Disability Visibility Podcast

Episode 74a: Coronavirus and Faith

Guests: Rabbi Elliot Kukla

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: Greetings earthlings. Welcome to a bonus episode from the *Disability Visibility Podcast*. I typically publish two episodes a month because that's just the right workload for me. But we are in a most unusual time, and our stories are needed now more than ever. Today's episode is about the coronavirus and spirituality with Elliot Kukla, a rabbi at the Bay Area Jewish Healing Center in San Francisco where he has provided spiritual care to those who are dying, ill, or bereaved since 2008. Elliot asked me to mention that he is grateful to his partner Abby Weintraub for her care and collaboration that makes all his work possible. I got a chance to talk with Elliot about a recent essay he wrote for *The New York Times* titled *My Life Is More 'Disposable' During This Pandemic*. Please note there'll be discussions of genocide, the Holocaust, eugenics, and intergenerational trauma. Are you ready? Away. We. Go. [electronic beeping]

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

ALICE: So, Elliot, thank you so much for being on my podcast today.

ELLIOT KUKLA: Thank you for having me.

ALICE: And Elliot, why don't you introduce yourself and share a little bit about your background, if you don't mind.

ELLIOT: I am a rabbi as well as personally chronically ill and disabled. And I work at the Bay Area Jewish Healing Center, and I serve people who are also chronically ill, as well as running a volunteer hospice program and working with people who are coming to the end of life, offering spiritual care. Yeah, that's me.

Elliot's essay, *My Life is More "Disposable" During This Pandemic*

ALICE: Great. And we met last year at a book event for the anthology *About Us: Essays From the Disability Series* in *The New York Times*, co-edited by Rosemarie Garland-Thompson and Peter Catapano. And you sat next to me, and both of us read short excerpts from the essays, which are part of the book. And on March 19th, 2020, The New York Times published another essay by you titled *My Life is More "Disposable" During This Pandemic*. What led you to pitch this piece, and what lead you to write it?

ELLIOT: Ah! [laughs] Well, that is the question of this moment. You know, from the very beginning of this pandemic that we're in the middle of, it felt clear that disabled, chronically ill, elder, fat lives, the lives of other marginalized people were being seen as more disposable. At the time that I wrote it, it was before there was the immediate medical rationing happening in this country. It had just started happening in Italy, but it felt like it was going to happen here. And that, in fact, had begun to happen here. But at that point, right at the beginning of this pandemic, from the beginning of the messaging about the pandemic, the earliest messaging was, "Stay calm. Don't worry. This virus is pretty mild. The only people that might be at risk of dying are, you know, elders and disabled people. So, it's really not that much for us to worry about," with this very dehumanizing way of talking about our lives as disposable.

I am personally immune-compromised. I'm on immune suppressants, and I'm in that high-risk group, as are pretty much everyone I work with and most people that I love and care for and am in intimate relationships with and organize with. So, the tone of the conversation from the beginning was really alarming to me and really dehumanizing. And the conversation really has continued that way, in this kind of very quick downward slide into there's medical shortages. And that means that on a triage list, we're gonna look at, you know, who has the best chance of surviving and who has the most life years left and categories that are not going to benefit us. And those alarms that were raised for me at the beginning just kind of keep ringing and that sense of feeling disposable.

ALICE: Yeah, and I feel like clearly, racism, but also ageism is so endemic in our society right now with, especially with the coronavirus pandemic, people are really kind of discovering this for the first time.

ELLIOT: Yeah.

ALICE: Just really like, oh, I didn't realize this! And what are some of the main themes or messages from your essay that you really want readers to come away with? What are some of the most basic ideas that you want readers to understand?

ELLIOT: Mm. Thank you for that question. Mm. You know, there's so many types of seeing lives as disposable that are caught up in that. You know, the racism of how we're talking about this virus, as you are pointing to, is so crucial. And one of the things that I talk about is the ancestral trauma that this conversation brought up for me. So, one of the key points that I talked about was the way that sick and disabled people are being talked about, you know, brought up for me, I'm a second generation Holocaust survivor. My father was a hidden child in the Holocaust. And he was actually in hiding at the same age of my son is now, which is just something I'm really sitting with, my son being in quarantine in this moment.

ALICE: Mmhmm.

ELLIOT: And that when my father was hidden as a child, the occupying Nazi forces killed sick and disabled people first and referred to us as "useless eaters." And that was this term that really referred to this idea that we use too many resources, and we're not productive in a capitalist sense. And that feeling of that language really pervading the way that sick and disabled lives are being talked about now. And all of the other prejudices that get caught up along with it: that the more multiply marginalized people are, the more easily it is for our lives to be discounted in this time, which feels like is happening in this very real way. We're not just talking about being seen as disposable in a emotional way, but actually in terms of getting lifesaving medical resources. That is really one of the key points that I wanted people to take away with it. And all of our ancestral memories of other times in history when we've been

treated as disposable and how dangerous that is not just for us, but for society as a whole. And how hard it is to come back from that.

[peaceful, mellow guitar music break]

Long history of oppression, eugenics, genocide, and being treated as disposable

ALICE: And it feels like history repeats itself, and we apparently do not learn or just are willfully denying it. And that's what's so incredibly harmful about not learning and not realizing that this is just part of a very long history of oppression and just eugenics and genocide that's always been happening, whether it's in more subtle forms or explicit forms.

If it's all right, I'd like to read a quote from your essay that just, I just felt so deeply. It just resonated with me. And I just really, I just think your writing is beautiful. So, I'm just gonna read this quote, and then I'm gonna ask you a question after that. So, you wrote, "The feeling of being disposable is not new to me. It is knitted into my bones and sinews. It lives in my cells and the parasites in my gut. I already knew that for many of the doctors and policymakers that my health depends on, that my transgender, fat, disabled body is simply worth less than others' bodies. This is even more true of my Black, brown, poor disabled and ill friends." So, how do we, as people who are disposable in the eyes of society, how do we keep going on? What kind of advice or words of comfort us, if I may ask?

ELLIOT: You ask all the hard questions, all the important questions. I mean, I think the only way we keep going on is with each other. Is by affirming that we are not disposable to each other. That is how I have survived, you know, from a very young age, is surrounding myself with other people who have also been told that they were disposable and cheering for each other. And I know not everyone has access to that. That it's, for some of us, it's harder to even access those voices. But offering, even listening to this podcast right now as a voice of telling you, you are not disposable.

And there's a really wonderful campaign going on right now called No One Is Disposable with images where you can post a selfie and connect to other people's images who are of people being told that they are disposable in this moment of showing their faces and claiming their voice. And I really do feel like finding each other in this moment is the way that we survive, not just to build power and change things, although that, too, but also to just survive in the day to day of that, you know, of mutual aid and care and of being seen and seeing each other in those moments. That this moment, more than any other time in my life or as much as any other time in my life, it feels so clear that all we really have is each other in this moment, of this moment where we're far from each other and depending on each other. We're physically separated in our own homes and depending on each other so completely.

ALICE: Thank you for that.

Faith for grounding an understanding of the world and belief in humanity

ALICE: You're currently a rabbi at the Bay Area Jewish Healing Center in San Francisco, and you work as a chaplain at various Bay Area hospitals. And I wanted to ask you about how does your faith ground you in your understanding of the world and your belief in humanity?

ELLIOT: I feel very connected to my ancestors in both in the ancestral trauma that I'm speaking about and in all the things that my ancestors have survived. So, my faith isn't, my faith is in a

sense of mystery in the universe and in God[1]. But it's also in my ancestry and in other people's ancestors as well. But for me, my own connection comes through my own ancestors and in finding that. I wasn't, you know, I was raised in this Holocaust-surviving family that didn't talk about the past. One of the only sort of family stories I was raised with was the story of the last time my biological grandfather was seen alive. My grandparents were walking down the street in Belgium in 1940 with my father in a stroller, and he was an infant at the time. And they saw SS officers coming and knew they were coming for my grandfather. And he started walking in a different direction and said, "Turn away and don't look back." And they did. My grandmother and my father walked in a different direction, and the SS officers took my grandfather. And then my grandmother and my father went into hiding, and they never saw him again. And they never went back to their home. They couldn't go back to their apartment 'cause they knew that they were being looked for.

And this was kind of like a central story of my upbringing, was the story of us not looking back. And I was raised going forward and not looking back. And I kind of sought my own story as one of looking back, of going back and finding those stories and finding the stories that were lost and drawing strength from them, of being the one who, in my family who was like, well, wait a minute. I feel like I need to look back in what was left behind there and how did you survive those times in hiding, and what are those stories that are missing? And needing to talk about the suffering and the trauma and having that give shape to my own traumas and illness and stories.

[peaceful, mellow guitar music break]

Tenets of Judaism that speak to these times

ALICE: What are some of the tenets of Judaism that you feel like really speak to these times?

ELLIOT: In Jewish tradition, saving life is always gonna be the highest value. And that's anyone's life. So, there's, you know, Judaism has a whole lot of— And that's how I interpret Judaism and is really a common interpretation of Judaism. That's not like a fringe one. There's always a million different Jewish interpretations. But, you know, there's so many Jewish rituals and principles. But the notion of pikuach nefesh, which is to save a life, is always gonna be the primary one. And that feels so relevant right now when lives are being treated as disposable and when we're having this utilitarian view towards life. That Judaism has a very different view towards life. And Judaism also has a view toward life of that each person is created in a divine image and that when you save a person's life, you save an entire world. Which I feel like is a really interesting idea for this moment that I haven't fully unpacked, but especially in this moment when keeping people safe does have this whole impact in terms of the world, in terms of trying to prevent the spread of this virus and does have a global impact whenever we keep one person safe right now. So, there is this idea in Judaism that each person is a world and each person's life has global impact that I'm still thinking about and mulling about right now.

Judaism also gives a lot of shape to life. Like we rest every Shabbat. Every Saturday is about the value of rest and of doing nothing that I feel like is a very important concept for this moment in terms of sheltering in place where, you know, I'm really experiencing this, that maybe other people are experiencing in their worlds as well, this sort of frantic rescheduling of absolutely everything to be online. And feeling like maybe we could use more of this shelter in place time to rest, to let things go, to reevaluate: Do we need to do all the things that we're always doing?

[1] Although Orthodox Jews follow a convention of not spelling out the word for "God" even in English, Rabbi Kukla, in conversation, explained to me that he does spell it out fully.

And draw more from the concept of the holiness of rest, which is also a disability justice concept that's also shared by Judaism, that rest is generative, and rest is creative. I think a lot of spiritual traditions value rest, and capitalism really doesn't.

ALICE: Mmhmm.

ELLIOT: And I feel like a lot of us are missing, myself included a lot in this moment, are missing the boat of we're missing the opportunity to really seize the rest that we could be valuing in this moment and filling up every moment of their space.

ALICE: And how do you nourish your spirit and find comfort?

ELLIOT: Mm. I mean, Shabbat is a big one, that day of rest. I'm so grateful for it. I was not raised with any Jewish traditions at all, and I came to them when I was 19. But I've had Shabbat in my life since I was 19. And it literally gives sort of shape to my memory to have Shabbat. As a trauma survivor and someone with cognitive loss, I have a lot of trouble with memory. And having Shabbat every week is something that actually helps me sort of keep track of life, to have those pauses and time with my kid. I have a 21-month-old. So, just silliness with him and time with other sick and disabled people. I mean, I'm so glad to be talking to you today. When we met, I just felt this instant kinship with you. I sort of knew your public presence, but when you sat down next to me, I just instantly felt like, oh, we could be friends. [laughs]

ALICE: I felt the same way too. I was like, I am so glad you sat next to me. I was like, it was meant to be that we were side by side!

ELLIOT: Thank you. I feel that way, too. Yeah. There's just something. Being with sick and disabled people really does just fill me up in a, I mean, you know what I'm talking about. There's people where we can just be in truth of the body and truth of what is in terms of real limits and real what's actually going on with our bodies right now. And I feel like in sick and disabled community and fat community, there's an ease of truth about the world as well as our bodies. And there's an ease in loving each other. Because we know that we are all that we have, and we have to love each other. So, there's an ease of intimacy and an ease of truth that is so soul nourishing.

[peaceful, mellow guitar music break]

Care and love

ALICE: I feel like care comes in so many big and small ways in ways that are very apparent and things that are really subtle as well.

ELLIOT: Yeah.

ALICE: So, it's always around us, I think.

ELLIOT: Yeah.

ALICE: So, I wanna end our conversation by reading another beautiful quote from your essay, near the very end of it. And I just wanna read it also ask you for some final thoughts, if that's all right. So, you wrote, "In this moment, we must find a way to make the spaces between us holy. In this pandemic, it is the white fire that will hold our abundant love, our exquisite care, and our unwavering belief that each of our lives is worth saving." Do you have any final comments or reflections on that quote, what you wrote, and just anything else you'd like to share?

ELLIOT: [heavy exhalation] At the end of the day, love is that piece that holds us together. I know that sounds almost cliché, but I think that love in this moment is really what is driving me. I've been feeling so much anger about how our lives are treated as disposable. And a friend of mine yesterday sort of challenged me to breathe into the anger and figure out if all of the anger was coming from love. And I feel like that is really helpful. I think that the anger primarily is coming from love. And that I think that it is our love for each other in this moment that will assert that our lives are not disposable, and our love for ourselves.

ALICE: Well, Elliot, I am just so appreciative of just sharing this moment with you, and I'm very grateful for your friendship.

ELLIOT: Likewise. I'm so glad to talk to you today.

Wrap-up

[peaceful, mellow guitar music plays till the end]

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 Elliot at my website.

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

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Thanks for listening! Stay safe, and see you on the Internets! Byeeee!