

Ty Dykema

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SPEAKERS

Ty Dykema, Hannah Soyer

Hannah Soyer 00:00

Today is November 27 2020. My name is Hannah Soyer, and I am about to be talking with Ty Dykema 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, so thank you so much for being here Ty. If you could just start out by giving me your name, age, pronouns and where you live.

Ty Dykema 00:41

Yeah, definitely. Thanks for having me. My name is Ty Dykema. I'm 30 years old. I use he/him pronouns. And I live in a suburb called Wyoming. It's just outside of Grand Rapids, Michigan. Yeah.

Hannah Soyer 01:03

Thank you, and how do you identify? So this could be disabled, chronically ill, neurodivergent, etc. And then any other identifiers you wish to use as well.

Ty Dykema 01:17

Yeah, I identify first and foremost as a disabled person. But I really, I like people having the freedom to label themselves however they, they want in that category. But you know, I like using the word disabled first and foremost. And then also, I'm a power wheelchair user. And I think that's important too.

Hannah Soyer 01:46

Absolutely. Thank you. Okay, so we're gonna go ahead and move into the big meaty questions. So when did you first learn about the pandemic? What was your experience with learning about it? So for example, if you remember where you were, what was going on? Those sorts of things.

Ty Dykema 02:08

You know, I can't remember specifically, like, the first time I heard of it, but I feel like it was a gradual thing. Like, I just kept hearing about it happening, like overseas, you know. And, but I do have a very vivid memory of like the first conversation I had about it. My little brother is a basketball coach, and I

went to one of the games, one of his team's games, and he beelined for me, you know, it was before, right before the game started. He beelined for me across the court, and sat down next to me. He's like, this COVID stuff is getting scary, don't you think? I was like, you know, it's starting to worry me a little bit. But you know, it's not quite here yet. So I don't know. And he was actually more worried than I was, which in hindsight, is a lot. But but yeah, I remember the first time talking about it was with my little brother who was very worried, for my sake, as you know, an immunocompromised person. And, yeah, after that conversation, I started paying attention a lot more. And shortly after, you know, it was right here. In Michigan even, it came to Michigan pretty quick.

Hannah Soyer 03:41

Yeah. So did answer the question? Yes. Absolutely. Um, so. So I guess, how has your experience, if your experience has changed in, you know, that could be like your emotional response, anything really. How has your experience with the pandemic changed over the course of the pandemic? If that makes sense.

04:11

That is a lot, I feel like it's been a lot for, I mean, it's obviously been a lot for all of us.

Ty Dykema 04:22

And it feels like I went through like, the whole, all the stages of like, grief, in a way, you know. It was like, it was again, or I talked about it being like, kind of a gradual thing. Even like coming to terms with what COVID really meant was gradual, like, even a fear of it was very gradual. I remember tracking it, you know, in like March, and it was like the day there was a first confirmed case in the US and I was like, "Oh, dang, it's getting really real." And then like, the first day, there was a confirmed case in Michigan, it was like, it's getting really real. And then the first confirmed case in my city, and it was like, four blocks from my house. It just got gradually more and more scary. And then, you know, I, my birthday is in March, and there wasn't that many cases, in the US anyway, at that point. But like, everyone was really worried, and things were getting shut down. And just thinking about the contrast between how serious people were taking it then, when there were so few cases, to now where there's so many cases, and people aren't taking it nearly as seriously. It's just been really frustrating. Obviously, the losses are more than possible to take in, you know. It's just so sad. And then to have to, like, keep, keep living our day to day lives. It gets hard sometimes, you know?

Hannah Soyer 06:30

I absolutely do know.

Ty Dykema 06:33

I know you know. But you know, I've taken like, I've really had to lean on our community, our community as disabled people, specifically. I've really leaned on that throughout this year. And that's also been a beautiful thing. So I think those connections are, they're obviously crucial. I feel like the, the, there's no way that they can ever go away after this, like going through this together has been. I mean, we don't want to have to go through it together. But the fact that we have it's like a different, it's a new bond, you know?

Hannah Soyer 07:22

Yeah, absolutely. Um, so. And, yeah, that's something I definitely want to return to later that idea of like, the community and the bonding. Um, so how has your disability, specifically impacted how you have experienced the pandemic?

Ty Dykema 07:47

Um, well, kinda like I said, right off the bat, it was, you know, once we kind of learned that it was that COVID was something that affects the lungs directly, I have SMA. So it's a pretty, you don't want to mess with the lungs, you know. And so that was scary, just from a pure diagnostic standpoint, it was scary. But, um, so yeah, right away, it was very clear that it was something I needed to take very seriously and stay home. And limit in every way that I can, you know, being in contact with people. And that's been tough because I'm very active in my local community. And I try to be present, you know, and in that community in a very direct way. So this is totally out of my norm, being, being home this much. But obviously, it's important and it's the right thing to do. For all of us.

Hannah Soyer 09:11

Um so, do you have like personal care attendants?

Ty Dykema 09:18

Right now, it's just family. My mom is my PCA right now. And then on the weekends, I have friends that do it so yeah. But I am, I'm like, yeah, that was like a big goal for me this year. Like before the pandemic it was my goal was to sort of overhaul my, my personal care. And that sort of it's made that difficult to, to change much, you know,

Hannah Soyer 09:57

Yeah. So is that situation I mean, beyond that idea, like, wanting to overhaul them or overhaul that situation has your care situation been impacted by the pandemic?

Ty Dykema 10:13

Luckily, not so much. Because like I said, my mom is my main PCA. And she's a cleaning lady. So she is like going, she's still working. But like, luckily, she's already usually like masked up, and gloves and she works with chemicals. So like, luckily, I'm not, I haven't been too worried. As far as her, like bringing something home. Plus, she's like, very cautious about being out or being in contact with other people as well. So luckily, my personal care hasn't been affected too much. Aside from the, you know, trying to try to change the situation so.

Hannah Soyer 11:08

Yeah. Um, okay, so this is sort of related to, that is sort of related to this other question who you currently live with, and then also has that been impacted by the pandemic?

Ty Dykema 11:25

I live with my mom. And, ironically, this is also the year that I was going to be moving. And that's honestly still in the cards though. There's not a lot of time left in the year, but I might be moving and

getting my own place, so. But yeah, the only the only, I guess, change in who I live with, because I did live with just my mom before the pandemic. The pandemic kind of just pushed back my plans again.

Hannah Soyer 12:11

So, in your, like, thinking about moving out are there certain things that you are having to take into consideration now more because of the pandemic? I mean, I know, that's kind of an obvious question, but.

Ty Dykema 12:30

Oh, definitely, you know, like I guess it's all really affected by it. All the aspects of moving are really affected. Because I don't want to be in contact with any, anybody that I don't need to. Even as far as like, you know, as a disabled person, other people are gonna have to move my stuff, you know so. Even even stuff like that is always on my mind. And then too like, not really being able to actively go and look at places. That's a factor too. Luckily I do want to, I'm planning on moving into my own place alone. So as far as like roommates and stuff goes, I don't have to worry about that too much. Which is good. But again, kind of like we talked about overhauling my personal care. There's a whole new layer to that, you know, making sure that the people you're trying to hire or work with are, are being safe, COVID safe.

Hannah Soyer 13:49

Yeah, absolutely. Um, okay, so, okay, this is another big one. What have your relationships with people been like throughout this? And have they changed?

Ty Dykema 14:06

Definitely, like I said, I'm someone that really tries to be present in my local community. And all of that has switched, had to switch to like a virtual version of that. And I feel like there's been people that I thought I was really close with, before the pandemic that, frankly, have been no shows, you know. And I know that everyone's going through things. So I try not to like, blame people too much. But it is kind of sad to feel like some of those relationships are drifting. And then there's other ones though, that I feel are closer than ever. Because there's like a real, there has to be intention behind everything now, like a real, concerted effort. So, yeah, my relationships are all different. Because if the if the effort isn't there, then it simply doesn't, it doesn't happen. And so yeah, some are better, some are worse. But the ones that have gotten better, it's been really powerful and really, really important for me.

Hannah Soyer 15:37

So have you had to distance yourself from certain friend groups or friends or people because you haven't felt comfortable with things they're doing?

Ty Dykema 15:56

Yeah. I have definitely had to, you know, I try to be polite about it, but I've definitely had to call out some friends and even some family members for going to bars and restaurants. And I mean, I guess it's one thing to do that and be safe about it. But I've seen people not being safe. And they post it all over the internet. And it's, it hurts, you know. So I've definitely had to distance myself from people like that. And obviously, I've I've not been around many people. Mostly, it's people that aren't taking the

pandemic serious enough or still making daily trips to the store when it's totally unnecessary. Yeah, it's been, it's been hard distancing myself from people like that, especially because I've just, I'm, I'm always right, in the thick of things, so.

Hannah Soyer 17:13

Yeah. Can you speak a bit more about your role or, like, how you were involved, or how are you are involved in your local community? And how specifically that looked pre pandemic?

Ty Dykema 17:29

Yeah. A lot of my role in my local community is in like, the local music and art scene. I kinda do a little of everything in in that space. I book events, whether that be music events, or like public speaking. I've been involved in art shows and zine festivals, things like that. And I perform, whether that be music, and I also do some public speaking. Mostly, my speaking stuff is about like disability topics. Yeah, so like I said, I kind of do a little bit of it all. I perform and I organize.

Hannah Soyer 18:28

And so that has largely taken a completely virtual shift right now.

18:37

Yeah, yeah. For sure.

Hannah Soyer 18:41

Yeah. So could you speak a bit more to I guess, you mentioned a few times that like, you know, it hurts to see people you're close to going about and doing these things. And that this, this having to not be as involved in the same way in your community has been really hard. Can you speak a bit more to sort of like the emotions behind that? Why it's hard, why these things are so hurtful.

Ty Dykema 19:18

Part of it is that some of these people are, you know, ones I've worked with on events and stuff. And some of those events are ones that I spoke, you know, and about disability stuff. And it felt at the time like it was really impactful. And then some of those same people that it seemed like it made an impact on are now the ones that are just discarding my words. And so that's where a lot of the hurt comes from because I thought they were understanding then. And now it seems like either they never understood it. Or maybe they're putting, now they're putting their own desires in front of my needs. And that's, that's hurtful because I feel like that's not something loved ones should do. I think that's where a lot of the hurt comes from those their priorities.

Hannah Soyer 20:28

Yeah, absolutely. Okay, so do you feel your relationships with different institutions has changed during this time? So that could mean health care, government media?

20:48

Oh, big time.

Hannah Soyer 20:51

Can you expand on that?

Ty Dykema 20:56

With health care, I feel like, part of it, it's a good thing. I feel like I've done a lot better job this year of advocating for myself when it comes to health care. And, you know, part of that is too, you know, maybe about halfway through the year, I realized, like, you know, pandemic or not, I do have to, I do still need to, like work on what I can, as far as like, self autonomy stuff goes with the move and personal care stuff like I that. So part of that, you know, I need to be a better advocate for myself when it comes to healthcare stuff, and researching what I need more. And always having questions and suggestions to my doctors and such, and getting on the phone a lot more often, and calling and checking on updates and stuff like that. But even you know, like, recently, I was supposed to have an appointment across the state at a hospital. And as the numbers are spiking again, I told them like, it's just not, it's not right, that you're making me go across the state to a hospital for this kind of appointment. Like, the last thing I should be in unless I need to be there is a hospital right now. So. So just being more vocal, it has been a shift as far as my relationship to healthcare goes.

22:52

Government, what a mess. You know, obviously, our president is not kind to people, our people.

Ty Dykema 23:07

But that's not been new. But some of the legislature, that's been, you know, talked about in quiet has done, really difficult to hear, like, especially, I think it was in April, I think it was Tennessee, where they talked about, you know, not treating people with SMA, if they were if they had COVID. Things like that just like the health hierarchy, I guess has been

23:42

I, which I guess is also attached to health care. It's just been, again, painful to see and hear that kind of stuff.

Ty Dykema 23:54

But that always drives me back to our community and driving and drawing strength from that. Because we all see it, you know, and we're there for each other through it. So that's really good. Is that a tangent?

Hannah Soyer 24:15

No, that was good. It was good. Yeah, so I guess now would be a great time then to ask more about I guess, you know, we we talked about, like how your relationship with people has changed throughout all of this. So similar to that, how has your relationship with the disability community changed throughout the pandemic?

Ty Dykema 24:46

It's I feel like it's never been stronger for me. In one of your workshops, I think or maybe it was the, your graduation thing, where I said, very early on in the pandemic, I realized, like, in some ways we're all we have, well, that's what it felt like anyway. Because even for as much as people were taking it more seriously, back in March, it was always disabled people that were taking it seriously enough, you know, at least for the most part. So, it was very immediate, where I started feeling like, like, we were all that, that I had, or that we were all that I'd have, at the end of the day. There was like a different level, there's always been a different level of understanding between us. And nowadays, it's, it's even deeper. Yeah, I have like group chats with disabled people only. And we like all check in on each other. Even like, seeing you online, it's been really helpful. I've also engaged more with, with the community through my art this year. I've been working on a series of portraits of like, just our peers. And that's been a lot of fun. And helped me connect a lot. So, yeah, even even just hanging out and like playing games together was fun. So, and really important. Just like I don't know, I don't, I don't like throwing the word normal around. But like feeling like more the normalcy with my community, you know, like, let's just play some games.

Hannah Soyer 27:13

Yeah, absolutely. Um, okay, so, what has been the hardest thing about living during this pandemic?

Ty Dykema 27:26

Um, man, that's a tough one. There's a lot of difficult things. It's, um, my best friend?

Hannah Soyer 27:41

Yeah.

Ty Dykema 27:44

Can I can I name a couple of things?

Hannah Soyer 27:48

Yes, that's what I was going to say. You can name more than one thing for sure.

Ty Dykema 27:51

Okay, cool. Normally, I get to see my grandparents every Wednesday. And in person every Wednesday, and now I don't. But my grandpa has gotten to be a professional at FaceTime. So that's been nice to still see them. But it's different. I want to hug my grandparents. And then my best friend. Since we were 12 years old, he lives two blocks away from me, and I haven't seen him since February. Because his mom and sister are both disabled, and he's their personal care person. So he doesn't want to, you know, end up bringing anything back to them, doesn't want to bring anything to me. So it's really, it's wild to think that he's like, right there. But you know, so far out of reach. And then my favorite place to go is this little bar venue downtown, called the pyramid scheme. And I've had my art displayed there, I've booked shows there. I've done speaking engagements there. I've seen some of my favorite artists of all time play on that stage. And all my friends make up the entire staff of this place. And I just love being in that space. And I haven't gone there in now the longest, you know, the longest stretch of time since it's been open. So that's been tough. And then like I said, just things kind of being on pause. As far as like, my life goals for this year. That's been challenging too.

Hannah Soyer 29:59

So have there been any silver linings then with the pandemic?

Ty Dykema 30:07

Yeah, definitely. It's given me, obviously a better connection to our community. I've met a lot of people in our community that I think I'll be friends with for a long, long time

Ty Dykema 30:29

It's, it's let me see, like we already talked about it a bit. It let me see like people's intentions more. And like, when I do get to spend time with people, it feels, it feels really good. Because they're, you know, there's intention and care behind it. And also, this year has just given me a lot of that pause has also been kind of a good thing, because it's given me time to just work on myself, and read a lot and work on my art like, I've never, like I've never been able to do before. Like, someday it's like, that's all there is to do. So let me draw all day. And it's great. Because that's what I want to be doing so. So yeah, I guess the silver lining is as weird and fluctuating as time seems to be. That time is filled with things that we probably should be doing in a safe way.

Hannah Soyer 31:43

Yeah, so sort of like a reworking of priorities almost.

31:49

Yeah. Yeah. Like everyone's getting, you know, a restart, if you will, like.

Hannah Soyer 32:01

Okay, well, I don't have anything else. Do you have anything else you would like to add or speak about?

Ty Dykema 32:11

Um, you know, I guess everyone should just hang in there and watch Crip Camp.

Hannah Soyer 32:22

Absolutely.

Ty Dykema 32:24

For sure.

Hannah Soyer 32:26

Okay, so I am going to go ahead and stop recording. Okay.