

# Where are the disabled artists?

## ADA 30 – NOTHING ABOUT US WITHOUT US – A CELEBRATION WITH JUDITH HEUMANN

### Transcript

**Abby King:** Hello, everyone. My name is Abby King. I'm an Accommodation Specialist at the University of Kansas ADA Resource Center for Equity and Accessibility. I'm a white female with medium brown hair. I'm wearing a black shirt with a gray blazer and have pink glasses. I use she/her/hers. It's my honor to begin this panel, Where are the Disabled Artists, by introducing our moderator, Rebekah Taussig. She's a KU alum with a doctorate in creative writing and disability studies. We first had the pleasure of meeting Rebecca while she was a student here at KU when she presented in the Hall Center for Disability Studies Seminars. After listening to this, we knew we had to have her in our presentation for our lunchtime conversation sessions. A year later, since then, she's written a book. She's published-- called *Sitting Pretty, the View from My Ordinary Resilient Disabled Body*, which is now a bestseller. She's also a KC writer and a brand new mom to a newborn. We're so glad she could join us along with our other panelists. As a reminder, ASL and captioning are provided during the session. If you do not see the captions, please be sure to refresh your page. I would like to thank the 62 sponsors and over 1,000 people who have registered for our event to help make this conference happen. I'd like to specifically thank the William Allen White School of Journalism and Mass Communications, the Spencer Museum of Art, and the Department of Theater and Dance. As a reminder, there will be one more session of our two-day celebration, which will feature Judith Heumann and Wesley Hamilton after this, starting at 4:00 central time. Rebecca, take it away.

**Rebekah Taussig:** Thank you so much for that introduction. I am a white woman with bangs that I cut pretty short by myself in this quarantine pandemic. I have a bookshelf to my left and some plants and an orange couch behind me. And I use she/her/hers pronouns. I have been looking forward to this conversation since I first learned that it was going to happen. Before we dive in, I just want to introduce you to the incredible panelists that we have with us today. We have Dior Vargas, who is a queer, Latina, feminist, mental health activist, and the creator of the people of color and mental illness photo project, which is a response to the invisibility of black indigenous people of color in the media, in the media representation of mental illness. We also have Katelynn Schultz, who is a Disability Inclusion Fellow at KU's ADA Resource Center for Equity and Accessibility. She is also a recent theater and dance student, focusing on the representation of disability through theater, and has also served on a theater and dance panel on mental health within the theater community. We also have Judith Heumann with us today. Judith Heumann does not need an introduction from me. But I will just say that she-- when I think of the word activist, Judith Heumann, her face pops up into my brain. She has been fighting

for disability justice since before anyone knew what disability justice was. And she hasn't stopped fighting since. The longer, lengthier bios for all of these incredible people is up on the website if you want to read more about them and look into their projects. But without any evidence—

**Judith Heumann:** Before we get into the discussion, I'm holding up Rebecca's book because Rebecca didn't hold her own book. Go out and buy it. I did. Oh, you can't see it?

**Rebekah Taussig:** I can see it, yes. It's right there in your hands.

**Judith Heumann:** Yeah, there it is. Buy it.

**Rebekah Taussig:** Thank you, thank you. Wow, that is a surreal feeling for me, seeing you hold my book in your hands. My heart is doing a little bit of racing. I am so excited to dive into this conversation with you all. So I thought we could actually just start with a more personal question because I am so eager to know about your own experiences and thoughts on some of these topics that we're going to cover today. So to begin, I'm thinking about the tremendous power of storytelling in all of its forms. And one of the powers of storytelling is being able to see yourself represented or reflected in a story, to see your body or your experiences represented somewhere on the page or in that screen. For me, I thought about this quite a bit. I was having to dig a little bit to think about my first experience with that. But for me, I think it might be a movie that came out when I was in my early high school days, *Notting Hill*. And Hugh Grant has a friend. I don't even know if you remember her, but Hugh Grant has a friend in that story who uses a wheelchair. She's a woman who has a vibrant personality. She's quirky, she's fun, she's a whole person on the screen. She maybe has six minutes on the screen. But in that story, there is this one moment where her husband is carrying her up a flight of stairs. And it's not cast in any sort of dramatic pitiable frame or light. But it's just this actual moment of intimacy between them. And I remember watching that as a freshman in high school, just like, dazzled and in awe of that tiny little moment. I don't think I have necessarily seen anything quite like that sense in film. But I'm wondering, I'm curious for you all, if you can think of a first moment when you would have felt reflected in a story or in media, or if you're still waiting for that. So I thought, maybe we could just start with Dior. I would love to hear your own personal experience with that.

**Dior Vargas:** Yeah, I was trying to think of when I saw someone who was Latinx and lived with a mental illness. And the only thing I could think about was maybe something like two years ago, or something like that, where Penelope in *One Day at a Time* lives with PTSD. And I live with PTSD. And she stops taking her medication. And I've done that plenty of times. So that was one example of me seeing someone who I could relate to. And so it makes me sad that I couldn't think of anyone until a few years ago. And I'm 33, and I feel like I should have, at least once, seen someone who I could relate to because often, if I saw any representation, it was white women, unfortunately. And some of the films like *Girl Interrupted*, *Streetcar Named Desire*, *Sibel*, *Valley of the Dolls*. I could just name so many of people who just, I

don't identify with. And I wish I could have seen someone when I was younger. And it's amazing to think about you waiting that long. I mean, that's three decades of consuming and seeing stories and not having that there.

**Rebekah Taussig:** That's incredible. Katelynn, I would love to hear from you about your experience with this.

**Katelynn Schultz:** Yeah, of course. As Rebecca said, my name is Katelynn Schultz. I'm a white woman in my mid 20s. I'm wearing some pink glasses and some broken earrings and a pink blazer. And I think, for me, the first time that I saw myself represented in the media was this Facebook chain that people were sharing. And they were sharing their identities and the different mental health communities that they fell into. And I remember seeing these posts going around. And at that time, I didn't have a diagnosis from a therapist. And I remember wishing so deeply that I wanted to be included. And I wanted to be just as seen as everyone else was in that moment. I wanted to be able to say, hey, this is me. But because I didn't have that diagnosis, it was kind of a weird, do I actually get to identify with this? But I did. And that was kind of the best moment for me, to really come to terms with who I was and the movement itself.

**Rebekah Taussig:** Yeah. And I think that that just crystallizes the power of that representation, how that can be a game changer. Judy, what do you think about this? Can you think of the first moment, if ever, that you felt represented or reflected in a story?

**Judith Heumann:** You know, when I read that question, I just started laughing. So I'm the oldest one on this panel, right? And so, you know Dior, you're 33, you said. So I'm going to be 73. And I'm really trying to--excuse me, I'm getting tutored on my right, to give my description. So I'll finish my question. Then I'll give my description. At any rate, I saw a film called *A Patch Work Blue*, which did not represent me. It was a nondisabled woman playing a blind woman in a film with Sidney Poitier. And so what was very kind of revolutionary on one level, you had a black teacher with a white blind woman developing a relationship. Not on a sexual level, but as-- she would be put under a tree every day when her family went off. And he came over and started learning about her and was helping her learn and be educated because she wasn't receiving an education. So that is one of my first recollections of someone who had a disability, where there was an effort being made to educate that person. When I went back and looked at that film last year, what I didn't remember is that she has this scene in the film where, I think she's been blind her whole life, but nonetheless, there's this scene and her not being blind, playing her real self as a nondisabled actress, dancing under the sun, implying that she wishes she wasn't blind. So that's kind of one of my first. Then there was a film called *Coming Home*, which had Jon Voight and Jane Fonda in it, which came out in the 70s. And it was about a returning disabled veteran. Of course, Jon Voight did not have a disability. And the film was being shown in San Francisco in a theater that... And we had big demonstrations outside of the theater for a number of days to get the movie moved to a place that wheelchair riders could even go and see. And I guess that's some of the beginning reflections we would discuss how we weren't really represented in disability films. And so I will now give my

descriptor. As I said, I'm going to be 73 years old. I'm a white disabled woman. And I'm wearing little gold earrings with little pearls on them. And I have brown hair, which is short, red glasses, a red blouse, and a green and red scarf. And my backdrop is the Brooklyn Bridge with the word Brooklyn across it.

**Rebekah Taussig:** Thank you, Judy. I think it's really interesting to hear you talk about some of the tropes that have been around for so long with disability representation and storytelling, that trope of the nondisabled actor playing the disabled role, the repetition of this idea that the only desired that this character must have is to be cured of that disability. But then also to think about the ways that you were just looking for any representation of any disability on a screen at all, that that existing in the first place was so revelatory. So there's a lot to unpack there.

**Judith Heumann:** one more person, I'm sorry. Geri Jewell. Geri Jewell was in-- I don't remember now the name of the program. It's a Norman Lear series. And she actually has a disability and is a comedian. She's the first disabled person that I remember seeing who is authentic. And we all thought that it was great that Norman Lear did this. And it was wonderful that he really cast a person, not only with a disability, but with cerebral palsy and a speech disability.

**Rebekah Taussig:** That sounds like an incredible example. I think with all of these, it's interesting to me that we can we are striving to remember that one moment, which I guess just highlights that this is not a ubiquitous experience for us. We're not saturated in these kinds of examples. And when they happen, they're rare and sometimes fraught. I actually want to switch gears a little bit and hear you all talk about the work that you are doing to change and complicate and add to these representations of disability in media. All three of you have done beautiful important work to enhance the representation of disability in media in lots of different ways. And so I'm going to ask you a couple of questions here. One is, in your experience, why was your work needed, specifically? So in other words, what prompted you to action or to create? And then the second part of that question is, I'm wondering how you would describe the impact you've seen so far on the work that you have done. So Judy, I thought we could start with you for that two part question.

**Judith Heumann:** When I was asked to be a fellow at the Ford Foundation in 2017, it was because Hillary Clinton had lost the election. And so I was expecting to have a job that I didn't have. And I mentioned it because when this offer was made to me about becoming a fellow and it was stated to me, do something that you've wanted to do before but you haven't been able to. I actually spoke to Jimmy LeBrecht and Nicole Newnham and Sara Bolder, all who were the ones who directed and created Crip Camp. And we were talking about the lack of representation of disabled people in media. And I created a project to look at the issue of lack of representation of disabled people in media. But also, I wanted to look at what was happening to other minority groups, Latinos, Blacks, Asians, Indigenous populations, others. And how did we compare? And when I started out, it wasn't to do a comparison at all. It was just, really, to learn. But what became very apparent, and so there's a paper that--I'm doing

something called The Heumann Perspective. And we have a YouTube channel. And you can come on and look at the paper. So the paper is a roadmap to inclusion, changing the face of disability in media. And what I was finding, by meeting with various groups like GLAD, which is media and the LGBTQI community and various other diverse populations, is that these groups had established organizations that were really looking at underrepresentation of the different populations. A number of them work in the area of documentaries, not all of them. And the fact that there was very little data that was being collected on the issue of representation of disability, that University of Southern-- USC and GLAD we're collecting information. And when I was meeting with these groups, it was groups including, like, PBS and CPB and others, that the thought of the inclusion of disabled people, in their respective groups, basically didn't exist, really. There was no serious discussion about the absence of disabled people in Black media or the absence of disabled people who were from the Asian background in the Asian organization, etc. It was, you know, just not there. And so the paper really-- one of the other aspects of the project, was we convened a group of about 26 people that was composed of many different types of organizations, including representatives from the disability community. And the ultimate conclusion was that we need to be able to establish an organization that really can be looking at disability from a diversity perspective with a view of getting disability integrated across the board. And that's work that I continue to do today, plus they have a book out called Being Heumann and this film. But I really want to underscore the fact that I believe one of the big issues is that organizations-- it's not a criticism, it's the fact, that organizations that are representing other diverse communities, just like within the white nondisabled communities, have frequently not seen disability from within their own communities as-- I don't want to give it a label. I just think it's been--they haven't thought about it. And so I think there is a real need for the diversity within the disability community to work on this. I think Alice Wong has been doing some really great work with a number of other organizations. You can see some of the diverse communities, now, really beginning to look at the inclusion of disability in the work that they're doing. And all of that, I think, is really important.

**Rebekah Taussig:** Thank you, Judy. It stands out to me that you are tackling this problem from so many different angles because you are bringing that critical lens to evaluate the facts of the reality of how representation is unfolding with disability now. But also, you're contributing to it with Crip Camp, with your book, with your YouTube channel. And I have to say, I think that Crip Camp might be the first time I've ever had that many nondisabled people come to me with any sort of media that is disability focused and saying, have you seen this documentary? And I'm like, I have. I'm glad to hear you have too. It seems like it has reached such a broad audience, which is really exciting. Katelynn, let's hear from you on this one. So thinking about the work that you do, what prompted you to do that work, and thinking about the impact of it?

**Katelynn Schultz:** Yeah. So I was a theater student. In one of my classes, we had to do a Chautauqua presentation talking about some research that we did. And the thing that I'm

most passionate about is disability rights. And so I wanted to find a way that I could incorporate disability rights and activism into theater. And I found that it was really difficult to do that. Really, there are only a couple of things that I could pull from. But the thing that I pulled from the most was a play called *The Curious Incident of the Dog in the Nighttime*. And in that show, the author never says that the main character has autism. It's just understood that he has autism, which for me, is incredibly important because we don't have to make a story about disability if somebody has a disability and they're represented. It doesn't have to be about that. It can be about their life, and that's OK. That is true honest representation. And so I'm researching this play. And I'm doing this presentation. And I'm finding that a lot of people haven't really thought about it at all. And the people that are listening are then confused about why this is an issue. And for me, that made this topic incredibly important, more so than it already was. And so later on that year when I found out that our department was going to put on that show, I advocated very heavily to make sure that this role that required a disability was put portrayed by an actor with a disability. And in doing so, we realized that we have actors that have disabilities. And they can act. They can represent themselves on screen. They can represent themselves on the stage. And that's really important because they are seen. And they can also play other parts. And that's the most important part of the work for me, is that I can see those actors who auditioned for that role in their other roles, in roles that don't require a disability. And that's even more so representation, for me. And so that's been the most gratifying part of this work for me.

**Rebekah Taussig:** Thank you, Katelynn. I love hearing about the theater side of things because that's a whole world in storytelling that I just don't know very much about. And it sounds like-- I'm not surprised. But I also really appreciate hearing the details of how this has been something that's been overlooked for so long and how you're getting right in there and making things happen. So that's awesome. Dior, I would love to hear a little bit more about your work as well and what brought you to it and the impact of it as well.

**Dior Vargas:** Absolutely. In 2013, so that's been seven years, which is a long time for me, I decided that I wanted to focus on mental health advocacy. For years, I had been focusing on a whole bunch of different topics. And then I just realized that mental health just had a huge role in all of them. So I started volunteering with mental health organizations, trying to learn more about the field and the conversations that were being had. And so through there, I learned a lot. Also, like I mentioned before, just seeing a lot of white representation when it came to mental illness and a lot of black and white photos and people just looking absolutely miserable. And I have those moments or days, but I don't look like that all the time. And there's not a look to mental illness. So that was something that shouldn't have been surprising to me, but it was. And so I decided that I wanted to create a project where we could have those conversations and highlight the experiences of Black Indigenous people of color. And so it's been really amazing to have seen and hear all these really amazing stories from individuals who live at that intersection between race ethnicity and disability. So a lot of people really appreciated it. I got messages where people started talking about how the project gave them the strength or the power or the agency to share their stories as well as start those conversations with their families as a way to show them that this isn't a white person thing.

And I think that that's something that we're all raised to believe, at least with BIPOC communities. And so also creating a book in order to make that more accessible. Not everyone has internet access. And you also have to know about something in order to find it online. So I just wanted to make it more available to individuals. And it really matters. It matters to me because I didn't want another Latinx person or someone who is part of the BIPOC community to not see themselves, to feel like whatever they're feeling is wrong, that it's their fault, that they're weak for feeling that way. I didn't want anyone else to feel alone like I did. And so that's why I wanted to do this work because I really wanted to show the humanity and the complexity of the BIPOC community. Because when you see representations of people, it kind of makes it seem like those who are represented are worthy of their humanity and having those certain experiences. So it truly matters to me. And I'm hoping that my work can continue to impact everyone.

**Rebekah Taussig:** Yes, Dior. While you were talking, I was over here vigorously nodding and just saying yes, yes. Also, I want to do a quick plug. I think Dior's project is linked on our website, at least the digital online version that she was describing here. Everyone should go check it out. It is incredible to just peruse that page and look at the images that are running through it. It's definitely worth your time to spend some time in that space.

**Dior Vargas:** Thank you. Sorry to interrupt. I just realized that I keep on forgetting to describe myself. And so I just wanted to make sure I did that. So my pronouns are she/her. I'm a light-skinned Latina wearing gold dangly earrings. My hair is short and blond-ish. My background is a white wall. I'm sitting on a gray couch. And then you can see the window behind me covered by gray drapes. But thank you so much for being patient with me. And I finally described myself, so thank you.

**Rebekah Taussig:** Thank you, thank you. I think one of the things I love about the way that you responded to that initial question was how beautiful you pinpointed why this matters, like what that impact, personally, was to you, and what you wanted to do in the very real, lived experiences for other people who encounter your work. And I thought we could maybe spend a little bit more time thinking about that, why does this matter, question. I taught-- I just finished teaching a few years of high school. And when I was teaching high school, I taught this class on disability literature. And we read and watched a lot of different stories that included disability. But I remember, especially when we watched *Me Before You* or *Million Dollar Baby*. I remember a lot of pushback from students who really couldn't understand why we would be so invested or care so much about a story. It's just a story, right? It's entertainment. It's something that we just go get our popcorn and watch and then go home. And there was a little bit of a gap that I had to fill in, trying to establish why stories matter, why this representation is worth our attention and why it needs to change. Katelynn, could you speak a little bit more about that?

**Katelynn Schultz:** Yeah, of course. So for me, I get this question a lot. It's something that most people want to know when you bring up this topic. And honestly, it's about not disappearing

in the world. It is already so invalidating to be someone with a disability in the world because we live our lives, and we go out in the world. And everything tells us that we are wrong or that something about us is broken and needs to be fixed. So when we see ourselves in the media, it's like we get to exist for a moment. And we don't have to worry about when the next time it is that we get to feel like we belong somewhere because we just get to see somebody just like us on the screen. And it goes deeper than that. If we exist for people in the public, then we exist for them when they're fighting for rights and when they're fighting for legislation and when they're fighting for people to just be heard or to even sit at the table. Being represented is about more than just, oh, well like, anybody can portray somebody with a disability. It's not that hard. You just-- you just sit in a wheelchair. That's all there is to using a wheelchair. But it's more than that. It's about the individuals watching the show. It's not about the actors. Although, it means a lot to them. It's about the whole community just existing in the first place. And it means it means like having a voice and just feeling like you belong.

**Rebekah Taussig:** You did such a beautiful job of articulating these simple but fundamental needs, right. We get to exist. We get to belong in that moment. It was beautiful said. Judy, I'm wondering what you

**Judith Heumann:** I don't know, but I'll give you my thoughts, whether it adds or not, I don't know. I think, in disability, it's very complex. And basically speaking, when one doesn't see oneself, when one doesn't learn about oneself, you're invisible. And I think invisibility is really what this is all about. We're trying to strengthen a movement representing diversity. Our movement isn't represented at all, let alone from BIPOC etc. There are more white disabled people that are playing in roles, absolutely. But the number of white disabled people that are playing in roles is ridiculously small and the-- you know what I mean? It's like, the overall number of people with various forms of disabilities is 2 to 3%. And it's very low, according to GLAD and these other reports. So I'm reminded of a story a number of years ago, where someone was telling me about a young deaf person who asked if he was-- this is a true story-- who asked if he was going to die when he was above a certain age because he had never met an adult who was deaf. And so I think you know the points that Dior has been raising about absence is another important issue because so many people have invisible disabilities. And so it's one thing to get people who are deaf or blind or have an intellectual disability, which may be apparent, or a physical disability. But there are so many people who have invisible disabilities. So representation in the area of disability has to go much deeper than just the physical appearance. We really have to be looking at telling stories. And since invisible disabilities are a normal part of life, that's what media is reflecting what appears in life. We have to be very much involved in the creation of the different art forms, in the writers room, the photographers, in every job that is producing various products. Disabled people have to be meaningfully involved. And it also means that we have to have people who are willing to disclose, who are willing to bring that part of themselves, whether you have a visible disability or not, up front. For me, one of the important parts of Crip Camp and the writing of my book with Kristen Joiner, was the ability to really try to tell personal stories. And as all of us know, telling personal stories is painful. But if we can't graphically explain why disability of



discrimination that we have experienced, and the forms of victory and change and things that have happened, and joyousness, just on a regular daily basis for whatever it may be, we're not going to get authenticity. And the reason why I was really intrigued with meeting with people from various other diverse organizations in documentary filmmaking, was to say, you know, i.e. the group that I spent most time with was the-- I'm sorry. I can't remember the name of the group right now, but the center on Asian-Americans in documentary filmmaking. And we were talking to the director. And he says to us-- very nice guy-- he says to us, after our discussion you know-- and he's Chinese. In the community that he came from, when babies were one-year-old, there was a big celebration. And he had never thought about why, a cousin or whoever, when the child was one-year-old, did not have that party. And they didn't have that party because he was deaf. But he never thought about it that way. And we were talking about, there are so many rich stories in all of our communities. And if you're looking at, pick a group, you really need to understand. And you need to consciously be looking at disability. And you need to have knowledge about the different communities. And people from those communities need, very much, to be a part of the discussions, to get people to come forward and tell their stories.

**Rebekah Taussig:** Judy, there was so much there. You just added so much that we can just unpack for the next hour. I think one thing I'm so glad you brought up, is all of the people with invisible disabilities. And the point being that it's not just a matter of putting this wheelchair on a screen or having the blind person on the screen, but it's about the stories attached to all of these experiences, all of these bodies and minds. We need those stories. And not only do we need them, but storytellers need them. It's such an untapped reservoir of stories that are waiting to be told and need to be told. So I'm really glad that you pinpointed that for us. I think now might be a good time to switch to one of our first recorded questions from the community. This is the first question that we have from John Watson.

**[Video Playback]** Pictured on the screen is John Watson. John is a white man with short dark brown hair, thin plastic rectangular glasses, and blue and silver braces. John is wearing a blue KU basketball sweater with a white t-shirt underneath. Hello. Watching Crip Camp, we see how the media and journalists, like Hollynn D'Lil, played a role in informing the public of the 504 Sit-in, and drew some awareness to the movement. In your memoir, Judy, you write about how we must move from passivity and feeling like we are a lone individual voice, to speaking actively and collectively. We now see a more widespread use of social media and disability activists, using these platforms to bring people with disabilities together and improve awareness of the disability rights movement. Can you just talk a little bit about how you've seen digital media change the movement, as well as some of the advantages and drawbacks of social media for social change across all marginalized and underrepresented groups? Thank you. **[End playback]**

**Rebekah Taussig:** I love that question from John. It seems like such an important part of this conversation. And I'm really eager to hear what you all have to say about this. Judy, maybe let's start with you. How have you seen digital media changing the disability rights movement

in your lifetime? And I'm curious what insights you might have about the benefits and the limitations of that medium.

**Judith Heumann:** So that's a great question. I want to underscore that I'm 72, going to be 73 years old. And the reason I underscore that is I have two great people that I work with. One is 22 and one is 24. And they really know how to use digital media. I really don't. I think we really need to be paying attention to a number of issues. The digital divide, which is not allowing people, regardless of their age, to be able to have access to social media. Social media itself, in digital-- I don't even use the words correctly, but is really obviously opening up a world to people to learn and share information, particularly those people who have access to the internet and people who know how to use the technology. But I think we're also needing to recognize that we need to really get a better sense of who we're reaching. You know, when Dior was talking earlier today at this panel or an earlier one about her family and how mental illness was an issue that, culturally-- and it's not just in the Latino community. It's in many, many communities, probably all communities if we're really being honest-- how the material that's being produced in social media or others is really reaching those communities. So I think one positive thing that's happening is people who are working in this area, identifying other people, people who would not necessarily have been able to gain access to a much larger audience because they had to go through more formal approaches, now have a way of putting materials up there without having to get approval from others. And that, of course, is really great. And then more people are learning about and sharing it. And so there's a richness of communities that are moving forward. But I do feel very much, also, it's not a but, it's an and, that since the majority of people who have disabilities do not identify as having disabilities, and the organizations that they work with, like AARP and others, do not represent disability, that we have got to figure out a way that we can also be expanding these very important discussions into a very large population. And I think we're also needing to look at the fact that most of what's happening is happening, at least in the US in English, there are a lot of non-English speaking people. And Dior, you would know, I don't, unfortunately, how much social media, from a disability perspective in other than English, is being moved out there in order to get other communities to be able to become a part of these discussions. And then I think, also, from an international perspective, how we are or are not connecting up with other countries that would be also having similar experiences of more people using social media to get stories advanced.

**Rebekah Taussig:** It strikes me, Judy, in your answer, that you are doing this thing that I think you've been doing all along from the earliest times that you started working towards disability justice, is including more people. Your mind is so bent to who is not a part of this space. Who is, what are all the different ways that people might have a barrier to access this movement. And I just love hearing you talk about that in real time, particularly with social media. It's beautiful and important to see in real time. So Katelynn, is there anything you would want to add to this particular question?

**Katelynn Schultz:** Yeah, yeah. I would start out by saying that Judy is completely right. But the great thing about social media is that, for me personally, that has been my outlet. On

Instagram, I see everyone living their best lives. But for me, if I were to just show all of the good moments in my life, that would only be showing about 60% of my life because there are a lot of moments where I am sad. There are a lot of moments where I am broken. And there are a lot of moments where I am shaking with the inability to move forward. And so I found that by speaking about these experiences and letting people see me as I am in my scariest of moments, I not only validated myself and told myself, hey, this is a person that I am, this is OK to be like this, but it validated all of the people who were seeing these posts. Because all of them were messaging me and saying, you know what, I really appreciate you saying that you're experiencing these things because I experience it too. And I felt very alone. And I felt like I was wrong for experiencing it. But because you said something, I wasn't alone anymore. And I was seen. But the thing is, is that posting about that is really great. But it also takes a huge mental toll on everybody because the onus has been placed on us because nobody else is representing disability in the media. We, as disabled individuals, have to represent ourselves. And that is so taxing. It's so tiring. It is hard to go out every day and say, hi, I have anxiety. And today, I can't talk to people because if I talk to you right now, I'm going to cry. And it's nothing that you said. It's just that my body can't handle it right now. And then we also have to deal with, well, what if we're applying for a job and somebody sees that we are incredibly active on social media and we're talking about our disabilities? What if they see that? What if they see that and they say, oh, well, I don't want to hire you because you have this going on or you have that going on? It's illegal. But they can still do it and not tell us. And the reach with social media can be so amazing. But these are very personal stories. So sometimes we are not sharing them outside of our private closed group of friends. And so sometimes, while social media can be very amazing, it can be very restrictive as well.

**Rebekah Taussig:** Thank you, Katelynn. When you were talking about your experience sharing the whole range of emotions and experiences that you have on a day-to-day basis on your social media account, that resonated with me. I feel like social media has become that space for me as well, to kind of unpack the highs and lows and everything in between as a disabled woman. But my second thought was, I've got to find Katelynn on Instagram or whatever your social media platform is. I want to follow that person because that's the kind of content I want to be around. So thank you for that. I thought we actually-- you know, I cannot believe the time. It's flying by as I knew it would. But it's flying by faster than I can believe. I think I might have us hop over to the second question that John Watson asked because it's a really important one. And I think there's a lot for us to unpack here. So if we could just have-- this is the second recorded question that John Watson asked for us.

**[Video playback]** The widespread use of social media has afforded those with access to social media the opportunity to bypass traditional media outlets and production companies, who, Judy, as you and your colleagues note in the Roadmap for Inclusion, tend to represent people with disabilities in stereotypical ways. And now, we can present as individuals on our own profiles and websites. Can you just talk a bit about your own digital media presence, whether that be on your YouTube channel or other platforms? And how can we, as individuals with disabilities, represent ourselves in ways that advance the movement? Please and thank you.

**Rebekah Taussig:** We also have a question from the community asking specifically about YouTube. So another reason why I thought this might be a good question for us to tackle, because Judy, you have a YouTube channel specifically. So I'm wondering if you could talk with us a little bit, Judy, about your experiences developing an online presence through your YouTube channel? And other social media spaces, too, if you want to talk about that. But what advice do you have for us, based on that experience?

**Judith Heumann:** So I'm wondering, Dior, do you want to add anything this before I jump in? Are you using these various media forms?

**Dior Vargas:** So I personally don't use YouTube. I use Twitter, Instagram, and a little bit of Facebook. I do have a response to that question. But I definitely want to--

**Judith Heumann:** Why don't you give your answer?

**Dior Vargas:** OK. So I would say if you want to represent yourself, it's important to really think through why you want to do that and being intentional about that. At least from my experience, I think, maybe it's my anxiety or it's just a sense of urgency, where I want to do something. And I kind of throw myself into it without necessarily really thinking it through. And there times where I wasn't intentional about things. And I ended up suffering some consequences. And so I think that in order to protect yourself and your ultimate well-being, really understand why you want to represent yourself. And perhaps there are other ways where you can do that for the community, but not necessarily you personally. And so being open about your experiences, I think that's also a form of advocacy. So just definitely being intentional about it and not worried about why when you want to go ahead and do that because I don't think people should sacrifice themselves for the sake of the movement.

**Rebekah Taussig:** Thank you, Dior. Spoken like a wise woman from experience, I think. That is some real wisdom right there. Thank you for that.

**Judith Heumann:** So this is Becca Howell.

**Becca Howell:** Hi.

**Judith Heumann:** And over here, I have Stevie. And the three of us do our social media. And I guess, as in everything that I've been saying, I'm a very broad brush person. I'm wanting to bring in as many people's information as possible. The Heumann perspective that I do, we only do twice a month. And that's really because we don't have the wherewithal to do more. Heumann perspective, which we have up on YouTube, is really intended to allow people to meet many, many different people who have various forms of disabilities and are doing work that I think might be of interest to some people and might get them interested in learning more. It is certainly not a be all and end all, because there's so many

people doing great work. We do a Monday Minute, which is really intended for people to see me lighter because everybody said I was too serious. And for a younger audience, I needed to do things that were funnier. So we're doing that.

**Becca Howell:** Well, you are very funny.

**Judith Heumann:** I am very funny, but most people don't see that. And so Becca, Stevie's been with me since December. And Becca has been with us since August. Do you want to give a thumbnail sketch of what it is that we're trying to do with our social media?

**Becca Howell:** Well, I think mainly with the YouTube channel, which I would say is the bulk of the project with the Heumann Perspective, is I think what's really great about the YouTube videos is that they're longer form interviews. And I think on other platforms like Instagram or Twitter, it's just a really quick snippet. You don't really get the whole discussion. And so with the longer form interviews, I think we really get to hear someone's story and their experiences. And it can be really powerful. And it's also just fun to reach out to people that we really think are doing great work and share it with a larger audience.

**Judith Heumann:** And really, a lot of what I'm trying to do is, as I said, introduce people and issues. So on Tuesday, I have a friend who's an economist and into data. And I had been talking with her about a month ago and said, if you've got time to put some stuff together on data, could you do that? Because I think data is really important. And she came up with something. So once a month, we're going to put something up on data. What we put up on Tuesday-- right, Tuesday? Yeah. We put something up on Tuesday about data, which shows information from Rutgers University that's been doing work on data and voting and disability, about the number of people who have voted with disabilities and how we could change the outcome of elections if a larger percentage of us voted. But we're going to, over the next number of months, talk about the importance of data and give further examples. That's just kind of one example. Yeah. So I may not be as focused as I could be. My focus is telling people's stories, really.

**Rebecca Taussig:** Oh, I think you're plenty focused, Judy. I think that you dig pretty deep, which is, it's rare. It's interesting, because I think you said something about not being so good at technology. But you are going through and expanding and navigating that territory quite well. YouTube, as a territory, is a land but I have yet to enter. I'm very intimidated. But you're doing it all, it seems like.

**Judith Heumann:** I guess I know what I don't know. And I look for people who know more than I do.

**Rebekah Taussig:** And you're doing it. I mean, you figured it out. We could all learn from that, I guess. I could learn from that I thought what we might do with the time that we have left is bring in some of these questions from our audience because there are a lot of really good ones. I know we're not going to have time for all of them, but I want to bring in some of them.

And there's this question from Lisa Kabulcrins, that I think brings up some pretty important application for some of the things that we're talking about here. So this question asks, how can an able-bodied person incorporate artists of all abilities into their works, particularly theater and dance? So Katelynn, we'll probably go to you for that part of it.

**Judith Heumann:** Yeah, but I have to just say one thing, please. Yeah. I don't know who the person is asking the question. But I really would appreciate it if people don't use the word able-bodied. And what were the two able words? Able-bodied artists of all abilities. Yeah. I don't like those distinctions being made around disability. You have abilities. I have abilities. But the word ability is only used around disabled people. So one way that you can start working with disabled people is to kind of listen to our language and use our language and not use the language of others that maybe don't intend to be harmful with their language. But when I was on the Trevor Noah show and he used the term able-bodied, and I said, we're all going to get a disability at some point. And I said, I don't use the term able-bodied. I use nondisabled. And he said, are you threatening me? I love Trevor Noah. And when he said to me, are you threatening me, I thought for a second and I said, what did I say? Yes? But I didn't mean it in a negative way. And I felt the fact that he used that term. And none of it was rehearsed. It was completely off the top of his head. And he didn't mean anything offensive by it at all. But I think it's the way nondisabled people think. It's like they are afraid of becoming us, whether we're visibly or invisibly disabled. And I think that's what everybody's been talking about today in the last couple of days. There shouldn't be a fear around disability. There needs to be a knowledge around disability. That needs to be a knowledge about who we are, how we experience things, and how things can change. And so, sorry, but the answer the question for me is, do you have friends? Can you have open and honest discussions with people who have various forms of disabilities to listen to what people have to say? And equally importantly, are you engaging them in your work?

**Rebecca Taussig:** Thank you, Judy. And no need to apologize. Able-bodied is a term that is pretty ubiquitous. It's used often. And I think that a lot of nondisabled people don't necessarily have in mind, the implications of that term. And so I think that you articulated that really beautifully. Nondisabled, I'm glad that you're pushing for that shift in language because that's a shift that needs to happen. And I love the way that you're answering that question too, talking about, pay attention to our language. And I think part of that comes with the very thing that you mentioned, which is do you have people in your life, disabled people in your life? I think that's part of how you start to learn that language, is actually listening and being close to and connected to people who are disabled. I'm curious if Katelynn and Dior have anything to add to that, specifically the part of it that, Katelynn, the part of it that addresses theater and dance in particular. But just wanting—nondisabled people wanting to be inclusive, what advice would you have for how to go about doing that?

**Katelynn Schultz:** Yeah, so we have conversations all the time about race and theater and how to go about race. And we have conversations about gender expression and identity and how to represent that in theater. But when it comes to disability, that is an identity that people are so afraid of that we don't have those conversations. But I think you go about it in

the same way. When you're putting out a casting call, you are requesting people of certain identities to audition. And so the responsibility isn't on the individual with a disability to show up to the casting call or to say, hey, can you audition me because I have a disability and this part requires a disability. The onus is on the casting directors to say, we are calling out. And we are asking for people with disabilities. And it's on all of the actors without disabilities to then be responsible and not audition for roles that they cannot portray because acting is about portraying a lived experience. And that is a lived experience that you cannot portray if you have not lived it. So the onus isn't on the person with a disability. It's on everybody else to get comfortable with having conversations about disability, because it isn't a scary topic. It isn't taboo. And it's not something that we should shy away from, but to also, then, be responsible and take responsibility for the actions that we are doing, for the shows that we are putting on, and for the way that we are representing people, because we already do it for so many other identities. Why can't we do that for disability too, when the conversation should be the same? So that, ending with a question, is my answer. Just represent people. It's not scary. And just do it.

**Rebekah Taussig:** Well, it's interesting to me to hear both of you talk about the fear and address, kind of name that fear, because I think both of you are 100% right, that so many of the barriers for inclusion of disabled people, and I mean that in terms of this conversation about representation and storytelling. But I think in many realms that we exist, I think fear contributes to so much of the erasure, isolation, and exclusion of disabled people. So it stands out to me that both of you are naming that. Dior, would you want to add anything to this conversation as well? What insights would you have about this question about inclusion?

**Dior Vargas:** I think that they both said it. And I also want to be respectful of time, just to make sure that everyone has their question answered. But thank you for asking.

**Rebekah Taussig:** Perfect. This is a question that stood out to me from our audience because I do not know the answer at all. I think, Judy, you might be the most equipped to answer this. But Katelynn and Dior, feel free to jump in on this as well. But the question comes from Bobna Metta. asks, are there any examples of how artists cultivated their work during the disability movement in the past? It strikes me that we've been talking so much about now and media and social media and storytelling in the moment right now. But I am, I am also curious, Judy, if you could talk to us a little bit about how maybe the arts had been a part of this movement in the decades past as well?

**Judith Heumann:** Absolutely they have been. And I'm sitting here really not prepared for this. But there's a guy named Lawrence Carter-Long who is a disabled guy over at DREDF. And we're working on a project called D-MAP, Disability and Media Alliance Program. And he has, now, twice, hosted on TCM, a series of films depicting disability and both positive and negative representation of disability. He's a really good historian on this. Obviously, the question, also, is how far back we're going. There really are more knowledgeable people who could speak about this. I'm sorry I can't give that great an answer.

**Rebekah Taussig:** Oh, no. I was just kind of curious. And I'm sure there are people who have been talking about that for a long time. And I feel a little silly that I don't know the answer either. But I guess that just kind of points out what a good question it is as well. So I'm looking at the clock. And I know that we only have a few precious minutes together remaining. And I really, honestly, I could talk and listen to you all talk through the afternoon and into the night. But I want to be mindful of our time. So I am thinking, if we want to just close with some of our final thoughts. I know there's a lot that we didn't get to talk about or address in this conversation, and there's a lot more to discuss. So if there's any final thought that any of you want to add to what we've started here, I would love to hear from you. And I know-- I think, Katelynn, maybe there's something you might want to add. But Dior and Judy, also, if you want to have any final thoughts before we close this conversation, I would love to know where you all are thinking in this moment.

**Katelynn Schultz:** So I think my final thought would be, going through the process of auditioning people with disabilities for the role of Christopher in the Dog in the Nighttime, I realized that it had become a burden upon the casting directors to cast someone with a disability. And the biggest take away that I hope people can take away from anything that I've said is that it's not a burden to cast disability. It's not a burden to represent disability. People with disabilities aren't burdens. We're just people. And I think Judy's last name is perfect for this, because she's a human. And that's really all it's about.

**Rebekah Taussig:** Oh, man. I felt that in my chest when you were talking, Katelynn, because that word, burden, is so heavy and loaded and wrapped up in narratives about disability and have been for so long. And so I just love hearing you say that, that we are not a burden. And this is not a burden. And you're right, Judy Heumann. That really worked out, that last name, because that's perfect, like human being. Dior, Judy, any final thoughts that you'd want to share?

**Judith Heumann:** Dior, you go.

**Dior Vargas:** I would say that there's nothing wrong with the word disabled, that people who live with mental illness should claim the word disabled. And then just in general, it's an absolute honor to be on a panel with you, Judy. I'll stop there. I'll get emotional.

**Judith Heumann:** What I want to say is, we're not a burden, but we're burdened. And we're burdened because of the absence of ourselves. We're burdened as we're trying to more rapidly move forward to really allow our stories to be told. We're in the middle of COVID. And there are so many stories that need to be told about disabled people at risk of COVID, disabled people dying from COVID. But also, mental health issues that are going on for so many people as a result of COVID, who may have had mental health disability previously, may have not, where there's such limited discussions going on where because the weakness of the peer support model around mental health is still so limitedly infused into our society. And now that we have another huge number of people who have had COVID with very little understanding of what long term impact COVID may have on their lives. I think of, I had polio. And there's a



lot of similarities between the virus with polio and COVID, not identical, but similarities. And a real need to be consciously reaching out into this community that A, everyone never expected to contract this virus, are really experiments because no one knows what's going to be happening. We're hearing more and more stories of people who have impact of COVID much further on, whether our organizations and us as people, how we make sure to be able to reach out to those people and let those people who have experienced the virus, or their family members or others, really get a better understanding of what disability is and what it isn't. And by that, I mean, why it's important to be a part of this family that's an ever-growing family, where we don't necessarily want to be in this family because we don't understand it. And part of what we're trying to do in journalism and film and television and radio, etc., these are the places where our stories being told by us need to be coming forth, reaching into new communities that have never ventured forth. I want Dior's grandmother. I want the religious communities, for those people who are involved in the religious community to understand the role that they play in legitimizing disability.

**Rebekah Taussig:** Thank you, Judy. That's such a good place for us to land and finish this part of the conversation. I know this is a conversation that is ongoing. But for the moment, thank you for bringing us to that point. And I want to second Dior. And I think Katelynn would probably third Dior's sentiment of just the privilege and honor that it has been to share this space with you today, Judy, and to have your time and energy and thoughts here. And I also want to just say, Dior and Katelynn, it's also an honor to be here with you. I really admire the work that you all are doing. I think it's important and exciting. And I can't wait to keep following you in the coming days of our lives. So thank you all so much.

**Judith Heumann:** I want to just say also that I really appreciate that everybody is happy to be with me. But I'm much more happy to be with all of you. So thank you.

**Rebekah Taussig:** Well, it's a contest. So we'll see who wins.

**Judith Heumann:** I win because I'm older.

**Rebekah Taussig:** This was amazing. It really was. So thank you all. And Thanks for our audience for being in it with us too.

**Judith Heumann:** Thank you. Get her book.