Disability Visibility Podcast

Episode 58: Twitter Chats

Guests: Alex Haagaard and Dawn Gibson

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Hola! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong. If you know anything about me, you know that I'm on Twitter. A lot. And I'm not just there for the cat memes. I've been involved in various Twitter chats as an organizer and participant, and today I'm talking to Dawn Gibson and Alex Haagaard about the Twitter chats they lead.

Twitter chats are discussions set at a particular time online using a hashtag as a way to organize and find one another. Dawn is the founder of #SpoonieChat, a community on both Twitter and Facebook. Alex is the creator of #MedTraumaChat that gives people space to share their experiences of medical neglect and abuse. You'll learn more about the origins of their Twitter chats, the utility and power of online communities, and the process and labor involved in moderating these conversations.

Are you ready? [electronic beeping] Away we go!

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

ALICE: So, Dawn and Alex, thank you so much for being on my podcast today!

DAWN GIBSON: Thanks for having me.

ALEX HAAGAARD: Yeah, thanks for having us.

ALICE: You two are just real dynamos at Twitter chats—

DAWN: [chuckles]

ALICE: —especially Twitter chats for the disability community, for the spoonie community. I was wondering if both of you would just introduce yourself first.

DAWN: My name's Dawn Gibson. I'm from Detroit, Michigan. I founded Spoonie Chat in the summer of 2013 as a way to bring together rheumatology patients and kind of organize them around self-care and pride. Over time, the chat expanded across most diagnoses. We're entering our 6th year, here in 2019.

ALICE: That's awesome. Thank you.

ALEX: So, I'm based currently in a small town north of Toronto, and I started Med Trauma Chat about a little over a year and a half ago, I guess. When I sort of started getting into Twitter, one of the first chats I came across was Spoonie Chat, and then of course, the Crip The Vote chats. And they were such an incredible way of connecting with other people in the disabled community. I'd sort of found as someone who was struggling to get diagnosed and access care was that there wasn't a lot of space online to talk about experiences of medical trauma and neglect and abuse, and that when those spaces did exist, they often existed in sort of explicitly patient groups, which were often not very aware of broader things like disability justice, often not very intersectional. So, I wanted to create a space that would be a little bit more tapped into the wider disability community but making space to talk about those specifically medical experiences that a lot of us have.

[light, bouncy music break]

ALICE: Why Twitter chats versus other ways of creating community?

ALEX: I've been mostly housebound for the last, oh god, three or four years at this point because I lost my license for medical reasons, and we have like zero transit where I'm living. So, Twitter has been a huge and really important way of enabling me to connect with other disabled people. And the other thing: Twitter chats were something I could engage with even when my spoons, as we call them, were at their lowest. You're able to just sort of even just read along with and like and retweet other people. There's still ways of engaging and participating even when you're sort of really, really struggling physically, I find.

DAWN: Yeah. I was talked onto Twitter in 2011. A friend of mine, he worked on me for quite a while. He felt like I had a story and a voice that would be perfect for Twitter. And I was highly resistant because I was still unclear about how much I wanted to say about myself and about my disability, about my health, just anything. And I saw this dietician's chat, a weekly chat, and I was so enchanted by this community of people so interested in food. I have food allergies, and so I understand the need to focus on food in ways some other people might not understand it. I thought, OK, I'll get myself going on Twitter just to try and help other people and to try and understand what people are saying. But my motivation, it came from a lot of different places. First of all, spondylitis is not a diagnosis that gets a lot of attention, and there wasn't representation of color. So, I thought well, let me just see what I can make happen and then we'll just see.

So, I put out some tweets saying I wanted to use the hashtag #SpoonieChat. I gave a two-week comment period. And I just started with basic Q and As about *The Spoon Theory* by Christine Miserandino and tried to get a sense of was my experience typical, did people feel that they themselves were disabled, what was it like? And over time, we all became some kind of friends and just kept going. So, being able to kind of get together on Twitter, it breaks the geographical boundaries. It breaks time boundaries because those tweets are just there, and people can engage when they want to or when they can engage. And it just, it breaks open space. It breaks open public thought, social thought, political thought, all of it, and that's why I'm on Twitter.

[light, bouncy music break]

ALEX: I think one thing that's been incredibly interesting for me with Med Trauma Chat in particular is finding out how global so many of these experiences are. You have people from all over the world coming together and sharing the exact same experiences that are just, the policy’s a little different, but the clinical experiences end up being very, very similar for everyone.

DAWN: Yes, yes. I don’t wanna quite call it an equalizer ‘cause the barriers are there for people who are dealing with certain intellectual barriers, people who have issues with Internet connectivity. Even for myself as a dyslexic, sometimes I have to work really, really hard [chuckling] to keep up with what’s happening with the chat! ‘Cause all the words are moving! But there is something like a maybe choose your own adventure, at-your-own-pace-ness about the Twitter space that is special.

A lot of people, they can’t speak publicly about their health, or they can’t give intimate details the way that I might because they’ve got a child custody issue or whatever, you know. But they are watching, and these tweets are doing things for them that nothing else will do. And I’m not saying I’m doing something nobody else can do.

ALEX: [chuckles]

DAWN: There are lots of great people out there. But it’s Twitter that is not barrier-free but, I think, low-friction for most people to use it.

[bright, playful music break]

ALICE: And Alex, talk to me about how you started the Med Trauma Chat and why did you select this hashtag?

ALEX: What I’ve found for, gosh, most of my life is that I felt incredibly isolated by these things I was experiencing within medical spaces. What was really sort of a first turning point for me I found was in around, I guess, 2013, I actually found an article on Medium about idiopathic hypersomnia. It was actually the first time that I saw anyone articulating this idea that people don’t believe you that what you’re experiencing is real. People think you’re just not trying hard enough. And so, it was through that that I sort of entered patient communities on Facebook. But then I often found those spaces very exclusionary. As Dawn has mentioned, there’s not a lot of space for recognizing the distinct experiences of people of color, for example, also for queer people.

And oddly enough, there was often a lot of ableism within them as well. You get what I call the Gold Star Spoonies, who are the people who are like, “Well, you know, I keep exercising ‘cause at least it means I can still walk.” Which, as someone who doesn’t really walk very much anymore and who uses a chair can be incredibly alienating. So often what you see discussed, too, within a lot of sort of medically-oriented spaces is people having these same experiences but not realizing that this is a systemic problem and asking themselves the same questions that I had for so long and not realizing that this is in fact a disability justice issue. One of the things that’s been most meaningful to me has been when people have direct messaged me and said, “I don’t feel able to participate openly in the chat. But I’m reading what you’re saying, and it’s really resonating.”

ALICE: There are a lot of drawbacks to visibility, but I think being visible through a hashtag, through a series of tweets, it’s really important to really share that lived experience and that perspective.

DAWN: I like the idea of speaking to myself, my past self. And I think about what would a 25-year-old Dawn have gotten from being able to go right to Twitter and read all of this stuff and to know it is still possible to be a part of a community. It's possible to feel proud. It's possible to still feel beautiful, all those things. That would've been so different [chuckles] than what happened, which was being handed a stack of pamphlets and some prescriptions and not understanding anything about my body, about how I felt. Just not understanding. And it's not even like my doctor was a mean person. She understood the clinical facts of spondylitis. She did not understand the social facts of being a Black woman with spondylitis. She didn't understand the fact that there was no support group in my area.

[light, bouncy music break]

ALICE: Dawn, you mentioned on Twitter yesterday that this is Spoonie Chat's sixth anniversary, and that's—in Twitter life—that's amazing.

DAWN: [laughs] Yeah. Thank you.

ALICE: So, what do you think you've learned about doing Twitter chats, about organizing chats, and just building community?

DAWN: So, part of the chat process is building trust, and we build trust by modeling good behavior. We build trust by consistency, having a similar format, having a space that is inviting, that allows people to be themselves. It's just a place for people to be and think of what they want to develop in themselves and what's possible for themselves. There was a big hunger for identity, a big hunger for understanding ourselves outside of concepts of productivity and usefulness and all of that stuff. I'm gradually scaling back questions. I had this sense when I started that I needed more and more question to keep people's attention. And I don't know why I thought that.

ALEX: [chuckles]

DAWN: Maybe it was just the hangover of a productivity mindset, or I just felt I had to earn the attention to build the community. I dunno! It could've been any of that.

ALICE: Alex, what's your approach to organizing and hosting Med Trauma Chats?

ALEX: I think that it's sort of a merging of my sociology, designer, and activist personas that leads to some of the way I set up questions for Med Trauma Chat. Some of these topics that we deal with such as misogyny in medical care are just so big. It's hard to sometimes stop yourself and say like, no, it's important to create something that's more digestible to engage with rather than asking everything all at once. I feel like Med Trauma Chat has a dual purpose, the primary of which is creating a space for people to talk about what are often really painful and difficult experiences. And I think just creating that space for people to talk and not necessarily feeling the need to offer advice, but just create that space and acknowledge and validate that, that's been really important. And it's often really hard to do 'cause people are talking about experiencing medical assaults, and it's hard to just have nothing to say other than, "I'm so sorry that happened to you." But sometimes that's what's needed.

I am aware that probably there are some medical professionals, medical students who read this, and I want them to learn from what's being discussed. So, being mindful of that dual focus but always trying to ensure that it's primarily just a space for people to share their experiences, and trying to keep that as safe as possible for them. And trying to keep it as safe as possible for people who are coming from marginalized communities and for whom patient spaces often aren't safe.

[pensive ambient music break]

ALICE: A lot of the conversations that happen during both of your chats can be very distressing. What do you both do as hosts to really kinda help remind your participants how to practice self-care or just protect themselves?

DAWN: Yeah. I start every chat with a reminder that I don't have a disclosure requirement. I ask people to introduce themselves in a way that they're comfortable with, and part of that came from my concern about the pre-Affordable Care Act days about people really having to live forever with a disclosure of an illness. Because once that's out there, that's out there. What you do on Twitter is real, and it will always be there.

ALEX: I borrowed Dawn's introductory question, which is to identify yourself however you feel comfortable. I also always do sort of a little introductory thread, which is, again, it fulfills a couple of functions, one of which the sort of educational purpose. Another is for accessibility purposes. So, providing a little bit of context and definition around some of the terms I'm suing in the chat or what the topic is that I'm focusing on for people who may not have a clear idea going on or may struggle with processing. But I also try and make an effort within those introductions to provide a very broad list of content notes that are likely to be applicable to what's discussed during that particular day's chat so that people can have a little bit of warning in advance if they want to mute my account or the tag to protect themselves. And I also always put in a reminder to people that if they're discussing something that's more specific or that falls outside the scope of those notes that I've identified to try and label it themselves.

One of the big things that I try to challenge with the chat is this idea that medical spaces are oriented around compliance, and I think they need to become more oriented around consent. And so, for me, giving people, as much as possible, the ability to actively consent to engaging with the chat is really important to me, that there's no pressure, really. It's about sharing the experiences as much as is helpful to you, rather than doing it for other people.

DAWN: Yes! Oh my gosh, yes.

ALEX: [chuckles]

DAWN: It's important to [heavy exhale] to make sure that people are participating on their own terms and for themselves. The advocacy machine is real, and it uses a lot of our stories and experiences—

ALEX: Gosh, yeah.

DAWN: —and may not transform the space around us. I want people to do it if that's what they really want to do, but at the same time, nobody owes anybody else advocacy. And people don't owe it to their disease communities or their diagnosis communities to just burn themselves to light the world. [chuckles]

ALEX: Yeah! [chuckles]

DAWN: It's not owed to anybody, and I'm just careful with it now.

Sometimes I run chat as a hangout, which is just a super-chill set of questions or topics. I try to keep it as non-medical as possible. That's a nice break for people. But then, the other thing is I feel it’s important to model self-care in my community. So, I will say to people, “We have a hangout this week because I don’t feel great.” It’s important.

When I first got into chat and Twitter in general, I was thinking from a somewhat ableist mindset that if people just had the right information and the right tips, they could conquer this. OK, that’s such bullshit.

ALEX: [laughs]

DAWN: That’s bullshit with bullshit thoughts with bullshit sprinkles. I had to really go back to basics and understand that a lot of it has to be about us being a people together. That some of us are too sick to conquer anything. And now I see that, just as you said, Alice, being ourselves in public, that is the victory.

ALEX: Mmhmm.

DAWN: And the tips? If they help, great. But I’m less and less on tips or anything that seems like, if we could just get the right cheat code, people would be great.

ALICE: As a co-partner of Crip the Vote, a lot of people ask us, “Oh, why aren’t you all organizing events or rallies?” We really feel like our niche is really carving out spaces for conversations that also are catalysts for action.

I’d like to talk to both of you about the amount of labor that you put in and also, some of the biggest kinda misconceptions people have about your work as organizers of Twitter chats.

DAWN: Well, I think some people are under the mistaken assumption that I am paid by someone. Some of the misconceptions about chats go back to the basic, gendered misunderstanding of labor so that what a woman or a femme does is the commons, and she should do it—or they should do it—and it should be done well. But it’s something that’s expected, and it’s not professional. And so, it’s just this thing that people are used to having, like dinner.

ALEX: [chuckles]

ALICE: They get upset that dinner is cold or not to their liking.

ALEX: [laughs]

DAWN: [guffaws] Exactly!

ALICE: Where’s my steak, woman?!

DAWN: [still laughing] Exactly.

ALICE: How about you, Alex?

ALEX: I think there is also an overlap in this idea of invisible labor too with what goes into so much of what you do as a chronic patient, and especially as a chronic patient who is in any way sort of, has a marginalized identity. Because I mean I tell people that I haven’t been unemployed for the past four years. I’ve been working full-time as a patient because I became an admin assistant for my six doctors’ clinics that I was having to call one and then the other one and then the first one again when they each told me something completely different and were like arguing with each other via me. There’s so much work that goes into it, and it is invisible and uncompensated so much of the time. Yeah, there’s an element of this kind of work that we do in creating sort of patient and chronic illness and disability culture that is unrecognized in the same way. And I think, for me too, part of it is that it can just be tiring ‘cause again, like so much of the stuff that we talk about is, it’s hard stuff. And on the one hand, I often come away from the chats feeling really renewed, but it can also wear you down after a while when you’re still sort of fighting those battles within the health care system yourself. If you sort of keep trying to burn the candle at both ends, that can be really damaging to us as disabled people, as advocates and activists.

Well, and you know, a couple months ago actually, when the Doctors Are Dickheads hashtag was going viral and I shared a little bit of one of my medical horror stories on it, and a doctor replied to me saying, “Well, I’m so glad that you self-advocate for yourself.” And I said, “You shouldn’t be. You should be horrified that I’ve had to self-advocate in this way.” No one should **ever** have to do the things that I’ve had to do in order to access care just to survive. That is not a thing to be happy about. [laughs]

DAWN: That is 100% correct.

[bright, playful music break]

ALICE: What are some of the things about being a host and organizer of a Twitter chat that’s not so great?

ALEX: The biggest struggles, I think especially now that I’m going back to paid work, is being able to make the time. The other major issue for me, I think, is accessibility. I do have some mutuals on Twitter for whom chats are just straight-up inaccessible because they have cognitive disabilities or low vision and don’t have a setup that enables them to engage easily with Twitter chats in real time. So, finding ways of increasing that accessibility as much as possible and creating as open a space as possible has been a challenge, and especially since Storify has disappeared. So, I’ve been sort of trying to figure out ways of creating archives that are accessible to people. But again, how much do I limit myself in order to just get the chat done versus sort of how much energy do I expend to make it as open to as many people as possible?

DAWN: Alex’s words, I think, hit the mark. Addressing accessibility is difficult. And the chats, [sighs] they’re definitely biased toward someone who’s brain is quick and someone who is sighted and someone who is suited for certain rough and tumble.

ALEX: [chuckles]

DAWN: [laughing] You know, that kind of thing! But I just think about what it was like to be 25 years old and to know that my life had changed and that nobody was helping me. And I can’t shake that from my mind ever.

ALICE: You know, we’re doing this out of love and out of community. And people pick up on that energy and that place of genuine authenticity.

ALEX: I think often, we’re so socially and geographically isolated. When you’re a disabled person and when you’re chronically ill, it limits your ability to access a lot of physical spaces for community building and organizing. So, as much as Twitter is sort of often derided as armchair activism or what have you—

DAWN: [chuckles]

ALEX: —it has been incredibly meaningful. And I think the same goes for a lot of people who engage with these spaces. For all their problems, social media platforms are still often a way of making space for people who never had that space out in the real world, in meat space as I call it.

DAWN: Yeah.

ALEX: An interesting thing about engaging with digital activism is that I've become a lot more connected to people in the UK and the US initially versus Canada, and there is a really incredible tradition of disability rights and disability justice organizing in both those countries that has not been as strong here in Canada for a variety of reasons. But the Disability Justice Network of Ontario was launched latter half of 2018 by an activist called Sarah Jama. And they are doing incredible, incredible work within this province to start creating some of the conversations that I think we really need to have. So, their account, it's @DJNOntario. So, if you're looking for another incredible community of activists to follow, they are really good ones.

DAWN: I think that Twitter chats are kind of the unsung hero of organizing and advocacy. The bonds that people have are very strong, and these bonds translate offline. So, I know people through Twitter and through my chats that I never would've known. And I have been to their homes. They've been to my home. It's real. It's not just this series of ones and zeros. It's not just a bunch of avatars. And I know some people are not necessarily who they are representing themselves to be and all of that. But for me, and in my life, Twitter is very real, and my chat is a big part of who I am out in the world. And so, I hope people can understand that for me, and in my community, that's what Twitter chats are about.

ALICE: You know, our worlds are so much richer because we know each other, and I just wanna end this podcast with some gratitude toward both of you. Dawn and Alex, I just feel like we are friends. I see you both, and I'm just so thankful to be in this world with you both.

DAWN: Thank you. I feel the same.

ALEX: Yeah, same here.

Wrap-up

[hip-hop music plays]

♪ Oh, yeah yeah
How far will they go…. ♪

ALICE: This podcast is a production of the *Disability Visibility Project*, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Alex and Dawn's work on our website.

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Well, thanks for listening, and see you on the Internets!

♪ Rock it till the blast off
Stop drop dance off ♪

ALICE: Byeee!!