR. ROBERTSON: Thanks.

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