Disability Visibility Podcast

Episode 74: Coronavirus and Caregiving

Guests: Dawn Gibson and Heather Watkins

Host: Alice Wong

Transcript by Cheryl Green

For more information: DisabilityVisibilityProject.com/podcast

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Hello, dear friends! What a time to be alive right now, huh? How are you all holding up? Me, I'm honestly trying not to freak out. The shit is real. What gives me hope and keeps me going is seeing the wisdom of disabled, chronically ill, older, and immunocompromised people in the beginning of the coronavirus pandemic in the United States. We have seen and been through things. Today's episode is about the coronavirus and caregiving with Dawn Gibson and Heather Watkins. Dawn is the founder and host of Spoonie Chat, an online community on Twitter and Facebook. She's also a patient advocate, writer, and consultant. Heather is a Boston-based disability rights activist, author, mother, speaker. Dawn and Heather talk about how they are taking care of themselves right now, the impact of the coronavirus pandemic on their daily lives, and their experiences as caregivers. I believe we are modern-day oracles, and it's time for people to listen to us. And I just wanna thank you all for being in this space with me right now. Are you ready? Away. We. Go! [electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: Heather, Dawn, thank you so much for being on my podcast today.

HEATHER WATKINS: Thank you for having us.

ALICE: Both of you have been on my podcast before, and I'm delighted to talk to you about caregiving in the age of coronavirus right now. And before we get started, I would love for both of you to introduce yourselves. Heather, why don't you go first, and then Dawn.

HEATHER: Sure! Again, my name is Heather Watkins. I'm a Boston-based disability rights advocate, a mother, blogger, writer, caregiver for my dad, who passed after 11 years of me being his primary caregiver, and I love to read and daydream. And yeah, that's [laughs] that's me.

ALICE: How about you, Dawn?

DAWN GIBSON: [coughs] Excuse. Of course, I'm coughing on the podcast!

HEATHER: [laughs]

DAWN: [coughs again] Excuse me. I'm Dawn Gibson. I'm the founder and host of the Spoonie Chat, disability community. I'm a writer and patient advocate. My hobbies are listening to baseball on the radio, gardening, and cooking.

Local responses and observations on the coronavirus pandemic

ALICE: So, you know, right now we're talking, it's in the middle of March, 2020. And we really are, I think, just at the start of the corona pandemic in the United States. So, I just wanna check in with you about how you two are doing now, and what are your thoughts in terms of the pandemic, what's happening to your local communities. Dawn, do you wanna go first, and then Heather?

DAWN: Yeah, sure. It's...the pandemic is such a weird time to be alive, just because I knew it was coming, of course, 'cause I listen to a lot of international news. And once it got to a certain point in East Asia, I was like, oh, yeah. This is a thing. And I started thinking about our communities and everything. But [sighs] it's almost like I'm watching a movie sometimes, you know, because there's no one outside. And then when I do go shopping, everybody is just kinda looking like, oh, which one of you is gonna cough the doomsday cough on me? You know that. And then, of course, my aunt, I live with my aunt. She works at a big box store stocking shelves, and so she's been in the midst of the panic buying and people yelling and grabbing things off carts, acting the fool in every way. And in some ways, because I stay, I'm mostly at home anyway, I feel a little safer than some people. But in other ways, I feel less safe because she is out there with the public, and people are acting the way that they're acting. And I am very scared that something terrible is gonna happen in a store. And I don't like to talk like that, but I know what Americans are sometimes capable of. We all know. And that really, I hate when she goes to work. I'll admit it. I hate it, you know.

And then I got into this whole almost game of [chuckles] of stalking stuff on Amazon trying to get it, you know, because I have a diet that I have to eat. I can't just eat any old food. I just I'll be sick. I can't do it. And then, you know, I'm looking at all this stuff, and it's going up and up in prices and all of that. And I don't wanna buy it all because other people need things, too. And not like I could buy everything on there, but, you know, gotta balance that community sensibility with our own needs. And I have a friend, when I ordered a bunch of rubbing alcohol, I let her know. I said, "I have a bottle for you." And I said it aside. And initially, she wasn't going to take it, 'cause she knew I ordered it at a high price and everything. And this is a woman who is married. She and her husband make good money. But her medical bills are really high, and they have two children with food allergies. And so, they have to buy their food a certain way, just like I have to buy it. And now she called me. She said, "Do you still have it?" And I said, "Of course. You know, I set it aside for you." And so, now we're going through this process of how to exchange it, exchange things offa my porch, because she wants to give me something for it, which I don't care. I mean, I'm happy. I'm happy for her to have it because she is a mother of two children, and I adore her. And I do not want her without this rubbing alcohol. But, you know, it's this whole thing about, OK. I'm gonna come to your house at this time, and you leave it on the porch. And then I'm gonna leave you something too. It's bananas!

ALICE: How about you, Heather?

HEATHER: You know, I've been trying to temper my anxiety. I mean, I stay in most of the winter months anyway a lot of the times just to ride out whatever, you know, low temperatures here in the Northeast, in Boston. But we've had a pretty mild winter, so that's good. And I live with my boyfriend who runs most of the errands, if something is needed outside. Otherwise I can just do a lot online, like ordering groceries and things like that, in-home services. So, that part is fine.

But just to see, you know, keeping up to date with what's going on, it just all, just like Dawn was saying, just feels so surreal. And so, I'm having to balance how much information I'm taking in and then take breaks because it becomes overwhelming. Yeah! So, yeah, a lot, you know, I'm used to being indoors. But still, when you have that choice kinda taken away from you all together, then you start to get a little, you know.

I'm just thinking about how you said your aunt lives with you, and also works outside of the home in the big box store. Now, my boyfriend works at a hospital. So... Right! So, the fear right there. You're thinking, please don't come back with anything. And you know, and then I'm also being more cautious with who's coming over. Make sure that people call before they come. Because, you know, I don't want any surprises, of course. And so, those are things, those are part of our new normal now, right? So, yeah, and it's a lot to think about. Like I said, we're kind of used to that anyway; however, now, this is another layer.

[mellow music break]

Disturbing responses to the coronavirus from a disabled person's perspective

ALICE: You know, we're only really at the very beginning, I think, even though it feels like it's been forever. We're really just at the very beginning of, I think, what's gonna be a long road. And Dawn, you mentioned some of the foolishness of people. I wanna ask you both, what are some of the disturbing things you've seen by people in your community or online in response to the coronavirus, as a disabled person? Heather, do you wanna go first, and then Dawn?

HEATHER: I see a lot of varying degrees of just misinformation, and along with the run of the mill, I don't wanna say, well, actually run of the mill racism and xenophobia. And it's just all of the wild things like, Black people can't get coronavirus. And being a Black and disabled person, I'm thinking, huh?! So, there's all of these strange things that people are throwing out there. I don't know if it's a way to offset their own anxiety, but just seeing things like that. And then the hoarding of the toilet paper. And yeah, and I'm not sure why people are doing that. Maybe they're thinking the more they eat, the more they'll have to go to the bathroom, I guess. But I do know that a lot of online services are now backing up, so that affects so many of us, right who use these services. So, when I ordered my groceries, I had to wait, I now have to wait a week, whereas I only had to wait a day or two. So, it is going to affect us all, and I'm wondering....

Which, you know, it just brings up this whole other issue of we had to get to a pandemic for things to be more accessible in that way? You know what I mean? And then it scares me, like, are we gonna default back to, oh, no. We can't do that. Oh, well, that will be difficult. You know what I mean? Come to find out now all of these services and more of these services can do online. And you can see concerts, and you can see, you know, go to these events online. It's just, yeah. So, it's a lot to process all of that, to answer your question, Alice!

DAWN: Yeah. This whole thing is, in some ways, it's like I can't give a percentage of it, but I'll just say a sizable percentage of every fear I ever had [laughs] since becoming disabled has come together [laughing] and is walking the earth as a COVID response monster. I [sighs] I was really worried when the COVID-19 was being referred to as the "Wuhan virus" because it's true that many viruses are going to start in the East and travel west for various reasons. There's nothing to.... It's inappropriate to just say that China and Chinese people are somehow uniquely disease-riddled. And I was so worried about that. They switched it quickly, for the most part, in public health parlance, and even the news switched over quickly. But of course, some public officials are clinging to the idea that this is a foreign invasion and are using that to maybe protect themselves from questions about their irresponsibility in exercising their public offices and that kind of thing.

And then, of course, we're seeing physical and microaggression attacks on people who I guess are being seen as Asian and seen as a source of disease. And that is deeply disturbing on every level. And the fact that that's being let loose in any way in society is really tugging, really firmly tugging at the seams on the rule of law. And I worry, even though society has never been perfect, I worry about what it will mean if we keep tugging and people just feel that they can let out all their feelings and their anxieties and prejudices on some poor person who's just standing on a bus. So, you know, there's all of that stuff.

But then the risk has been discussed, saying that it's **only** people with pre-existing health conditions or elderly that are at high risk. Which first of all, that's irresponsible because by it's nature, novel coronavirus is not well understood. So, we're not able to say for sure. We can say what we've observed. That's all we can say. And we don't know necessarily the connection between the current observations and what we might conclude in the future. And being that we're talking about people's lives and the economy and society, prudence and caution are called for, at least in my opinion. So, there's all that.

But then, to see both online and just in person, to see people flouting the recommendations and guidance of public health officials that they should stay home, that they should limit congregating in large groups, that they need to shut it down right now. That is the way. That is the way that we will get out of this. And maybe this goes with the overarching theme of being anti-science in some ways, anti-reason, and anti-community. In some ways, maybe that's what this is. But yesterday—was it yesterday or today. I don't know, whichever—I saw on TV that the beaches in Florida are still open, and they're full of people. Ack! [laughs] I just couldn't even process what I was seeing because these are people that are congregating. COVID-19 has been circulating for some time. So, it's not an if people will be exposed; it's a when and how many times they'll be exposed at this point. And to see that when a lot of us are online, we're making calls, we're doing everything we can, begging for our lives, saying we are at risk from this. We know that about ourselves. And we would please like do not die or be in the hospital. Could we please avoid it? And the answer is to go swimming or a pub crawl.

ALICE: Right. And I think this again, you know, I think there's already having to deal with so much ableism and ageism just already, just not even in times of crisis. But when push comes to shove, we really see how much our society cares about certain people and who is expendable. And again, time and time again, we see just like you said, Dawn, about all this kind of rhetoric about, oh, it's only, you know, **those people** and not us. And who is the us, right? The us are always assumed to be non-disabled, healthy, young or middle-aged people. Like, oh, we're safe. And it just is, it just...it just makes you feel even more marginalized even though clearly, we are all marginalized. But it just really hurts. I just like, it's a real punch to the gut that again, when it really comes down to who our society values, it's not us.

HEATHER: Yeah, I was just gonna say that it's like that, it definitely speaks to the devaluation of disabled persons and disabled bodies, right, and our lives. So, I kinda laugh when people keep talking about don't politicize this.

DAWN: [laughs]

HEATHER: And I'm like quality of life [laughs] is political. I'm just like ugh. And I keep hearing that: “Don't politicize this pandemic.” And it's just, I don't know. I don't I can't rock with that. I don't even know how to, you know, internalize that 'cause it's so bizarre. And it just speaks to privilege that somebody would say that.

[mellow music break]

What the public needs to know about chronically ill, disabled, and immunosuppressed people

ALICE: You know, I think there's a lot of things, most the public does not understand about chronically ill, disabled, and immunosuppressed people. But I feel like, is there anything specific that you're willing to share about the way you're living right now that the public needs to know?

HEATHER: Well, you know, what I'm constantly talking about is the connective tissue to the community and how our lives are, you know, what we're— We almost have to think beyond ourself all the time because what I do affects my family, and then they go out into the world. So, I'm always thinking about the ripple effects. And it feels like so many non-disabled persons only think in the singular and not the collective. And so, as a disabled person, I'm always thinking, if I do this, this'll happen. And it's always trying to offset my own sense of safety and well-being in the world. And so, to see people just be so casual and cavalier about that is always alarming to me. Because you don't see how we affect one another, our choices, right? Like you said, Dawn, going out into these pub crawls and you going home and you're not realizing you might be a carrier. When you're on the beach and you're splashing around, and then you go back home or you go into another place where someone who is very susceptible to this virus unknowingly, and you infect them! And so, just to go about in the world and have that kind of attitude is always just so disturbing and speaks to our own value system, like we're like unruly teenagers. That's what we, that's the age and mindset, right, that we have. I'm gonna buck the system. We're gonna talk back. It's like trying to train people to understand it's not just you that's going to be affected. You're gonna affect a large swath of people negatively.

DAWN: Yeah, I think Heather's right. A lot of what we're talking about, the stress that affects us as a community and as individuals, is just about, you know, how can I be in the world? How can I make my life work when all these things are coming at me, and I'm always having to think of my safety and meeting my needs? And one thing that a lot of people don't know about me is I spent a period of time—it was a short period of time—but I was a missionary in East Africa. And it was wonderful in a lot of ways. But one of the most important things that happened to me while I was there is I got to see in-person what it means to live in a subsistence agriculture setting. And that means that people are just growing and doing animal agriculture, anything that they can do just to live. They aren't—at least where I was. I wanna be clear—where I was, it was subsistence. There weren't people who were having a level of prosperity that allowed them to sell outside of their community. They weren't able to accumulate much wealth that they could transfer generationally. You know, they were just stuck in this one way.

And disability can be like that. Because our lives, so much of our time and attention and waking hours and just bandwidth is put toward meeting our needs or finding a way to meet those needs. And then, when we want to go out into society, whether it's to work or just to be, just to live [laughs] and connect with others, there are these limitations based on what our bodies can do and what the spaces can do, as they are currently formatted, to accept our bodies and to bring them through whatever process—whether you're going to a restaurant, a museum, going to a concert—to bring ourselves through that without severe trauma. And that's what our lives are in many ways. And there are all these other things. That's true. You know, a lot of us are in this place. We're blessed to be in this place where we're being seen and heard, and we're writing and working and recording and all this stuff. And that's wonderful. But there's always that piece to us that we are linked heavily and obviously to subsisting. Now, other people who are of typical ability, they are linked to subsisting, but society meets their needs so they don't even notice they're subsisting. [laughs] And somehow, they also feel very...they manage to feel very proud of themselves for how well they subsist, which I find hilarious. But [laughs] there's all of that.

But for me as an individual, I am not able to have gluten. It makes me very sick, and it exacerbates my arthritis. And I am not able to have corn. It makes me violently ill, and I cannot have it. And if I were to eat it for any amount of time, I would probably need a hospital. It's the same for both things. And most of the food in this country has gluten and corn. So, when I have to fight my way through a store to find enough food to eat, that is very hard. I'm blessed compared to many others because I have a middle-class skillset. I have an education. In the summer, I can grow lots of fruits and veggies alongside our house. You know, I have more than most, but so much of my time is spent essentially making sure there's enough food. And then I prepare food for our household, and my aunt needs diabetes food. So, she has more flexibility than I do, but that's still real. Diabetes is real. We can't take a vacation from it. It's serious, you know. So, that is what we're living.

So, when I have to go to a store and try and find, like today, I was looking for some gluten-free mac and cheese, and it was all sold out. The gluten-free was all sold out. And then above it, there was all of this conventional mac and cheese from a very prestigious brand, 5 for $5. You would never even see my mac and cheese for $2.50 a box. It doesn't happen. So, you know, I had gone through this whole labyrinth process of trying to get some gluten-free mac and cheese that we can both eat and keep us on budget and keep us with enough food through Amazon and all these other things. And none of it worked. So, then I had to sit down and think, all right, well, how can I get these noodles, and then how can I get some cheese that will go on them, some cheese powder? So, then I did that. But that took up half of a day. And people just do not understand when these stores, when it looks like the vandals have sacked Rome in these stores, there's nothing. And then I go there. You know, that's a problem. And then some of the stuff, they'll sell it to you online, but then they'll say you have a waiting period to receive it.

Well, I'm looking at how bad things are with this pandemic. I'm not going to bet my ability to have that food on a waiting period. So, then I have to go into some type of what some people would see as panic buying and buy as much as I can carry. Yeah, that's just, that's how it's going to be. So, I just I hate this, that my life continually comes back to this center point of just trying to stay alive. And then I also hate that I'm doing better than a lotta people. [nervous laugh] That is horrible.

ALICE: Yeah. I think just there's so much labor, you know, you emotional labor and just actual labor that goes into staying alive that most people just really take for granted. And either they take it for granted or they just don't believe us, you know. I think that's a very cynical thing, but I do think that there has been so many people who are been sharing their stories and saying, "This is my reality. And you need to pay attention. Even if you don't share the same background or attributes that I have, just like this is the straight up truth." And yet it's still not really believed or taken seriously. Which again, is this casual, this whole like, oh, you're just overreacting. When again, people in marginalized communities are like, no, this is not an overreaction. This is a very reasonable response. Because we know what happens when shit goes down, you know?

[mellow music break]

Dawn and Heather as caregivers

ALICE: Yeah, and I also wanna transition into talking about caregiving because similar to survival, there's a lotta work that goes in caregiving. So, I would love to know, for both of you, what have you learned about yourself by being a caregiver? Heather, do you wanna go first and then Dawn?

HEATHER: Sure. As I said, I was a caregiver for my father for 11 years until his passing last summer. He was a diabetic, and then it began to affect his kidneys. And he was gonna start dialysis, but then he didn't take too well to dialysis. And I think it's because he was older, you know. And so, I learned throughout those 11 years, I mean, we got a lot closer. Because prior to that, he had been such a workaholic. And so, I thought, you know, what a premium that you pay to get closer to your family. He neglected his health for so many years, and then at this point, he was forced to retire and really concentrate on his health. And he did well for a while. So, I was able to help him manage his healthcare, his healthcare team, meals, medication, and just his appointments. And then he had a lot more time and a lot less worry, and he was able to spend a whole lot more time hanging out with the family and really enjoying himself. And I don't think he was gonna like it at first, retirement, forcing him to retire. But he got real relaxed into it, you know. He was out, and he'd be feeding the birds and chatting with little kids. And he really got into it.

And I was able to really hone in on his needs better as a disabled person. And it taught me how to be a really good caregiver that way and to really wrangle his team together and pinpoint areas where they needed to focus on more in terms of medication and the type of healthcare direction they were moving in. It was easier to navigate that 'cause I had already been doing it for myself. I learned patience. I learned just how to be a better advocate in general. So, I feel really honored that I had that time with him, because it taught me a lot of things: slow down so that I wouldn't get so snappy when things weren't going my way. 'Cause, I mean it's stressful, right. So, I had to always—

Yeah, I would have to tell myself, OK, he's trying. I mean, he just, you know, he's, you know, you gotta slow down. You don't wanna turn and become like an abusive person by saying, "No! Don't do that." 'Cause he might overeat or he'd love to get into the snacks. When I went to bed, I could hear all the chip bags rustling. [laughs] I could hear the freezer opening. And I would come out in the morning, and he had put away ice cream, the whole gallon. I'd see half the cookies, the sleeves gone. I'm like, "Dad, you didn't." He's like, "I did." [chuckles] So, it was funny just learning the whole process of keeping him alive and keeping him safe.

But we lived very independently. You know, we relied on one another. He helped me out a lot, physically. So, he gave as much as he got, and it was this balance. So, I never wanna talk about him in the, you know, in sort of these limited perspectives like this is all he got. I mean, he was **just** on the receiving end of care, which is fine as well. I mean, you can, you know, sometimes you may just be able to be on the receiving end of care and not maybe give as much back as you'd like. But yeah, it was a very well-rounded relationship, so. Yeah, very fulfilling, and I was honored by being able to help out in that way.

ALICE: Thank you for sharing. And how about you, Dawn, I know that you've been really outspoken on Twitter, especially about your experiences caring for The Dude.

HEATHER: [laughs]

DAWN: Yes, The Dude.

ALICE: Long live The Dude! And I love the fact that you call him The Dude. And it's like, I just imagine this very cool dude, you know?

HEATHER and DAWN: [huge laughs]

DAWN: He was, in many ways, a very cool dude. [laughs] My uncle, well, I'll say he's our uncle. He was my mother's uncle. So, my mother's two sisters and I took care of him after his life kind of fell apart. He had been a mortgage inspector for one of the big companies. And when he retired, he was the director of the Southwestern United States. So, he would go and audit banks and look at how they're handling their mortgages, and he was a very powerful, important man. And he retired, and that went OK. But then he got dementia. I think it was probably around the time my mother died in 2012, and he was acting a little weird, but he was also kind of like one of these low-key annoying guys where you're like, come on, dude. [laughs] Like, you're so much better than that. Not scary, not creepy, but just like, oh, man, you know? [laughing] so....

But he was acting extra, just extra annoying when my mom died. But we were all upset, so I didn't really understand that I was seeing the first signs of his dementia. And then three years later, he ended up a victim of identity theft in elder financial abuse and all this. And so, we had to go get him. He was living in Texas, though, so I didn't go. I stayed home to prepare the house for his arrival. And my two aunts went to get him and bring him up here to Michigan. And I knew when he got out of the car from the airport that he had dementia. I had no doubt in my mind just from his face and his some of his body mechanics. And I don't have any special training, but I had read enough about dementia to know what I was seeing. And I had heard from other caregivers in my life that dementia was possible. So, it was clear to me.

So, we got the diagnosis after all this. We had to go through this again, a labyrinth, because we had to restore his Medicare, and then we had to restore his pension deposits. It was just this collapse, this utter collapse of his life and his ability to live independently. And I had to untangle all of that. And we got him his diagnosis, and then we went through this long process with him of trying to figure out, well, what is dementia, really, and what does it mean for a person? Because generally, dementia is seen in society as memory loss and kinda goofy behavior. And it's true. There is memory loss, and there is some non-typical behavior. But there's also the very important fact that this is a brain disease, and a brain disease affects every part of a person. So, what happened to me as an advocate, you know, I'd already been doing a lot of disability advocacy and education for rheumatology patients and then anybody who really wanted to be in my chat. And I would try and help everybody I could, but I had to learn about dementia, which was not easy. And then I had to learn how to operationalize the concepts with an old man who didn't wanna listen and lives in my house with me. [laughs] You know? So, there's all this, this stuff. Like when people are having a baby, unless you're on one of those shows, like the surprise baby show, you know that you're getting one, and you have some time and whatever. But I got an elderly dementia patient over a two-week period. [laughs] And so, I didn't know what it would mean to be a caregiver and just everything that I had, I would have to learn. And that was really devastating just the, all the logistics of it.

But then one thing that people don't mention—it should, it should be obvious—but it's really hard watching someone suffer. Even if he was a stranger, it would've gutted me to see him like that. Because he was confused and scared and hallucinating sometimes and all of that. So, to have the person I've known my whole life and had been a leader in our family and someone we could trust, to have him go from that to a person who I had to keep from escaping the house in the middle of the night, it was not easy. And there's no roadmap. You know, people come at you and say, "Oh, did you call the Alzheimer's people," and whatever? And it's like, OK, by the time the elder is in your house hallucinating in the middle of the night, you are so tired, nothing these people can say will make a difference. That is such a key part of what it means to be in an emergency caregiving situation: that it's immediately devastating, and even if you're healthy, it's bad. But if you're disabled and low energy, it's hard. It's hard to make your way out and figure out what to do. So, there was all of that.

But then what I really learned about myself is that I'm good at this. You know, when I first started my chat and kind of entered public advocacy, there was a period of time where I thought people were very nice to follow me and care what I said, almost what they were doing me a favor. But over time, I became more confident, and I've gained more knowledge and contacts. But having to manage his care all the way from getting him, getting his diagnosis, getting guardianship of him, then placing him in a memory care facility when we couldn't care for him at home anymore, and constantly managing his hospital visits, and then putting him in hospice and making sure they did everything they were supposed to do for his pain management until he died, I understand what I can do. I can do things. I really can! I can do hard things.

And I had struggled initially about how to talk about him online because he was never in a position to consent. So, of course, I kept his name and face private. And then I made the decision to talk about what it means to be a caregiver versus what it means to be a dementia patient. I'm not a dementia patient. I don't know what that's like. I can only say what I've seen in him, and I saw the total destruction of his personality, the total destruction of his ability to relate to others, and ultimately, the destruction of his body from this disease. So, I can talk about that. I'm an expert on what I saw. And I try, in that work, to be as honest as possible, because I don't want people coming to it the way I did, which was surprise! In two weeks, you're gonna be taking care of this guy all the time. And good luck with that. [laughs] It's impossible. It just was impossible.

There are so many things I didn't know to do. We lost money, because I didn't understand what we were supposed to be doing. We didn't always have the right help for our problems. Even with a good lawyer and all of that, we still, we lost a lot of money. We lost [sighs] a part of ourselves, even, 'cause it was just overwhelming. And as I talk about how overwhelming it is, I want people to truly understand: I am not saying that taking care of someone is not worth it. I'm saying that society abandons us to figure this out again and again and again. And so, it's ridiculous. This is as normal as having a baby. It's as normal as moving from one house to another. It's as normal as any other life event: Getting old, getting sick, dying, whatever. It's all normal. But we act like it's, oh surprise. This thing happens to you. There's no surprises in the world. I'm sorry. [laughs] There's none!

[mellow music break]

Uncertainty and the power of interdependence

ALICE: I wanna wrap up by just asking you both another question, if that's all right. So, I personally feel vulnerable basically all the time, and especially, even more right now. And in these times with such heightened uncertainty, and many of us already live under such uncertainty already, what are your thoughts on the power and value of interdependence, especially based on your own experiences as caregivers? Dawn, do you wanna go first, and then Heather?

DAWN: Sure. I think interdependence is the strength. We can, I guess technically, find a way to, you know, gain as many resources and power and things for ourselves and hold it close, but not only is it unsustainable, but it's, I think it contains, deep inside of it, it contains a heartbreak. But when we're together, when we're valuing each other, and we have a common horizon, that is good. That makes me feel strong. And that's one reason I love disability social [laughs] so much! It's because we all love each other so much. A lot of these leaders are just deeply committed to each other and a movement that includes everyone. And that gives me hope.

HEATHER: Yeah, I definitely think we lived in this household for so many years being interdependent, and it was multi-generational, 'cause my daughter was here. So, each of us helped out in a way that made the family really successful and things run very smoothly. That definitely is a model for many, especially many families of color, right, who live that way. I know so many of us, so many of us who live with tons of people in their house, all different ages, and they're making it work, because they have no other choice, really, right?

ALICE: It's not about you give me this, and I give you that. It's about what can we all bring in that can help everybody just be accepted for what you can do and not what you're expected to do. And I think that's the other thing too, that so many people assume disabled people are just recipients of care. But as we've seen with both of you, we could be both. We are both, right? It's never that binary or mutually exclusive.

Wrap-up

Well, I am so humbled and so full of gratitude for both of you to be in my life, and I just wanna thank you both. You two are just part of my people, so thank you so much.

HEATHER: Thank you! Likewise.

DAWN: I feel so good right now.

HEATHER: I do too. I feel so enriched by this conversation. Dawn, I mean, you just dropping jewels here. Thank you.

DAWN: [laughs] Thanks to both of you.

[hip hop]

ALICE: This podcast is a production of the *Disability Visibility Project*, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Dawn and Heather on my website.

The audio producer for this episode is me, Alice Wong. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

Subscribe to our podcast on iTunes, Stitcher, Spotify, or Google Play. You can also support our podcast for $1 a month or more by going to our Patreon page at Patreon.com/DVP. That’s p-a-t-r-e-o-n dot com, slash DVP.

Thanks for listening! And see you on the Internets! Stay safe and by for now!