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(Music plays)

JUSTICE SHORTER:

Welcome, everyone! Good morning or good afternoon, depending where you are joining us from. It is a pleasure to be in conversation with you this afternoon and to welcome you to decoding discrimination 2023! Today's event is brought to you by the national disability rights network, Foundations For Divergent Minds, and the Johns Hopkins disability health research Center.

We would, of course, like to extend or extreme appreciations to the (unknown term) foundation and the grant funding that has given this initiative in second year. With that, let us do a quick round of introductions, because we have to get acknowledgment to the Team who helped put the spectacular events together today, as we talk about the disproportional ways that people of color, and folks with developmental and intellectual disabilities... And this includes the ways in which this has caused harm to people with intellectual and developmental disabilities. I will introduce my partner, Morenike.

MORENIKE GIWA ONAIWU:

Hello, thank you so much for joining us today. My name is Morenike Giwa Onaiwu and my pronouns are she/her. I am coming from the Foundations For Divergent Minds which facilitates equity for everyone through programs in education. I am a dark skinned African American non-binary woman, with my camera off, wearing a shirt that says (indiscernible).

JUSTICE SHORTER:

(Laughs) thank you for being with me in partnership... We appreciate you as you and I coordinated and co-facilitate today's event. Also, anybody who is not comfortable being on camera, you do not have to turn them on for any reason unless that is something you choose to do.

Also, if you have any accommodation needs feel free to recheck to Devon, who is part of our behind the scenes team, in addition to (indiscernible). If you see their names amongst the list of the participants, please reach out to them at any time if you have a request for something you need. We want to make sure we address that in real time, as opposed to waiting until the event is over. Want you to engage and watch her participation.

With that being said, we have another person from the Foundations For Divergent Minds: Oswin is here for us today, would you like to come off me and said hello?

OSWIN LATIMER:

Thank you, I and a light-skinned (unknown term) Two-Spirit person. I am wearing a green button up shirt, tinted dark glasses and I have shelves behind me that have various toys on it. I am very happy to be here today, to do this for the second year in a row. It was great last year and I am really hoping to find more information about how people are experiencing things since.

JUSTICE SHORTER:

Last but not least, another phenomenal team member is Dr. Bonnielin Swenor.

BONNIELIN SWENOR:

Thank you so much, Justice. I am also grateful to be included in this. I am the director of the Johns Hopkins disability health research Center, and I am a (indiscernible) woman with light brown hair in my office here in Baltimore. I am excited about this conversation.

JUSTICE SHORTER:

Please tell us more about this time we are in. We have strategically (indiscernible) one week after the health emergency has ended, for the pandemic. I would love to get your thoughts if you could give us some perspective as to things you have noticed in your work, which quite literally is rooted in disability health research.

Can you tell us about anything you have noticed since we have done this event since last year? And any reflections you might want to share given the time we are in?

BONNIELIN SWENOR:

Thank you so much. I really do think this is a critical moment. I will start by saying as a public health professional I recognize that the public health emergency has been declared to be over, but this is certainly not the end of the emergency for disability community.

My center is working to connect disability justice to (unknown term) and that certainly feels much-needed these days. (Indiscernible) is increased focus and COVID 19 and we hope it continues to be so.

... We hope there is continued condensation and movement around using data in more community-centered ways. Working on understanding the urgency to collect better disability data so that we can make better policy decisions, recognize the value of people with disabilities being a part of these discussions. Quite simply, what was in the Center, in order to count, we must all be counted.

That being said, that is just a snapshot. It is so critical for stories that we will have shared with us today, that lies with disabilities are part of the discussion. And it is more important that we center on those who are experiencing (indiscernible) oppression, people of color and recognizing this is where we need to do our work.... I want to thank Justice, Morenike and everyone here for sharing in this event.

JUSTICE SHORTER:

Thank you so much. It reminds us why this event, during this time and during this phase of the ongoing pandemic is so critical for the health, wellness, safety and dignity for people with disabilities, and in general people of color with disabilities. A lot of our conversations today will center around intellectual and developmental disabilities.

To give people a quick snapshot of how we will interact with each other today, we are going to have 2 panel discussions. They are going to feature the voices, the perspectives of advocates, professional folks who have really been deeply connected to these issues, so that we can really start off hearing the voices of those most impacted and work alongside those most impacted.

Once we finish those 2 panels, we will get into the centerpiece of our time today. That is a roundtable discussion. All of the attendees here will be randomly placed into a small breakout room. And all of you, our attendees, can come off mute to share your ideas, your insights, your stories, your reflections. This is what we are hoping to gather while you're together today.

We want to get a sense of any words, phrases, or examples of language you have that has been discriminatory or harmful. We created a resource (indiscernible) last year and we can put that resource into the chat. This year we want to update it. Those types of resources should never set in stone, they should be updated because the times continue to change. We want to make sure the resources are reflective of those changes.

So, our purposes for the roundtable later on during the session today will be an opportunity for people to contribute any of those words or phrases, anything they may have noticed - policies or things you may have noticed in practices or official comments or commentary about the pandemic. If there are examples you want to provide, that is the place to do it. We will do that during the roundtable that will happen to were the second half of our time today.

After that, we will come out of the roundtable to this main room and there will be opportunities for share out. There will be moderators in each room and the moderators will share out the wonderful things you have shared in your smaller spaces. We will have extensive time for Q&A if people have more questions or if you hope to have follow-up information if we do not have all the answers.

If there's an opportunity to point you in the right direction, that is our goal. So that is how things will go this afternoon. With that being said, let us get into the voices of the people. We want to start here with the powerful message from Robert Baums who is a self advocate coming from New York. He has a lovely message and was unable to join us in person, but he has a message and he wanted to start us out here today. This is what he had to say.

(Captioned Video plays)

JUSTICE SHORTER:

Morenike, I love this video so much! It is a wonderful way to ground us and I also wanted to point out that Morenike has been putting various resources into the chat. As we go today, we will be having a wide variety of different resources, fact sheet about public health, emergency, all of that will be posted the chat as well to provide you with additional information and resources that may help you spearheading your advocacy, directing or advocacy.

Morenike, I love that video! It's a wonderful start to our conversation here today!

MORENIKE GIWA ONAIWU:

It is! For visual description, Robert is an African-American male of dark skin wearing a shirt and grey pants who is sitting on a sofa in his living room. It was an amazing beginning to do -- kick us off because we have awesome panelists here with us today to continue discussing these points he brought up so poignantly.

JUSTICE SHORTER:

Absolutely. With that said, let's get into our first panel here today. Which will feature advocates Sacheen and Heidi and I am going to let them define and introduce themselves for themselves. With that being said, Heidi, would you like to introduce yourself?

HEIDI LIEB-WILLIAMS:

Can you guys hear me?

JUSTICE SHORTER:

Yes, you sound grateful

HEIDI LIEB-WILLIAMS:

-- My name is Heidi and I live in Anchorage, Alaska. I'm currently in Seattle today at the hospital because I just had spinal cord surgery. I am white and Cherokee Indian mixed. I have straight, dark hair and olive skin. I have a unique perspective as the oldest child in a family of 10. Five of which are African-American and Filipino mixed. I also have two black southern mamas that I was raised with, so I am familiar with being raised in a family with multi ethnic backgrounds.

I identify as an autistic person who is hard of hearing and functionally deaf. -- Deaf with five other physical and mental diagnoses. I am a chair of lasting governors Council on disabilities -- Alaska's governor Council on disabilities and special education. However, today I am not speaking on their behalf. Today I am speaking as a disability self advocate.

Hopefully this brings different perspective that you might not have heard before. Take you.

JUSTICE SHORTER:

Hopefully it does indeed. Thank you so much for that lovely introduction. Sacheen, over to you, dear. Can you introduce yourself to the group?

SACHEEN SMITH:

Hello! (Speaks Indigenous language) Hello! My name is Sacheen Smith and I am DNA and I just introduce myself in my DNA language and I talked about my clans after lineal society and my mom's clan is Sanja can, and we go down our lineage. I just wanted to let you know, I am Indigenous, lesbian, and I am also blind. I became blind my freshman year of college and so during that time I learned how to self advocate. So I have become passionate with advocacy.

I am also an artist. My hair is dark brown and long. I am brown skin. I am wearing a black and white top with I guess some geometric designs and I am wearing a turquoise nugget necklace that was

handed down from my grandmother. Thank you.

JUSTICE SHORTER:

Thank you so much for joining us! This is justice. Sacheen, let me go ahead and start with you. CDC just released some new guidance last week on the importance of ventilated spaces. Taking sure the air around you is properly ventilated, in constant motion, in an effort to remove germs things in the air that may make you sick.

The issue is that they list -- released this information that was around ventilation but it was only for physical structures, buildings, and did not include any additional details about vehicle. I wanted to bring this up because you have raised the issue in your advocacy around paratransit. Often in those vehicles, riders are not able to open the windows and if the driver does not open the windows and if the AC unit is broken, it creates quite stuffy conditions and also causes, perhaps, terms to continue to be circulated within the vehicles that have multiple passengers from around the city as people are being picked up and dropped off or rides.

Can you talk a little bit more around your advocacy trying to make sure that transportation options remain safe for people with disabilities?

SACHEEN SMITH:

Yes, I started advocating for safe transportation that actually started when the pandemic hits New Mexico. I remember, it was March 2020 and hearing COVID had hit other states, it had not hit New Mexico yet. I was on the Fan on the Parent -- the Son Van on the Paratransit Service and I knew the driver and we were talking about COVID and the pandemic and I had asked them at that point, and I believe that it was around March 10, if they had heard from the driver's perspective, if they had any protocol implemented from the city from the director of paratransit services.

He said he had not. So we were discussing about how hazardous it would be for individuals with disabilities because half the time the air conditioning units don't operate and it is very stuffy and with me, I live on the outskirts of Albuquerque. So when I get paratransit rides I am usually on there with at least five or six other individuals and I'm usually the last one being dropped off because I live the farthest out. So I am usually on there for about 1 to 2 hours at times. So I had huge concerns.

The next week is when COVID hit New Mexico so then I was making calls and I was calling the city, I was calling the Governor's office, the congresswoman's office. And nobody had anything for me. I kept leaving messages and wasn't getting any calls return. At that point, I had asked my friends and family to start making calls as well because I knew it was going to be very important for us to have some sort of COVID protocols in order to keep our Disabled community and elderly safe during this period, because I've had a lot of experiences on Sunman, paratransit in Albuquerque. In some other states.

Finally, we were able to get a hold of the director of sun Van paratransit and they said the only thing they had implemented at that point was they informed the drivers to clean their vans more, and that was it. And they were cleaning the vans at night as well after all the services ended. And I said, "so, you don't have any protocol of cleaning the vans after people get on and off? You don't have any

protocol of having less patrons on the sun van?" Because I told them of my personal experience is being on the van for an hour and a half to two hours at times, depending on where I was and how many people they picked up and dropped off on the way to drop me off.

Then of course the windows don't open, so she said they would discuss it further and then I had contacted the Governor's office and talked with her personnel about my issues and experiences with son Van as well and after that, I heard on the news that they had implemented some sort of cleaning, but I never heard anything about what they were going to do with the ventilation systems because I know half the time they don't work. So I don't even know if that was ever resolved.

JUSTICE SHORTER:

If it was ever addressed, yes. Sacheen yes. Then during the pandemic --

SACHEEN SMITH:

And then during the pandemic my friend started giving me rightly as they didn't want me on the paratransit service will stop

JUSTICE SHORTER:

Thank you for sharing your story. So many of us use alternative modes of transit. Morenike, I think you had a question here related to the various needs you have in serving our families and showing up for other folks. We don't just receive care, we also provided and having access to resources and the reports of the city is important!

MORENIKE GIWA ONAIWU:

Absolutely justice! What Sacheen was saying really hit hard. Heidi, I wanted to bring you, with that, because the king about those of us who have intellectual and develop mental disabilities such as myself and yourself and several of us who are here, a lot of people see us as people who receive care. They forget about the fact that we don't just receive care, we also provide care (Laughs) We are caregivers!

And I think there have been words, rules, his phrases, that have caused problems for caregivers with IDD in general but particularly in the pandemic. But if you can weigh and I would love to hear your thoughts on this.

HEIDI LIEB-WILLIAMS:

Thank you. First of all, I just wanted to clarify that when people's AIDD, it is a person with intellectual and developmental disabilities. Just so people know why we are saying a shorter version of that. --

MORENIKE GIWA ONAIWU:

Thank you Heidi, that's correct.

HEIDI LIEB-WILLIAMS:

During the pandemic, it was extremely difficult for caregivers because they were not allowed to enter medical facilities with their individual. It came to a point where you could not be present with the

individual with disabilities even if you are a direct service provider. What people failed to realize is that this impacted people with disabilities so greatly that their healthcare services were being abandoned.

For example, if they were physically unable to wear a mask, then their caregiver was not able to take them along into a store, making it impossible for the basic needs such as food, hygiene products, and getting medication. Another important issue was that often people with disabilities have a hard time making health care decisions. When presented with information that was confusing to them.

And without a caregiver or an advocate by their side, communication became an obstacle. Ed prevented necessary future options from taking place. COVID made it extremely hard because the barriers created were not made in consideration with those disabilities. In Alaska, I was part of creating COVID emergency packets to include resources like flyers and cue cards, making them available to educate others about the reasons for people with hidden disabilities. Often having difficulties wearing masks.

And so, I was thinking please don't judge or jump to an assumption of defiance or disrespect from people with disabilities when you cannot wear masks. And I kind of wanted to build a little off if that is OK, on a tangent, or what I call an autism tangent. That is, with people with autism, when you are required to wear a mask, for me, I can't wear things behind my ears. I have had hundreds of years surgeries and then with the autism, it is a sensory issue.

And it also makes you feel like you are going to hyperventilate, which causes breathing issues. So I have to wear a special kind of mask if they don't accommodate the fact that I have trouble wearing them. Even here in the hospital, I am dealing with that issue still. Because Washington hospitals are still on COVID policies. That said, thank you.

JUSTICE SHORTER:

And we know that hospitals are rolling back protections in terms of color. We also know that the protections that workplaces had in place for the pandemic being rolled back as well. Such as the options remotely, and the options and considerations around making sure there is consistent sanitation practices and hygiene practices. These things are winding down, consistently.

Sacheen, I want to bring you back in here, but I would like to hear your tips and suggestions for why it is so important to make sure that people with disabilities still retain a lot of the options that they had in the pandemic, as it relates to workplace protections.

SACHEEN SMITH:

I think many workplaces have been designed without disabilities in mind, giving little thought to the ways individuals with disabilities navigate life in the workplace. For me, sanitation is important because a lot of individuals with disabilities have multiple health issues, along with their core disability.

I know, for me, my concerns are with being a cancer survivor and having asthma. During the time I was employed in the course of the pandemic, I was very concerned with COVID. I would spray Lysol in my office before people would arrive, and I have somebody tell me that she was allergic to Lysol even

though we had Lysol bottles throughout the building.

We had facemasks in the building... I would wear mine all the time, and I would eat my lunch in my office with my mascot. People would come in without wearing their masks, without giving me the time to put mine on.

... During Thanksgiving we had a luncheon, and I was told to be part of the team I had to attend. I and up getting sick and getting a respiratory infection. During that time, I asked if I could work part-time from home and go in part-time. I was only 4 days a week. So I did that, stayed at home for two days and went into the office for two days. But the executive directors that there was a perfectly good office space not being utilized, so a week after that I was fired.

For me, sanitation is important because I cannot see, so I cannot see if a person is waving their hand on their nose or just different things. For me, I was very cautious with sanitation, always having hand sanitizer on hand and wearing my facemask more than I needed to, sometimes I double face masked!

But I think it is important because there is just so many different barriers. The part of working from home, like there are professional barriers and obstacles that have become the norm. Remote work options have many benefits for individuals with disabilities. I know that transportation would totally help, because with me when I use the paratransit service, I am usually on their 40 1 1/2 to 2 hours.

If I worked solely from home, I would have 4 hours of my life that I would be able to get other things done. Along with that, there is navigating public transportation. If you ride the bus, it is not always disabled-friendly. Then there are accommodations, more disability friendly work environments.

When we work from home, our homes are already curated to meet our needs and our particular lifestyles. When you go into an office, they are not always like that because it is more for non-disabled people. Working from home removes distractions as well.

JUSTICE SHORTER:

I want to point out something you said, a coded phrase which is "not being a team player". That is an example of language that is used sometimes to force people to comply or to make people feel uncomfortable so that they make decisions they otherwise would not be comfortable making. For example, you didn't want to participate in the group activity in the way it was set up. But you were told that you would be a "team player". We have seen this linger before. You are not a team player, you are not working with the spirit of collaboration. If you do not conform, somehow you are the problem. In sessions case, this is being used to punish an employee as well.

MORENIKE GIWA ONAIWU:

Absolutely, it is horrible. And then even more ironic is your concerns were valid because you didn't get sick!

JUSTICE SHORTER:

Absolutely. I know you have another question Morenike, so I don't want to take you away from that

one.

MORENIKE GIWA ONAIWU:

This is a question for Heidi, because we are talking about the fact that some people are ashamed or what have you for wanting to keep themselves safe. One way that people have been trying to keep themselves safe, as well as just generally having accessibility that works for us, is telehealth access. Heidi, I know this is something you have been concerned about. I would like to briefly share how telehealth helps to reduce discrimination for people with disabilities.

I think you are muted.

HEIDI LIEB-WILLIAMS:

Sorry about that. The telehealth campaign that sparked up during COVID 19 was revolutionary in helping patients with disabilities to have access to healthcare, not only in their state but out of state as well. Follow-up appointments could be made easily sitting home on Monday.

Often the logistics of being transported to an appointment (indiscernible) for people with disabilities. Transportation resources are not always available so telehealth removed that issue entirely. For appointments, doctors are often rushed due to time constraints. And then they get frustrated with people with disabilities who might have more concerns or take longer to communicate what is needed for the next steps.

People with disabilities are also discriminated against or dismissed based on physical appearances, limitations, and automatic judgments of their capabilities. With telehealth, longer medical appointments can help people to remain in their home environments, for doctors to better assist the needs of patients and caregivers.

If I may add something as an example? People with autism are autistic. If a doctor wants to evaluate that person, it is best to keep them in their natural home environment. Which would be through telehealth. In order to see what is more realistic things that are going on in their daily, everyday life.

When you pull a person out of that, to even go in to a doctors appointment, it changes how things come across for the needs, because we are somewhere else and that someone else may be causing behavioral issues or behavioral issues that you do not see when they leave the office.

So, that is why I feel like if we have learned anything with telehealth, we should be keeping it instead of getting rid of it.

JUSTICE SHORTER:

Absolutely, Morenike has provided some fact sheets that give you a bit more information about the course of how things are going to happen over the next months as the positions in terms of: resources available, when this will, of all things will continue. Because our short today, we cannot get into detail, we really wanted to center the voice and advocate like Heidi, Osman and Sacheen.

We are going to gear up for our next panel in just a second, but I want to ask you quickly: do you guys have any closing words that you would like to say for other cell advocates?

SACHEEN SMITH:

I would say just continue to be a voice. I know it is hard sometimes. I know, for me, it is emotionally draining to try to advocate for yourself for, for me it is been the last 20 years.

But I have gotten so many comments like "get over it", and "you people", it is disheartening at times. But there is always perseverance to keep moving forward and keep doing the work. And as (Unknown name) always tells me: go forward and keep fighting!

JUSTICE SHORTER:

Powerful words. Appreciation for you, Sacheen. Heidi, do you have a short note of advice for other advocates as well?

HEIDI LIEB-WILLIAMS:

Yes, thank you very much. The first and most important piece of advice that I can get is for you to understand that you do have a voice. And even if you have to repeat yourself five or six times you need to stand up for yourself! So that you feel like you are being heard. No one has to write -- the right to make you feel you shouldn't be heard.

For example, the other day something was poking me in the neck. I continue to repeat this, but everybody kept dismissing this as pain in my incision area. But, it turned out that when I got the with a new neck brace, the old one had the back piece on upside down and it was pushing against the incision in my skull. That is one example of people speaking up when you know something about yourself!

JUSTICE SHORTER:

Absolutely, such a strong point.

HEIDI LIEB-WILLIAMS:

And protect yourself.... Take and advocate for someone with you to all appointments. Be sure the advocate hears an understanding thing information that you do so you can make the right decision. There are advocacy support groups that you can participate in and then (indiscernible) alongside parents, educators and professionals.

I recommend you take training to become a person who can help others, which is where I am not in my life being a national speaker/self advocate.

JUSTICE SHORTER:

You have done such a great job.

HEIDI LIEB-WILLIAMS:

... Going through the experience of the pandemic, to focus on positive things, we should continue to

use moving forward. One of those options should be to fight for telehealth access nationwide, especially for people with disabilities.

JUSTICE SHORTER:

Yes, such a strong note to and on. Panel 1 thank you so much. I want to make sure we have enough time to bring in our panel 2 and have time for the round panel.

... Let me start off with our next analysts: Tinu, can you tell us who you are

TINU ABAYOMI-PAUL:

Hello, my name is Tinu Abayomi-Paul and I use she/her pronouns stop I live in Texas and I am a founder of Everywhere Accessible. Our organization was founded on the premise that disabled people are everywhere so everywhere should be accessible.... Then the pandemic happened and we started to do mutual aid. That is what we do exclusively now.

I am a brown skinned, black woman with shoulder length hair. I am wearing dress that you can open sea when stuff, sparkly hearings -- did I mention I am Black and dark skinned? (Laughs).

JUSTICE SHORTER:

That is perfect, appreciations to you, Tinu! Doctor Diana, can you introduce yourself before the panel?

DIANA MERCEDES CEJAS:

Sure, my name is Diana say has. My pronouns are she/her. I am a black woman whose hair is kind of an curly and Afro today. I have ... what is this cold? An N-95 mask that is looped backwards around my neck. I'm not sure you can see my dress but I'm sitting in front of a boring wall. I am a pediatric neurologist at the University of North Carolina, Chapel Hill. All of my clinical work, research, and advocacy focuses on improving the kind of care that we give to young Disabled people, particularly young people with intellectual and developmental disabilities and especially those who belong to multiply marginalized Nordic group, including racial and ethnic minorities, gender minorities, LGBTQI+ individuals, and what have you.

I am pretty much living in the world of disability full-time. I am also a cancer and stroke survivor so I am very, very passionate about trying to be able to facilitate communication tween the Disability Community and physicians so that Disabled people can get the care they deserve.

JUSTICE SHORTER:

We are so thrilled to have you with us this afternoon! You will actually be moderating one of the roundtable discussions here in just a few moments so we are so thrilled to have you with us. Tinu, I want to bring you up here because folks will remember who would have been following this initiative, you were one of our son storm storytellers from Leicester. We wanted to invite you back -- last year, we wanted to you to come back and create some perspective on why it is so important to continue censoring the voices of people will colour with intellectual and learning or developmental disabilities. Have you your cell flute -- noticed any coded language during the pandemic or towards the end of the pandemic that you read as discriminatory or a problem?

TINU ABAYOMI-PAUL:

Yes I have, where do you want me to start!

(Laughter)

(Multiple speakers)

JUSTICE SHORTER:

We have the Roundtable to so you don't have to go into everything! (Laughs) But whatever you want to give your briefly!

TINU ABAYOMI-PAUL:

I will fire off some really quickly. The thing that stood out to me the most was during the pandemic, in the beginning, it was like team everyone and then suddenly, you know, people got picked off on the fence, like people who were unwell anyway. While that means Disabled people! So basically just screw us? Don't worry about the pandemic if you are unwell anyway!

Half of America has a chronic illness condition so that is a lot of us! If you are overweight, at one point, they said you are one of the people who should worry about the pandemic but not everybody else. While that is two thirds of America. So we got two thirds of America, you've got one in four people who are Disabled. Then they said the elderly. That is 16 point 8% of America so they have about 55 million people. Half of America will get cancel, so cancer patients, people who are immunosuppressed will stop a paragraph they eventually made a list of people who were the only ones who should worry about the pandemic but it was like 90% of the country! But they didn't tell us that. So there was all of this, don't worry about it unless you are with one of these special groups ... accepts everyone is in the special group.

That was one big thing I think got ignored a lot, especially pre-existing conditions which, why say pre-existing when you could just say condition? It is insurance code, which used to mean if you don't have – we are not going to give you insurance for a disease that you already know you have. If you don't know you have it, sure, we will cover you and help you. But if you don't know, to be for you. Hope you have cash. I used to have to pay out of pocket before Obama care for all of the things that I knew was wrong with me. And now, they just kind of give you the run around and make it really, really expensive after they started tampering with the program.

One that is really disconcerting now is how people are saying that pandemic is over. And it is not over. The emergency is over, the first stage is over, but it is not, you know, you have to know what a pandemic is to know that it is not over. Pandemic is a disease that is spreading out of control in more than one country, according to the WHO revised policy changes from 2005. So if that is the case, how are we post-pandemic? Because it is not controlled. It is not – we don't have a vaccine that prevents spread. It slows down spread, but it doesn't prevent spread. Every time we have a new hybrid, which seems to be every other week, there are more things happening.

But that is just a short list. Was there anything else you want to do now?

(Laughter)

JUSTICE SHORTER:

Oh, no, there is tons of stuff! I think the next question I want to ask you in just a few, I will bring it back here but I want to ask you about your freedom drains here. In a just a second full stop before I do that, Morenike, I know you wanted to bring Doctor Diana here to talk about some of those issues in terms of things she has exchanged in her work in the medical field.

MORENIKE GIWA ONAIWU:

Absolutely. So I wanted to bring up, and I will actually link to where you work at the Carolina Institute for developmental disabilities. Because I know that this is an area of passion for you, working with you into adult transition. And that you have seen a number of challenges and successes throughout this pandemic. So in your role as a doctor, if you could share phrases, practices that you have noticed that are being used throughout the pandemic, particularly also in this "(Indiscernible)".. You could pose a danger to patients with IDD and also people of colour with IDD in general.

DIANA MERCEDES CEJAS:

Yes, I mean the first thing that comes to mind is this concept of quality of life. And when we are in medical training, some of the first sessions you learn about in school is that everything you do in theory should be something that improves either cures disease, treats disease, or increases the patient's quality of life in some way full and I think that is a phrase we have heard a lot is the beginning of the pandemic. Unfortunately for Disabled people, or to guiltily Disabled people who are multiply marginalized, low income, have other kinds of social stressors going on. I feel like quality of life is something that has been used as a cudgel of sorts. To explain why we shouldn't be offering some treatment to some people and not others.

One of the things we don't talk about in medicine is how when we are assuming that quality of life or assuming how someone's quality of life actually is, we are doing so by looking through our eyes at that person and saying, this is what I think that your quality of life is. Rather than actually actually -- asking the person what their thoughts are about their own quality of life, what they need, what they think their own health is, what they want for themselves. Any of that. So sometimes, too often, even before the pandemic, with the patient popular coalition that I work with, I work with a lot of kids, adolescents, and love – like young adults with multiple disabilities who have high support needs and someone else might look at them and be like "oh this poor person, such tragedy, their quality of life must be awful!" Their quality of life isn't awful because there are Disabled! Maybe there are some things they need some help with. AB is a child who needs better accommodations in school, I kid whose seizures I need to get under better control so they are able to go to their baseball game. Maybe it is something like that that would make them feel a little bit better and a bit more engaged with their communities and families. But if I was just going to look at your visibility and say – practice ability and say you have a poor quality of life, what kind of ablest nonsense is that?

This idea of quality of life is even worse in the pandemic. People, particularly when things were bad

and we were talking about equipment and all of that, again you have people looking at Disabled people and saying, "your polity – my quality of life must be poor, therefore maybe we don't need to offer this kind of care or maybe we don't need to be able to provide this service and the support you."

So I think if we could, in medicine, start to try to retrain our concept of what quality of life is and what a good quality of life is for a person, not use our own individual assessments but actually see what the person feels about the quality of life, then maybe we could start to make sure that people are getting the kind of care they actually need.

JUSTICE SHORTER:

And Tinu, I want you to come in. Because this phrase, the perceived quality of life. This was brought up during last year's session that we did on Decoding Discrimination and it is disheartening to see that is still in high circulation and people are still saying it. I want to ask you, Tinu, what are your freedom dreams? As you think about a public health response that actually does centre and celebrate the lives, the interests, the body/minds of people with intellectual and developmental disabilities. What do your freedom dreams look like for the public health system that was run in such a way?

TINU ABAYOMI-PAUL:

, May mean freedom dream is that we all, at some point, will enjoy kind of the program that I believe it is Norway has, where every person has clean water, shelter, food, healthcare, and meaning not just at the point of injury but in general, good health. To make sure that maybe we don't – if we have existing issues we don't get worse and that those conditions and problems are addressed instead of being allowed to become worse or sometimes can even be prevented from happening at all.

I would like to see us all be able to be independent and even have basic income on top of those needs that we have. Because as a nation, we have seen that a lot of the jobs that we have can be done, can be worked from home. A lot of the healthcare we need provided like telehealth, video sessions, they can be provided, it is just whether or not they want to provide it.

If we have the ability and we have the money and we are not militias, why don't we have these things? They always say, America is one of the richest countries in the world and yet compared to other industrialized nations and we don't have basics because of capitalism? That doesn't make any sense. We had a time in this country where we had more regulated capitalism. We had higher taxation of wealthy people. We had – not a complete social safety net, but we were getting started in that direction. And then we introduce, you know, the civil rights movement – now we don't want to give those things that we were preparing to everyone.

And that became the main bone of contention that is hated in all this coded language, but, you know, welfare recipient, they will save a where the average welfare recipient is actually a Caucasian person. It is not those welfare queen pictures they have conjured up. -- Conjured up. So a lot of the people who are against us having the social safety net are people who would benefit from it except for, you know, the racism and the race baiting and all these other things.

And people who feel like if you can't work, you are with us. It is another idea that is tied into the

overreliance on the concept of capitalism. Yes, we should have the free trades of goods and services but not at the expense of people. Some people cannot work. Like right now, right now I am broadcasting from my bed because there is not a lot of different jobs that I can do. Luckily for me, I know some freelance things but there are a lot of people who are worse than me with long COVID who can't even get out of bed. Half of us have ME CFS. I have it to and it has completely changed my quality of life. If it wasn't for telehealth or my cooperative oncologist, if it wasn't for the fact that she demanded that they let me say -- stay on the oxygen, who knows what would have happened to me by now.

But the providing supplemental oxygen isn't really being investing in for long COVID. There have -- they have no plan. There is no treatment. So my freedom dream is everyone doubt, for example, whatever they are giving to the Senators! [

JUSTICE SHORTER:

OK!

TINU ABAYOMI-PAUL:

Everyone gets the highest quality of care that is available.

JUSTICE SHORTER:

Absolutely. Thank you so much, Tinu. And Morenike, I know you had a closeout question here and Tinu has given us so much for minimal information and talk to us about some of the oppressions that we were talking about earlier about those multiple oppressions people were talking about that they have to deal with, oppressions connected to racism, ableism, and so I know you had a final closeout question but before we get into our Roundtable, where there will be more than enough time to get -- might continue our conversation, so Morenike, I will kick it over to you.

MORENIKE GIWA ONAIWU:

Sure, I will be brief, this is a great conversation. I want to ask Diana, could you provide any thoughts or advice quickly for other medical professionals or lessons that they could learn? Because I know with yourself being a doctor with a disability, you know. You were multiple hats. So even if you have advice you would give, some of them you mentioned in your previous answer but even your hopes for the future in general and for public health being able to better serve the IDD community?

DIANA MERCEDES CEJAS:

When I think about this I think bringing it back to basics.... And revised entirely. If we are talking about the basics, the first thing we need to do is listen to the patients, which means listening to disabled people, and the wider community about what it is we actually need from our positions.

There is so much hierarchical power dynamic weirdness within medicine, and ostensibly we comment saying we want to help people, we want to make sure that we can provide some service to you to help you live the happiest, healthiest life that you can, no matter what that looks like for you individually. But somewhere along the line there is been a complete breakdown in the ability to be able to take what our patients are telling us and translated to something that is actually going to be beneficial for them. And I

do not just mean there is good health, their mental health, but all aspects that go with that.

That means employment, if you want to be employed, going to school if you would. All of these... The prescription you are taking every day. As far as things I hope for for the future, I hope that medicine will start to look less - you know I am the doctor up here and you are the patient down there. More of a partnership where you have collaboration going both ways.

... That all starts with listening to people. I think things are there that would make a big change.

JUSTICE SHORTER:

What a beautiful segue way. That is precisely what we are preparing to do right now. We are going to move on to the next section of our time here today. Thank you so much for all your input, we appreciate you.

We are going to continue that theme of collaboration in our roundtable section. This is the opportunity for everyone in attendance today to come off mute and share your thoughts on anything you may have noticed in the last two are related to words or phrases, policies that seem discriminatory, that you would like to highlight and flag. We are going to use that information, that you provide, to update the decoding discrimination resource. We have linked to it in the chat in case you want to see what we produced last year. Hold on tight and we will put everybody into small breakout rooms.

If you need an accommodation, please let us know at any time. If you need interpreter or CART services, tell Devon, she will put you in the room.

MORENIKE GIWA ONAIWU:

Hello hello, this is breakout room 1 which will be the accessible room. We have ASL interpretation and captions for anybody in this room who needs it or wants to utilize it.

OK, it looks like I am -- thank you so much for putting the captions link into the chat. It is there for anyone who needs it. We have broken out into 5 rooms. There is just one person being assigned to a room.

Thank you so much for being here, I love your presence. I have something to start a software sharing: basically what we are wanting to do is we have a tool that we created where we are looking at themes about things that happen discriminated. Things like "healthy volunteers" or, requiring the use for an online portal for certain services. We want to know if you all had anything to share personally or from people you know or potentially new phrases and words. If you all, there are 11 of us total, if you want to just put up your hand or type in the chat we would be happy to hear. Please tell us where you are joining us from, as well, that would be great, too.

While you are thinking, I will share one myself. I have a variety of different disabilities. My children have disabilities as well. One of my children is over the age of 18 and it is often believed that if you did, you do not need another person. And they were barring a lot of people from joining others because of that. That created a lot of difficulties because having an advocate is important. So why was understood

that he didn't want a team of people inside the hospital room, potentially spreading COVID 19, in cases where somebody needs that, making that a barrier was a huge problem for us.

I will ask a few more questions because it look like anybody has anything to add. Feel free to add your thoughts. If anybody wants to share examples of discriminatory or negative language that has appeared in recent policies? About ending the protections and about workplace policies, (unknown term) hospital policies etc.

That I can think of that I have seen recently is there is this one establishment near our home where customers can require observers or whomever is helping them to take them off if they did not want them to read. So masks are often. Some people wear the mask for their own protection, and now the policy is that a customer to decide for you. And essentially demand you take it off (Laughs).

I do not see any reason and, for any chats. Again, that is fine. I will go to a couple other questions and if anybody wants to share something not in these questions you are free to do so.

I wanted to ask, what are some of the terms when you think about the pandemic or things you have heard people say, I am wondering some of the words and phrases that people have described? Some people say that the pandemic was such a unique period, as though it is finished... For some people it was not a great time, it was a time of great fear, illness or struggle. I am wondering if you have heard anything or are aware of thoughts and ideas similar to that? When people are saying, "That was in the past. That was nothing." Again, do not feel pressure. This roundtable is just for people to share their thoughts and there is no requirement. Please feel free to type into the chat if you have something to add.

I do not see any hands or anybody on muted. I will ask the remaining questions. One of them is: if anyone wants to share any programs or policies initiatives that you noticed, maybe in your state or city, that were trying to be more creative or inclusive of other people? And reaching out to the disability community, or other communities in ways they had not before? If you want to share anything you are aware of, I would like to actually share one that I know of: I was very happy to see a lot of messaging going out in the Houston Texas area, was multilingual. So instead all being in English, they were sharing information in Spanish and in Vietnamese and certain other languages, as well, to get the message out. I found that to be very helpful and important.

I will ask the last question, and then from there -- thank you so much Rachel! Rachel stated that she is in New York State. "I'm in NYS and I've been a new public forum being promoted: "Join the Conversation: OPWDD Embraces Diversity, Equity and Inclusion to Improve Service Delivery and Quality for People With Developmental Disabilities". In closing, are there phrases you would like more of in terms of people with disabilities or IDD? Are there any terms or phrases you would like to see more frequently used?

I, personally, like when the provider is speaking to me but they still address my child. If the appointment is for my child, and even if my child appears not to answer, if they still direct the conversation to them and to me, not talking over my child just to me as though my child doesn't exist.

That is something that, to me, I enjoy and I would like to see more of. It makes me feel that my children are seen and heard.

If anybody has anything like that they want to share, what you would like to see more of, terminology usage, but people have mentioned, it may be in an email that providers have offered... How we would like to be communicated with by text or email. Those are a few things that people emailed us with. But if there's anything like that you would like to share, please do so.

We can also use the rest of the time to fellowship with each other until we go back into the larger room, before we close out.

JUSTICE SHORTER:

Hi everyone, this is the five minute mark. We will close the record runs at about 320, or a minute before that. I wanted to pop in and say that some of the phrases we had listed prior to the session were something like "lazy bombs", or "women's problem" or it is just a women's issue. Or "COVID crazy". These are phrases that are coded and in common circulation sometimes by people who are... Whether it is in an article or circulating through the population, it is difficult and hard and it creates a problem or barrier for people with disabilities. We always want to be mindful of the language, that is why we are talking to you all in case you have other examples. Morenike, I will toss it back to you.

MORENIKE GIWA ONAIWU:

I just got a message that I will share with you all: this is something people would like to see more of. This person stated they would like to see legal guardians of people with disabilities would allow the person with the disability to talk and to share their thoughts and not just talk over them. To allow them to address the physician or not have everything be so one-sided. I really appreciate that being shared, because that is something we do not see enough of.

Just got another message, someone just mentioned they like when medical providers speak to them in a normal tone of voice. Not using a patronizing voice, like talking to a baby. I sometimes call it (Laughs) disabilitese. It is very interesting, thank you for sharing that as well.

It looks like we have about two minutes. Does anybody want to say hello or hear anything we have talked about so far? Resources? Questions? Otherwise we can hang out. I really appreciate you being here with me.

We does have another minute or so before they move us over.

MORENIKE GIWA ONAIWU:

I have pulled out the breakout rooms and I have see -- I see some of them have started to collapse. I don't know if they are doing it in a particular order. You might be last because we are room one. Thank you for your patience, it might be a little longer or another minute for us. (Laughs) OK, we are closing in 30 seconds. Thank you everyone.

JUSTICE SHORTER:

I was floating around to each of the breakout rooms and heard some interesting stories, I heard people giving interesting descriptions of outfits of things they had been using to protect themselves. Protect their peace, bodies, minds, and I thought that was beautiful.

I will ask now that the moderators charity highlights you may have gathered from the breakout rooms very briefly that we had in our Roundtable, anyhow takeaways?

SPEAKER:

Yes, and one I will pop in the chat a little bit before we'll close because it is about a forum that sounds really fascinating in your state but our group is pretty quiet. There were a few things that were chair -- shared in the chat. That includes our love ones. So if you are under a guardianship for decision-making or someone who wants their -- to be there for us, we still have our own support and our own thought and voice and we want to be able to contribute whatever it is think we should and not only have the proxy do so.

Another thing we shared is that we really appreciate when medical providers treat and speak to and communicate with us in our own respectful manner. Don't use baby voices! Or open your eyes really widely and all of that. It is OK to try to communicate in a way that is more accessible, whether that be plain language or speaking more slowly, if that will help with understanding. But remember that we are still people. Communicate with us the way you -- not the way you talk to a cute puppy. Lastly, remember there are lots of different platforms and mechanisms for munication. Email, messaging, talking, other languages.

JUSTICE SHORTER:

Appreciations. That is such a good point! Something you raised this year that was not raised as much last year, I don't over captured it. But it looks like some of the things your people rates, especially that point about the baby voices, that focuses more so on how you say what it is you are saying. So although it might not be a specific term or word that feels discriminatory, speaking down to people and talking to them and baby voices or the voice that you would speak to an infant or this presuming that people don't understand. So you should automatically talk to them in a certain way, that's a huge point. It is absolutely something we have to include in the new iteration of the resource guide this year.

Looking out for how people can be condescending or speaking down to folks using those baby voices, as if they are speaking to children. I appreciate that perspective was up I want to bring Bonnie off of mute here, you were in breakout room to, any highlights or take away?

BONNIELIN SWENOR:

Yes, I have to say. We had similar comments about patronizing voices and so thanks Morenike for highlighting that from your group. It is interesting to hear that team. We also had some discussions about the use of minimizing language and it struck me, as it is usually common words like "only", Right? And how powerful and sharp that can be.

There was some discussion around how advocating for accommodations is being viewed as entitlement. And how dangerous that can be and how that is really coded language and that word "accommodation" Has perhaps become even more coded. There was also some discussion around a take what you get approach. Where, when individuals had really gone above and beyond to get access or to be included, and if there was a response, it often was, you know, I will give you something but you will take whatever and giving you. And how that could even be in a coded action. There was also a request from public health professionals to give more information about long COVID, how it impacts people with disabilities, people who are new to the disability community.

And importantly, how these individuals can best advocate in light of that. And how that can be used to erode stigma. And thank you to my group!

JUSTICE SHORTER:

That word "act -- "entitlement" And Morenike, I don't know we had that, before, entitlement, but we will definitely include it in this year's new edition of the resource! That is huge, figured about how entitlements are negatively flame -- frame. Feeling that if you are entitled to something you should be ashamed for it and it should be something that is guilty full top and a lot of the things are right that folks have! People are voicing their rights and fighting for their rights. That is extraordinary. Thank you all so much group number two for bringing those perspectives into the conversation.

Let's go over to group number three and I think that was Doctor Diana.

DIANA MERCEDES CEJAS:

Yes, sure. One of the things that came up in multiple comments was this idea that Disabled people have to present themselves a certain way in order to be taken seriously. And even then, not always taken seriously. By physicians. They have to maybe say things a certain way, dress a certain way, look a certain way for their concerns to be seen as important. And if you are anyone who does not fit whatever that physician deems as the ideal or the respectable kind of person then maybe they are not taken seriously. So maybe that is a person who has dark skin, who is a racial minority, maybe that means this person has physical -- visible disabilities, maybe their existing and a fat body, maybe there is something else about that person that just does not conform with what the doctor things is respectable.

So they will not necessarily be treated the way that they should because of those things. Other things we talked about or someone made a comment about was the idea of having to negotiate for your needs. Whether that is your medical needs, your accessibility needs, or even your needs around your identity or your gender, trying to get people to understand and having to recognize that your needs are where you are starting, but people will try to see if they can bring you down to where they think you actually need to be, even if that means your needs are not going to be met.

Some other things we talked about was the fact that disability and community and Disabled people are kind of the canaries in the coal mine, for this whole pandemic. We are seeing -- saying the things, showing the data, talking about how things will go and what is going to happen. And even though we are able to have all this information, public health professionals, doctors, are not listening. So then

exactly what we say is going to happen happens and everybody is trying to play catch up and of course Disabled people are going to be the most effective and the most harmed by the fact that no one else is listening.

JUSTICE SHORTER:

Appreciations! We are listening here today. And I want to listen in and bring Oswin. Inc. you so much Doctor Diana for those reluctant. We will absolutely incorporate the feedback and insights into the new resource will stop Oswin, I want to come over to you but I want to be mindful of our time, but I can't forget about group number four full can you share any highlights her team had?

OSWIN LATIMER:

Yes, what we talked about is that most of these problems are not problems of the pandemic, they were problems before the pandemic and I know we'll know that but I think that is important, and that one of the problems we see or what we focused on was the fact of how, by asking the questions even that we are here, that we are not necessarily able to hear from the people who are the most marginalized because they are the ones that cannot access this space. And had that equally makes it difficult for these communities to be able to even believe that or even trust that the voices of what they are willing to say are going to be heard.

So that was most of the focus of what we heard.

JUSTICE SHORTER:

Absolutely fall top I think in the importance of getting to be Deaf people where they aren't beating them in that space. Group number five, I have not forgotten about you. I believe Doctor Taylor did have to leave but your input will still be counted. She had another meeting she had to run off to that's all you are here! OK!

(Laughter)

(Multiple speakers)

SPEAKER:

Had great experiences in Group 5. We had somebody sharing about being in the hospital during the pandemic. Her family saw that the physician put "obese" in the chart, regardless of weighing her. Just experienced a lot of dismissive behavior from providers in that state. So the wording obese with harmful language, but just dismissive language from providers at that time.

Also, group said that ending the COVID pandemic was dismissive language in itself.... Resources that were going to be cut off, concerns about finances to PCR tests. We did talk about that in the group, and also there were conversations about workplace accommodations for workplace schedules.

One particular participant said that colleagues had said, "Aren't you going to be happier working a four day schedule versus a five day?" Overall, the comments of that putting pressures of costs of having a workplace at your... Place of employment. Just the guilt feelings and assumptions surrounding

workplace accommodations, and the need for them.

It also came up just questioning the legitimacy of symptoms being experienced by members in the group as well. I think that sums it up. There were really great thing said. Oh assumptions of defect, "defect" was a word that came up.

JUSTICE SHORTER:

I don't think we have the word defect in our last guy. I want to be mindful of time, thank you very much Doctor Taylor for staying on with us. Thank you to everybody who has been in conversation and community with us this afternoon!

We will soon put up a new version of the resource, so that will be coming in the coming weeks. Everybody who has registered for today's event, we will shoot you out an email once the new resource has been published. Morenike, do you want to add any additional comments?

MORENIKE GIWA ONAIWU:

Yes, I want to thank everybody so much for being a part of this. We will be in touch with everybody about updating. I put my email address in the chat. We had somebody in group 1 who explained to us there is a phenomenal opportunity coming out for the public. I want to share that information through equity and inclusion service delivery for our community. We would really love to have people register for those forms coming up in June.

New Year's Day providers and people with IBD for their families and advocates.

The email address is: OPWDD-NCCCpartnership@georgetown.edu

JUSTICE SHORTER:

Appreciation to all of you! We will stay on a few minutes just in case folks have any questions. So much, have a great week!

HEIDI LIEB-WILLIAMS:

Thank you, I just wanted to say what I said in my group: the word "impossible" means "I am possible". Take all of the "I can't"s that you are told... When you get to the end of it see how powerful that change the statement and utilize that for all of us to go forward and be the best community that we have ever been!

JUSTICE SHORTER:

Appreciations, Heidi, thank you so much. Folks we are closing out and thank you again. We will stay on, myself and Morenike. Have a spectacular day, a wonderful week, do let us know if you have any questions that we can follow up with later, let us know. We will stay on the line in case anybody has questions we could get to during the session.

MORENIKE GIWA ONAIWU:

If you are able to see the three little dots on the left of the left. If you click it, it should be there. Oh, I

see that Devon says it will be in the zoom recording!

JUSTICE SHORTER:

... Appreciations.

SPEAKER:

I have a question for you, this is Deborah. I am an interesting place as being a parent of an individual who needs high level supports and this would not be accessible for him. When can we start discussing our own discrimination among yourselves in the hierarchy? I would love to have that discussion because that is the elephant in the room. That often happens and how we develop programming, how sponsors develop new items to use. To have that discussion of dual (unknown term)... It could be blindness. We don't discuss that at all, we leave in the parking lot and pretend it doesn't exist.

JUSTICE SHORTER:

I really do think it depends on what form it is being discussed. I have discussions with these issues being raised all of the time. One of the cool things that is happening now is people are trying to find as many points of entry is possible. For example, we had somebody participate... He couldn't show up to the session that we were having in the way we work, but he could, in his own way.

So this is just one event, but in addition to this we have a series called (unknown term) stories that allows us to work one-on-one with individuals with a range of disabilities to speak for themselves. This is a process that takes much longer in terms of coordination and the support provided, but the results are simply amazing.

We did the series last way, we are planning to do it in a different way this year we are more focuses on people with intellectual and developmental disabilities. Intellectual disabilities in particular is going to be a huge focus for us, this upcoming year.

So you are correct, you are absolutely right, not every (indiscernible) works for every person. We wanted to hold us in person, but... NDRN is getting ready for another conference where in person opportunities to connect, until the, to engage, will be provided. So many advocates come to the conference every year. That is another option, I think we need to be in the practice of it, and deducting as we go. I appreciate so much.

SPEAKER:

I just want to say thank you for that because often times the discrimination that we face with our son comes with the disability community. The ableism sometimes is just -- you have to look at it and say "oh, OK." He does have multiple things and he is IDD. In our family you could never say, "I can't do that." So, like Heidi says, "I can't yet."

JUSTICE SHORTER:

(Laughs) and this is why we structured today's meeting the way we did. To get people time, those identified with, the voices refers to providing additional opportunities with the wrong people. Additional opportunity to send their responses. This is not always -- people do not process in the same way,

sometimes we need more time. Sometimes we want to call. This is why we make ourselves available during this time, here, in case folks have additional questions or comments that they are not comfortable making in a large group. Thank you so much.

SPEAKER:

I was going to say that something was placed in the chat that addresses this. There was a particular group that this person mentioned they belong to where they can safely discuss needs (indiscernible) selecting a television character - who has similar needs to accommodate the character (?).... This way they don't have to state their own particular needs. For some people that is more comfortable to do it in a way that seems (indiscernible), or in writing or what have you.

I think what you mention is very important, because there is a lot of internalized ableism, "blah, blah, blah, but my mind is fine."

JUSTICE SHORTER:

We can do all of that, it's just too much!

SPEAKER:

And disability justice looks at all of our needs. There's also a comment about science fiction being in being a great place for finding disabled characters....

JUSTICE SHORTER:

... I am looking at one of the things I always say I never want to feel like I'm between a rock and a hard place. I want multiple exits out of any intuition. I also work in disasters and emergencies so I always look for minor points of entry and exit the house and we get people in the and out. I absolutely agree. It has to be done on a consistent basis and has unique needs of the folks who are most.

HEIDI LIEB-WILLIAMS:

I wanted to say,... Appearing of people with disabilities. I want to say for me to get to the point to speak today and have the opportunities that I did, that is a 48 year journey in the making. When you are finding yourself banging your head against the wall, or you can go in a grocery store because everything is too much, or life is overwhelming, the never giving up on the individual changes everything.

So when people tell you... The explosion is often used because people in the community band together to help connect the pieces, then dreams and goals still become reality. You can still become something beautiful in life that people didn't see.

I should never have been able to speak. I was told I couldn't talk. I was told different things, you know, so no matter who the individual is, you just keep investing because there is either things at 40 years old that I all of a sudden understood that a 15-year-old should have automatically understood. And it keeps advancing on my journey. And everybody has gifts. Everybody has a purpose and a plan that they can (indiscernible), no matter who you are and what struggles you have.

JUSTICE SHORTER:

Morenike, we should at this: "we don't expect" as a phrase we should mention. Heidi just said she was not expected to speak and to be able to do these different things. Those expectations that are often given to our parents were given to us in the medical industry can be so limiting and restricting. Heidi, once again still here at the end (Laughs) you make us think of things that we can absolutely use. That is not a phrase we had last year I don't think.

If we can grab that that would be great. Here's a quick announcement for anybody still here: we are doing the Q&A with anybody with questions. If anybody is online that wants to get a question again, and you have been patiently waiting is there anybody with a question for Morenike and I that we can support?

JUSTICE SHORTER:

Yes, please, whose voice is this?

SPEAKER:

This is Tara. Quite honestly the most disabling condition that I have never found any adequate help for his cluster B diagnoses. For mental health. And those are some of the most comprehensively difficult to manage disabilities. Some of the most socially difficult to manage disabilities. And there are, as far as I can tell, fuck all help for preventing it before it blows up in your face, so any resources that would go along with that, I would love.

JUSTICE SHORTER:

A great, I think we can put a call out. I don't know if anybody on the line as any specific resources but if – we can also ask Doctor Diana. She had to jump off but we can also ask Bonnie. Again, Tinu, Morenike and I do not presume to have all the answers but if we can find something we will try to follow up. You register for this event under your name and email address so if something comes out we can provided. Morenike, can you take down the questions we can pass along?

MORENIKE GIWA ONAIWU:

Yes, about cluster B. I don't serve that too, but in passing, it seems basically like silence. No one has anything to say. Like OK, so you don't know but is anybody working to now? (Laughs)

SPEAKER:

All the stuff I know is SEVERELY underground. Unsupported. Unsupported in the way that you have to know a guy who knows a guy who knows a guy to get entry into the space with people who are actively working to prevent this shit.

JUSTICE SHORTER:

That is something we can look into. Again, we are not posing that we heavily answers but we get out some of the people who are participating in today's excited. I have to write now be mindful of our captioner who has to leave. And so we need to officially close out this form. I don't want to do it without any captioning so if there is anyone again with a question, I won't say we can answer it right now but we will capture it right now. Is there anyone else who has a question?

SPEAKER:

There is one more statement, as a physician. That needs to be on your list. When parents are given a new diagnosis, often when you have a disability the next question is "well, what do you want to do about this?" And that is so discriminatory. As a doctor, when I take my son, and I said well what would you do for your son? That is what I want to do. But a lot of people don't have that voice to say that.

JUSTICE SHORTER:

Absolutely.

MORENIKE GIWA ONAIWU:

I am definitely writing that down.

JUSTICE SHORTER:

OK, we got it! What else? Our captioner has to go in a bit. I just want to make sure I squeeze in everything I can.

HEIDI LIEB-WILLIAMS:

Just thank you guys so much! For having me be a part of this. And thank you for everyone who has spoken out today because I believe we all made a difference.

JUSTICE SHORTER:

Alright, folks, we are going to go ahead and close out this session. Thank you so much! We appreciate you. Have a wonderful day, a great week, and hopefully a spectacular way -- we can. Thanks so much. Bye-bye, folks!

(End of session)

Live captioning by Ai-Media.