EMILY HARRIS:

Welcome to the Disability & Philanthropy Forums, 2022 webinar series. My name is Emily Harris and I'm Executive Director of the Disability & Philanthropy Forum. I use she, her pronouns and I'm proud to be part of the disability community. I come to you from the unseated land of the Council of Three Fires, the Ottawa, Ojibwe, and Potawatomi nations, now known as Chicago. As part of our commitment to accessibility, our panelists and I will each provide an audio description of ourselves. I'm a white woman with dark curly hair, wearing rectangular glasses and a navy and white polka dot top. Behind me as a white and tan screen. My access needs are met today because we have CART caption.

A few housekeeping items for today's webinar. There are two ways to access our live captions today. Use the CC button at the bottom of your screen and choose subtitles or full transcript, which will pop up as a box on your screen within Zoom. Or to access the captions in a separate window, see the link to the external caption viewer on chat. Today only our moderators and panelists will be on camera. You will be muted throughout the event. The webinar is being recorded and you will receive a link to the recording in the next few weeks.

Although we will be using the chat to share links with you, it will not be available for you to communicate at. Instead, please use the Q&A button at the bottom of your screen to share your questions at any time during the session. We will have some time to share them with the panelists at the end. If the Q&A is not accessible to you, feel free to send your questions to communications@disabilityphilanthropy.org. We will be tweeting today and hope that you will join us on social media using the hashtag, disability philanthropy. You can also follow along by connecting with us on Twitter @disphilanthropy.

Before we start today's conversation, just a short reminder of how we define disability. Disability is a natural part of the human experience. According to the CDC, one in four US adults, 61 million people have a disability that impacts major life activities. Disabilities can be apparent such as a mobility disability, but many disabilities are non-apparent, including chronic illness and mental health disabilities. Disabilities can be lifelong or acquired. And we often say that we are the only minority group that anyone can join at any time. The COVID-19 pandemic has laid bare the systemic oppression of people with disabilities and is increasing the size of the disability community as we speak.

Disability is more than a diagnosis. For many people it is a community and a culture. This is particularly true in the arts community and we are in for a fascinating discussion today. To moderate our panel, I'm delighted to introduce Elizabeth Alexander, president of the Andrew W. Mellon Foundation. The nation's largest funder in arts and culture and humanities in higher education. A poet and renowned author herself, she's one of the 16 CEOs who serve on the Presidents' Council on Disability Inclusion in Philanthropy, which founded the Disability & Philanthropy Forum, and is joined by three disabled artists, thought leaders and advocates. You'll find the link to their bios in the chat. Take it away, Elizabeth.

ELIZABETH ALEXANDER:

Thank you so much, Emily. I'm very, very happy to be here today, and excited about the conversation with these terrific creative, innovative, righteous folks. I'm president of the Mellon Foundation. Mellon is based in New York city, the original lands of the Lenape people who were forcibly removed and continue to be dispossessed land on which many people have lived. And as an organization committed to accurate and complex understandings of history, we at Mellon are currently engaged in a process of ongoing deep land acknowledgement work and learning and repair.

I am a black woman wearing big gold hoops and a blue top. I'm seated in front of a painting. The portion of which is abstract green, the watery deep and was created by my late husband, Ficre Ghebreyesus. My pronouns are she, her and my access needs are met today. I would now like to welcome our panelists. Joining us today are Lillie Lainoff, author of *One for All*. Jen White-Johnson, disabled artist, designer, educator, and activist. And Day Al-Mohamed, author, filmmaker and disability policy expert. Rather than read the bios of our panelists aloud, they've done so much that is rich and extraordinary, we have posted links for your reference in the chat so we can get right to it.

I would also like the panelists themselves to introduce themselves along with a sentence they would like us to know about themselves. Let's start with Jen, followed by Lillie and then Day. Jen.

JEN WHITE-JOHNSON:

Hello everybody. Thank you so much for having us today. I'm Jen White-Johnson, coming to you from Baltimore, Maryland home of the Piscataway people. A quick image description of myself. I am an Afro Latina woman with caramel color skin. I'm wearing purple earrings that say decolonize, resist. And I'm wearing my favorite leopard print or cheetah print headband. I have a gap in my teeth, and I'm wearing a yellow shirt that has a black power fist and underneath it says Black Disabled Lives Matter. It's one of my favorite t-shirts of a symbol that I created for disability, solidarity on behalf of my black and brown disabled folks.

I'm in my studio at home with a whole bunch of artwork behind me that says create and resist, Black Disabled Lives Matter, and create more anti able spaces. I also live with ADHD and also an autoimmune disorder, and I'm just so excited to be here as a mother, as an artist and a designer and as an educator as well. Happy so much to just share my love and joy with everybody today. Thank you so much for joining us.

ELIZABETH ALEXANDER:

Thank you, Jen. Lillie.

LILLE LAINOFF:

Hi everyone. And just to reiterate what Jen said, I'm also so excited to be here. My name is Lillie Lainoff. My pronouns are she, her, hers. I am coming to you today from the land of the Anacostans people, which is also known as Washington, D.C. A visual description of myself, I'm a white woman with long curly brown hair. I'm wearing a blue shirt and a gray jacket. And behind me is a print of a black and white photograph against a tan wall. And there's an outline of a window on one side. I have postural orthostatic tachycardia syndrome, which is also known as POTS for short and a few other chronic illnesses as many people with POTS have.

I'm very excited to be here representing disabled writers. And I'm also the founder of Disabled Kidlit Writers on Facebook. And I'm just excited to chat with everybody today.

ELIZABETH ALEXANDER:

Thank you, Lillie. Day.

DAY AL-MOHAMED:

Awesome. Thank you. I'm super jazzed I think like everybody else to be here. My name is Day Al-Mohamed. My pronouns are she, her. I'm an American woman, brown skin, black hair. I'm rocking great white strike at the front right now. I'm coming to you from the unseated land of the Nacotchtank and the Anacostan, which is the Washington, D.C. region. I'm actually at my office here in the White House. So there's absolutely nothing behind me, it's just a white wall. But I am rocking one of my favorite bright purple shirts. I wear a lot of hats as a filmmaker. I was one of the founders of FWD-Doc, Documentary Filmmakers with Disabilities.

I'm also among many of the things currently the Director of Disability Policy at the White House. However, today I'm here to talk about the arts and philanthropy. I'm very excited about that.

ELIZABETH ALEXANDER:

Fantastic. Wonderful. Let's begin our conversation today by asking each of you to share your stories. And the questions that I've asked that you think about is, little, teeny tiny questions, what has shaped you as artists and activists? And how has your personal experience enriched and informed your understanding of disability arts and culture? We'll start with Jen, followed by Lillie and Day

JEN WHITE-JOHNSON:

A note to the audience, because of my ADHD I am hyper verbal, which means that I speak very fast and also credit to my Puerto Rican mother, I use my hands a lot and I'm very... A quick note that I will do my best to speak nice and slow. It's a really beautiful broad question that evolves every single day in terms of what my story is, especially what my disability journey is. I've been, I'm diagnosed ADHD since I was a little girl, partly because ADHD looks very differently in especially black little girls because we're excited and we're talkative. And no one really views that as any space that's rooted in disability because we're very joyful and we're happy.

But I did struggle in school with staying quiet and simmering down and I would get pulled out of class and I would get reprimanded for talking a lot. But I grew up in a very supportive household that allowed for me to be joyful and to express that individuality. I didn't even really grow up thinking that ADHD was a disability until my son was diagnosed as autistic and also having ADHD. It wasn't until I started to notice a lot of really beautiful and wild similarities between me and my child, that I started to recognize how uncomfortable I was with the way that black and brown disabled folks and neuro divergent folks are viewed in the media, in visual culture, in the school system, K-12 and also in higher education.

I started to get really uncomfortable with how much joy was left out of the conversation and how rooted in ableism it was, and how rooted in sadness in the charity model of disability that we have to eradicate and cure this neuro divergent soul, and how we have to fix them, and how we have to, basically heal them. I was like, this isn't the language that was preached in my household, and I'm not going to preach it to my son as he's growing up. And becoming introduced to autism culture, autism activism, culture. I just felt I wasn't really seeing a lot of that community really amplified and really celebrated through art, through photography, through graphic design, which are a lot of the things that I really love to use to just talk about disability and to uplift disability.

I was very busy advocating for my son who was diagnosed at two years old. And I was like, okay, how do we move forward? How do we continue to express to him that he's a great kid and that he's going to continue to be amazing? My ADHD started to become a lot more pronounced as I struggled with executive functioning, mothering, being a full time college professor, which is something that is very rare among Afro Latina women being able to teach and mother and all of that under the helm of neuro divergency. I struggled a lot. I struggled a lot and I was very micromanaged at times. I was stigmatized. I was, don't talk about your disability. Don't talk about some of the things that are very personal to you.

Don't share with your students that you have a disability, don't share with administration. And I was like, I don't want to continue to live my life under this umbrella of ableism, under this umbrella of stigma, especially if I'm really trying to emote acceptance and joy to my son, I'm going to have to start flipping that narrative and that script within myself. And art activism and design really became a way for me to just channel all of what I wasn't seeing and to use that to give it, to share it, to not create disability justice, art and creativity in a silo, but to share it and to amplify it, like Day, like Lillie, we've been doing this work for a really long time.

Some people have been following us for a minute and then others are just becoming very introduced to the work that we're doing. I just love that we're all speaking the same language, but we really need support. And we really need folks that are in industries or in philanthropy to realize that the work is being done and what are y'all going to do to continue to uplift this culture that we're good at. We know how to, we're in the trenches, we're in the ground and we're ready to work. That's just my story in a nutshell.

ELIZABETH ALEXANDER:

Thank you. Thank you. Thank you. I should have said early on, thank you to Destiny, who is our ASL interpreter and is so beautifully and elegantly doing her thing. Thank you. As was listening to you as well, Jen, I was thinking about a line from June Jordan's poem about my rights, a poem that many of you may know, where she says, "I am not wrong. Wrong is not my name." And so let us turn to Lillie.

LILLE LAINOFF:

Hi. I didn't identify as disabled until I was an undergraduate in college, partially because of stigma, partially because of the fact that I'd bought into the narrative that society tells us, that if you can hide your disability you should. And that it's something to be ashamed of. I was diagnosed with POTS syndrome when I was 14 years old. I had just started high school, a brand new high school. I was learning to navigate high school while I was learning to navigate this body that was not really doing what it was supposed to be doing. At the same time I was having to explain to so many students, other students and teachers, what my condition was, when I didn't really even understand it completely myself at that point.

There were a lot of times when I struggled to get the accommodations that I needed, teachers would refuse to give me the accommodations that were granted to me by my IEP. I remember poignantly one memory in high school of being on the elevator and a security guard pulling me off the elevator, even though I had an elevator pass, because she said that I didn't look like I belonged there. And so that informed both how I talked about my chronic illness and also how I felt about it. Before I went off to college, I decided that I was not going to tell anyone that I was disabled.

Because in my mind telling people, these new people at college that I was disabled would make it harder for me to make friends, would make it harder for me to find anybody who would want to date me because we're taught that disabled people, specifically disabled women are not desirable. I thought that people would think I was weak. Obviously hiding a chronic illness and disability is pretty difficult, especially when those symptoms manifest physically. So that lasted for all of about a week. And I realized because I was surrounded by people who supported me and friends who supported me, that I felt comfortable in talking about my disability for the first time.

I still wasn't calling it a disability yet though. And that didn't happen until I was lucky enough to have an op-ed published by the Washington post in which I talked about being a chronically ill teenager. And at that point I had always wanted to be an author. I had always wanted to be a writer, but I very quickly realized after the outpouring of love and support, but also messages from people who had POTS saying, I didn't know anybody else who had this, thank you for talking about this in a national newspaper, in this large scale. I realized that it didn't just have to be about my words being in print, that they could mean something more.

That I had the opportunity to use my platform, to use the thing that I love, which is writing, to provide representation for the teenager that I was and for teenagers today. And that's why I wrote *One for All*, which is my debut novel, which is one of the first, if not the first, it's a bit hard to track with publishing, novels published by a major publisher with a main character with POTS syndrome, which is alarming since millions of people in America alone have POTS. It's also why I've founded Disabled Kidlit Writers, because I don't want to just help readers. It's also important to help support disabled writers who are coming up, because as Jen mentioned, we're doing the work. Disabled creatives are doing the work.

There are so many stories that have been written that just aren't getting the industry support that they need. And making sure that there's a space, a community space for disabled creatives to support each other, but also to lift each other up and give each other advice and to try to push publishing for the better was what I wanted for Disabled Kidlit Writers. Yes. I'm just really excited to be chatting about this and feel excited to hear Day speak too next.

ELIZABETH ALEXANDER:

Thank you, Lillie. Day.

DAY AL-MOHAMED:

Oh my goodness. Wow. I think a lot of what you guys said really resonated, because Jen was going, I had to fight myself not to go, did you get the notes back from your teacher that said talks too much in class? I'm sure that was a part of it. In some ways my journey is the same, and in some ways a little different. I think we all have the same kind of things. I've spent a lot of my time working around disability and policy and ways to improve and advocate for folks with disabilities. One of the things that's important piece to consider is, disability isn't necessarily just defined by the laws that exist. It is defined by the values of the society in which it exists. I think that is what Lillie alluded to, the law can say, you shouldn't discriminate. The law should say, folks with disabilities have the same rights.

But it's the values of society and people in it that say, yeah, it's better if you hide that or that's not really something that's considered important or a value. And in some ways disability culture pushes against that. Disability culture in and of itself is a celebration of the uniqueness of disability. It's a recognition of the value that people with disabilities bring. It's about pride. It's not about how we exist in society, but how we are driving and transforming that society. I think one of the key things as a part of that really also is the arts is one of the most powerful ways to impact culture. And so I think for many of us, it was, this is how we can work on people, on getting them to recognize that, yes, it exists as a part of the world as a whole and it can be just as simple as showing up.

I think Jen, and Lillie both referenced the idea that representation of even being seen. I'll give a very short example. I'm an Arab American woman with a disability. I'm also queer. I have a wife. It doesn't always come from conversation, but I have a lovely long bio. And at the very end, she lives in Washington D.C. with her wife, Renee brown. I remember getting a note or was actually part of an article by someone who had talked about the work that I had done, but what got them so excited was to recognize that I was part of her community, that I was a person with a disability who was queer. And that representation works for disability. It works for race, it works for LGBTQ stats and it works for the intersections of any and all of these. We all want to be seen. We all want to be part of the grand story.

ELIZABETH ALEXANDER:

That's beautiful. I'm really taking that in. The end of your answer is a perfect segue to what's next, because each of you is an advocate, an activist, someone who works on behalf of others. I would like to understand how you would describe when you came to consciousness about that work. It's in the stories, it's in the story that you've told too Lillie, but even to sharpen that and to talk as well about intersectionality, at about your own understanding of intersectionality in yourselves and in the communities that you speak to, and that if we could know of any writers or artists who have been particularly clarifying to you on this part of your journey, and we'll start with Lillie.

LILLE LAINOFF:

Right. As you mentioned, I did speak a bit about this in my introduction, but to build upon that, like I said, I first identified as a disabled woman when I was an undergraduate in college. Because of that timing I was also at the moment in my life when I was first being introduced to theoretical texts as an English major, but also just as an undergraduate in college. I was reading books by Rosemarie Garland-Thomson. Extraordinary Bodies was my first disability theory text, which I was handed by my English professor, junior year, professor Jill Richards, who, if you're watching, thank you.

And then I started reading books like Feminist, Queer, Crip by Alison Kafer, and trying to get my hands on as many theory texts that I could about being disabled, but also being a woman. Because I think that there's a really interesting dynamic in how we talk about disability and femininity or disability and being a woman. And that's one of the things that I write about a lot, both in *One for All* and in my other texts, my other short stories. As far as other authors are concerned in terms of creative works, Marieke Nijkamp and Emily Lloyd-Jones, and Leigh Bardugo are all really incredible disabled authors who are working in the Kidd Lit space, the YA space, who have laid the groundwork for other disabled authors to be able to write their stories and publish their stories.

Because I think that one of the most difficult things about being a disabled author and publishing, is that when you're trying to get published and your agent submits your book to editors, you have to prove in a way that your book will sell. And when there aren't any comp titles, which is a way of, it's a way of comparing your book to other books that are on the market. If you don't have any comp titles, marketing departments can say, well, we don't know if your book will sell, so we're just not going to buy it.

And when there's not a lot of books out there by disabled writers about disability and about disabled characters, what do you do? Just the cycle continues, and you have to break the cycle, which is why those authors are so important and why I hope to continue their work by also laying groundwork for other disabled authors.

ELIZABETH ALEXANDER:

Thank you. Day.

DAY AL-MOHAMED:

I completely forgot the question. I'm so sorry.

ELIZABETH ALEXANDER:

No. Just talking about your own as an activist, as an advocate, a sharp moment of coming to consciousness about your work and purpose, furthering the question of intersectionality, both as, you've talked about this, but as you think about the communities that you serve and also important works of creativity that have helped you shape your thinking.

DAY AL-MOHAMED:

Sure. I think a lot of the disability advocacy ended up coming with me because I think when you have a visible disability, I'm visually impaired. I have a guide dog. It's not something I can put in my pocket and forget about or hide as easily. So wherever you go, you end up having to do that advocacy because you don't have a choice. So sometimes it's been a little difficult on that front. But there are other places too, where I think there's a choice to be made. And early on, I started with writing before I moved into film, and none of my early work included disability, and that wasn't an accident, it was a conscious choice. Because one of the early things I'll tell early creatives is, and particularly writers, you don't put anything in unless there's a reason to put it in.

So why should the character of a disability, unless it's important to the story, unless it's a metaphor for something else, but that argument erases the very idea that, why can't there be a person with disability in there, we exist. There shouldn't be a special reason to do that. And that was one of the toughest things I think in some ways to personally graph and be willing to break that and go, what if I do this, is it going to sell? If I do this, am I hamstringing my own creative career? And for many folks early on, this was a very difficult decision for many folks to make. I did solely have that going, yeah, I need to put up or shut up. If I'm willing to be an advocate in one arena, I should be doing the same in another.

I think everybody's going to have that moment and different people are comfortable at different points in their career. I am certainly established now that I don't have a problem saying it anywhere and everywhere, but I also know some folks maybe aren't ready yet. And that's where having those models, having people out there like Lillie and Jen, folks who are saying, I am here, I am doing this. Emily and others, it makes a difference in showing that. I think one of the most powerful moments for me was I was sitting in the audience watching my first film at a theater in California, and it was The Invalid Corps. And it was a story about a bunch of disabled soldiers in the civil war.

Immediately afterwards, there were so many people saying, I never knew this. I thought I knew everything about the civil war. Reenactors, history, technique. This is great. They wanted to know more. And it was a recognition that for me, that it really I think sharpened the point that disability is a part of the story. And no matter what we may think of about the idea that it's not seen as important, there are folks who are hungry, who are desperate to find out this missing, and like I said, most of my stuff is more historical, these missing pieces of history, these missing stories, because it is something that resonates with them but they've never even realized they were missing.

ELIZABETH ALEXANDER:

Thank you. Jen.

JEN WHITE-JOHNSON:

Beautiful. Thank you, Lillie and Day. So many beautiful gems. Thank you just for uplifting how much art and design have just helped encapsulate so much of what you do. And so similar, just piggybacking off of what both of you said, I was searching and I just felt very empty when I was looking for design books or literature that helped to define my story. Especially as a black and brown woman, Afro Latina, disability is still very much viewed as a stigma. No one wants to believe that if you're black and brown, if you're queer, that you will have a harder time being a disabled person. It's just no one really wants to talk about that or write about that. And no one wants to celebrate that joy.

I was like, well, I'm an artist and I can no longer keep this out of my art. I need to be able to celebrate what so much of us don't celebrate and what so much of us want to hide and mask, which is something that we've talked about so much, especially when there's just a constant war on black and brown lives, seriously. 19 children were just murdered, that were all Latino in Buffalo. There's a war on black and brown people. There are countless names, Korryn Gaines, Stephon Watts, so many beautiful black and brown souls that were disabled, who are no longer with us just because of their disability and what they felt they couldn't communicate, or the support that they didn't have or how much they were invalidated because of their disabilities.

And so I was like, well, who's really speaking about race? Who's really speaking about race and disability? And that's when I started looking at the beautiful disability justice work of Sins Invalid, and all of the work that those folks were doing so unapologetically. And one of the books that really stood out to me in the beginning of my own autistic, neuro divergent journey with my son and embracing so many different aspects of autism activism culture, was All the Weight of Our Dreams: On Living Racialized Autism, edited by, Lydia Brown, the amazing Lydia, and Morénike Giwa Onaiwu, and being able to kind of, so there are folks that are actually speaking about the intersection of race and disability and what that does to us and how it's often not viewed as this empowering thing to be.

And that book is filled with poems and essays and it's so thick and it's just so beautiful. And I was like, wow, there's actually people writing about this, but it's such a cult classic that you wouldn't even know about it unless you were really entrenched in advocacy and activism, because so often activism, advocacy, and disability aren't necessarily all rooted within the same universe. It's very much rooted in, how can we research autism so that we can eradicate it, so that we can completely nix it out? How can we research chronic pain so that you no longer have to experience that? Not how can you just live with it and really celebrate all of the amazing things that you can do.

And so I knew that early on that I was like, well, what is this journey going to mean? And how can I continue to show up for my community knowing that not all of us are isolated, not all of us creating a silo? What can we do to really speak this really beautiful language that we're just holding in? And we feel we're alone. And so one of the first books that I wrote was entitled, KNOX ROXS. And what you see here is me and my son, a few years after he was diagnosed as autistic, and I'm still really finding my own neuro divergent journey. And it's just showing us, rolling around on the carpet, just in disability love and celebration and joy.

I was very much opposed to writing a book about him specifically celebrating disability with me on the cover. But my independent publishers, Homie House Press, God bless them. Small publishing house, not a huge, widely recognized press. They were like, no, Jen, it's really important to be able to put you and your son on this cover about disability celebration, because oftentimes you don't see that really beautiful, pure moment until it's too late, until either I'm no longer here. I've been pulled over by the police or I've been murdered. Or my son has been pulled over by the police and he's gone oftentimes, and this is just what happens.

This is an everyday language and vernacular that we speak, I'm not making this up. And so it's like, how often do we get a chance to celebrate who we are, the pureness and the loveliness and the joyfulness of our disability while we're still alive to be able to tell that story. That's what I want to do. I want to be able to proclaim in the moment who we are and how we should love on each other.

ELIZABETH ALEXANDER:

Thank you. I'm going to zoom us through the next couple questions, rather than have everyone answer I'm going to direct each of them to one of you, because our audience has questions as well. And I want to make sure that we get to that. Lillie, this is a wild card. This is not in the preparation, but I'm so curious as a literary person. What you think when you hear i, Jen's talk the word joy repeated, the word love repeated, what do you take with that and how do you respond to that in thinking about this moment, your work, the movement?

LILLE LAINOFF:

This is highly specific, but something that was really important to me when I wrote *One for All*, was that it ended on a moment of disabled joy. And the last sentence of *One for All* has been the same last sentence since the very first draft. It's, and I smiled. I knew that that was the one sentence, in edits that was the one sentence I was not going to change. Of course there were other things that I was very adamant about not changing in edits like the authentic representation of disability and the authentic representation of being a chronically old teenager. But I didn't want *One for All* to end on a moment of misery.

I think that publishing is getting better, but it's getting better very slowly. There are a lot of books because publishing thinks that's what sells well, where the only chronic illness representation that we get is Sick Lit, which is stories that romanticize terminal illness or chronic illness. And usually they end with at least one character dying. It's gotten to the point where it's not even a trope, if you're going to be ableist, at least don't bore me, at least don't bore us, because as people we're used to. It's very typical. I'm used to reading about the disabled character that dies tragically in the hero's arms in order to advance the main character arc or to teach the readers about the fragility of humanity. That's very typical.

But as Jen was saying, this idea of love and of joy, I think is really important. And that's not to say that I don't think that books by disabled writers about disability, that look at pain and look at ableism, and that look at suffering aren't important, because they are important, because most of those books are also not getting the recognition that they deserve and are also not forwarded by the market. It's usually books by non-disabled writers who are writing what they view to be as disability suffering, as about all these things. But I think that it's also important to marry the two together.

In *One for All*, there's a lot of discussion about ableism and internalized ableism. It's funny because a lot of people ask me, well, is there a love story in *One for All*? And what I like to respond is, is that the big love story in *One for All* is that Tanya, my main character, it's her learning to love herself. I think that that's an important thing that I think that Jen's work does and that I think Day's work does, and that your work does Elizabeth. But to encourage readers to love themselves as they are, or to be authentic about themselves or to be open about themselves as they are.

LILLE LAINOFF:

I think that's important for all ages, but I think especially for teenagers and young adults and for middle schoolers and even younger, I think that you're at such foundational stage in your life, formative stage of your life, that the books that you read are really going to influence you and shape you as a person. And so it's bittersweet being able to, looking back and thinking about, well, what would my life have been like if I had had the work that Jen was making or that Day was making, or that you were making Elizabeth or that I was making? What would my life have been like as a chronically ill teenager if I was reading books that showed people like me in a way that encouraged me to not feel ashamed and to feel joy instead?

LILLE LAINOFF:

I think that one of the most important things that our work can do is to further that latter point, is to encourage self love and joy and just acceptance of everyone and ourselves in general.

ELIZABETH ALEXANDER:

Thank you so much. Please put your questions in the chat, we're just about there. Day, what do you think is the unique role of disability arts in centering equity and social justice, not just in philanthropy, but in society as a whole? So beautiful.

DAY AL-MOHAMED:

I had to think about that. I think the biggest thing, and I alluded to it earlier is that, the arts and disability in the arts particularly when it is centered, has the ability to change culture. It has the ability to change the way we think about things. And so many things we may not even realize, if I go, may the force be with you, we all know whether you have seen the movies or not, it is part of the zeitgeist. And there's an expectation of what that story is, even if you don't know the details of it. If you see people with disabilities as heroic or as joyful, and that is what you're hearing, it actually creates this idea of what being disabled is.

And when the arts historically may have only showed folks as the angry, disabled person, the victim, the villain, the person who's cured, the metaphor for something else or somebody who basically has to die so the main character learns a good lesson, right? That's all you see. And that actually has real world ramifications too. If you see a disabled life as lesser, than what happens to you or a family member, or we can give examples from as recently as during this last pandemic, when they're talking about priority of care, who gets care in an overburdened hospital, and in real life, hospitals were putting people disabilities lower on the list for care. Not because they were less likely to survive COVID, but because of the perception of disability as less.

And the fact that arts can actually change that because the law actually, and yes, there actually was legal intervention to address that, because yes, it is illegal. But the law wasn't what the problem was so much, it's the perceptions that people have. And a law is cold and inflexible, and it's not something that's at top of people's minds. But that idea of film and television and arts, that's how you slowly change the way people view things. And so that's why I think having disability centered is so important. That's also why I think having disabled artists are centered. It's the part of any community, there's very nuanced storytelling. And one of the toughest things is to make sure you're supporting that.

I will put that out there specifically because in film, there have been films about disability. People with disabilities have had no rules of power in the creation of those films, which means they often follow stereotypes, those same tropes. They meet those same kinds of problematic ableist structures. And so that becomes an issue, and that I think is one that is more directly connected to philanthropy in so far as when funding, who are you funding and those projects who controls them? And in film in particular, it's real big on, we'll bring in a consultant, you can bring in a disabled consultant, but a disabled consultant on a film set does not have as much power as say the director or the producer.

It's one of those things where who controls makes such a big difference. And I think that's why centering not just of the content around disability, but as in who has the right to tell those stories. I'm not saying disabled people are the only ones, but I'm saying there should be a locus control that is recognized there. Otherwise you're missing some of the nuanced storytelling and the depth of what makes it actually meaningful.

ELIZABETH ALEXANDER:

Thank you. And that also gives us a segue to, I'm going to call out a few audience questions and want to conclude with asking each of you for your prescription for philanthropy. We need to hear that. That's where we're driving. But before that, here is a question and I don't see who asked them, so I won't say your names because I don't know them. Again, let's just catch the ball if you like the question so we can get a lot on the table. How have you filled your creative well while being disabled during a pandemic? Do you have any effective tips for other disabled creatives to do the same?

There's a lot of specificity in there. And also I think just the broader question of when you have work that is challenging and out there, how do you also think about what you're bringing forth from within and how you protect that? Anybody can take it.

JEN WHITE-JOHNSON:

I don't mind answering that question, because a lot of people, it took the pandemic for a lot of folks to realize that disabled people existed and finally started paying attention to what we had to say. I knew early on that disabled people really had to exhibit the one principle of disability justice, leadership of the most impacted. We really had to be out there, at the forefront, leading this conversation on how millions of people were going to be left permanently disabled because of COVID. And advocacy requests that the disabled community were requesting even before the pandemic began, that we weren't getting access to, for example, virtual conferences and interpreters and things like that were so important that we had always been advocating for.

And virtual activism and virtual creative activism really just came alive, because disabled folks I felt we were finally able in some interesting way to take control of the conversation. Personally for me, I just started making artwork and I just started sharing it for free. I started making downloadable resources, principal posters that people could use in protests. And that's what really helped. And that's how I ended up meeting Day for the first time. Two years ago, on the hottest day of June, on June 6th, we marched all the way from GW university all the way down to the White House with our other stable advocates, like Justice Shorter, Keri Gray, Mia Ives-Rublee was there.

We all headed down to the White House. Some of us were rocking the Black Disabled Lives Matter shirt. Some of us were rocking this poster that you see here in the background that says Black Disabled Lives Matter, with a black power fist that has the infinity symbol here that amplifies neurodiversity. And it really just came from us just showing up, being there, making the artwork, we weren't getting paid to do any of this. We just used our knowledge, used our resources, shared resources to just create our own virtual activism. And then when we felt comfortable, we just spread it. We got out there, we marched.

And so the work can be done [inaudible] you don't create it in a silo. And as long as you're just there, I was blessed because people were paying attention, folks were passing my name along, but it really just started with me not waiting to be asked to do something. I just had to do it. I'm definitely happy to continue that chat with whoever answers that question later, because [inaudible].

ELIZABETH ALEXANDER:

The clock is not our friend today, but the question where we were going is actually what people are asking about. I'm going to throw a few more questions out that are under this larger rubric. What advice would you give foundations that support arts and culture institutions that are not accessible to disabled people? What advice would you give foundations? Sorry. There's another one. How would you help foundations move their disability work forward? How can philanthropy better support independent artists with disabilities? All of this under the question of, what would you each prescribe for philanthropy? That's what we want to know. Yes, please, Day. Start with, Day.

DAY AL-MOHAMED:

All right. Hopefully you guys will forgive me. I am known because I have a list of six things that I always recommend because I don't see them. And I think it works very well for this audience. I think some will be ones you guys agree with, and you might have others. One, specific inclusion of disability. A lot of folks are talking about diversity, but disability, I actually think needs to be called out specifically. And I'll give a very good example. ITVS has a diversity grant, does not include disability. I think knowing you're welcome makes a big difference. So that means you can have disability specific programs, but if you do anything diversity, please put it in there. Use the word. It's not a bad thing/.

Two, data collection. For any grant stuff, I'm assuming you are collecting demographics, and if not, you should, as an optional measure. You should know about race. You should know about LGBTQ status, and you should know about disability, who are you funding? You can make it optional, but this is important to know, your projects, your programs, your membership. And what's also important is leadership. How many folks with disabilities are in roles? And this relates to the comment I made earlier about who controls. Three, outreach. If you are not finding folks with disabilities, you need to start looking in new and different places. I think that's where there are groups. I think Lillie mentioned, I'm going to butcher the name of it. And I even know it. I'm a member.

LILLE LAINOFF:

Disabled Kidlit Writers.

DAY AL-MOHAMED:

Thank you. You can find a plethora of folks and there some who actually are contracted with mainstream publishers, some who are working independent, some who are still trying to get an agent or finishing their novel, but you can find folks. Four, is to recognize that no one thing is going to be it. So create more, create broadly. And that's not just to artists, but also recognition for philanthropists. Someone's going to complain that *One for All* does not cover POTS. Well, I'm like, no, it covers Lillie's experience. I refer to this as the Wonder Woman problem, right? In the Justice League, you just have Wonder Woman as the one woman, which means she has to represent all women, which means nobody's going to be happy.

Amongst the guys you could have Batman, you can have Superman, you can have Aquaman. They can show different facets of masculinity, but Wonder Woman has to do it all. So recognize you have to have more than one. I have heard a grantor say, we already gave out a disability grant this year. We don't need to do another one. That is actual language. I'm also going to put a note in there also to recognize, a lot of times when you're given funding, you want to know that it's going to be successful, especially if it's early on. Recognize that folks with disabilities may not have had a chance to build up the experience or the resume you might otherwise see.

And so sometimes it might be a little more risk taking. And that has to do with the problems we already have with society and values. Five, put disability everywhere. One of the biggest problems is you'll see disability panels, you'll see diversity panels, but you won't see a person with a disability on a directing panel or on a panel on, was it a cutting edge design? Right? Or character development? And the thing is, who you lift up for what you lift up is what they're viewed as an expert. If I'm only seen as an expert in disability, and Lillie's only seen as somebody who can write about POTS, and Jen's dealing with that, Jen's that whole autistic and ADHD writing thing, then what it does is it creates that one dimensional element. So those artists are never seen as anything other than their identity, which is true of multiple identities.

The idea is, make sure you put disability in a variety of programs, especially the ones that have nothing to do with it. Look for it everywhere. And the last item, six, is to speak out about that diversity and disability everywhere. I make it a point if I'm asked to speak somewhere, hey, is there going to be accessibility? Or do you have captions? I don't use captions. I'm blind. I can't see them, but I will ask about them. And if you don't have them I'm not going to attend. It's really hard to put it on the folks this way, is to ask for the stuff all the time. There's nothing hurting folks without disabilities.

If you are in a panel about diversity, you're in the audience, raise your hand and be one of those folks asking a question about it. If you are putting together a jury for determining who gets grants or funding, or as part of a gallery showing, do you have anybody with a disability on there? Even if it has nothing to do with disability. That speaking out, it is your industry too, and so you have a responsibility not to make it a more diverse industry, but to make it a better one. Okay. That's my six.

ELIZABETH ALEXANDER:

Yeah, but you know what, you just did it. Can we co-sign on the six?

LILLE LAINOFF:

Everything I was going to say, Day said. It's great.

ELIZABETH ALEXANDER:

Well, I think what we're going to have to do now is wrap it up. I'm going to turn the mic back to Emily, aware that in this beautiful and rich conversation, we couldn't get to everything, but we got to so very, very much. Thank you so much for all you do, and for all you are and for all you brought to this hour. I turn it back to Emily.

EMILY HARRIS:

Thank you so much. This has been incredible. And yes, Elizabeth, you already have co-signed, because the Mellon Foundation is one of the signatories of the disability, inclusion pledge, and they're very similar principles to what Day just described. If you work in philanthropy, please check out the pledge and consider signing it. You'll receive a short survey after this session, please fill it out to help us plan our next learning series. We hope you'll join us for the next session on economic justice in September. Thank you so much for the panel joining us today, we all learned tremendous amount.

Please check out disabilityphilanthropy.org, the Disability & Philanthropy Forum. We will take your questions and use that to inform the resources that we are currently developing. And we'll be sending out a lot of the references that the panelists mentioned in a follow up email, along with the recording of this webinar. Thank you. Thank you. And please fill out our survey before you leave.

SPEAKER 6:

Thank you. And this does conclude today's webinar. Have a fabulous day.

ELIZABETH ALEXANDER:

Thanks all. Bye-bye.