

Jessica Oddi

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SPEAKERS

Jessica Oddi, Hannah Soyer

Hannah Soyer 00:00

Hi everyone, Today is November 13 2020. And my name is Hannah Soyer. I am about to have a conversation with Jessica Oddi 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. Jess Oddi was the first person that I interviewed for this project. And so her interview is a bit shorter than the other individuals that I collected the oral history from.

Jessica Oddi 00:47

My name is Jessica Oddi. I use she/her pronouns. I live in Hamilton, Ontario, Canada, which is situated on the traditional territories of the Erie, Neutral, Huron-Wendat, and Haudenosaunee and Mississaugas. Yeah. So my experience, being a disabled person through this pandemic, um, it's been interesting, it's been very stressful, I find, as far as my sense of community and, or lack there of, of community support during this has been a real hit. Um, you know, at first, when it started, you kind of go through the, oh, okay, I'm immunocompromised, I'm used to this, I'm gonna buckle down. Like, I know what it's like to isolate, I was using that to like, cheer up my non disabled friends, like, I've done this before, let's do this, we're in this together. And then as it's gone through, and you just see, time and time, people not adhering to the rules, people all of a sudden, then contradicting saying that it's not real, and all these conspiracy theories coming out, just forcing me into isolation and forcing me into having to lock in myself, because I can't trust those around me has just been, honestly, it's been devastating. It's been exhausting. It's like that, I'm usually quite an optimistic person for people and humanity. And I'm trying to find that again. Because like, I lost it, I really did. Um, you know, every time you'd read about someone, considering that it's not real, or that they don't care, or just the vulnerable should go inside as if I don't have a life to live, or I'm, and then also seeing them complain that, oh, life is not normal. And then still going out to bars every weekend, while you're sitting here, like really? Like, the amount of resentment that's built up has been huge. And I find it's impacted me emotionally. A lot more than physically, which I'm still privileged within this community to have to say, like, I've had to, you know, do some things to change around my daily life. But realistically, I still have the best case scenario out of this where my parents are able to take care of me during this time. And I know not everyone else is available to that. And it's just been so disheartening, just even for the community to just—you read the

stories of people getting positive results, or, you know, their caretakers having results, and then they have to go get tested and that fear. And that, and you're seeing this while everyone else is just going around arguing as if it's a hypothetical scenario while we're battering down the hatches, and it's just—it's been so frustrating. I don't think I've had a positive experience through this.

Jessica Oddi 03:54

And I've really had to, like undo my social time, you know, I've been using this as a way to like connect to disabled people even more because you want that support group you want. *dog barking* My dog has opinions about this. *laughing* You want people to understand and I know what you're going through and be able to vent with because right now those non disabled spaces just seem so frustrating, And excluding that I just, I can't, my own mental health, I just can't read another post about someone trying to argue their way out of wearing a mask while I'm sitting here, inside for... since March, while friends have been ill and not feeling well. While people are even arguing with our own community because we even have our own community members who don't want to be afraid of this, whether it's through either internalized or just through that's their opinion, or maybe they're less immunocompromised than others. And it's just been so frustrating that it's like, the whole mood of 2020 has been I don't know how to tell you, you should care about people. I don't know how to say that and it's... It's been hard not to be bitter throughout that and not to put that on other people, because I tried to remember that it's not ... people only know what they experience. And now we're experiencing something together on a large scale that disabled people deal with all the time. And seeing everyone fail at it is just like, Well, hey, you kind of suck compared to us. That's more of a joke, because I don't want to judge people. But like, we're doing this, we were doing this, you had to do this for one year, and you're, *laughing* you're falling apart, are you okay world? Like... yeah, that's my sense of using humor to deal with it too, right? How's my disability impacted the way I've dealt with the pandemic and informed me about how I deal with the pandemic? it's like, going into expert mode, on my own experiences, you know? like, I've had to cut out care, to two days a week, because our system is supposed to be promoting that PSWs take time off when they have to go get tested, or that they'll get their clients back. And they're not. So they're lying about their health, because they don't want to lose their job, which is putting me at risk, which is just the whole frickin system just collapsing over that, and no one's doing those things. We're trying to put out all these little fires. And so I had to cut down care. And again, I'm completely privileged in the sense because I don't have 24 hour care, I have my parents as my main caregivers, my dad's been fortunate enough to work from home during this because he works in a job that can be worked from home. But I'm also dealing with those experiences now where you know, they're getting old, they're not able to take care of me as they were. And I was just in a transition stage of getting care before the pandemic hit. And all of that had to be put on hold, because I don't feel safe to hire people, when I don't have a say, of what they can do outside their job, because that's not... I can't do that. So I have to worry about if they're going to parties, and then coming to deal with me the next day, and then saying, Oh, it's just a cough. And it's like, well, I don't want to cough anyway, even if it wasn't COVID. Like, I don't want to get sick. So, um, it's like, I've already had the tools to deal with isolation. And now I feel like we're, I'm experiencing that on a whole new level, because it's like, every day, it's like, Alright, I'm going to, you know, adapt to being a shut in right now. Because I can't justify going to a patio or going to get my hair done that you can't see my hair through this, but it is long *laughing*. And that's the least of worries for this, right? So there's, I think it gave me the tools to prep. And it gave me the tools to be able to adapt quickly to this because of past

experiences being disabled. It's like, Yeah, I'm an expert. And then at the same time, it's really just shown me that when the chips are down how society feels about disabled people. And it's not good *laughter*. It's not good at all. It's like, at the end of the day, and maybe this is just me becoming cynical, but at the end of the day, people can — are only concerned with their own circles and their own groups and their own lives. And what a privilege, it must be to be able to say that this isn't real, because I don't know someone who sick while

Jessica Oddi 08:36

over 1000s of people are dying, and over 1000 people are suffering from this, but you don't want to see it. So it kind of gives me those perspectives, it gives me the tools to kind of deal with it on the long end. As far as like, I'm not prepared to enter into society until late 2022. And that's if vaccines go well. And if there aren't any neurological side effects to the vaccine once it comes out. And that's even me being pro vaccine because not everyone is pro vaccine. And everyone in the disabled community needs to take their own precautions because they know what's best for their own health and when to take it and when not to take it and all those sorts of things. And then, and so I've kind of like did that from the beginning. When this started and to see everyone being like, it's gonna be over in 2021. Like, *ha ha ha* no it's not ... but okay? Yeah, that's all I can think of right now. I'm not sure if there's any more points that I have to get across. *laughter*

Hannah Soyer 09:33

Thanks, Jess. Would you mind briefly expanding on your care situation? So you said PSW's and that stands for personal social worker, right?

Jessica Oddi 09:47

Yeah, so it stands for Personal Support Worker. That's the Canadian equivalent of PCAs. I think they're called in the States? So yeah. So they are people that come in and — they — before this for other personal reasons, we've been transitioning into care anyway— so they take us to the washroom one time a day during the day, because my parents take over all the other shifts. And my sister and I are transitioning into getting that care and more as far as like actually doing a morning routine and a shower routine with them and a washroom in the day or one or two washrooms in the day, that way all I'm putting my parents on is nighttime routine. Um, and so during the pandemic, we had gotten approved for self managed care right before and everything got put on hold, because it stopped me from being able to go to the bank to open up a bank account that I needed, it stopped me from being able to hire people because they're not in my bubble. And I don't feel, you know, safe coming into contact. So we were forced to kind of just stay in the agency care that we already had. And we made the decision ultimately, to cut down to two days a week, because every day we were getting a new PSW. Someone else, someone who hadn't worked with us before, because they're short staffed, and I'm not even judging it, because it's like they had — they don't have the resources. They were given PPE and it was all like, scratched and foggy. And like, it's like, how are you supposed to do this work? So like, we were giving out masks to people a couple times because it was just horrendous what they were dealing with. And so every day we were being exposed to people. And at the time, they were actually still working in nursing homes and high risk areas that were actually experiencing outbreaks. So we made that decision to cut down our care to two days a week, because there's two days a week where the same PSWs come in, like they've always worked with us. And it's been more consistent.

Because with agency care, you kind of like don't have a say it's like someone's coming in between 12 to 2pm, to take you to the bathroom. And that's before the pandemic. That's just how it works. So yeah, so we've really had to change that as far as just, you know, being overcautious, and then the emotions that sink in... like one time, I had to deal with someone who had said, Oh, by the way, I went to go get tested this morning. And then they came into work. And they were in our house and they were working with us. And like that's not even like being a germaphobe worried that is just like that is not protocol. That is not what the government is saying we should be doing. But then the government's not doing anything to promote these things. They're saying, Yeah, we're gonna give extra money here, or Yeah, we're gonna make sure you all have your shifts. And then nothing gets done, nothing gets changed. They're being told to go back to work. As soon as they're feeling better before they even get a negative test result. And it's like you're putting so many people at risk that way. And I realized that I am so privileged to be able to choose that care, because there's so many friends that I know that don't have that opportunity. They have managed care, and they need to have people come in to take care of them and they don't have that choice and they're putting themselves at risk every time.

Hannah Soyer 12:55

Thank you so much for this.

Jessica Oddi 12:57

Thank you for having me. It's so nice to be able to have this platform and to be able to have our stories told