

Heaven

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SPEAKERS

Heaven, Hannah Soyer

Hannah Soyer 00:00

Hi, everyone, today is November 20 2020. My name is Hannah Soyer, and I am about to have a conversation with Heaven for the COVID Disability Archive. These oral histories are being recorded as a way to document the lived experiences of disabled, chronically ill, and neurodivergent individuals during the COVID 19 pandemic across the world. Okay. Thank you so much for being willing to do this interview with me. If you could start just by giving me your name, age, pronouns, and where you live.

Heaven 00:49

My name is Heaven, my pronouns are she and they, I live in Canada.

Hannah Soyer 00:56

Thank you. And also, how do you identify? Just so I know how to continue with the description, or I'm sorry, with the interview. Do you identify as disabled, chronically ill, neurodivergent, etc?

Heaven 01:13

Um, neurodivergent and disabled, I do have chronic conditions.

Hannah Soyer 01:19

All right, thank you. So Heaven, I guess, if you would like, we can start by talking about the sort of your backstory that you sent me, sort of back history, if that's something you would like to talk about.

Heaven 01:37

I can try, that is quite extensive.

Hannah Soyer 01:41

It is quite extensive. We can also just start, if you would prefer, we can just start by talking about the pandemic and then we can just go from there. Yeah, sure.

Heaven 01:51

Just the pandemic and the questions and then we can come back. Sure. Yeah,

Hannah Soyer 01:55

Absolutely. Okay, so when did you first learn about the pandemic? And what was your experience with this?

Heaven 02:04

I learned about it when we went into lockdown. And it was that big news coverage. So back in March, I guess. And for my experience, honestly, the short version of that it's that it's not nothing I'm not used to. I'm used to having to learn online and do things in bulk and experience like structural barriers and restrictions. So I felt a little bit comfortable and at home, I guess.

Hannah Soyer 02:37

Okay, yeah. So um, so what about specific, did you have specific like emotions about the pandemic, when you first learned about it? Or about Lock Down?

Heaven 02:55

My biggest concern really was not the lockdown in itself, but the reintegration. Because for myself, personally, in my personal history, I was just coming out of a really traumatic experience, where I was essentially cut off, similar to now. And so I had only been out of that for about a year. And so I was just learning how to live again and then I get cut off because of lockdown, so.

Hannah Soyer 03:24

Right? And would you mind? Are you? Are you? Are you comfortable talking about that experience? If not, that's completely fine.

Heaven 03:34

I am. I do have to mince my words a little bit for legal reasons, but I'll do what I can. So with my living situation before, just my routine, and the situation with my caregiver was really restrictive. And so I had gotten used to not having access to like schooling and needing to learn online and struggling to access medical care and things. And so now during lockdown now that we're all learning online and struggling to see people, it's been an experience.

Hannah Soyer 04:19

Thank you, um, has your experience with the pandemic, so that could be like your emotions about the pandemic, or I guess, how you are dealing with the pandemic, has that changed over the course of all of this?

Heaven 04:39

I think it's changed. Um, I hope this makes sense. But I think it's changed my relationship with myself. Because I've it's been an opportunity to highlight my resilience, and to put me in a position where I can comfort people and teach others from what I've experienced before and sort of guide them through this. And I'm also really comforted to see that access issues and barriers and things are starting to come to light a lot more frequently. So I'm really comforted to see that disabled people, and experiences like this

are starting to get like a decent seat at the table. You know, we're really starting to have our opportunity to voice ourselves.

Hannah Soyer 05:27

Absolutely, um, could you talk a bit more about those access issues and barriers that you're seeing now becoming perhaps more talked about?

Heaven 05:39

Things like online learning, and the lack of medical care, and the lack of protections and routines, like going to the grocery store, or not being able to reach things and have access to things and find things.

Hannah Soyer 05:55

Right, absolutely. Thank you. So what has your experience been as a disabled person throughout the pandemic?

Heaven 06:11

And I mean, no disrespect to the dead at all, I absolutely have rage for them, because no one should have to die. And certainly not in rough situations like this, in order for there to be progress. But I do feel to a degree, I do feel empowered. Because like I've said, I think people are being more conscious. And they're forced to sort of look at all these aspects of like systemic structure, and the things that aren't working anymore. So I'm relieved and glad that there's an opportunity to sort of really address that head on.

Hannah Soyer 06:46

Right, so, um, yeah. So would you say that you feel like a lot of these issues that you have been dealing with, personally for your, for most of your life, if not all of your life are now sort of being discussed more by the broad public? Absolutely. Okay. Thank you. Yeah. So this is sort of a similar question. But how has your disability impacted how you have dealt with the pandemic?

Heaven 07:33

Well, I'm I use a wheelchair full time. And so not being able to go outside and being in lockdown kind of makes me a little bit stir crazy. But but the opportunities to connect online and to learn online again, is something familiar to me. So I've been able to, I guess, go back to my comfort zones, and sort of find regulation in that sense.

Hannah Soyer 08:02

Absolutely. Are there, are there like new online communities that you've become involved with since lockdown?

Heaven 08:13

A lot of art communities and things like media with you like having the opportunity to share. I used to be quite reserved, so.

Hannah Soyer 08:25

Alright, that's wonderful. Thank you. Yeah. Um, okay, so what have your relationships with people been like throughout the pandemic, and sort of related to that, have your relationships with people changed throughout all of this?

Heaven 08:47

In terms of changing, because of my experiences and my trauma from before, I did really struggle to connect with people verbally, and I was socially delayed. And so I struggled to adjust that way. And I struggled to be understood. And I think now that my friends and my colleagues are seeing how hard it is to socialize now when they're having that experience in their own way. They're able to relate to me better. And it's fostered this greater sense of emotional understanding and empathy. I mentioned, you know, talking to my professors and my doctors about feeling alienated and struggling to feel connected and to feel human. And I noticed before the pandemic it was very limited to like, oh, well, that sucks. I'm sorry. I believe you and best of luck with getting through it. To now it's more like, oh my gosh, this is a fundamental need. This is traumatic. How can we actively address it? So there's been people understanding gravity, a lot more the gravity of the situation a lot more. And so I've noticed and I've been comforted by by seeing all those active steps, and we definitely have a long way to go. But I'm really glad it's very healing for me, and I'm sure for many others, to see it genuinely and fully being considered.

Hannah Soyer 10:25

That's fantastic. Um, so let's see. So if you're comfortable sharing this, who do you currently live with? And has this been impacted by the pandemic?

Heaven 10:42

No impacts, I live alone at this point. So, like I've said earlier, I guess it's sort of changed my relationship with myself, and I've been able to do some interpersonal work.

Hannah Soyer 10:57

Um, okay, yeah. Could you perhaps talk a bit more about that? Like, how are there you know, can you think of like specific instances where you know that your relationship with yourself has changed throughout all this.

Heaven 11:15

So, when things were, quote, unquote, normal, and we were socializing outside, I always felt very alienated. And I, like, I'd be talking to my professors. And I'd feel I'd say that I didn't really feel human. I was feeling very dissociative and disconnected, I know that I've been able to have that moment and have that space for myself without distractions, I can sit with myself and do like activities and understand what my triggers are and sort of do some inner healing. Halloween, and being able to participate with gathering candy. And if the house had stairs, and things like that, that would be an issue, because I wouldn't be able to reach. And often, people wouldn't travel down to me. And so I often felt very isolated and left out in that sense. But then, I don't know if they've done this in any other part of the world. But for my city for Halloween this year, to keep up with the six feet social distancing, people had started to attach little pipes to their stair rails. And so they would sit at the top of the stairs and send the candy through the little pipe way. And we could reach our candy that way without having to climb up

the steps. I'm too old to participate in Halloween in that way now. But I remember thinking, finally an accessible Halloween. And again, I think I think that COVID has finally helped the rest of the world to understand that, yes, this is essential. And yes, it's important. And yes, there are ways to adapt to these things, and how can we make that more prevalent? So it's been nice to see and very healing for my traumatized inner child.

Hannah Soyer 11:54

So it sounds like that it sounds like and please correct me if I'm wrong, that the the lockdown specifically has allowed you space, and time to really reflect on your own self and your past experiences and spend more time with yourself. Yeah. Wonderful.

Heaven 12:22

Without the pressures of outside influences and deadlines and things. So yeah. Before I guess I kind of felt like I had a role to play. And I had, my health team had all these expectations for healing and recovery. And then now, that's all kind of paused, and I'm able to like come back to myself without any sort of expectations.

Hannah Soyer 12:43

Right, that makes a lot of sense. So this is actually related, this next question's actually tied very well to what you just said. Because you mentioned your health team. So do you feel like your relationships with different institutions, such as health care, has changed during all of this?

Heaven 13:07

Absolutely. Similar to my personal relationships, there's a deeper level of understanding. Because again, I struggled socially, and so I preferred that online emailing kind of thing. And there was always barriers against that, because the expectation is to see people in person. So just a deeper level of empathy.

Hannah Soyer 13:35

So have you been able to conduct appointments and whatnot remotely?

Heaven 13:42

Yeah. It flows a lot better I find because I'm more comfortable in my own space. And with that level of sort of communication.

Hannah Soyer 13:54

Right, that makes a lot of sense. Um, so you talked earlier about how the pandemic, in many ways, is sort of bringing to light these different access barriers for various individuals. Are there have you experienced any instances of increased access barriers during the pandemic, if that makes sense?

Heaven 14:29

My condition, my disability, it's dystonia. So that in itself is fairly rare. And I by no means I can't speak for everyone. But um, I suppose the only barrier that I've experienced would be there's a little bit of a

disconnect with with timing and there's certain things in recovery that need consistency. And now that you're waiting six months to see someone, sometimes it's a little bit of an issue.

Hannah Soyer 16:34

That makes sense. All right, well, I guess what would you say? These are, I guess, seemingly more simple questions. But I think that I think that the responses are really important. So what would you say the hardest part about the pandemic has been for yourself?

Heaven 16:59

To be honest, watching other people struggle. Because I see people, you know, just being drained and overwhelmed and lost. And for me, this is this is my territory. This is what I know. And so I want to help, and I can't reach everyone. So.

Hannah Soyer 17:17

Right, that makes a lot of sense. Have there been, do you have specific people that are really close to you in your life that have been struggling that you've had to sort of reach out to?

Heaven 17:31

I do, yeah. All my close people, my friends, my everyone. A lot of the people. I'm studying psychology and social sciences. So a lot of the people in my circle are doctors and things. So they've really been directly impacted. And so I see that. And so.

Hannah Soyer 17:52

Right, that makes a lot of sense. So then, on the flip side of that, and I know you've already touched a bit on this, but how have there been sort of silver linings to the pandemic for yourself?

Heaven 18:12

For myself, yeah, I am feeling a lot more human now. And I'm able to relate to myself and conduct my relationships a lot better. And again, as an advocate, and as a student, I'm able to contribute a lot more to projects and things. So I feel a lot more fulfilled.

Hannah Soyer 18:37

Fantastic. Thank you Heaven. Yeah. So. So would you like to speak more a bit about your advocacy work?

Heaven 18:51

I could try. Is there a specific point that you wanted to expand on?

Hannah Soyer 18:56

Yeah, so I was really interested in let's see, I was really interested in this case study on discrimination that you sent me. Yeah. If you if you would like we could talk about that. Yeah.

Heaven 19:20

So, I was the subject of the case study I did, I put that graph together as a info point for my sociology class, and so it was shared with the class and we discussed on certain issues that way and so it was really a learning opportunity for them. And it was an infographic, the case study's based on my own lived experiences. So I was the subject. And I worked with my sociology teacher at the time. And I created that infographic to create, I guess, an awareness and some talking points in regard to access barriers and the struggles for resources and the struggles with socialization and different things. So the graph touches on essentially every aspect of life from play, to education, to social interaction and things. So I was able to discuss that with my sociology class. And that was sort of the beginning of recovery for me and the beginning of finding my path, I guess. And that's in the healing in that sense has been sort of accelerated and highlighted during the pandemic, because again, we're back to limited resources and limited social avenues. So it's been really interesting to see that and go full circle.

Hannah Soyer 20:52

Wonderful. Um, and so can you tell me a bit more about your project, the Survivor's Grace Initiative?

Heaven 21:02

Yes, in my part of the world, my corner. My country's laws really struggle with domestic violence, specifically, in the cases that are non spousal. We don't really have a framework for people with violent caregivers, and people in certain age groups, like myself. And so with my experiences, and in my recovery, I've decided to try to enact certain policy changes so that there's a broader coverage. And then hopefully, it'll gain traction internationally, too, because I know domestic violence is an issue around the world. So I really want to make an impact somehow.

Hannah Soyer 21:44

Thank you. Um so so what would you say the goal of Survivors' Grace is?

Heaven 22:01

Again, for laws to be enacted, but also more personally, for survivors to have a space to, sometimes they fall outside of the deadlines and outside of the criteria. And so I want Survivor's Grace to be like a space for them to have their moment to be heard and understood.

Hannah Soyer 22:25

That makes a lot of sense. It seems like an incredibly important project. Um, so I don't think I have any more questions, although I would, if you would, like, I would love to talk more about your story and background that you sent me. I'm really, I'm really interested in this idea of the word free, you said, you know, you mentioned when I was freed, but then you say, use the term free very widely. So if you're comfortable, we can talk about that a bit more.

Heaven 23:06

I'm open to anything, but like I said, legally, I do have to mince some words. And so I'll do my best. And hopefully it makes sense.

Hannah Soyer 23:13

Absolutely. Thank you, though. Yeah.

Heaven 23:17

So when I say free typically, during freedom, you have like, a space that's distant, you have a certain level of distance from your abusers. But in my case, because of lack of accessible housing, and things they put me quite close by. And so I feel a little bit tethered still, because I'm within a line of sight. So and I wasn't given any sort of legal protections because it was felt that I had chosen to live here. So I didn't choose that it was a systemic limitation thing.

Hannah Soyer 24:02

Absolutely. And so, let's see. So that that moment where you were semi freed from this abusive situation. Are you is that like, are you still in a situation where you're living close to the abuser or no?

Heaven 24:32

Yes, I am. Okay. Um, I've been told that the housing waitlist collectively is 15 years long, because there's five years for funding and eight to 10 years for housing vacancies. So I'll be here for a while. But my plan before COVID was to relocate. I was going to relocate to Australia because their accessibility is so much better and as are their laws and stuff. And just to live life a little, you know, so I was hoping to go on a little adventure, but then COVID stalled things. So

Hannah Soyer 25:10

yeah, COVID has stalled a lot of things. Yeah. Um, I yeah, I can imagine that that would, that would cause quite a bit of frustration and fear as well to continue to be in that situation. Um, would you like to talk a bit more about your work as a writer?

Heaven 25:36

Yeah, sure. So I started, it's been a dream since I was 14, I started with poetry. It was essentially an outlet for all of my, my pain, and to sort of deal with those structural barriers that I was facing. And then eventually, I was 19 when I released my first fiction book. And I like to use my writing as an opportunity through fiction, to touch on certain things like mental health topics and abuse and things. So I write characters that have like PTSD and certain traumas and sort of open up the conversation in a way that's a little bit more relatable. Because I feel like sometimes when you talk about it directly, as a survivor, there's this sort of disconnect, like because there's people think, Oh, that'll never happen to me, this is just a person on TV, you know, but when you can hold a book, and you can put yourself in sort of a fictional situation. I feel like it goes far better that way. And so it's just a better way to connect.

Hannah Soyer 26:45

Yeah, that's really neat. Yeah, do you are you working on a specific work right now?

Heaven 26:53

Um, I continue with poetry. I do poetry all the time. I'm also working on a memoir. And this week, I recently started a collection of affirmations that are disability positive and body positive for the disabled community. And I'm hoping to release that in 2021.

Hannah Soyer 27:13

That's very neat. Thank you. Let's see. So yeah, I think that I don't have any more questions. Is there anything else that you would like to talk about?

Heaven 27:34

Not specifically.

Hannah Soyer 27:36

Okay. Well, thank you so much for doing this interview with me. Yeah, I'm gonna go ahead and stop recording