Good afternoon, good afternoon, good afternoon, everyone. Hello, my name is Justice Shorter. Thank you so much for joining us for part two of Decoding Discrimination, which will be a resource reveal and panel discussion. You currently do not see me on your screen and that is because I'm using multiple pieces of assistive technology in order to fully participate today. But if having an image is important in terms of access, please do feel free to just check out some photos of myself and some of the other panelists who will not be on screen. You can look up our photos online if that is important to connect the photo to the voice. I do want to note that we do have sign language interpreters today in addition to a live captioner. If you are having any trouble with accessing those two points of accommodation, please do shoot a message to our IT director, Charles. And his information should be available in Zoom if you are utilizing a computer. With those minor details taken care of, let me start by introducing some of the phenomenal partners that have been working with us thus far and then I will give you guys a little bit of a back story about decoding discrimination, before we get into the actual reveal, in addition to what we hope will be a riveting panel discussion toward the latter part of our time here today. Let me have Bonnielin Swenor introduce herself to the group.

Hi, I'm Bonnie. I'm the founder and director and associate professor of nursing at the school of public health. This is such an important session and I'm just grateful to be associated.
We are happy to have you. And of course, as Bonnie mentioned, we have two rock stars on the team, Oswin and Morenike from Foundations for Divergent Minds. Do you two superstars want to introduce yourselves?

Certainly. This is Morenike. I was just going to quickly allow Oswin just to share a little bit about Foundation for Divergent Minds. And you all will be hearing from me a little bit later. I'll introduce myself then.

I am Oswin Latimer, the Founder and Principle Executive Officer for Foundation for Divergent Minds. We are an autistic disability justice organization with practical supports for education, healthcare, and what we're kind of terming crisis management, I think, where we're looking into some more quality of life things, such as police brutality and domestic violence, as well.

Fantastic. Thank you so much, Oswin. I appreciate it. Morenike mentioned they would give a more detailed introduction of themselves in a moment. Before they do, let me give people a bit of background on what Decoding Discrimination is. For some of you, it may be your first time joining us for this series, and some of you may have joined us back in November which is when we held a round table discussion. The entire focus of that discussion was to collect information around some of the words and phrases that have been used to discriminate against People of Color with intellectual and developmental disabilities. We wanted to understand this in a way that understood how people with intellectual and developmental disabilities in general were impacted. But then we wanted to drill down and specifically focus on how People of Color who were dealing with some of those multiple, compounded forms of discrimination, how they were feeling what they were dealing with as it related to discrimination throughout all phases of the pandemic. The administrative process, registering for appointments, getting access to treatment. Being deprioritized in vaccine distribution early on in addition to some of the long haul things, such as long haul COVID and some of those long-term recovery supports people may need. That was the entire purpose of this series, to hone in on what some of those words and phrases were. Words can be used in a way that is weaponized. In a way that hurt and harm particular communities. We wanted to get a better sense of what some of those words and phrases were throughout the pandemic in particular. Having done that, after getting ideas and suggestions for you all during that initial round table discussion, we did what we promised, which was to compile all of those ideas and insights into two singular documents that folks can use as an advocacy tool. We wanted to make it easy so people can print it off and put it in their back pocket. We were not interested in doing a big lengthy white paper or something that was a bit too dense for it to be practical. With that in mind, we went for something that could be printed front and back and used at their discretion. All of the words appear on one side and their plain language interpretation is on the other. And then behind there you will see a bunch of advocacy strategies. I won't go into that in extreme detail, because Morenike is going to walk you all through what those resources actually look like. Because the team over at Foundations for divergent minds were the source for putting those together. I will pass the baton over to them. Following today's session, these resources will be made on NDRN's website. I will also be sending them out via email before the week is out so
that you all can have direct access to them there. So, we really look forward to you using them. And we also want to make this very clear in that this resource will change. All that we used were the things that we received and the things that we have researched, but there is so much more information, we know. We want to receive those comments and contributions. So, soon enough you all will have access to a specific email address and there will also be a comment box that you can use. As the weeks and months go on, because this pandemic is still in full swing, you will still be able to make contribution to some of those words, some of those phrases that are commonly used to discriminate against people with intellectual and developmental disabilities. With that being said, I'm going to pass it over to Morenike to talk in more detail about what those are and how to use those resources. Morenike, over to you.

>> Thank you so much, Justice, Bonnie, Oswin, and all of you here who are here today. My name is Morenike Giwa Onaiwu. My prenouns are she/her/hers and they/them/their and I'm coming to you today on behalf of Foundation for Divergent Minds. We're excited to be here with you today. We're really trying to find a way to empower people. A lot of times people try to use knowledge as a weapon. And knowledge is power. So, having knowledge is important. So, I'm going to share my screen and show you all some of the resources that we came up with that came up from the round table that we had in November 2021 and some of what those things mean. So, I am going to, I have my screen up. And I'm going to go to the NDRN website, which is www.NDRN.org. And there is a place near the bottom where we have the resource reveal. If you go to the URL, and we will put that in the chat, at the URL you can see not only the event flier for today, but the tools we're talking about. The first one I wanted to talk about was essentially the three R's. We had a discussion, we had people from all over the United States, various different regions as well as some people who were joining us internationally. And we talked about the language and the circumstances and we really started to sort of decode everything that was being talked about. Some themes emerged. And really we saw that there were three main R's that were occurring related to ranking, related to rights or denial of, and related to resources. And so all of those things intersect with people across race, of course. So, some of the comments that were made, as you can see on the documents, let me try to get it a little bit bigger, were things such as people will talk about the price of care being too much. And that's a reason not to render care to someone. Or stating well, if someone is harmed or ill, they're not normal anyway or they are medically vulnerable. Essentially, is there life of value? You hear terms saying people are being called sheeple for following the crowd or putting the onus on the individual. Well, if you request this, of course it's available to you. Don't be a COVID idiot. Make smart choices. All of these things are phrases, but what is really being said? What is the statement behind it? If you're saying someone is not making a smart public health choice or they're a COVID idiot, what you're doing is assigning blame to individuals without looking at the other risk factors that might exist. And then of course there's the hording of resources and in that there's statements such as well, we do not offer that service at this location. Gatekeeping and ensuring that certain things are not offered so that you can try to keep certain populations away. Or telling people that they don't meet a particular threshold so that you have your arbitrary guidelines as to whether or not a person deserves to
have care. And then there's things such as pressuring people to utilize telemedicine or healthcare portals or not allowing them to have a support person. All of these things that may look really benign or look on the surface like there isn't anything wrong, but all of them are being utilized to weaponize care and to keep being from being able to access the care that they need. In this document, we break down the main statements that were given and then what it truly means. And then another tool that we are very excited about from the website is the strategies. Knowledge is power, but it needs to be applied. If someone is communicating with you in a way that's problematic or things are happening, you need to be able to know what to do. There are several different things here on this document on the suggested advocacy strategies. But one of the things we would like you to encourage you to do is Section 504, the Americans with Disabilities Act, there are lots of things that are you are entitled to by law. And people have to, there are certain things that people must abide by. So, we have some tools for what to do if someone is being condescending, talking to you as if you don't have sense. Intentionally using a lot of confusing jargon or acronyms. Insinuating you're out of control or dangerous or what have you. Or are they ignoring you altogether? Are they invisiblizing you? Only speaking to your attendant or essentially not making it seem like what you're saying makes any sense? Or are they patronizing you in a different way? Patronizing you for your disability. We have a general recommendation of things you can do to protect yourself and address these in the situation as well as after the fact. And then we have the information for all three of the organizations. It is our goal that if these documents, if the first document can be folded in half, if a person wanted to review these things, or it can be folded in like trifolds. And the same thing with this document. It can be folded. If you need to glance at it to see if there is a recommendation because you're feeling a certain way or something is happening, you will have access to that. And finally on the NDRN website under Decoding Discrimination, we have a plain card and we have a few other messages you'll be getting. This is one you can utilize. It states I am disabled. I still understand you. Talk directly to me. Thank you. This can be used in a situation if there is invisiblization or ignoring. There are other one ifs you want someone to repeat something or write something down or to allow you to contact someone for support. There will also be imagery, as well, with image descriptions that you will be able to use. All of these resources are free. And as justice mentioned, this is meant to be a living document. We want to add to this, improve, and we want to be able to have feedback from everyone to know how we can make it better. So, there is going to be an email address that you're going to be furnished with, that you're going to receive this from Justice soon as a follow-up. But in addition to that, so, I believe there will be an email address that you will have that you can reach out to directly related to this resource if you have any questions or concerns at all.

>> Thank you so much, Morenike. That email address is active. Decodingdiscrimination@NDRN.org. If you want to get additional information about some of the resources that Morenike mentioned or contact information for some of our fabulous panelists, if you're hoping to engage them or learn more about the work they do. If you have contributions or comments that you would like to make to this body of work, we certainly welcome it. Again, that email address is
Charles, am I correct? Is that email address active at the moment?
>> Yes. I was muted. (Chuckling).
>> There we go. Thank you, thank you so much. The man behind the scenes always making sure things are working for us. Thank you very much. With that being said, Morenike, thank you so much for such a detailed description on what that resource is. I'm going to open it right back up to Morenike to provide some introductions because now we're going to move onto our panel discussion. So, if you have any questions about the resources we've worked on, please feel free to shoot us an email. Our contact details are on NDRN's website. Please let us know what would be the best method of communicating for you. We will also have a Q&A session at the end of today's presentation. But we don't want to rush you. If you have questions, please put them in the chat box. Please message Morenike directly. I will personally have to mute the notifications on my phone for just a moment because it is difficult for me to hear multiple devices with those notifications coming in consistently. However, if you need to get a specific question in, please Morenike is my cofacilitater of today's panel and of today's general workshop, so please feel free to send them a direct message and they will answer questions. Or just feel free to put it up in the chat box. I also want to encourage folks to create access for one another. So, if you have good links or other resources to reveal or share, do not hesitate to do so by putting those links, those resources up in the chat box. Without further ado, Morenike, I'm going to pass it back over to you to introduce our panelists for today.

Awesome. And I'm so excited to have the panelists that we have today. So, I'm just thankful for the perspectives that they're going to bring. And so the first panelist that I'd like to introduce is Emmanuel Jenkins, who is the founder of a nonprofit organization, We Stand for Something. And I put his bio in the chat and we will put his organization in the chat for you, as well. So, We Stand for Something supports individuals with disabilities and their families. In addition to that, as Emmanuel is employed by the state of Delaware working full time as a community relations officer for a Developmental Disabilities Council. That is a ground breaking role for someone with disability in that role, in addition to many of the local and national boards and commissions that Emmanuel is involved in, and in his role for the consortium for individuals with disabilities. Emmanuel is vice chair of Delaware's rehabilitation Council, and the Delaware Developmental Disabilities Services. He is a proud graduate of Partners in Policymaking in 2014. The next individual that I will be introducing is Kayla Rodriguez. And sorry, Emmanuel's pronouns are he/him/his. And Kayla's pronouns are she/her/hers and they/them/their. Kayla was trained in the leadership education and LEND program of Georgia and the My Voice My Participation Board. Kayla speaks on many panels and won the Golden Goldie Award, and the Luminary award. Kayla has worked as an intern at the Georgia Council for Developmental Disabilities and was the VA of Autistic Self-Advocacy Atlanta. Kayla is a published author in the edited collection Sincerely, Your Autistic Child. And last, but not least is Dr. Taylor or Janiece as we call her, and her pronouns are she/her. And she is an assistant professor in the Johns Hopkins School of Nursing. She is the principle faculty member for the Johns Hopkins Innovative Care in Aging. Dr. Taylor's
work, the research is about identifying and addressing pain disparities and also looking at differences in outcomes in older women, particularly those from underrepresented groups and from all individuals with disabilities across the life span who are aging. So, in addition to having a doctorate, Janiece completed a post-doctoral fellowship at interdisciplinary training and is testing interventions about pain and depression symptoms, particularly in African American women with frailty and physical function limitations, as well as interventions to address the unmet needs of caregivers who themselves have disabilities, as well. And I will be placing Janiece's bio in the chat for you right now. So, we are very excited to have these panelists. And again, I will share their organization's links for you, as well. Back to you, Justice.

>> Thank you so much, Morenike. I feel like we're newscasters. (Laughing) We're just...

>> I know, right? (Laughter).

I am extremely thrilled to have you on the line. I want to open it up in a rather general way. I'm hoping that you guys can share a little bit more information about some of the ways that you all have noticed discrimination popping up for individuals of color with intellectual and developmental disabilities throughout the pandemic. Can you share any examples or stories or specific things that you can point to that you've observed over the last two years and ways that people with intellectual and developmental disabilities have been impacted by this pandemic. Dr. Taylor, you noted to me as we were prepping for this event that this was something that you certainly had observed. Can you share a little bit more with us about your thoughts?

>> I sure can. Thank you so much, Justice. And hopefully you can hear me. I apologize. I lost track of the specific case study, but I can remember several participants who have participated with me in some of the research who are older and have various types of disabilities, including some hidden, some developmental disabilities experiencing pain. And throughout COVID did experience some discrimination in seeking care for whether it was their pain or other conditions outside of COVID. Oftentimes they were described as anxious or overseeing for care and were discriminated against because of the intersectionality of their race, ethnicity, and disability status. They weren't necessarily taken seriously and I would say discriminated against in receiving the necessary care. One individual in particular, now that I'm remembering, wasn't able to get the needed, had a fall. This individual had a disability, had a fall, and wasn't able to get care because they pretty much told her that her pain wasn't that bad. It did turn out that she had dislocated her shoulder, we found out later. But she was not taken seriously and I would say that was discriminatory based on that intersectionality. Those were some of the things I did experience and hear from research participants.

>> Dr. Taylor, you brought up a good point. Other reasons for seeking out medical care did not end because the pandemic began. People dealing with falls and people dealing with other sort of health conditions and concerns, all of these things were still ongoing throughout the pandemic and people gaining access to the types of care and other pain management still remained a vital piece of the equation. We're going to come back to this issue of pain management for People of Color. But before we do...
that, let me bounce over to Emmanuel. Can you talk to us a little bit. You work a lot with individuals in community-based settings. Can you talk to us a little bit about the importance of creating community amongst people with developmental and intellectual disabilities as a means of dealing with the discrimination that they may face?

>> Absolutely, absolutely. I think really when it comes down to community, we talk a lot about people are advocating and really connecting with agencies and providers to gain information. Or to other individuals in the community. I really believe that comes to working together with other individuals with disabilities. Individuals with disabilities really deal with social isolation. When the pandemic came, the pandemic just magnified the social isolation.

So, when we talk about discrimination and barriers and challenges and all of these things, it's really important that as people with disabilities that we work together, that we work together to learn from each other and be connected to each other, and most importantly to support each other. We know that it's platforms like that this that allow us to come together and educate and advocate in the sense that we shouldn't just wait until March, which is developmental disability awareness month. And as they always say, you know, together we are, together we stand, divided we fall. Really drawing strength from one another to really move conversations like this forward. Communities don't have to be next door. The pandemic has shown us that communities can be across the water, over the bridge. For example, if it was not for the pandemic I highly doubt this discussion would be done using a virtual platform. Now we as advocates can really utilize something such as the pandemic to really advocate in such a stronger way because now we can do it via Zoom.

>> Thank you, Emmanuel, I absolutely agree. You brought up so many strong points there. The importance of being able to learn from one another, and helping individuals deal with the various elements of discrimination that they're dealing with, by learning from people who are simultaneously going through some of these issues. It's often said that people want to speak up on behalf of the voiceless, but I hear you and many others says you can pass the mic and let people speak for themselves or sign for themselves, or however folks communicate in a way that is most accessible, because they also have things to say. So, just really, really strong parts. Stacy Park Milburn referred to this idea of helping people through different phases of disability and bringing them into the disability community as disability dulas. I wanted to open it up to you, Morenike. I have a whole list here, but I wanted to bring you back into the fold to talk about this idea of community and why it's so important.

>> Absolutely and I'm just really enjoying the dialogue that we're having and thank you to everyone who is making remarks in the chat and kind of sharing thoughts and resources and continue to do so. I wanted to actually, we heard from Dr. Taylor and Emmanuel. I wanted to ask a question of Kayla, who is a panelist of mine. Kayla, I was hoping you could share with us some thoughts about the importance of developing and building community and advocating for oneself? Particularly in these times, but how you would essentially like this is for most of us, this is not just work, this is also life. You know? This kind of bleeds into one another. So, it can be difficult to kind of discern okay when how much advocacy, when is it the right time? When is it the right kind? Are we reviewing things properly or understanding what's happening? The way
that we think we are? Are we being gaslit? It would be good if we could share some of your personal perspectives of this, we would love to hear that.

>> Thank you, Morenike. Yeah. Definitely, actually I had an experience like this even yesterday where I had to advocate for myself. I was in, I'm in an IOP for binge eating disorder. I'm autistic and I have ADHD. And I was advocating for myself because I wasn't having a good day. And I was just on this webinar for three hours. And I had to advocate for myself. This pandemic, we're zoomed out. I had to advocate for myself and they were proud of me. It was scary. You don't know how people are going to take it. I was fortunate in my case that they were accepting and they understood, but sometimes it's not always the case. But I think you have to do it anyway because you really need to take care of yourself and it's really important now more than ever before that we take care of ourselves. And another example is like with me I have to advocate with my insurance because I don't understand. Because I was told I was going to get a better insurance, but yet I'm getting more bills than ever before. I had to advocate for myself and then the health journey I had over the past year. I had COVID and now I'm thinking maybe the COVID was related. I don't think I have long COVID, but I developed a couple of like nodules I kept getting led from one doctor to another and I had to advocate for myself and be like what's going on. You know what I mean? And when I went to a terrible mental health hospital, I also had to advocate for myself and like it was in Lawrenceville, Georgia. And by the way, most of the patients there were Black, Indigenous, and People of Color. I think it was part of the school to prison pipeline. It was the worst care I ever received. They weren't even giving me my insulin that I needed. I'm a Type One diabetic. They weren't giving me the insulin I needed. I could dive more into this. But point is, I tried to advocate for myself because I needed it. And sometimes you're not just advocating for yourself, people think you're advocating for yourself, it's not important. But it is very, very, very important and you need to advocate for yourself. I know it's scary, trust me. I am so scared. But I think it's very important to advocate because you need it and you deserve it. You deserve to be advocated for and you deserve to have your needs met. I hope that answered the question.

>> You answered it perfectly and it actually kind of really emphasized what Dr. Taylor was sharing earlier about people not being believed by others or people not, you know, services not being rendered. We're seeing a lot of correlation there. And so Justice, I know you had a few other questions. And there was a question Brian Russell had in the chat, as well.

>> Yeah, I want to bring David Boyar to talk about ventilators. He is one of the lawyers at NDRN who did a ton of work around rationing. In some of the cases the language was very explicit. Noting that folks with certain types of disabilities, especially folks with intellectual disabilities would be deprioritized around ventilators. I wanted to ask the panelists, were you familiar of these policies? And then also Dave, did you have any specific insights that you wanted to share, having really monitored this with legal directors and legal teams from across America's protection and advocacy system. Dave, I'll let you chime in, but I want to get back over to our panelists to get their thoughts on it. David Boyer, if you're speaking, you're on mute. It seems like we might have temporarily lost Dave. That's all right. I'll kick it back over to our panelists
while we get Dave back up online and operational. Emmanuel, Kayla, were you aware of those policies, and did that have any impact on your physical or mental health throughout the pandemic?

>> Emmanuel, do you want to go first?

>> You could go first.

>> Okay. Well, I didn't specifically hear of this issue, but I'm not surprised. Basically, I've heard stories about like how we have been low on the vaccine distribution we have been, yeah. We've been low on the vaccine distribution. We haven't had the best access to vaccines during the vaccine rollout. And I also heard like before COVID, there's a law in Georgia about this I don't know if you've heard of it. I don't know which law it's called. I forgot the name of it. But it was because this young girl who has a disability was denied an organ transplant because of her disability. And I looked it up and that's a similar thing in other states, including autistic people. I think you can get denied an organ transplant because you're autistic or have another disability. It's surprising to me and makes no sense because our lives are just as important as anybody else's. And if we need an organ transplant, we need it, you know? So, to hear something like this is not surprising to me, unfortunately. But it's just another, I've seen it all over Twitter. I've seen it all over the mus, like how people with disabilities have been treated as a last resort during this pandemic. I think there was another one where they were like oh like, a not resuscitate or something like that. I don't know for sure on any of this. But I've heard stories of how we've been a last resort during this pandemic. So, to hear that is not surprising. It's disappointing, but not surprising. So, yeah.

>> Emmanuel?

>> Yeah, this kind of discussion or lack of discussion when it comes to rationing equipment, et cetera. I think it happens on a regular basis, however it's not regularly talked about. We read about it in the paper or online. And one of the things and I keep saying this is the pandemic forced people to talk. You know? They could no longer run and hide from their motives or secretly discuss. For a long, long time people with disabilities have been looked at as maybe the last people to receive funding. But as far as life-saving measures, we are one of the last ones to be talked about as far as treatment. I can tell you that here in Delaware, I was really instrumental on the rollout of the COVID vaccine. I actually got to sit on the board to discuss that. But it was because of my presence and people around me that understood that we needed to be in the higher tier as far as rollout. We didn't get to be number one, but we were not completely at the bottom. But I think, you know, you brought up a really good point about the mental health side of all of this. Knowing that there's a risk that if you go to a hospital and you need other treatment that you may not get it because you have this pre-diagnosed disability, that's like, you know, that's like tug of war. Tug of war with your mind. You know, as someone mentioned earlier, the treatment that you need or other medical things don't stop just because the pandemic came. So, imagine having a symptom or a lump or some other thing that just popped up over night. Now you're laying there and wondering do I go to the hospital or do I stay home? Well, if I go to the hospital, they're probably not going to treat me because I have XYZ. This same thing happens with people with diabetes and other things, as well. So, I think this has
always been an ongoing thing. But again, it's platforms like this. To put those kind of things on notice. It's one thing being a person of color, but it's also another thing being a male. It's also another thing being a person with a disability. So, I think when we really look at these kind of questions, we're really looking at three cards already stacked against us, and the only way we're going to change it is by really advocating to ensure that our life matters, not only in a quick fix to get someone a quick alternative, but our lives matter. And when deciding do I go to the hospital or stay home?

>> Strong points. I love that quote, our lives matter. So many poignant things you said, as well as Kayla who spoke before you. We have Dave back online, one of NDRN's legal managers, to talk about some of the issues they noticed from a national perspective around the rationing of care and how some of that was really enshrined in policies and practices across the country in various states. Dave, I want to bring you off mute just to see if you have any thoughts to share on the issue before we kick it back over to Dr. Taylor for some of her thoughts around pain and People of Color.

>> Sure, thanks Justice. You step away for a second and see what happens. Apologize for that. You know, all across the country we discovered when COVID began that many of these states had established these crisis standards of care, which mandated health rationing and who could get healthcare and essential services when medical supplies or personnel ran low due to demand. And we found out that many of these, not surprisingly to the folks who are on this call, many of these were discriminatory to people with disabilities and People of Color and a whole wide variety of folks that are traditionally discriminated against. The P&A network took a lot of steps. Almost every P&A filed complaints against their state's crisis standards of care. Remember each of these crises standards of care are localized to a state or region. Each of these P&As filed complaints in either letter form or to the national government, to CMS, to the Office of Civil Rights complaining about these and many got very good results. I can think of some language in the state of Alabama that specifically referred to people with intellectual and developmental disabilities as folks that shouldn't be getting care if it ran tight on resources. Many of these had good results. I saw a question back here specifically referring to, yes, Brian Russell asks about ventilators. Ventilators were often a hallmark. That was something that if you went into the hospital with your ventilator and they felt like your standard of living wouldn't be good, they could take that ventilator and reallocate it to someone who had a better standard of living or quality of life or short-term likelihood of living. We very actively fought those across the nation and were very successful. Those particularly play well in the public. People understand you shouldn't have your ventilator taken away from you under any circumstances. Those were fairly successful. The only one that I know that is still being contested is in New York where they have provided guidance that your ventilator could be reassigned. It's not a state law. It's a suggestion to local jurisdictions that one of the things they could do is reallocate those ventilators. That case is now being argued in the federal government system and I can link that case in the chat. But it's Not Dead Yet v. New York and NDRN and some others have signed on in briefings in their efforts to stop that silliness because everybody should keep their ventilators, obviously. So, I guess that's kind of the wide view of it.

>> Many thanks, Dave. I appreciate your insights and being able to provide us with a
panoramic perspective of what the P&A has been doing since the onset of the pandemic. I want to come back over to Dr. Taylor. And this will be before we get into some of the really great conversations going on in the chat. I can hear Morenike engaging directly with some of the participants, some of you all, and some of the questions and comments you have. I'm going to bring Morenike in after we talk to Dr. Taylor here about pain management. Dr. Taylor, you spoke about this in the very beginning. You kicked us off in our panel conversation. Can you talk to us a bit more around the topic of people with intellectual and developmental disabilities not being believed when it comes to discussions around pain and around their care in general. You gave us an example, but talk to us a little bit more in depth around this concern around credibility and believability and some of the issues that Morenike talked about when we were getting at what we did with the resources that we created, this issue of being invisibilized and pushed aside. Can you just share a little bit more about your experiences in that regard?

>> Sure, thank you so much, Justice. I think there is a big, it happens commonly, and oftentimes healthcare providers don't see that they're doing it or they assume that we're healthcare providers and we are able to treat all patients equal, but that's not the case. Oftentimes we see patients coming in with intellectual and developmental disabilities. If they happen to have a care partner with them, the provider will talk to the care partner even to the person with the intellectual or developmental disability can speak on their own behalf about what their desires for their care should be. And it's just a bias that happens and it's so common across all healthcare professionals that really needs to be addressed. And I will definitely talk about the pain piece, but also just thinking along the lines about what David was saying about quality of life. I think a big part of it, as well, is healthcare providers, assuming that they can define what quality of life is for individuals and patients with intellectual and developmental disabilities and being able to define what they think quality of life should be. And I think it's a stigma, especially among people with intersectionality who are from underrepresented groups in addition to having these types of disabilities. I think there are situations where they're frequently seen in perhaps ERs because they can't get primary care for one reason or another. Or they might just have multiple diagnoses that require emergency care quite often. And they get this stigma, you know. Obviously, there's horrible stereotypes out there about being frequent fliers or drug seeking. They make a lot of assumptions and that really limits the credibility and believability of a person. And it's almost like I've heard this from participants and even among family members who have some type of disability that I don't want to be seen because it may affect my credibility if they think I'm coming too much or they think that I'm faking whatever is going on. It will affect my credibility. So, I will only go when it's a life-threatening situation. That's very unfortunate, but very common. And when it comes to pain, of course, you know, we have this adage with the nursing, pain is what the patient says it is. But that's not always lived out in nursing practice. And as I think Ian just said in the chat, it's very true. You know, we're taught in nursing school, and I would think in medical school, as well, there is a myth, however, that creeps in. The mechanisms behind physical, mental, even spiritual across the board for all people, however these biases come in that you make assumptions that people with intellectual or developmental disabilities don't feel pain the same way, or
I've heard their brain is not able to understand what is going on in their bodies so they don't feel it. So, of course that definitely causes disparities in pain treatments and then oftentimes they're not believed. There's also, you know, intellectual and developmental disabilities may have pain and they're still functioning very well, even to the point of physically they can do things. And the picture you observe, you think they must not be in pain. But there's a lot of people who have lived with pain for many years and have learned to cope with it until they do get to that point where they need to seek care. But because they're so high functioning, they're often not believed, and that's another way that creates disparities in pain management.

>> True, indeed. So many wonderful takeaways from what you mentioned there. One of the things that stands out to me is the connection between credibility to criminality. How sometimes people are put into institutional settings because they are deemed as uncredible, that they are not believed. So, kind of pushed into non-community-based settings. And taken away from family, friends, community, because they are not communicating in the ways that people deem to be the most easy and effective for them? But as opposed to the way that is most important for a person with a disability. The way that you communicate can be a marker of how you're viewed in a medical setting, but it can also be a direct marker of something that eventualizes criminalizes you. Noncompliant or menacing in that way. That's really important because you're talking about pain. There are so many layers to pain. The physical, the emotional, the mental, the spiritual. The way people are treated in these settings all contribute to somebody's overarching capacity to deal with those different levels of pain. So many great perspectives being added to the conversation and Morenike has been engaging with you directly. Morenike, I'm going to have you come off mute. Can you give us a snapshot of what's been happening in the chat. Some of those comments and some of those questions.

>> Absolutely. I just want to thank everyone who has been communicating. There are different resources that have been shared related to organ transplants, the discrimination in more than 25 different states about organ transplants that people are less likely to be considered a candidate for one. So, there is a place where the public comment period has technically ended, but they are still reviewing remarks. They might just not be shared with the public in the summary. But there's some information about that. Ray wrote a great article that's there. And we've talked a little bit about the criminalization of communication. You know, everyone communicates differently. Everyone does not communicate by speaking. Some people who are augmentive assistive communication or AAC users, or what have you. And these are often things that are people used, especially if you're a person of color, seen as aggressive or non-compliant or things of that nature. The amicus brief that Dave mentioned earlier is posted here. And there's a couple of articles about medical rationing and about pain not being perceived the same way in disabled people. And then there's a great comment from Miran about how traumatizing and disastrous things can be as a person of color, who is disabled in the hospital, especially during this pandemic. And that's actually a perfect segue just to mention that the part one of the round tables that we had in November is what helped us to formulate the tools, the resources that you're looking at. And again, we'll have the emails because we'd love to add to it and have more
thoughts or information that you all would share. There’s a great article about intersectionality. But there’s going to be a deeper dive into circumstances because with the limited time, there’s so much that we have to share in terms of specific experiences with disenfranchisement that has occurred that people have dealt with and some ways to address those things a little bit more specifically. So, we’re hoping to kind of do that. Those tools can be used for providers and can continue this dialogue. I don’t think it’s talked about enough. That, you know, as Emmanuel mentioned sadly, the pandemic has brought forth a number of things that were already existing, but was not as noticeable. And there’s also a comment about quality of life research in here, as well. And some how some of the measures aren’t necessarily seen as equitable for all of us.

And if there was anyone on the line who was wondering about our purpose, who was wondering why this type of work was vital for us to create a resource, I want to draw your attention to one singular point and that is the thread that has woven through every single comment of each person who has spoken here today and that is the importance of advocacy and having tools at your disposal to use. We are not saying that the tools that we have created should be set in stone and that should be the only thing used. In fact, we highly encourage you to use it at your discretion to adapt things so it could work more specifically and more effectively for you. But what we are saying is that this is a start and that we encourage people to continue giving us your contributions because we would love for this thing to continue growing. And that is the reason why as Morenike said we’re still adding stuff and we will keep adding stuff as capacity permits to make sure you all get the opportunity to continue participating and being a part of the conversation as we move along. And with that being said, I want to give you all the opportunity to ask more questions directly of the panelists. We have scheduled this event for an entire hour and 30 minutes, so this will go on until the 3:30 mark. And we did that as a point of accessibility. We did not want to cut individuals off who may need additional time to communicate during a session that is all about communication and language and words and phrases that might be discriminatory against People of Color with intellectual and developmental disabilities, but that communication is a common core there. So, we wanted to enhance communication access as much as possible. And that means prioritizing people who may have, who may need additional time to develop their thoughts and put them into the chat or to communicate in any other way that they deem most accessible. And to do that, there’s a couple of different ways. Again, here folks, you can shoot me an email at decodingdiscrimination@NDRN.org. That does come directly to us. We’ll get the opportunity to see your thoughts and comments. Or you can send direct messages if you don’t want to send a message in the chat to everybody. Please send a direct message to Morenike, who has been posting phenomenal resources throughout this session. But we want to get your questions to the panelists. We also want to specifically designate this time for your involvement in the conversation. If you have questions you want us to get to before we close out, please feel free to get those in the chat. While you’re doing that, we do have a couple of new events that are coming up in connection to this type of work, again focusing on People of Color with intellectual and
developmental disabilities. Our next endeavor will be Sun Storm Stories, where we will feature the stories of People of Color that we will really be pushing out to people in the medical field. But anyone and everyone is allowed to invite us for that conversation. The idea is to give us an opportunity to share their stories. We believe story telling is a very powerful tool for advocacy. We created these resources as a self-advocacy tool, and we also want to put a spotlight on story telling as a self-advocacy tool. This series will be coming up. It's actually a one-time event. We're hoping we can get it in in one go, but there may be some adaptations that happen as a means of accessibility and that's okay. We will be flexible and fluid in that regard. But that event will be coming up later on this spring. If you know someone of color with an intellectual or developmental disability who contracted COVID and has a story to tell, shoot us an email. You can shoot me a direct email that is Justine.shorter@NDRN.org. If someone wouldn't mind throwing my email address in the chat, that would be much appreciated. With that being said, Morenike, I'm going to kick back over to you. Have we gotten any additional questions in the chat before I ask our panelists if they have any closing thoughts?

>> Thank you for adding that. We've had some great comments related to this. But I don't believe I've seen a question. There was one, but I believe it was addressed a little bit earlier. I don't think I've seen any new ones since then. Just comments and resources. So, if anyone has one, please feel free to share it now. Or if not, for those of you, we can get ready to close out. Again, if anyone needs to stay longer, you know, we will be available to answer questions or clarify anything, but we do want to be respectful of time for you all and we just want to thank you again for being here and for just being so engaged.

>> Great. With that being said, let me kick it over to our panelists for any closing comments that they may have. Emmanuel, any closing thoughts you want to share with the group here today?

>> Sure, absolutely. First, thank you for allowing me to be part of such a dynamic discussion. I hope this is just one of many collaborations as we move not only our individual states but our country forward as a whole of really working with and for people with disabilities. My closing remark would be that again this is hopefully just the beginning. But I do want to quickly state as we were talking about people needing transplants. I was watching Chicago Med, and I know it's a television show. And people say it's not reality. But I was watching an episode where a father needed a transplant. He didn't have a disability, but the son did. And the son would have been a great match for his father, of course. And that really got me to thinking, you know, we may struggle to receive a transplant, but there's not a challenge when we are matched as far as being able to be chosen to be a match. So, I just believe moving the medical field forward. It really comes down to acceptability and really understanding that all of our lives have value and I will close and say this. For many, many years, we have always said you hear people with disabilities say I know my body better than anybody. When we go to a medical facility, I also watch a lot of court shows. But our credibility is shot before we even open our mouth. For example, when I go to the doctor, I typically go by myself. And one of the questions I used to get asked all the time that would irk my nerves was who did you come with today. Not did you come alone? How did you
get here? All the medical assumed that someone came with me because there is no way I could be capable of having a conversation totally about myself and my medical care. So, even in the delivery of the questions we ask, we must be mindful that how that may come across to someone, but again, thank you for the opportunity to be part of such a dynamic discussion.

>> Such appreciated. It is so appreciated. And you are always a man of many jewels. Jewels and gems. I love that quote you dropped, we may have challenges, but there is nothing we can't do when we are matched. Matched with various forms of support. And matched with various forms of equity. Equitable treatment in the healthcare system whenever we need it. So, appreciations to you. Do you have any final comments or thoughts you would like to share with the group, Kayla?

>> Well, first off, I want to thank you, Justice and Morenike and for letting me be here and for my copanelists for being just amazing. Even I learned something from y'all. And just really I'm glad that this conversation, we had this conversation and I hope you guys continue to have more conversations like this because it does need to change. And we deserve to live and have a life and live life and have a good life. And, you know, nothing about us, without us, right? So, I really am glad to have been part of this conversation. And there's a lot that needs to be changed. Like I was going to talk about insurance and stuff and my struggles with insurance. For example, with the eating disorder I mentioned earlier, I had to pay out of pocket because my insurance didn't cover it. And there's just like a lot of different things. But hopefully this is the start of change and I'm glad to have been part of it. So, thank you all.

>> We are so glad to have had you. And thank you for raising issues around continuity of care, issues around confusion and chaos that's embedded in the healthcare system that makes it so unbelievable and unnecessarily difficult for people to navigate it independently and with help when they have it at their disposal. You raised so many powerful points throughout today's session and I appreciate you for joining us. You have been wonderful. And now over to Dr. Taylor.

>> Thank you.

>> You are very welcome. Dr. Taylor, do you have any additional comments as we close out today's conversation?

>> Just very, very grateful to be included with such phenomenal panelists. I want to thank you all. Thank you, Justice, Morenike, everyone that made this possible. Bonnie and David. Just very grateful to be in this space. I learned so much today. I definitely think the conversations need to continue and action does need to take place within the healthcare system and you just made me think, Emmanuel, how you said the importance the minute you entered the door and the first thing the healthcare, whoever that is. That first person at the front desk says to you has so many implications. And it made me think about just our education and how we educate healthcare providers. The minute they walk through the door it's important equity is engrained within our education system, not just sprinkled within our classes, but it should be engrained so that we can address the biases and things that they come in with. I think that's one way that we can begin to really see progress forward in our healthcare system. So, thank you all so much. And thanks to NDRN.
(Chuckling) Indeed. So many strong points there. I love that you and Emmanuel and Kayla and noting that from the moment you walk through the door or pick up the phone or log onto a website the different compounded forms of barriers that one has to encounter in order to gain access to care. We literally created this resource, the resources that we were billed at the beginning and are publicly available for you to use at your discretion, we created that based on some of the lived experiences of People of Color with various disabilities. Were people who when they were checking in were told they failed. You failed to give us your insurance card or failed to book your appointment or failed to come at this specific time. Before you have a conversation with a healthcare professional, you are already made to feel like you are a failure or that you are wrong. That has to be changed. And again, one of our strongest tools is self-advocacy. That's why we created that resource and why we continue to shine a light on the stories of people who have lived it and gone through it again. Again, if you know any People of Color with intellectual and developmental disabilities who might be interested in participating in our Sun Storm stories, please let us know if they have a story they want to share. Again folks my name Justice Shorter. I am the national disaster protection advisor at the National Disability Rights Network. I want to thank our partners from Foundation for Divergent Minds, as well as the Johns Hopkins Disability Research Center. It has been a pleasure. You all have a gorgeous afternoon. We will stay on the line for just a few in case anybody has a question that they need more time to communicate. But thank you so much. Have a wonderful week.

>> Justice, one question.

>> Sure?

>> When is your video or podcast coming out?

>> Listen, I pulled it back out!

>> Because y'all sound like you need a video show tomorrow.

>> I'm feeling that.

>> Come on, we got to have this going.

(Laughter).

>> Emmanuel, did you think at some point they were going to say and to donate money call 1-8 ....

(Laughter).

Laugh.

>> Listen, that's only because we didn't have.

>> I was waiting. I was waiting for somebody to like give out their Cashapp QR code.

(Laughter).

Listen, we didn't have our NPR tote bags ready. We didn't have no coffee mugs and no pens, but it's coming at some point. Don't you worry about it.

>> Thank you for the opportunity. I enjoyed it. And I'll be reaching out to you directly. Because here in our state we're working to collaborate on so many different levels. I had a 45-minute conversation with my director about doing some collaborations. So, I'll follow up with you guys.

>> Absolutely.
Later on.
Absolutely. You keep us posted.
And I know that there is, we're going to do a quick debrief with the actual team, so that's everyone who is a copanelist. But I do want to just give folks who are leaving on out the room, I just want to make sure that no one who is staying around has any questions. We want to give people time who needed some additional time. We wanted to give it to folks. Morenike, are you seeing any last-minute questions come through? Or everybody is just saying bye-bye? (Chuckling)
I think people are just thanking others and there's a comment about in addition to the Sun Storm Stories that National Mental health and disability center would love to have people share some information if they want to share stories there, as well, so we could highlight those. And people are just kind of sharing a few additional resources and we're really appreciative of everyone who was here.
Absolutely. Absolutely. I love the collective access. It's a point of disability justice. And then we also, Zach Martin who is my manager over at NDRN gave a quick nudge here. We want to thank the WITH Foundation who is actually the force funding this type of work. We certainly appreciate everyone at WITH who contributed their support for making this type of work possible. So, much appreciations in that regard, as well. Anybody else have questions? With that, we're closing folks out before our team takes a moment and steps backstage in the Zoom room to do a quick debrief before we close out the Zoom room.
Did I do a good job?
You did a wonderful job, dear.
Thank you. If you have any other opportunities for me, just come my way.
You did a lovely job. We're going to cover the logistic details as soon as we clear the room. Just making a space here if anybody had additional questions. I don't think they do, but I'm just creating a little bit of space here before I transition us into the backstage area. Okay.
I'm not hearing any additional questions. With that being said, David Boyer and Charles, would you mind moving people over to the waiting room, kind of moving folks out of this area so we can have a chance to debrief. It doesn't seem like anyone who is still on the line has any questions. Sometimes people just walk away from their computers or have it going while they're doing other things.
No problem.
We just want to keep myself, Oswin, Morenike, Emmanuel, Dr. Taylor, Kayla, Dr. Taylor, and you. I think that's the whole team. We're just going to move folks back out to the waiting room. Sometimes they just get stuck there. No, we do not need the interpreters. Does anybody need the interpreters to stay on for this debrief? I don't think so. But just checking. Any of our panelists need the interpreters to stay on?
I think we're fine. Yeah. We're good. Maybe just the captioner.
Okay. And so the captioner, if we can have the captioner stay on, the interpreter, you can feel free to exit off. Charles, if you could also stop the recording during this debrief, that would be great. This does not need to be recorded.
Okay.
Recording stopped.
All right. And has everyone been successfully moved over to the waiting room? Not yet. Okay, I'll pause.

Okay, I think we're good now.

Okay, how many?

I think that's right. There me, Emmanuel, Charles, Morenike, Janiece, Oswin, Bonnielin, and the captioner.

Okay, I think we're good.

Okay, all right, good stuff. All right, folks, what are you thinking?

It was great.

It was great. I wish we had more time!

I know.

There was something I wanted to share, but I guess we didn't have time to share it. But other than that, it was all right. It was good.

Yeah, don't you worry, I think there will be more opportunities. The time is so limited. And I know folks, I could hear people jumping off. But there will be more opportunities, I am hoping, as we keep trying to push this work forward for you all to continue sharing stories. And like I told you, I will absolutely keep you in mind for future events, as well.

Thank you, yeah.

(Chuckling) Other thoughts from folks? I heard everybody start talking at once. So, does anybody want to share? We do these debriefs after every event. I wanted to give us some space to do it.

There was some really good, great engagement. Like the comments were thoughtful. You could tell, it just seemed like people were really, you know, the information was resonating with everyone.

Mm-hmm. And you were on fire with the chat box. I just want to be very clear about that because I cannot engage, like I cannot have that going in my ear in my computer and simultaneously talking. Some folks are whizzes. I'm turning off the sound. That's why when you'll hear me take these pregnant pauses at random points because so many things are coming at me at once. I have to keep turning it on and off. I toggle it on and off. I try to keep up with it. But thank you so much. You were on fire.

I agree. I'm always impressed when people can do that. (Laughter).

I understand.

I cannot do it. I'm tapping out. I am literally tapping out. But yes, somebody else was about to speak. I heard a baritone.

It was me.

It was me. It was my very deep voice. No, I was just going to.

You sound like Barry White.

That was amazing. The summary of that chat box was great. Sorry I had to step away. I had a dog emergency. We were at the dog oncologist today. We got a good report, but I was a little bit late with my thoughts. My dog was important.

That makes sense. That is true. That's not a problem. Thank you so much for jumping on even when you have personal stuff to do.
>> It was amazing. Everyone was amazing. I had to step away, but I came back and Emmanuel was turning it up over there. That was really good. I thought that was a good section. Morenike's chat was great. And, you know, the engagement in the chat window, like you said, Morenike, was really, it wasn't just chatter. It was more like engagement.
>> It was. I think that.
>> Oswin?
>> Yes, it is. I think on the FDM side, we definitely need to go ahead and get those cards made up because the AAC user comment was kind of the reason we wanted to do this in the first place, people who aren't speaking have a little bit more access to get their needs met. We need to get on those.
>> Someone was said those are great.
>> Yeah, it was their brain child. They've already got so many phrases and stuff that are planned.
>> And as we ...
>> I'm sorry, go ahead.
>> Yeah I just wanted to let Oswin finish. You were still talking, Oswin?
>> No, I have a trailing end sound that makes it sound like I'm going more, but I'm not. (Laughter).
>> All right. Wanted to make sure we weren't cutting you off. Emmanuel? You wanted to chime in?
>> Yes, I was just going to ask really quickly, are there any other plans as far as promoting those materials? And I ask that for a couple reasons. I know sometimes a lot of the stuff is created and we did this whole horrah, promotion, and then all of a sudden it sits on a website and doesn't go anywhere. That's part of my question. And the second thing is here in Delaware when the pandemic started, I created something called Let's Talk About It and it's a Youtube video series that has already gained some national recognition where I sit down, no pun intended, to talk with individuals to promote programs, resources, activities, resource guides, and et cetera. And I would like to discuss possibly doing a Let's Talk About It about those resource to share with people that may not be able to read an email or have access to email. But may learn differently through video resource to promote those resources that were so created for that purpose.
>> Absolutely. And Morenike, Oswin, this may be something, well first off, Emmanuel, Let's Talk about It, I think that would be a dope situation in terms of us getting together and figuring out how to support the Youtube channel and making sure you can come in and talk about the resources and do that verbally. Absolutely. Morenike, Oswin, I think it might be interesting to see if there is a way for us to, or maybe I can talk to our comms team at NDRN to create an audio companion to this, reading the resources aloud for folks might be really helpful. It would just be the audio version. Maybe we can talk to our comms team to see if that's a possibility. I'll talk to you more about this offline. Kayla, Dr. Taylor, I didn't give you a chance to speak. Did you have any debrief thoughts on the session?
>> It was phenomenal. And like everyone said, the chat seemed to complement everything going on. Everyone was fantastic. I'm just grateful to be included.
I'm grateful to have you. Look at that voice sounding slick and smooth. You were concerned about it. I'm glad you were here. Even among all of that, you joined us today. I appreciate you doing that. Thank you so much for that.

I have one more thing.

Okay, sure.

If any of you are hiring, just let me know. That's all. (Chuckling).

There you go. There we go. We need sustained employment. I hear you on that one. And like I said, we will certainly keep you in mind, Kayla, for some additional events that are going on. And Morenike and I are going to do some brainstorming about some stuff we're working on. And Bonnie, you were the last one on the team who I don't think we fully heard from. Did you have any thoughts about the session, anything you wanted to share?

It was great. I'm just really grateful this happened, that we're talking about this. You know, Justice early in this process we talked about having you come on our podcast and so let's think about a good time. Maybe you and Morenike and/or Oswin to sort of share out the deliverables.

I would love that.

Absolutely.

That would be a good way. To Emmanuel's point just to make sure it doesn't live on a website.

(Laughter).

Absolutely. And that's one of the things we were trying to do to get away from it becoming stagnant. Keep contributing. Let's update this thing as we know, as we can. Maybe doing a refresher and an update and trying to do things in that way. Absolutely. I appreciate it. Listen, I want to be mindful of everybody's time. It is getting late into the workday. I know some folks are wrapping up. Thank you guys so much. Dr. Taylor, Emmanuel, Kayla, I will be following up with you all because we need to connect with our finance team regarding the honoraria. I will try to do that before the week is out. You all will be hearing from me in that regard. If you don't hear from me or if something happens, feel free to shoot me an email.

You didn't say my name for the honoraria.

I will not be saying your name. You don't get anything.

(Laughter).

Justice.

You get together. You weren't even there when I called on you! I'm messing!

(Laughing)

Good point.

Yes, I just heard somebody say my name.

Oswin, do we need to send you our final invoice, because we haven't done that yet.

No, actually you don't need to send that until we wrap up Sun Storm Stories. Once we wrap that, then you send that final invoice and you are all good to go.

(Laughter).

You are entirely fine. But if you guys have any additional questions on the back end or if you need additional support with anything, we've got our wonderful IT director, Charles, on deck who has been able to provide some wonderful support. Charles, I
love you endlessly.
>> You're welcome.
>> God, I love this man! There is no end to my love. And also we have a communications team who has been stepping it up and trying to support as much as well. Really wanted to provide you guys a bit more assistance with any of the operational or technical assistance, whatever support needs you have as we continue with the second part of the grant, which is getting Sun Storm Stories wrapped up. And that's a one-time event. We're trying to get some people, get some stories and then we will showcase them and then have a panel kind of like this, just an open discussion and this will mainly be to the medical field. Really trying to get medical students, trying to get seasoned doctors and nurses and administrative staff, leadership at medical schools, really trying to get people to come in and engage directly with folks who have intellectual and developmental disabilities. I like to say when you're talking to a doctor, you can always say the phrase, "I have a Ph.D. in me" so you're also talking to a professional. I have a Ph.D. in me, too, sir. Or Madam or person.
>> As Emmanuel was saying, we know our bodies.
>> Absolutely, absolutely. With that being said, does anybody have any final questions or comments before we go ahead and close this out? No? Sounding good, sounding good? All right, all right thank you so much team. I appreciate you. And we will be getting back at it when it comes to planning Sun Storm Stories. I will try to get a meeting on the calendar in the next few weeks here so we can start actually. Yeah, I'll call you guys and send you emails so we can get it scheduled at least and come back around so we can start planning for that event in earnest. Thank you so much. Have a beautiful day and wonderful week.
>> Take care.
>> Take care.
>> Bye.
>> Bye.