

Shelby Hintze

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SPEAKERS

Shelby Hintze, Hannah Soyer

Hannah Soyer 00:00

Hello, everyone, Today is November 28 2020. My name is Hannah Soyer, and I am going to be talking to Shelby Hintze 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 joining me, Shelby.

Shelby Hintze 00:35

Yeah,

Hannah Soyer 00:35

If you could start by just telling me your name, age, pronouns and where you live.

Shelby Hintze 00:43

Yeah. So my name is Shelby Hintze. H I N T Z E. And I'm 28. My pronouns are she and her. And I live in Salt Lake City, Utah. But I am currently at home with my parents, and in a town just north of Seattle, and have been here and kind of riding out the pandemic. But I've lived in Salt Lake for about 10 years.

Hannah Soyer 01:14

Got it. Yeah. And that's definitely something that we'll return to later. Yeah. Well, I'm in the same boat. I'm living at home with my parents, and I've been here for the entirety of the pandemic pretty much so. Okay, so if you can also then just give me your identity description. So whether you identify as disabled, chronically ill, neurodivergent, etc. And then any other identifiers that you would like to talk, or that you would like to say as well.

Shelby Hintze 01:44

Yeah. Um, so I'm disabled, I have spinal muscular atrophy. And type two, which was diagnosed when I was about a year old. And I'm also a journalist. That is my, I'm a producer for a TV news station in Salt Lake. So that's, that's my day job.

Hannah Soyer 02:03

That's really cool. I also have SMA type two.

Shelby Hintze 02:07

I kind of figured, yeah,

Hannah Soyer 02:09

I know. You can usually tell right use but yeah. And, yeah, I'm also a writer. So that's really nice. It's cool that we connected.

Shelby Hintze 02:18

I feel like there's a lot of us.

Hannah Soyer 02:20

I think there are as well, absolutely. Okay, so we're gonna go ahead and dive into the meat of the Pande- or I'm sorry, the meat of the interview.

Shelby Hintze 02:29

Perfect.

Hannah Soyer 02:30

So my first question is, when did you first learn about the pandemic? And what was your experience with that?

Shelby Hintze 02:40

Yeah. So I first heard about the pandemic, as a journalist, I'm like, pretty on top of things, so I started hearing some things about it in January. It was the end of February that I started thinking, like, Oh, this is actually something that's probably going to impact me. Which is ironic, because I started having these discussions with people that I knew and my, my parents and my friends and my co-workers at the end of February. And I was actually in the hospital with a unknown respiratory virus, which we now think may have been COVID. And we, I obviously, I don't know and I, I got an antibody test that came back negative. But I was really, really sick with a respiratory disease, respiratory infection at the time. Um, so. So it was kind of, I think, at the time I was, I wasn't too worried about it when I first heard about it, because, you know, we, we hear about, we heard about SARS, we heard about Ebola, and, and while those were devastating in their countries of origin, they didn't really impact me. And even like h1n1, which had a slightly larger impact on my life, in 2009 still didn't like, change my daily life. So I just wasn't really too concerned about it. Obviously, it was gonna have to be watching this and be paying attention. But in the very, very beginning, it was just like, well, it's probably something that we in the United States are just and I and I trusted that we would take care of it and handle it, I think a lot more efficiently than we actually did.

Hannah Soyer 04:44

Wow, okay, so how has perhaps your experience with COVID and the pandemic changed, since that initial sort of learning about it, understanding about it?

Shelby Hintze 05:01

Yeah, I mean, obviously now it's a, then it was just kind of a possibility. And now it is a very real. It's interesting because I think it's kind of I mean, let me think about this for a second. It still feels slightly abstract. Because it is not a visual threat, it's not something that you can see. And I think a lot of times we view hardships as something with the beginning, middle and an end. And, and we kind of have an idea of what that beginning, middle and end is. And right now we just, I mean, this will end at some point there will, we'll be able to look back at it. But I think even most hardships, when you're in it, we kind of know what a general timeline is. So I think it's similar in the aspect of just, it's a, it's hard to, for a lot of people to take a not immediate threat seriously. And I have to I mean, I'm taking it very, very seriously. And I believe all the science and but I even still have to remind myself sometimes like, oh yeah, just because I can't see it doesn't mean it's not there. And so that's been an interesting kind of, it's been the same, but also my behavior has changed so much. Um, so in what ways has your behavior changed all that. Um, so I mean, the big one is moving 1000 miles back home, and I came home. So I guess a little background in Salt Lake. I am a producer at an NBC affiliate in the city. I live downtown with a roommate, I have caregivers that come in, and I have one like a live-in caregiver, and then a couple who come in and help with other tasks. And I go to work every day and have a very, like vibrant social life. And I'm involved in my church doing lots of different a pretty just like, busy person. And when the pandemic happened on March, oh, gosh, I think it's the seventh. So I got out of the hospital last week in February. I had like a week, the first week in March, that I was just kind of working from home. And we kind of knew at that point that this was coming. So we started getting a little prepared. And the last Saturday that first Saturday in March, I think it was the seventh we went to Trader Joe's and Walmart or Target and stocked up on a bunch of things. And then that was basically it since then. I have been working from home, um, which I'm very fortunate to be able to do. And my dad, my parents came out when I was in the hospital, because we were also planning on going on vacation that first week of March, which didn't happen. So they had tickets already they came out to visit. And my dad just stayed because he was also working from home. And he thought, well, I'll just stay. And I can help out a little bit for you know, next couple of weeks while this is going on. And because we I think we anticipated too, that it would be a full lockdown, that everybody would be fully locked down and that you wouldn't be able to go anywhere. And it would just be a few weeks. And it would really take care of this. Then that's not what happened. I mean, Utah just barely issued a mask mandate, which they've since rolled back. But so he was there. And he ended up being there for about three months. And we planned on coming back to Washington, me and my roommate and my dad, just to just to get a little bit of a break also. And I thought I'd come back in August. But I saw the numbers start rising in Utah. So we came back the beginning of July in order to beat the Fourth of July peak. And I knew that people were going to be gathering after Fourth of July and we are going to see a good spike in cases there.

09:55

And so we came back and I I mean, I'm very fortunate that I've been able to work from home. And the plan was to come to go back to Utah in September, the numbers just kept rising. So we decided to stay. And we also knew that if we went back to Utah, I'd most likely have to spend the holidays, just in my apartment by myself, which I didn't really want to do, either. So even in Jil in September, when we're looking at this, we just kind of took the gamble of staying. And since I have to drive, I won't be able to

drive home until probably March or April, when the passes are clear, because there's several mountain passes you have to go through. And we're not about to do that in the snow. So and so that's kind of the situation. Daily I mean, I go a couple, I can go probably about a week without leaving the house, and we leave the house and I'm like, oh, yeah, I haven't left since last Wednesday. And I've gone into Target, I think twice during all of this. And that's really it. Other than, like, doctor's appointments. I yeah, I think it's changed my like social life a lot. In the beginning, it was interesting, because everybody was like, Let's do zoom meetings. And let's like, do Google Hangouts, and let's get together and let's talk on the phone. And, um, that lasted about three weeks. And, and I think a lot of my friends are doing a good job of also you know being careful, but I'm definitely doing a lot just being a lot more isolated than they are I think. And during the summertime, when I was still in Utah, we'd like meet up in a park and have dinner outside and be you know, 10 feet apart from each other. Or we'd meet up in a parking lot. And, you know, our cars and, and that was it was kind of fun. It was like you're doing something different is it's kind of fun. And it may not be ideal, but just the fact that it's novel is fun. But um, yet, it's gotten old. So, I think I probably answered like five questions there. But

Hannah Soyer 12:40

No, that was great. Um, so a couple things. Um, you mentioned Utah's mask mandate, that was like, barely there. Could you speak a bit more about like, your reaction to that? Your feelings around that?

Shelby Hintze 13:03

Yeah. And so Utah, Utah's a very unique state. And first of all, it's a conservative state. But I'm the, the people are very focused, the religious state, people are very focused and about 60% are members of the Church of Jesus Christ of Latter Day Saints, and very focused on helping your neighbor, serving people. And that's a very big tenant of the religion. And so, um like, Utah is totally a red state. But, um, you know, we were one of the first states to pass, you know, Republican states to pass on protections in housing and employment for LGBTQ people. And we our governor refused to sign when the Muslim ban happened, the travel ban happened and a lot of Republican governors were saying, we're not going to take Muslim refugees and our governor said, No, send them here. Like we will take them, we want people. And I think from a, generally people want to try to help each other and help their neighbor and, and are interested in loving and supporting each other. And that doesn't always, in practice that isn't always what happens. But the there's also a lot of, when you have that, there's also a big emphasis on personal responsibility and having people do the right thing because it's the right thing. And because they want to do the right thing, not because someone is telling them to do it. And that I feel like backfired pretty immensely in Utah. And it's frustrating and I think this will be really interesting, there's something to look back on when we're out of it. It's hard to really understand in it, why people feel the way that they do. And a lot of people just don't want to be told what to do. And there's this distrust of government and of being told what to do. There's a distrust of science. There's a big emphasis on family. And so being told that you can't see family or things like that, people also have a hard time with. And I think it goes back to, like we talked about at the beginning, just an invisible threat, people have a hard time understanding. There's, you know, when it's a, so over the course of the pandemic, Utah has had an earthquake, and a huge windstorm that just knocked out power and trees, all across the valley. And, and actually quite a lot of Black Lives Matter protesting. So there's been these kind of big events throughout. And, and people are prepared to help with natural disasters, they know what it is that they need to do. And they're very good at mobilizing and helping each other. But

when you're in this kind of uncertain situation, especially when there's not a lot of federal guidance, as well. And when people don't have kind of a playbook for how to handle this. And I think that's one of the biggest problems that there was no outline of this is what you do during a pandemic. So I wish that we would have had a mask mandate earlier, I also believe that the people that weren't going to do it, were never going to do it. And so I understand, there's a part of me too, that's like, well, how helpful would it have really been? I don't know, um, I think probably the more beneficial thing would have been some public health and public service campaigns, just from the beginning. And helping people understand that like, just because information changes, doesn't mean it's wrong. And I think the reason we're in the predicament that we're in now, it's years and years and years of build up to get to where we are, we weren't going to, we were never going to handle this well, no matter who was in charge, or what was going on, which is unfortunate. And I hope that this is a wake up call to a lot of people that there are a lot of things that need to be changing. Because this will happen again, like I think I think we're pretty confident at this point that this is not going to be a new, a novel occurrence.

Hannah Soyer 14:43

So I know this is kind of a weird question. But what has your experience been as a disabled person throughout the pandemic? So I know you've already spoken a bit like, you know, how your your activities and whatnot has changed. Yeah, I guess. Just yeah. What has it been like?

Shelby Hintze 19:03

Okay, I'll try to keep this like, as organized as possible, because I have like, a few I've been thinking about this in like a few different facets, I guess. Um, so I mean, first of all, as just in general, it's been hard to listen to people talk about the pandemic, in terms of, well, it only impacts high risk people, so I don't need to worry about it.

Shelby Hintze 19:34

And it's hard to, I mean, first of all, that's not true. I mean, just, that's just factually incorrect. But second of all, even if that was true, and just the idea that, you know, I don't need to worry about it because it doesn't impact me. And that to me, is just a very um so I think. Let me kind of start that thought again. And this is a conversation I have with people even during the flu season. People say, why don't you get a flu shot? Because you know, I never get the flu or last time I got the flu shot, I got the flu. And you anyway, so why would I go get it and I don't think people understand this idea of doing things that may be a small sacrifice to you, in order to help other people. I see it as a journalist, we get calls all the time from parents about, you know, well, my kid is having this issue at school. And, and then, but not having any regard for the other children in the classroom. Things like that we see a lot of. You know, well, this is the best choice for me and my family. So I'm going to do what's best for me and my family, as opposed to well what is going to be best for what small sacrifices can we all be making, and to help everyone? Um, so that's really hard. I mean, that's something that I think kind of also overall is, none of this was a secret. But I feel like we're, you know, it's the saying the quiet parts out loud now. And none of these things were something that I view that I didn't think people thought, but it's just very obvious now that that is what they think, and how they view their roles in society and my role in society. I think I had another, I mean, just from like a caregiving standpoint, it's been difficult because I have a couple friends who come in and help with things, but they have to also go to, to work at full time jobs. And then they also have husbands who have full time jobs. So their exposure is a lot more than mine. And then

they're coming into my house. And so I had to cut back that a lot, which is hard for me to put all of that extra care work on my live-in roommate, and also part of the reason why we came home. And, and then also just economically, like, it's hard for them. This was, I mean, it wasn't a huge job, but it was enough, that was kind of their money that they used to buy the extra groceries or, you know, get those couple little extra things that they need every month, pay the car insurance. And so that was gone. Um, I think let's see what else? And then also in Utah, um, Utah initially had a crisis care plan that would deny care to, like, specifically people with my disability, like it, like basically said neuromuscular disorders. I actually discovered that in a very roundabout way, um, I was reading a New York Times article about how some states were doing that. Somebody commented, was quoted in the article about their state and Kentucky, and their, their care plan, and I went looked at their care plan, and it was called the Utah principle. I was like, excuse me? So I went and clicked on that and went to ours and found Oh, so I specifically would be denied care. Um, and it was, and it was frustrating because it was purely

Shelby Hintze 24:16

because they wouldn't be able to provide like, the personal care for someone like myself, who would need help, using the restroom, eating, moving, things like that. And which, for anybody who has, who is disabled, there's a million different workarounds to solve those problems. And it was just very obviously written by somebody who didn't want to take the time to think about how do we help these people in these different situations.

And, and, and then this, the Disability Law Center in Utah, filed an injunction and they said we won't use disability to determine care. But that's still something that's like, well, they may legally not be able to do that. But is it still gonna happen? Probably. And if it gets really bad, that's something. And, and I understand that, um, you know, if I was very, very, very sick with COVID, I probably would be less likely to survive. And I get that and not because of my disability. But to just say, a blanket statement of, you don't get care. And I think that's a very fine line that I think a lot of people don't quite understand. Um, but so that just knowing that has also been frustrating, that thought of, okay, well, if I do get sick, and I need to go to the people that are going to help me get better, is that is, is that what is going to happen or not? Am I going to have to be in a hospital? Because usually, if I am hospitalized, one of my parents just stays with me the whole time to help with personal care themes, um, or like, my roommate will stay with me. And if they're not allowed to do that, I mean. It's been a lot of time, a lot of time kind of spiraling in the what ifs, that I think a lot of people haven't had to worry about. And because generally, you know, if they did get sick, they would be fine. Um, and then on top of all of that, as well. And the possibility of have having having had COVID, in February, has added another layer of uncertainty, because I'm also having some of the long haul symptoms that people are having, but I don't know, since I don't know, if I had COVID. Is the exhaustion, the heart rate, and the prolonged cough, I had a blood clot, all of these things, are they a result of that, or they were a result of stress? And I don't really know, and nobody really knows. And so I think a lot of just the uncertainty and the what ifs that I have had to think about. And as a disabled person, constantly thinking of the what ifs and the contingency plans. And the okay. I mean, I don't think most people have like a plan for if their car breaks down on the side of the road, how are they going to get to where they need to go. I think about that every single time I get in the car. And so, so just adding that on top of it, I think has been just something that a lot of people the the extra stress of the actual virus, and then the extra stress of people's reaction to it have been have been very psychologically draining.

Hannah Soyer 28:21

Yeah, I 100% relate to that. And that has also been the general response.

Shelby Hintze 28:33

Yeah.

Hannah Soyer 28:34

From interviewees as well.

Shelby Hintze 28:36

I imagine that's probably not a unique thing.

Hannah Soyer 28:39

Um, so. Okay, so we've spoken about people's responses to this. And I guess what I would like to do is ask you more about your personal care attendant situation.

Shelby Hintze 29:00

Yeah.

Hannah Soyer 29:01

And we can sort of circle back to this question of your relationships with people throughout this pandemic.

Shelby Hintze 29:09

Yeah, perfect.

Hannah Soyer 29:09

So you mentioned earlier that you moved home to stay with your parents throughout this. Could you explain a bit more about your personal care attendant situation, and how that has been impacted by all of this?

Shelby Hintze 29:28

Yeah, so I have when I'm home in Utah, I have three personal care assistants, one who's on a slightly more full time, she's my roommate. And then two who come in and help with things. So they help with getting in and out of bed, using the restroom, showering and getting dressed, cooking, cleaning, transportation, basically, all of those kinds of things. So when this first began I mean, first of all, I think one of the hard things was, it's something that would have made me feel a lot better from the beginning is we weren't sure about masks. And I emailed my doctor at the very beginning and said, Hey, should my care assistants be wearing masks like, even if even reusable ones? Should we be doing that because they do have to get within inches, not even not even six feet, or a couple feet, it's within inches. We're breathing the same air. And just no one knew. And looking back on it now I'm frustrated. Because I think we knew enough then to say, yeah, it's probably a good idea that they should probably just wear a mask. Honestly, now looking back on it, I'm like, we should always be wearing masks all the

time, anyway. I hope I don't turn into one of those just totally paranoid people but it may happen. But as the pandemic went on, we started saying, Okay, I think you should be wearing a mask when you're here. And so they wore masks. But it was always stressful, because just not knowing where they had if they had been exposed. And, you know, one, one of them who comes in and helps me get up in the mornings, her, somebody that her husband worked with tested positive. So we said, okay, let's not have you come for a few days, and make sure you know. So it was a disruption, also, just to the schedule of who does what and when. So, and there was just always that, like, I was happy for them to be there. And they're my friends, too. And so it was nice to see them and see some other people. But just in the back of my mind, there was always this worry of, are they bringing this potentially deadly virus, which at the time, I still hadn't even thought like, oh, maybe I had it. Because it wasn't in the US in February, we didn't know about it in February. And, and so it added a layer of stress to something that should have been making my life easier. And then it was nice having my dad there because he was kind of the designated like, grocery person. We did a lot of pickup, but he was kind of the designated, like, go out into the world person. So that if he did get sick, it would be easier for him to isolate. And my roommate would still be able to be there to help me with other personal care. So. So just again, those contingency plans for every aspect of okay, if this person gets sick, who fills in, if this person is sick, who fills in. If I get sick, where do I go to keep them because that was a concern, too. I was like, I don't want to, you know, possibly get people other people sick because I won't be able to isolate. And I think now that that's less of a concern to me, knowing now what we know about how well masks work when worn properly, but there was that period of just not knowing. Um, but so that so then we decided I decided to come home, initially just for a little bit of a break and

Shelby Hintze 34:02

quickly decided that it was just smarter to be here. And it's, you know, having having some more people to kind of take some of the load off of my assistant, um, but also having her here to take some of the load off of my parents. And, and, not having to worry about people coming and going. And and, I mean, there's still that and there's still that little worry that, you know, one of us is going to somehow get sick. But my, my dad works from home, my mom works a couple days a week and she goes in at like, four in the morning so she can get all of her work done before people get there. She overlaps with people just for a few minutes. Um, so it means then a big change for me my whole family. I have a younger brother who is a firefighter and lives about two hours away. And he'll come home to visit and just like sleep on the porch. For Christmas, my parents bought a camper trailer for him to stay in when he comes home for Christmas, and we'll just eat out, he'll eat out on the patio with the door open, and a heater. Like it's impacting everyone. And it's one of those things that we're all, we all understand why it's important. And nobody's doing it begrudgingly. But that doesn't make it easier. Knowing knowing the importance of it doesn't make it I should say it makes it a little bit easier. And knowing that we're doing what we can to be safe. But doesn't mean it's fun. I shouldn't say that. It doesn't make it an enjoyable experience. Did that answer kind of did you have any other specific questions about?

36:08

No, that's perfect Yeah, so. So related to that, then how, I guess, has your relationships, have your relationships with people change throughout all of this?

Shelby Hintze 36:27

Yeah. I'm very fortunate that the people that I'm closest with, are taking it very seriously. I'm very, very lucky about that. My, my boss has specifically said I am not welcome at work until it is safe. And I haven't been worried about losing my job, which is I am very grateful to not have to also be worried about that, because also my personal care hours are connected to my employment, which at this point, now, they're not taking anybody off the program, if they lose employment. They're not taking anybody off the program for any reason at this point. But for a little bit, that was a stress, and something I was worried about, before they made that decision. And then just something I will continue to be stressed out about as we get back to normal. Um, but my family is very much on board. My friends, most of my friends are like making good decisions. And a lot of them I mean, a lot of them are making decisions I wouldn't necessarily make, but I don't necessarily think are bad. And we're all kind of not having a great time right now. Which I don't want but also is oddly comforting too to know that there are people that are taking this seriously, even though they they personally maybe don't need to, which is very nice. But it's definitely made me like when I meet new people, especially when I go on dates, like how did you handle the pandemic is going to be one of the first questions, because honestly, and I know that this shouldn't be the case. But that tells me a lot about you and your values and what you think is important. And I've been trying really hard not to judge people off of that. But at the same time, I mean, and there's lots of things that you can tell me one thing, and it tells me a lot about who you are and what your values are. And I think this is just another one of those things, and partially because it's just become so politicized. Which it shouldn't. But also looking back historically, I mean, the flu of 1919. The same thing happened, it became totally politicized. It just is a different. It's a different level now, I think with the amount of information that we are, we have available to us. But at the same time, that's frustrating because I think if you aren't taking this seriously, that it's not because you just don't know. You're making a conscious decision at this point. If you don't understand what is going on. Or if you don't understand how other people are impacted by this right now. That is a choice you made at this point. There is no, no, there's no ignorance at this point, it's willful ignorance. So, on one hand, it is kind of nice, because it tells me pretty quickly what your values are. But I'm going to have a really hard time, probably for the rest of my life, not judging people for how they reacted during this. And, and placing a lot of yeah, just placing a lot of judgment on this time period, because it will, it does tell me so much about an individual's values and what they think is important. So that's something I'm gonna have to definitely, like, try to chill out about in the future. But I yeah, I've been very lucky that I haven't had, you know, close relationships. It hasn't dissolved any of those, it's hard to like, I think it's made almost some relationships stronger. I mean, I haven't been at home in 10 years. I haven't been home for more than, you know, a week at Christmas time, for six years. So so that's been nice to just kind of be able to be here and spend some time with my family.

Shelby Hintze 41:27

And, and the people that I do keep in touch with really well, I'm, like, obvious that these are the people that I want to be keeping in touch with, instead of just, you know, lots of just trying to get together with lots of people all the time. Which isn't bad, either. I'm excited to be able just to do that again, too. And to be able to have a wide array of people that I know and in contact with, but this has really kind of made the, you know, five or six people in my life that are important to me really important.

Hannah Soyer 42:12

Yeah, um, so, you mentioned that, you know, you mentioned that you like some, some people that you're close to, that you're friends with, you know, are perhaps doing things that you wouldn't feel comfortable doing. Do you feel like more isolated because of that?

Shelby Hintze 42:38

Yeah, hmm let me think, Oh, I think I have an interesting. So I think that there are a lot of things, choices that people are making, that while I wouldn't do, or not necessarily bad choices, I think people are doing what they can too. Not everybody, a lot of people are doing what they can to make good choices for their circumstances. We know that masks work, we know that being outdoors works. We know that just lowering the number of people that we're seeing, and interacting with, we know that those things work. And for me, as somebody who has a lot more at stake, I wouldn't do those a lot of those things, because like do I want to die because I wanted to go to Target like what is the what is the risk reward here. While I have gone to Target a few times, because it was it was getting very difficult. I went once at the beginning of the fall to look at all the fall decorations and once at the beginning of Christmas to look at all the Christmas decorations. Um, but I made you know, very conscious decisions of when to go we went early in the morning. And here there is a mask mandate. So everybody has to be wearing masks. I think I am probably more isolated. But that is also more of a choice that I am making just because I in general, I'm a very risk averse person anyway. I don't do things that have a lot of risk or even a moderate amount of risk, generally. So I think that while I am definitely more isolated, I could probably be doing more things than I am safely. Um, but I just don't want to take that risk right now. And it's just not worth it to me. But I did say that to my mom the other day. I was like, yeah, one of my friends had got COVID and he was fine. Um, but I said, yeah, he was probably doing some stuff that he was safe, but you know, stuff I wouldn't be doing. And my mom said, Yeah, but who has COVID now, and who doesn't? I was like, okay then that is also true. So, yeah, and I think I would also I would feel better about coming out of my isolation a little bit more, if I knew that other people were doing what they needed to be doing to stay safe as well. Just the fact that I can't trust, um, even I mean, everybody that I'm pretty close friends with, I trust. But no, like, you know, I couldn't trust all of the people I go to church with, or I couldn't trust all of my coworkers to be doing, to be making like really safe right choices. Or just, you know, anybody, target. This is, this interview is not sponsored by target.

Shelby Hintze 46:23

So I think that's, that another big thing is, if I knew that other people were taking this seriously, and even if we hadn't, I don't think we were ever going to be like New Zealand. We were never going to be like South Korea, like that was never going to happen. Um, but if I knew that we were at least trying to make good choices and trying to do what was right, as a general population, I would have a lot more freedom today than I do. Which is ironic that most people's arguments for doing whatever they want is freedom. But their personal freedom matters more than my personal freedom, apparently. So.

Hannah Soyer 47:14

Yeah, which sort of then seems to relate back to the idea of like, you know, being told what to do, for the benefit of the community versus, you know, making that choice yourself and how that has perhaps, affected people differently.

Shelby Hintze 47:36

And it's frustrating to me because, I mean, every single law is to benefit the society. And I know, there are plenty of people that would say, well, we shouldn't have any of these laws, like, they're all an encroachment on our freedom. But I'm like, but the general average person is not going and saying, I should be able to drive drunk whenever I want, I should be able to steal whatever I want. Because I made that choice. I should be able to, I mean, one that I was thinking of is like, I should be able to go hunt and fish whenever I want, wherever I want. Like, the general average person is not, you know, saying that we should get rid of those kinds of laws, because they keep you safe, and they keep everybody else safe. I mean, if you look at people who drive drunk, the person who is drunk very rarely is affected. It's usually if they get into a crash, it's the person that they crash into, or a passenger in their car. And it's the same with, with COVID, like, you may not have a problem, but there's a good chance, you will pass it on to somebody else who might. And I just, I would really like to understand the how that is different in people's minds. When to me, it is so clearly the same thing. And we talked about the spirit of the law versus the letter of the law, and the spirit of all of those laws are keeping individuals and keeping society safe. And that's what this is, as well. And so I know that that's a little a little side tangent there, but

Hannah Soyer 49:27

No, that was good. That made a lot of sense. Um, okay, so, do you feel like your relationships with different institutions have changed throughout all this? So health care, government media, etc?

Shelby Hintze 49:43

Yeah. Um, that's a very good question. Um, I mean, basically, the only places I've been are healthcare. Um, so it's almost like this is my outing for the day. Um, I don't trying to think what's the best way to answer this? I don't I honestly, I mean, I've had a slightly fraught relationship with health care anyway. Um, you know, really good experiences and really bad experiences. And that's been kind of the same. I will say, the sudden availability of telehealth has been awesome. And something that I hope doesn't go away. And something that I, I think I would be a lot healthier. Not that I'm unhealthy. But I think I would even have just better mental health, I think if that had always been an option, because there are so many things like, oh, I have this kind of weird thing. I don't know, do I need to go to the doctor? Just even I've loved with telehealth being able to say, hey, is this something I need to make an appointment for or am I okay?

Shelby Hintze 51:17

Um and, and then even them being able to say eah, let's do a telehealth appointment. And if you need to go get some blood drawn, you can just pop over to the clinic and get blood drawn or something like that. That has just made everything so much easier. And I would just be far more likely to go to the doctor if I have that option all the time. For just, you know, for simple things. I think government probably shouldn't talk a whole lot about that one because of my job.

Hannah Soyer 51:51

Um, yeah. Which I completely forgot. you're a journalist

Shelby Hintze 51:56

Yeah. I probably shouldn't share those feelings. That's totally fine. Yeah. And then media, I think

52:11

It's been interesting to me. Social media has been really great during all this, because it has helped me to stay connected with people. And I've kind of insulated myself, I think, at this point. I put myself in a liberal bubble, I guess people would say, um, but it is interesting to see just how quickly false information spreads. I mean that's a whole, that's a whole nother conversation. But like, even on Instagram, like I've started following some researchers, that have helped me understand and make sense of what is going on and helped even if I understand it already, helped me figure out ways to put the information into, into ways that other people will understand as well as a journalist, and just as someone who has a slightly larger sphere of influence, than some people, you know. How do I explain this to people who, you know, don't understand or, or, you know, how do I explain this to somebody who was trying to explain it to somebody who doesn't understand. So I've been really fortunate to have that, and I'm glad that we have social media. And it allows, you know, really smart people to dive a little bit deeper into their areas of expertise. You know, as for me, I'm, you know, I'm trying to fit how vaccines work into a minute and a half. And so that's hard. And so having social media and allowing, giving people a place to really dive deeper into some of the information has been really great. And, I mean, I think when it comes to traditional media, we're doing the best we can. There's a lot of criticisms there, but I, I believe that for the most part, people are just doing the best they can with the with the resources that they have, and there will always be room to grow, but yeah, we're trying.

Hannah Soyer 54:41

Okay, so, we're on to the last two questions, okay. And they're kind of meaty. So what was the hardest or what has been the hardest thing about living throughout all of this?

Shelby Hintze 54:56

Um, I think part of it I think just the, the general, like I said earlier, the people saying the quiet parts out loud. The like, you know, I kind of always knew that this is how society viewed not just disabled people, but just how society in general viewed there. What do we owe each other, and I've kind of figured that it was, well, most people don't think they owe each other very much. And I'm seeing that pretty clearly and especially, and seeing from people that you know, profess to love their neighbor and to, and you know, the people that are the first one out there to shovel your sidewalk. But then, and I think part of it is this idea that also you don't know who you're helping. When you're going and shoveling someone's sidewalk or cleaning up debris after a hurricane, you know the person that you're helping. Even if you don't know them, you see them, you know. That there is a tangible person that your actions are helping, and not being able to see that is hard for a lot of people too. So I think that's also part of it. But just knowing, knowing, having my suspicions confirmed, has been hard. And then, I mean, this is gonna get kind of deep. I'm gonna tell you this, and then I'll think about if I want it in there. But, um, you know, for me, I'm 28. And most people with SMA, as you know, live 50s, maybe, and I just have this constant

Shelby Hintze 56:55

reoccurring thought of, is one of the last years of my life going to be spent in quarantine? Um, and this was supposed to be like, my year. I had, I had a bunch of things, like, lined up for this year, I was looking, you know, I had a lot of things kind of coming on the horizon, that just came to a screeching halt. And you know, in the beginning, it was very much like, Okay, I'm just gonna be patient with myself.

This is hard, don't worry about, you know, just just get through each day, don't worry about excelling, or, you know, just get through the day. Because this won't last forever. And the longer it goes on, the more I'm like, Okay, I've got to start accomplishing some things here. But it's hard to want to do, also during all this time. So just trying to figure out that balance of how do I be patient and just get through this, while also knowing that, you know, I may not have another 40 years ahead of me, like most of my friends do. I may, I don't know. And that's also the very frustrating part of all of it, too, is just not really knowing. Can I just relax this year? Is it going to be okay? Or do I need to try to hustle a little bit more? Not hustle. I hate that word. But do I need to be, you know, trying to accomplish the things that I want to accomplish? Or, can I take a break? Should I be taking a break? Will that help me in the future to be able to accomplish things that I want to accomplish? It's just so many unknowns. And the decision fatigue is very real, as well. And and I think heightened when, yeah, just trying to make the best decision with the limited information that you have. So it's like, but

Hannah Soyer 59:19

No, I mean, I think, you know, I've asked that question to everybody. And the general response has always been, can there be more than one hardest thing? Absolutely. Um, I really liked that word decision fatigue. I think that speaks a lot to this feeling. Yeah, knowing what to do and trying to make the best decision.

Shelby Hintze 59:44

And like not wanting to look back on and be like, Oh, I made the wrong choice. I will say like, I have never had a decision so quickly confirmed to be the right decision than the decision to come home. Like I, we hemmed and hawed for a couple of weeks about it. And you know, when to go, how long to stay. Was it safe to travel? We just did the we did the trip in one day. I never even got out of the car. We just did the 14 hours in one day. But as I've just watched the numbers grow and grow and grow in Utah, and stay relatively even here, it's been pretty amazing. And I'm grateful that I've been able to at least have that decision confirmed that I made the right choice. And I've had several friends be like, I'm so glad that you're not here, you made such you made the right choice. And like at one point my roommate when once we decided that we were going to stay, she went back to Utah to like, get our winter clothes because we only brought, you know, summery things and and to pick up a few things that we needed. And then she drove back. And she even just a few days she was there, it was like it was so stressful. Because no one was wearing masks. No one, she like yelled at a guy in our apartment building who wasn't wearing a mask, like just all of those things that I'm just very grateful that that was the right decision. And at least we know that that was smart.

Hannah Soyer 1:01:27

Yeah, um, okay, so have there been any silver linings to this?

Shelby Hintze 1:01:35

Yeah. Um, I tweeted the other day, I was like, What's the opposite of finding Silver Linings because I feel like that's all I'm doing right now is. I was trying to, you know, do like a great what I'm grateful for, and everything was I shouldn't have to be grateful for that, like, that should just be a given. Um, but I do think there, there are truly some silver linings. I mean, we talked about, first of all the telehealth, huge one, and the change the like, overnight change, and realizing that, oh, we can work from home. I don't,

I don't want to work from home, like forever, but it would be nice to at least have the option in the future. To say, hey, you know, I'm going to work from home two or three days a week and come into the office two or three days a week. So I'm very much looking forward to that. And I think it's, again, I mean, going back to saying the quiet parts out loud. It's showing us the huge gaps in our childcare system. It's showing us the huge gaps in our education system. I think about a lot of the things that I that I hear people complaining about and being worried about. I think people deal with this all the time, not in a pandemic. And we're worried about it now, because it's on a global scale. Like, people saying, you know, I'm worried about kids that miss a year of school and have a year that, you know, that isn't very productive. But like what about all the kids that you know have to have major surgery in the middle of the school year, who have a parent die in the middle school year, who are bouncing around in foster homes, who are depressed, like, there are so many things that happen every year, that make a year of school a wash for a kid. And if our system isn't prepared to handle that, then that is a huge fault in the system. We should be able to handle every kid that's just kind of having an off year. I hope that a lot of the progress that we've made in working from home, school from home, all of those kinds of things, I hope that they stay in place, and that they become I mean, and I think people are going to argue that they didn't work. But they didn't work because we tried to put them together in a week. And so what we've seen that logistically it can work. Now how do we make that work better? And I hope that we do that instead of just saying like, Oh, thank goodness we can go back to normal because normal for a lot of people sucked. Um, so I hope that we continue the progress that we've made now and recognizing and looking out for people that may be in different situations and have different. And I hope that we don't just go back to normal and just say, Oh, thank goodness, we don't have to worry about that anymore. Because there are going to be so many people who always are still worrying about it. So, um, and I've got a lot of cute new clothes because I just shop online. So there's, there's that. I don't have anywhere to wear them, but I have them.

Hannah Soyer 1:05:39

Well, I think that's still good. Okay, so I don't have anything else. Is there anything else that you would like to add?

Shelby Hintze 1:05:51

No, I think I think that was kind of all the like, points that I was thinking. I mean I could talk about this all day, because I have so many grievances. But yeah, I think those were kind of the main things that I wanted to talk about. So. Okay, no, actually, I do have I do have one more thing. Go ahead. We're still recording, I do think it's gonna be very interesting as well, to see such a large swath of people added to the disability community, as we come out of this. I mean, I hope that people don't have permanent problems. Because I mean, I know that I've had problems the last eight months, and they've sucked, and they haven't been nearly as bad as some people. I think it's gonna be very interesting to see how medical practitioners handle long haulers, especially somebody like me, who may have some long haul issues that are like, a lot of the things that I'm worried about. I'm like, wait, is this because of my SMA? Or is this because of COVID? Or is this because of stress and anxiety? Um, and like the blood clot? Like, we don't we still don't know why I had one. I had lots, you know, several risk factors. But I've never had one before. The only different thing was COVID. Um, but how is that going to be handled? And then, and then I hope that as people get added to this community that, trying to think of the most diplomatic way to say this, they look at how the work that's already been done. Um, because I think a

lot of times people come into a new community, and then they're like, whoa, why are there all of these injustices? I need to fix them all. Well, you know, we've been trying, and so I hope that as people come into the community, there is an understanding that people have been working on this for decades. And maybe, maybe that's what we need to make some progress. And but I hope that the, that work isn't overshadowed and I hope we don't turn into a we got disability rights because of COVID. Um, but I would also like some rights, so I guess I, I can't argue too much about that. Um, but yeah, I think it'll definitely be interesting to see what that looks like in the next few years. Hopefully, people don't have super long term impacts, but who knows?

Hannah Soyer 1:08:47

Yeah, it's kind of hard to tell at this point. Yeah, for sure. Okay, last thing. Okay, I'm gonna stop recording