

REALTIME TEXT FILE

DISABILITY COMMUNITY PLANNING GROUP WEBINAR

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>> CLAUDIA FRIEDEL: [Laughs]. All right. So, I am very, very pleased to introduce Ms. Dunham. She is here from the National Black Disability Coalition. Ms. Dunham's experience in disability-related fields spans 50 years. For the past two decades, her work has focused on the intersections of race and disability. She is the founding member and director of the National Black Disability Coalition, NBDC. In her role of director of NBDC, Ms. Dunham spearheaded initiatives to establish Black Disability Studies, mentor family members, provide employment references and opportunities for black disabled individuals, international internships, network with incarcerated youth programs, an intermediary for an ADA lawsuit, support for community black disabled organizations and provide education, information, and referrals for black disabled people and their families. Also, under her leadership, NBDC partnered with the Seeking Ways Out Team, SWOT, to assist hundreds of individuals living in institutions to move into community living. So, Ms. Dunham, we are just so, so pleased to have you. Thank you so much for taking the time to be with us today and I'm gonna turn it over to you.

>> JANE DUNHAMN: Thank you, Claudia. And hello, everyone.

I have written a paper and before I get started with my paper, I just want to know a little bit about the group. I see that it is a community partnership. So, are most of the people in the group family members? People with disabilities? Because that will determine how much information I need to give in context to my paper.

>> CLAUDIA FRIEDEL: Sure, yeah, I can answer that. So, we have a few people with disabilities. The caregivers. People that work with people with disabilities. Work in organizations that serve people with disabilities. We have healthcare providers. It's a pretty broad partnership.

>> JANE DUNHAMN: Okay, great. Thank you.

So, I'm going to be talking a little bit about models of disabilities only in the concept of where NBDC works and I wasn't sure if the group understood models of disabilities.

I would say in the end if there's any language that I present that's new to you, feel free to ask me about it and we can talk about those type of things too.

But I prepared the paper so that it's an outline of what we do and what type of issues come to NBDC that we assist people with.

So here we go, everyone! And, again, thank you for having me.

The work of NBDC has been in racism, ableism, culture, and community engagement.

It includes black disabled people and their families from all the disability groups. We hear most often from black disabled people who are the least of us in the disability community; that is poor people and families and quite often middle-class families who know very little about the impact of race and disability in services or rights. For black families, introduction to disability is a new conversation, not just for our own personal lives, but from our social and political lives. The work also includes building bridges between the non-disabled black and disabled black communities, to eradicate stigma and ableism. Our work has not been in the medical model of disability, but the rights based and social models of disability. The rights-based model is on the socio-political construct within a rights-based discourse. The social model is on the economic, environmental, and cultural barriers encountered by disabled people viewed as having some form of impairment, whether physical, sensory, or intellectual. Your invitation really pushed me to think about ways racism impacts disability and redefines healthcare. There is so much that comes under injustice that is actually healthcare which creates violence and danger in the lives of black disabled people. So, what are the intersections of violence, neglect, and abuse? What I'm really talking about is looking at racism in healthcare and disability that far exceeds lack of services and information. Until there is real research and reporting of black disabled people, we can only guess at the numbers of those impacted. What we know is that institutionalized racism manifests itself both in material conditions and in access to power. It is especially dangerous, because there is no identifiable perpetrator; in fact, its effects are evident as inaction in the face of need and silence in the face of inequity. Inaction in the face of need and silence in the face of inequity are common threads in my stories, Today I am here to explore examples of what happens to individuals when systems fail. They are difficult to hear. And for each example, there are hundreds. At the end of my stories, let's talk about how we can work together to ensure that systems do not fail the safety, humanity, and dignity of human beings. Healthcare is more than a diagnosis, durable medical equipment, and services. I do not have all the answers. It will take a collective. Today I am here to talk about -- so this is a beginning of a different stories and there's quite a few of them, but they're hard stories and I laid them out because they're different and they are very impactful. And there is that connection between where people might not think well, where does healthcare come into this, but you'll be able to see just from different examples. So, I am here to talk about how jails and prisons are dangerous places for anyone. Especially children and teens. Yet, on any given day, approximately 4,500 juveniles, most of whom are disabled, are under the age of 18 or are locked up in adult penal systems. Children as young as 15 can be prosecuted as adults in many states without review by a judge or a court hearing. So how is it that at 14-years-old, a child can be sentenced to 100 years of incarceration? And it not be mentioned one time in any report or testimony that the child has lead poisoning which caused neurological impairment in behavior and impulsivity? Today I am here to talk about the time I received a call from a physician who wanted a

list of a provider agencies for a male, 24-years-old, who was being released after three years of incarceration.

She explained the young man had no evidence of family and that cognitively was incapable of providing or preparing food for himself.

Today I am here to talk about the brother and sister who were in a video store at a mall while their mom shopped elsewhere. The teenage brother shoplifted a CD. And upon reaching the door, the young man was restrained by the store manager and police. His younger 13-year-old sister, who has a developmental disability, only understood that the policeman was doing something to her brother, so she hit him.

The child was convicted of assaulting a policeman, while her brother was only reprimanded for shoplifting. At the end of the day, the sister had to report to a probation office with adult men who are released from prison.

Today I am here to talk about the family whose adult son, who has autism, ran out of a house in fun as a chase game with his direct support staff running behind him. He ran to a neighbor's home, who was a policeman. The policeman shot both the son and his staff without opening the door.

It was not until the mother arrived at a crime scene was it detected that her son was shot. The son could not communicate that he was shot and was left in a police car until his mother arrived.

There was never an investigation as to why a policeman shot through his front door rather than answer the door.

Today I am here to talk about Casper, who was shot and killed at his local police station when he went for help because his home was being robbed.

By the way, I knew Casper, he was also a member of NBDC and Casper was also an artist, and so quite often people in the neighborhood understood that there were expensive artwork as well as monies there.

Anyway, Casper was a frail senior citizen who had epilepsy and recuperating from heart surgery. His heart medication disoriented him. Upon entering the police station, he waved a toy gun, which he had to protect himself from burglars. The police found him to be a threat and shot to kill.

Today I am here to talk about the Patterson mother who asked many times often for assistance to move to a safe neighborhood. Her neighborhood is riddled with gun wars. She explained that although she could teach her other children how to protect themselves during gunfire, she could not teach her adult daughter with significant disabilities who attends a day program how to protect herself.

Okay. I just saw somebody said something. Yes, you can get copies of these accounts. Her daughter does not -- okay, where did I -- okay, she cannot teach her daughter how to protect herself.

So, her daughter does not understand to lie on the floor or to immediately go to the back of the home when the gunfire begins.

Today I am here to talk about the young man with developmental disabilities who for years sold drugs on a corner where I waited for a bus to return home from work. He knew I worked at the Council on Developmental Disabilities.

There has been much talk about young men with developmental disabilities being taken advantage of by drug dealers. It was clear this young man's support was from drug dealers and not provide agencies.

Today I am here to talk about Kathy, who was hit and killed by a city bus. Kathy was a young woman who had developmental delays and was in a wheelchair user who was supported by a provider agency.

She liked to go across the street at night where there was no crosswalk or street walks

or streetlights to a convenience store. There were many near misses with Kathy, until one day she was hit and killed by a bus.

Kathy did not have family in her life; she was a ward of the state. The provider agency said there was no need for her to move to her place where she could access a convenience store in safety if she did not want to move, because providing her choice in her life was most important.

Today I am here to talk about the 10-year-old child who has CP whose therapist explained to him that she was going to have people talk to him about the marks on his back because he was being beaten.

He replied yes, but I am bad sometimes.

After the case was filed, the determination was that it was a culture difference in how children were reprimanded, and the state should not become involved in cultural differences.

Today I am here to talk about giving a ride home to a man who has mental illness.

When we reached his boarding home, the door was locked. We had been at a disability meeting together and it was past 9:00 p.m.

I assisted him in having the owner unlock the door so he could get in. He explained that often when he did not meet the curfew, he slept in the streets. He had a room which was dirty and smelled terribly.

When I asked about the bathroom, he explained it was hard to get into, because so many people used it. This man's rent was paid by a provider agency.

Today I am here to talk about giving a ride home to a young woman who is a wheelchair user who pulls her wheelchair up two flights of steps while sitting and bouncing one step at a time to gain access to her apartment.

Today I am here to talk about why a man with CP must park his chair and bicycle in the lobby of his building because neither will fit in his accessible apartment.

Today I am here to talk about two apartment buildings in two different states that were funded and managed by provider agencies. Both buildings are in urban cities. Both buildings have security systems much like federal buildings because of gun and drug violence in the neighborhoods.

These buildings were not financed by random urban developers, they were financed by provider agencies whose responsibility is to provide a safe environment for their clients. Why are new apartment buildings for disabled people being built in dangerous neighborhoods?

Today I am here to talk about why a disabled advocate who has CP and is aging must have fundraisers for mobility equipment because he has been assessed as not needing mobility equipment because he did not use them when he was younger.

I am most haunted by the numbers of adult people who live with family members, most of whom are grandmothers, who think it's okay for their loved ones to go to a day program and sit home the remainder of the day or week because it is too hard "for them" to go out.

The guardians always told me how proud they are of taking care of the loved ones.

This seems so small, but it was the look on the individual faces as the guardians told me these stories that remain with me.

I feel like there are countless I let down from having the freedom they are entitled.

I wonder, does the disability community really understand what is happening in poor communities?

I was once told by a white disabled man that disability does not exempt poverty, meaning he believed that being born into poverty does not impact disability equity.

I questioned what responsibility does the disability community have to the least of us?

It has not been answered by disability activists.

So where do we go from here?

Thank you.

>> CLAUDIA FRIEDEL: Thank you so much, Ms. Dunhamn. I wanted to mention something in the chat about pinning the ASL interpreter of voicing that, I should have done that when we started, and I apologize to anyone who wanted to pin Ken, our ASL interpreter, please just go to the list of participants and find ASL interpreter Ken, click on his name, and make him a spotlight video.

And then you will see him on the screen, regardless of who is speaking

So, I wanted to apologize for interrupting there.

But, okay. So, does anyone have any comments or questions? Or want to hear anything else, anything from Ms. Dunhamn about her -- about the accounts that she has spoken about?

[Pause].

>> CLAUDIA FRIEDEL: We have folks can unmute themselves by finding themselves in the participant list and then clicking to unmute themselves.

[Pause].

>> CLAUDIA FRIEDEL: So, I'm also going to check the chat to see if anyone has put anything in the chat.

>> Hello, Ms. Dunhamn, this is Bryan Russell with the Department of Health.

Have you noticed if law enforcement is doing a better job in working with people with, like, intellectual developmental disabilities and people who are also people of color?

Or has there been any change at all in their interactions with them?

>> JANE DUNHAMN: I think that race plays a big part. When it comes to different situations, no matter what that situation is, that if the disabled person is white, that the treatment is very different than for black disabled people.

So that I think, what is it? - the ICT trainings- I think they're called, are working. So that part of the violence... um... still remains to be very directed by outcomes by race.

>> Thank you.

>> JANE DUNHAMN: Mmm-hmm.

>> Hi.

>> JANE DUNHAMN: I'm sorry, go ahead.

>> I'm Denise and I am from Miami. And I have -- I had an incident where I was accused of being with a person who was shoplifting and it's hard because of the color of my skin.

And when the individual approached me, he -- he approached me and he asked me to answer, he then went on and dismissed what I was saying, because he noticed that I have a disability.

So, so, for me, I am -- I am a social worker, by trade, so I understood what was going on.

It's disheartening that I have a disability and to think that I was challenged because of the color of my skin, it was a very -- it was a traumatic experience, to say the least.

And I am educated.

So, my -- I am my own advocate and I want to know what would you -- what would you recommend for somebody who -- who is not that cognitive in their situation and their surroundings?

What advice would you recommend that I give somebody like that?

>> JANE DUNHAMN: Okay. So, let me repeat back so that I am sure that I'm understanding the question.

You're saying that what advice would I give to someone who has a cognitive disability

that came into the same situation that you were in?

>> Yes.

>> JANE DUNHAMN: Okay. Um... [Sighs]... there's so many factors. Um... [Sighs]... one of the things -- I neglected to say that I began all of this work as a mom. I have a 50-year-old daughter who has cerebral palsy, significant impairment, and so I'm remembering back when she was very young, one of the things that I did, that I put a card in her wallet as a young woman, I'm talking about 10, 11-years-old when girls started carrying pocketbooks and ID.

That helped.

So, I think identification, a lot of times people with disabilities don't necessarily have identification.

And where I'm going with that is that if people with disabilities have that identification, especially people with developmental disabilities, should have a contact person at their Disability Rights organization as well as their Council on Developmental Disabilities, and so I think that would help for any sort of intervention.

We also have to go back to who do you know and who has status and privilege.

And because they are able to show immediately that they are connected to organizations, that will kind of level the playing field rather than being an individual who's out there in that particular situation.

That will make a big difference.

I don't have all the answers. I can take one situation at a time.

This is really, really tough work and we have yet been able to get people on board to look at well, why did a lot of these things happen?

I mean, some of the easy ones. The two... um... apartment complexes that I was talking about, one is in Newark and one is in Washington, D.C. and I knew about the one in Newark, New Jersey because I lived and worked in New Jersey and so I have many friends and folks that I pick up and take to disability meetings.

So I knew about this place.

And it was actually -- the building is maybe all of two blocks from the University of Medicine and Dentistry in Newark [chuckles], you know, so when I inquired, all was right, close to the hospital.

Well, there aren't many homes in that area anymore, but this was part of their plan in securing that property.

Well, years later, my daughter had gone to graduate school in D.C. and when she was looking for an apartment, we were looking for accessible apartments, housing and this was a place they told us about and it was the same place as was in Newark.

And looking at those situations, having tied into what you as a group look at around healthcare. Is this a healthcare issue? And for me, in the work that we do around racism, anything that impacts [on mute]

>> CLAUDIA FRIEDEL: Jane? We can't hear you. I think you accidentally muted yourself.

>> JANE DUNHAMN: Okay, there. That's better. I'm sorry.

>> CLAUDIA FRIEDEL: No, you're fine.

>> JANE DUNHAMN: So how do -- where does the advocacy begin, that no provider agency should be able to build new apartment complexes in... um... in very dangerous neighborhoods?

And so, then that gets back to the conversation that I talked about, a white colleague told me years ago. Well, you know, you're black and you're born with a disability, and if this is what your neighborhood looks like, then this is where you're going to be.

I have lots of arguments with that particular statement in conversation. But it's hard

work.

And so just what advocates would just want to take up the issue of housing being built in safe neighborhoods? I mean, because there's also the conversation of not all -- if you're looking at race, not all black neighborhoods are crime ridden, there are very many middle-class and upper-class black neighborhoods where these buildings could be built.

And so -- but who's going to take that particular challenge? Who's going to take the challenge on the mom who lived in a dangerous neighborhood, who part of her services could and should be to help her get into housing that is appropriate and safe for her daughter?

Um, you know, so... if you go down to the University of Medicine and Dentistry, they will tell you that's not a health issue. But in the Department of Justice, it is a health issue --

>> Um, excuse me.

>> JANE DUNHAMN: Yes?

>> Not the bad neighborhood, that's not an anomaly, that's something that's going along with this and in the social environment too that was going along with it.

And the mother moved to another -- to another location. He may not have the support that he needed that he has in -- in either the community that he is in.

So, although there is that part --

>> JANE DUNHAMN: Oh, yeah, absolutely, but this particular mom asked time and time again she wanted to move. She knew where she could move.

And so, because I had an inside track, because I worked on the Council For Developmental Disabilities, that we clearly knew that there was funding provided for fences for families that had horse farms.

And so, if you can provide fences to keep your child in five acres of land for a horse farm, then you certainly could afford to give this mom \$1500, which she needed to move to a different place. This is something she asked for, it wasn't something that was being put upon her.

Actually, she was begging for it and did not... um... was not answered from a place of need.

[Telephone ringing]

>> CLAUDIA FRIEDEL: We have a couple of comments from Lori and let me just read what she said. Lori said we heard the accounts and stories and what is being done to create equal access.

Another question from -- or comment from her in regard to Mr. Russell's comments, how are they working with deaf and hard of hearing, I think that was the police.

And what about putting in place for disabilities, for all disabilities on driver's license or state I.D.? For example, the Samuel Allen law for all first responders.

Lori, if you would like to unmute yourself and speak to Jane yourself, if you're comfortable with that, you can unmute yourself.

>> Hi, my name is Lori, and I am in Texas and I am hard of hearing and I volunteer within the deaf and hard-of-hearing community.

We see a big issue with the police and healthcare... um... trying to service the deaf and hard of hearing. Because in different situations, I think the deaf and hard-of-hearing community is fighting against them. But we're really not.

We don't have equal access for communication.

And one thing that I saw in Texas is that Emma, she has her silent aide has put together and helped with the autism... um... Samuel Allen law in Texas for the police.

I would like to see it, if you could have your state I.D. or your driver's license and it lists you as hard of hearing, so if you get pulled over, then they can run your driver's license

and that would be their first indication that you're deaf/hard of hearing, and why not expand it to all kinds of, like, cognitive or -- so that they know what they're dealing with. And make it available to all first responders.

In Texas, it's just police right now.

But that would be an awesome way to put some... um... information in front of people, first responders in emergencies and things, to be able to understand where they're coming from and what they need to -- oh, this is a different situation, we need to think about giving the deaf and hard of hearing, you know, sign language or captioning or VRI, which is video relay, like, through the phone.

Or allow the deaf and hard-of-hearing rehab cell phones to be able to communicate with, like, a live transcript, where we can hear the person, the officer or whoever, speaking and it would translate. And maybe they would be able to understand, the deaf person would be able to understand and write back to them

But I understand that the deaf and hard of hearing, they don't have the reading and English as their -- English as their second language

>> JANE DUNHAMN: Mmm-hmm, yeah.

>> So, that's an issue.

But at least Texas, we're trying to break down some barriers.

And I didn't know if... um... people with the disabilities, you can do that with a driver's license or state I.D.

I'm just raising that as a question

>> JANE DUNHAMN: Mmm-hmm.

>> Or another avenue.

>> JANE DUNHAMN: I think all avenues are a good avenue.

If you don't start somewhere, it might need to be perfected more a little bit down the line, but we have to start somewhere.

So, all ideas are good ideas.

What brings to mind is getting back to the race issue, give them what we've seen on the news, as well as some of the stories that I've mentioned.

Do you really think having a card and having the communications you think will make a difference with a black deaf male when he encounters the police?

>> Let me tell you --

>> That's where there needs to be education -- this is Lori again, sorry -- that's where there needs to be education for everyone.

>> Mmm-hmm.

>> LORI: That means police, that means emergency people, first responders, hospitals. At least they are aware. And if they don't know how to respond, they can, you know, if the situation -- be a little bit more compassionate in trying to understand what people with disabilities are trying to explain.

>> JANE DUNHAMN: Okay. So... um... Casper went to the police for help. He was 70 some-years-old, he probably weighed 110 pounds, and because he had a toy gun, they shot to kill.

He went to the police station. They shot him in front of the police station. And the response was because he posed a threat.

So... um... yeah --

>> Denise: Can I ask a question? Did they --

>> JANE DUNHAMN: No, mmm-hmm.

>> Denise: Did they ask a question? Did they ask a question?

>> JANE DUNHAMN: No, they did not.

>> Denise: Then, no, that man in America is one of the more dangerous pieces of what



I see going on on the news and what I have been watching documentaries.  
It is outrageous!

I have a husband, he is afraid -- everything that -- he leaves me in the morning and comes home in the night and every -- from what is going on in today's society, [indiscernible] it is so -- it is so -- it needs to be taught in schools, real American issues, not that part.

>> JANE DUNHAMN: Mmm-hmm.

>> And that's exactly what's needed in my estimation.

>> JANE DUNHAMN: I'm more than happy -- we can continue the conversation around the police, but what I want to try to do is link the different stories. What is that common thread? What is the common thread with the adult man who is now in his 50's who has CP who has been determined that he does not need a scooter because he never used a scooter as a young man?

And, you know, to the point that he has fundraisers and his community pays for his scooters?

But he's entitled to those services. He's on SSI and he's entitled to get a scooter.

So, what's happening there?

What's happening with buildings, these two apartment buildings?

What's happening with this young man and his... um... his staff being shot... um... by a policeman, their neighbor? And that there was never any investigation into that?

So, begin to look at these stories and say okay, where do we leave off? Is it just the race issue? And if it's the race issue and then it is... um... a combination of the disability, so what does that look like?

And what conversations do we need to be having around danger for black disabled people? Whether it's the police stopping them on the street; whether it's building housing.

Let me think, I had so many of these stories....

A provider agency using the excuse well, this young woman didn't want to move, even though we knew she was going to eventually get hit and killed by a bus because she was determined to go across the street, rather than finding another... um... group home for her that had a convenience store that she could get to safely.

So, whose responsibility is it?

And in each one of these stories, was there somewhere someone in that story that could have put supports in place, via education, that would have helped these stories have much better outcomes.

For example, let's get back to the little girl with her mom living in this crime-ridden neighborhood.

So, God forbid, if this child ended up being shot in her home, then it would be, "Why didn't somebody do something?"

And I am disheartened that the stories only come about after these tragedies happen.

What could have been done to stop these tragedies?

I am going to -- this is going to be recorded, isn't it, Claudia?

>> CLAUDIA FRIEDEL: Yes, it is being recorded.

>> JANE DUNHAMN: Okay. I was going to share my own personal story with you, but I don't know that I'm ready to have it recorded [laughs]. So, I will leave that one alone for now.

>> CLAUDIA FRIEDEL: We do have a question from Christine --

>> JANE DUNHAMN: Sure.

>> CLAUDIA FRIEDEL: -- in the chat. Do I have ideas to promote drowning prevention outreach efforts?

>> JANE DUNHAMN: For drowning? No, no, that's a new one for me [laughs]. I have to laugh because I go to the personal piece of that. Um... I am deathly afraid of the water; I stay away from the water. I've gone to the Islands, Jamaica, and I never get near the water, that's how much I hate being around the water! [Laughs]. So, I'm not the person to answer that question.

I do have a little sidebar that's just that dangerous. Um... took my daughter to Disney World many, many years ago. Like I said, she's 50, she might have been 8 or 9-years-old. I took her friend; my daughter has quadriplegic CP and she had a friend who was paralyzed from the chest down and they wanted to get in the pool. I don't swim. Okay.

We were walking, I'm holding them and walking, and I told them I would take turns. And so... um... it was the little girl's turn and my put my daughter up on the side of the pool.

The next thing I know, people are yelling "Lady, your kid is drowning! Your kid is drowning!" Well, my daughter had been taking swimming lessons since she was an infant, she was 9-years-old, and she went to camp every summer, but she knew she could swim and she has startled reflex and she lost her balance and she said mom is helping Dion, I can do this, I can do this by myself!

And needless to say, we did not go back in that pool for the rest of our vacation!

>> [Laughs]. Oh my gosh.

>> JANE DUNHAMN: These are funny ad-libs and stories on my journey.

But I don't have any experience or work in that area.

>> Um... yes, it's me again. Um... it seems that that is different from me, because I am from Jamaica and I -- we don't have that in Jamaica!

So, so, this is for me, it wasn't to add that incident in the store, I know that it was like that in America.

Because they see you as that way and then they see the disability.

>> JANE DUNHAMN: Exactly, yes, yes.

>> And they treat you -- and they pre-judge what you can and can't do because you have a disability and because you're black.

>> JANE DUNHAMN: And so does anybody have any comment about the right to choose even when your life is at risk and there isn't any family members to advocate and say well, you know... um... let's find a way of making sure that this young woman has what she wants, as well as being safe? Does anybody have any thoughts about the role the provider agencies when it comes to a situation like that?

>> I think it depends on what level of competency the individual has. But you need to include the individual in the process.

>> JANE DUNHAMN: Mmm-hmm. And so, the agency said that they did and that the woman definitely did not want to move.

>> Maybe she didn't understand what it is. Maybe it was them.

>> JANE DUNHAMN: Exactly. So, I mean, would it be helpful to have some sort of assessment... um... I don't know enough about the assessment process for provider agencies, but could that be a new discussion and what does that look like?

And so, there is that challenge where everyone deserves the right to make choices in their life. But if the choices are at risk, how much time and effort do you put in in the education piece and making sure that the individual understands that this is what maybe a new place looks like and this might be and really look at that, rather than well, we explained that we could find another place and she didn't want to move.

Um... I'm always concerned when adult folks... um... who have developmental delays don't have any families in their lives.

It seems as though folks who don't have families in their lives tend to be at more risk, because there isn't that, you know, that -- that visible sign there aren't people there that is an advocate.

Now, like I said, I've been doing this a long time. I remember 50 years ago there would be IEP meetings or any sort of assessment. The first thing, we would start out asking who at this table loves this person?

And, you know, it would be really hard for provider agencies, but it was a way of saying, you know, if you're here and you want input, you have to really care about this individual. It's not just a piece of paper. So....

I think a lot of the stories that I told and a lot of the stories that you might not hear that happens, I can tell you, one of the stories that I told you happened in Florida.

I'm not going to say which, but it did happen there in Florida.

And I happen to have a dear friend who wanted me to tell -- to include her story... um... um... and I don't remember her husband's diagnosis, but he was in the middle of a stroke. They were a mixed-race couple, my friend is white, her husband was black, and he was having a particular type of stroke, I don't know, and she -- while they were waiting for her to arrive at the hospital, they would not do anything to assist her husband.

Because they said he wasn't having a stroke, that he was drunk.

And I don't have all the information in front of me because it quite complicated, but that's to go through the medical history of what happened.

But it all began with him not being treated and being dismissed as being drunk.

This was an educated man who had been a schoolteacher and had done a lot of integration with kids with disabilities into the schools.

And yet when his time came and he was in the hospital, rather than being treated immediately, they were waiting for the wife to come because they were not sure that he wasn't drunk.

And so... um... particularly -- I didn't particularly -- this happened, oh, gosh, a long time ago, this was maybe, oh, 40 years ago; yeah.

>> CLAUDIA FRIEDEL: We have some comments in the chat from Lori. Lori, feel free to -- if you would like to say them. But I can read them as well.

She wrote: I think by self-advocating and having advocacy agencies support education, etc., we need to amend the ADA laws to assist people with disabilities.

She added: The ADA law and changes in the Government to change. What about an assessment like occupational therapy for assessing people with disabilities for quality of life

>> JANE DUNHAMN: Exactly.

>> CLAUDIA FRIEDEL: Quality of life assessments need to be done.

>> JANE DUNHAMN: Exactly. I have since retired and I now live in North Carolina, but one of the things that I did in New Jersey before I left -- and actually the day that Governor Christie signed the law, I put in my retirement and I requested the department add an assessment for minority families in the state and I think every state should have that.

New Jersey has not moved forward with that, because they have not, even though the laws is there, they have not really implemented the law, so they haven't done that assessment the way, you know, they should be doing it.

So, they neat advocates to stay on that, you know, just like with the 504, you know, it's there, but if you don't have advocates to stay on them, this is what happens.

But I really think, because race is such a big issue and the intersection of race and disability is really a huge issue, which has not really been looked at as carefully as it

should within the greater disability community, that every state should have some sort of mechanism that looks at services and the needs of minority families, because their needs are quite different, you know.

Needing \$1500 to move to a safer apartment than needing something for a fence for a horse farm are two very, very different needs.

>> CLAUDIA FRIEDEL: And we have our -- our Disability and Health Program assistant has asked, Meagan, what are some ways that the disability community can be inclusive and responsive to black disabled people and their experiences and needs?

>> JANE DUNHAMN: [Sighs]...

[Pause].

>> JANE DUNHAMN: I do anti-racism training, as well as I am really a -- I sit in my faith, I am a person of faith, and what I find really interesting is that both those pieces in my life say the same thing.

Anyone who has done anti-racism training, they know that white allies are told that they should do the work in their community. That they have access that their allies do not have access to.

And so the best way that an ally can help, so in this case white disabled allies can help is okay, if you want to take on the whole -- the piece around housing, that white allies who already have that door open to them demand that in our state, that any new housing that's built will be built in a safe neighborhood.

That's the type of work that our allies should be doing.

Finding out some of the needs, knowing some of the needs, and holding people accountable, and staying tall in that.

In my faith community, it's the same thing. But it's called "soul work" and I just happen to be Episcopalian and we're in the church and our dean in the church, Randy, he talks about soul work and the work of white people in fighting racism.

And so that both places say that our allies, we ask you to please go into those places and stand strong and tall in what needs to happen, what needs to change.

[Pause].

>> CLAUDIA FRIEDEL: So, we have a little over five minutes left on the call.

We have a message from Lori. I'm going to connect you guys after the webinar; she wanted to speak with you.

>> JANE DUNHAMN: Sure.

>> CLAUDIA FRIEDEL: One-on-one.

>> JANE DUNHAMN: Okay.

>> CLAUDIA FRIEDEL: So, I will send out that information.

If anybody else would like to say anything, ask anything, please feel free to unmute yourself or send something in the chat and I would be happy to read it.

>> JANE DUNHAMN: And also, Claudia, anyone who wants to reach out to me, can you give everyone my contact information? You have my e-mail.

>> CLAUDIA FRIEDEL: Let me --

>> JANE DUNHAMN: So please feel free to e-mail me.

>> CLAUDIA FRIEDEL: Yes. Let me send that right now; I'm going to type that in right now.

>> JANE DUNHAMN: There's so many different moving parts that I would suggest find a moving part that's real important to you and then do your work with that particular part. Because if you try and do all of it, the police brutality piece, if you try and do the housing piece, it gets -- it gets to be really, really complicated.

So, I would suggest that you find the piece that really speaks to you and where you might have access and power, and then you're able to build a network of allies and to

go at that particular demographic.

[Pause].

>> CLAUDIA FRIEDEL: And in speaking as -- I know we only have about five minutes -- but our program does do a healthcare provider training, and so, you know, if you need to think about this and get back to me later, but if there was -- if there was something that you would want healthcare providers to learn or to know when it comes to... um... people of color with a disability, what type of messages, what type of information would you want them to know?

>> JANE DUNHAMN: Oh, my goodness...

>> CLAUDIA FRIEDEL: [Laughs].

>> JANE DUNHAMN: It's not just one thing.

>> CLAUDIA FRIEDEL: Yeah.

>> Treat them as human beings. That's what I would say.

>> JANE DUNHAMN: Yes. Okay. However, what we need to add to that is they need to understand, and I'm going to say "we" because I do believe that when you have a child with a disability, that your world becomes, as a parent, your world becomes a disability community.

Many parents don't, but there are those in our world that become a disability community. I will get back to that.

Let me say this, please, I do encourage parents of young children to understand that that child joins a community that you are not familiar with.

And if your child is the only one in your family and in your social circle that has a disability, then they become the "other."

So, if you have a child with a disability, embrace a disability community. Go out of your way to meet and to find disabled people that you have something in common with.

That you do truly become social friends.

And then the message that you would be sending your child is immeasurable, immeasurable.

So, when I say "we," that should include parents.

But let me get back to the question.

With that said, providers need to understand that in the black community, there is so much stigma, so that there isn't the support for the black disabled family that white disabled families find.

You know, there is a long history of communities, you know, all the telethons and all the actors and actresses, that is not the history of black disabled people.

And so, you can go back from the beginning of time, before slavery, what was happening in the continent, and we know all of those stories, children were put into the woods, et cetera.

And then you move forward to the United States and slavery, if you weren't able to work, you were devalued. If you can't work on that plantation, you were devalued.

And then you carry it on, okay, we're past slavery, black people getting an education.

If I'm smart, if I have that Ph.D. from Harvard and I am black, then I'm valued.

So, what does that look like? Throughout history, there has been this conversation of how black disabled people are devalued in their own community. And that's one of the big pieces when I said that NBDC reaches out to the non-disabled black community, because we are doing our best to educate and eradicate that stigma and ableism that exists in the black community.

It is so embedded in the black community, that black disabled people and their families feel like we are on an island, because we experience racism from the greater disability community, and then we experience ableism in our own community.

>> Yes.

>> JANE DUNHAMN: And so that is the work of NBDC.

>> CLAUDIA FRIEDEL: I just want to thank you. We have, in the interest of keeping everyone's time, I just want to thank you so much for your testimony, for your stories, what you've collected from countless families all over the country.

You've given us a lot to think about.

I'm thinking personally about, you know, what we can do with our training, what we can add to it to really get a broader view of disability.

We talk about disability, but we don't really... um... we talk about disability types and are very, you know... this is a whole other dimension that we really should -- I think we really should address, so I'm very appreciative, we all are. A lot of "thank you's" in the chat.

Thank you so much for taking the time.

Anyone who wants to reach out to Jane, her e-mail is [jdunhamn@blackdisability.org](mailto:jdunhamn@blackdisability.org).

And just thank you so much!

>> JANE DUNHAMN: Could I -- can I just add one more thing?

>> CLAUDIA FRIEDEL: Yeah.

>> JANE DUNHAMN: That this is the first year that NBDC will be offering a \$10,000 scholarship to a black disabled student. They will receive the first \$5,000 in their first semester and the second \$5,000 in the second semester.

So, it is going up on our website in November and so the applications will be available from November through March, I think, if I'm not mistaken, don't hold me to it, I'm over 70-years-old, if it's not written down, I forget! [Chuckles].

But we are offering a \$10,000 scholarship to a black disabled student

>> CLAUDIA FRIEDEL: We'll definitely include that in our newsletter that goes out when it is announced. Thank you so much.

>> JANE DUNHAMN: Thank you for having me, everyone!

>> CLAUDIA FRIEDEL: Thank you, everyone! Stay safe and wear your masks.

[Laughter].

>> JANE DUNHAMN: Okay. Bye-bye!

>> CLAUDIA FRIEDEL: Bye-bye, everyone. Thank you.

[Concludes at 3:02 p.m.]

\*\* Edited \*\*

## Recommendations and Findings:

- There are economic, environmental, and cultural barriers encountered by disabled people and racism impacts disability and creates injustice in healthcare and elsewhere which creates violence and danger in the lives of black disabled people.
- Disability activism has historically had a face of whiteness that lacks the cultural competence to address the specific barriers faced by black disabled people.
- Recommendations include challenging racism in the disability community, making all activism both accessible and racially competent, and using any privilege you may hold to hold people accountable and fight for issues that impact black disabled people.