

## Stories from the brainreels transcript

August 1, 2014

[music]

### Introduction

CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at [info@storyminders.com](mailto:info@storyminders.com) with questions or topics and guests you want to hear on an upcoming show.

[music]

CHERYL: Well, Sarah, thank you so much for coming onto the show today, Stories from the brainreels. I'm really excited to have you here.

SARAH: Thank you for having me. I'm a free-lance writer. And I write about a lot of different things for a lot of different people. What I really enjoy writing about are disability issues and disability advocacy. And I'm lucky to have a chance to do that through the blog that I write and for a couple of different websites. I write for [Ollibean](#). And yeah, there've been a couple of others that have had me either as a guest blogger or as a paid writer.

CHERYL: What's the name of your blog?

SARAH: It's [GirlWithTheCane.com](#).

CHERYL: And you also have a website, [SarahLevis.com](#). So easy.

SARAH: Yeah. You can see some of my other stuff there too, some of the other writing that I do.

CHERYL: How long have you been a writer?

SARAH: I started writing when I was eight years old. Yeah, I've been at it, you know, a little while now [giggles] and have been keeping it up pretty steadily, you know, through my teenage years and through university. But the freelance company that I started was, that was about 2011. And that was just after I started writing the blog.

CHERYL: Oh great. OK. One of the things you said was that your favorite topics are around writing about disability topics.

SARAH: Mmhmm.

### Your relationship to disability

CHERYL: So I would love to know what is your relationship to disability?

SARAH: Well, I started being interested in the disability field when I was 15 years old, and I started volunteering with an agency in my community that supports adults who are intellectually disabled. And I didn't have an eye to make that my career or my life's work or anything, but just something that I enjoyed doing. But kind of prepared me for when I was in my early 20s, and I had a stroke due to a problem that I was born with, and I had no idea was there until I had a small stroke in a job interview [giggles]. And then another one later after some brain surgery and acquired some physical disabilities myself. And that just kinda put a whole new spin on my work and my life and everything and made me, well yeah, made me look at the world in a way that--even though I'd been involved with people with disabilities for a long time--that I really hadn't before. Made me appreciate the difficulties that people go through and the challenges that society throws up in front of these people, you know. And made me think, also, that this is the kind of work that I wanna do. This is where I wanna be involved. [giggles]

CHERYL: Tell me more about every single sentence you just said.

SARAH: [giggles]

CHERYL: You know, one of the reasons that I'm soaking up what you're saying, one of the reasons is that your story has a lot of similarities to mine in that I was working with disabled people in a volunteer capacity and then went into schooling to get some certification to work with disabled people in a professional capacity, and then became disabled myself.

SARAH: Oh, wow.

CHERYL: Yeah. So we have similar trajectories. I feel like I'm sort of interviewing myself right now. [giggles]

SARAH: Oh! Oh, that must be surreal [laughs]

CHERYL: It is surreal. And fortunately, the Canadian accent keeps it real, and I know I'm not talking to myself. [both laugh] I'm having trouble distinguishing that we're different people. It's just a weird cognitive problem that I'm having right now. It's bizarre!

SARAH: No joke.

CHERYL: I'm like, "Yeah, yeah, I know. I don't have to ask you anything else cuz I know exactly what you're gonna say." Wait a minute. Oh my gawd. It's very, very weird. Whoo. You started out volunteering, and then you did start getting some schooling to actually work as a professional in services for people with disabilities, right?

SARAH: That wasn't what my schooling was initially for. I initially went and got my university degree in Psychology. And then, after I'd had my first stroke, I was kind of in a transition phase then anyway. I was kind of waiting around to see when I was gonna have my surgery to correct the issue that was causing these strokes. And I was volunteering again in my hometown with this agency. And I suddenly thought, you know, I really like doing this, and you know, I'm not half-bad at it. [giggles] Why have I never thought about this as a career path? So while I was there, and you know, we were still waiting around to

see when my surgery was gonna be scheduled, I applied to a community college for what, in Canada, they call the Developmental Services Worker. And got in and, you know, was all ready to go off to school in September. And then I went and had my surgery in the summer and came out of that with a very, very weak left side and was going to need many, many months of physiotherapy and getting back on my feet again, literally. And had to call and say, "I'm really invested in doing this schooling, and I will come and do it as soon as I can. But I kinda had a stroke over the summer. [laughs] It's just not gonna happen for September." But I did eventually go and get it, yes. Once I was able to go and do schooling, I did go and get that course. And that and the Psychology degree have partnered together nicely to get me some work [giggles].

CHERYL: Yeah.

SARAH: I came back to I live in my home town, and I did do some work in a school program for youth with disabilities who were transitioning out of school and who were going to need a plan for when they became adults so that on the day that they graduated everybody wasn't saying, "Oh my goodness. What do we do now?" There's a real need for that everywhere. But, unfortunately, the funding for that position ran out. And so after I did that for a couple years and then had to sadly let it go. I really still miss that job.

### **Being a disabled person informed work with disabled people**

CHERYL: Yeah, I can imagine. I would love for you to talk a little bit about how your experiences as a disabled person maybe informed the way you did that job, working with other disabled people.

SARAH: Yeah, it was interesting. I think that it definitely caused me to bring something to that position that at least some of the youth that I was with found useful because while I was dealing with definitely different disabilities than they were--most of them anyway, most of them were intellectually disabled and weren't dealing with severe physical disabilities--they could see that there was a disabled person who was out living life and doing something that she wanted to do and working. I wasn't working full-time, but you know, doing some work and being a part of the community and not feeling that disability was a really a negative thing. And I don't think that some of those kids had ever experienced that before. They were in a special education class. They'd been called names for being in special education their whole life. And I know that for a lot of them it'd never really occurred to them that they could make their own decisions and go on and kind of construct a life that they wanted to live. And some of them took that and really ran with it. And it was really interesting to see where they ended up.

CHERYL: Yeah, that is fantastic to hear because I'm a really, really huge supporter of peer networks and peer support and peer mentorship in whatever form that takes. There's something so different about someone who's in the role of teacher or provider or clinician telling you, "you can do anything you want!" to the disabled person--the difference between that and then having another disabled person in any role--teacher or clinician or if they're not--having that other disabled person saying, "Actually, you can." It's totally different. I've seen it in other people. And I felt it early on. I didn't give much weight to what clinicians told me. But if another peer with a traumatic brain injury said the exact same thing, then I would believe it.

SARAH: Well, yeah, exactly. I think it does carry a little more weight, even if that's not explicitly talked about. Cuz you know, I didn't get really personal with the kids or anything and say, "You know, well, I've experienced this, and I've experienced this." Cuz you have to have those boundaries. But they kind of pick up on it. And they watch, they see.

CHERYL: Absolutely.

SARAH: On the blog, I'm very deliberately very vague about some things just for the purpose of keeping other people's privacy and for my own privacy too, you know?

CHERYL: Yeah, well, you have every reason and every right to protect your privacy. Have you found this, that when people find out you're disabled, or for whatever reason, perceive you have a disability, they suddenly think you don't deserve any privacy? Have you encountered that?

SARAH: Yes, yeah. I think I actually wrote a blog entry about that, about how people suddenly feel free to ask very, very invasive questions and things that they wouldn't feel normally, I would hope, comfortable with asking anyone. And thank goodness I haven't been asked some of those questions. But there was another woman that wrote a blog. I can't remember her name just off-hand. But she uses a wheelchair all the time. And she says that people have asked her things like, "Well, how do you have sex? How do you handle getting dressed in the morning?" and things like that. And it's like you wouldn't ask a person--That's just rude! [laughs] To ask anyone that is just rude and invasive. And why would anyone think that that's appropriate? [laughs]

CHERYL: I am totally with you. And I would add to that, why is it that non-disabled people think that's the biggest deal in a disabled person's life? Because I'm betting that that person you're talking about who is asked about how does she have sex, which is, oh my gawd, and how does she get dressed. I'm betting that person finds that lack of accessibility, attitudes, discrimination, unequal access to housing and jobs, I'm betting those are bigger problems to her than how she gets dressed.

SARAH: Well, exactly.

CHERYL: But people don't consider that! They just come up, and first of all, objectify you by asking questions about your personal life. But then they just don't seem to recognize that these are not the biggest barriers. I just wanna cuss and scream until my own head falls off about how outrageous it is that people will come up to you and be like, "What's wrong with you?" They're not actually asking about discrimination or oppression or being belittled and harassed in public (like they're doing to you).

SARAH: It's very true. And it kinda goes back to that medical model thinking of what's wrong with you? Rather than what's wrong with the greater society that's not permitting people to function and to thrive? But that distinction between medical model and social model, I realize that a lot of people aren't aware of that. But that's what it kind of brings to mind to me. I mean, I know that the Ontario Disability Support Program, which is the disability program here that's similar to SSDI for you guys, I would think. It pays an amount to people that's so low that in the cities, where the housing is very, very expensive, people are choosing between paying their rent and eating. I mean, those are the bigger issues. Yeah,

forget how I deal with those things. How do I deal with having to pay, having to deal with choosing rent or food each month.

CHERYL: People won't ask that! Cuz when they ask, "What's wrong?" If you were to say that, "Well, what's wrong is that my disability benefits are so low, I might not be able to eat," they're gonna walk away.

SARAH: Oh yeah.

CHERYL: Or they'll call you an angry disabled person. But they asked what's wrong. But what they really want is the ooey-goey dirt on your physical body so they can walk away and go, "Whoo! At least I don't have a weak left side! At least I don't have that, this that or the other!"

SARAH: "That goodness that's not me."

CHERYL: "Thank goodness I haven't had brain surgery." Yeah! Which is, again, so offensive and so demeaning on so many more levels that it just is really outrageous. And here, in the U.S., of course people will be like, "Oh, you're on disability benefits, you're on SSDI. So you don't wanna work." OK, um, except that with SSDI comes the opportunity to get government-funded health insurance.

SARAH: Yes.

CHERYL: If you work too many hours, and you start earning a paycheck, you may be able to pay your rent and your bills, but you will lose affordable health insurance. And I don't care about the Affordable Health Act. It's not quite working just yet, and it's not always as affordable as it maybe could be or was supposed to be. But some people who maybe could hold a job can't because the health insurance is part of what keeps them alive.

SARAH: Yes.

CHERYL: And so, if they lose that, they might be able to go to work until they need a doctor's appointment that they can't afford. Then, they're gonna lose their job. And then what? Go back and wait years in the backlog trying to re-apply for benefits? I think these attitudes that people who are on disability benefits they're just lazy moochers, those attitudes come from the same place as the attitudes of I can come up and ask you what's wrong with your body. And I'm not gonna share anything in return. I mean, these are all coming from a similar systemic ableist perspective, frankly.

SARAH: Oh, definitely. Yeah, there's a lot of work to be done about ableism. And I kinda call attitudes like that out in my blog when they start to piss me off enough. [laughs]

CHERYL: Oh, but you're so polite on your blog! [both laugh] I love it. Yes, you--

SARAH: I'm Canadian, right? No. [laughs] I try.

CHERYL: You know what? I think it's because you had an acquired brain injury. If you went down the traumatic brain injury road like me, you'd be much more rude than you are! Cuz I am so rude. I can tell

you. It's something about the stroke versus the smack to the front of the head that when you call someone out, it's polite. When I call them out, it is just a string of cuss words. And then I'm gonna walk away and go pet my cat and forget it happened. But anyway. [both laugh] So, we're talking about a lot of these concepts around systemic ableism and ableist attitudes. And then there's language and how we express these things. You're a writer. So I know that language means a lot to you. So I would love if you talk a little bit about the language that you personally prefer when you're talking or writing about disability and about your experiences.

### **The words we choose do matter**

SARAH: Well, the language is part of it, I think. And I've had a lot of talks with people that've said, "Well, words are words. And you don't need to have to worry about them so much." But the words eventually kind of shape the realities. So what seems kind of like semantics to people--and maybe ultimately it is--but it's kind of important semantics as well. Which is why I've still kind of stuck to the conventions that I learned when I first started off in work with people with intellectual disabilities of saying things like, instead of helping someone to do something, I'm assisting somebody to do something. Or instead of taking someone somewhere, I'm going with somebody. And that second one, especially, is one that I try to stick too. Cuz you know, helping isn't so bad; everybody needs help from time to time.

CHERYL: Mmhmm.

SARAH: But I think that words do shape our attitudes. And then our attitudes start to shape our actions. And I think that if we want to have a society that is going to be welcoming and inclusive of everyone, then we absolutely have to--I'm not in favor of banning words, but--we have to start to consider whether it's constructive to use words like "retard" or other ableist words. And you can probably think of a string of them. [laughs]

CHERYL: I'm thinking of a string of them right now! Yeah! [both laugh]

SARAH: You know, the people that would argue that, again, well, that's just a word. And people have to develop a thicker skin. Well, OK, that's one way of looking at it. But the other way too is what kind of society do you want? What kind of society do you want to build? And I will keep having that argument until I'm blue in the face. The one thing that I have kinda turned my head on is person-first language. Because I was brought up through the field all the way up through school with person-first language, that it was more acceptable to say "person with disabilities" or "person with Autism." And you notice sometimes I still slip into it sometimes because it's just easier or because it sounds a little more fluid. I remember the turning point on it was reading an essay by Lydia Brown, who's an Autism advocate. You probably know who she is.

CHERYL: Oh, yes I do! Yeah.

SARAH: Yeah. That argued that when you're trying to adopt this convention of separating the person from the disability, which is what person-first language is intended to do, and to put the person first, the intention is good. But you're saying that number 1, that you can actually separate that person from their disability, which I don't think you necessarily can. And number 2, why should you have to? Why is

disability, is disability something bad that people should have to be separated from? And particularly Autism, which is what she was writing about at the time, of course. And I thought she's right! [laughs] And you know, I went and I looked at the sources that she cited. And I read some more on it. And I thought you know what? It doesn't make a whole lot of sense to me when you put it in those terms. So I pretty much stopped using it from that point and started calling myself "a disabled person" instead of a "person with disabilities," which I swore I was never going to do. Because I always thought "disabled" is a negative thing. And I'm not going to be negative. Why should it be negative? Just because society says that it's a negative thing? But ideally, I think we should bow to people's personal preference on it, though. If somebody says, "Well, I prefer to be a person with disabilities," who am I to say, "Well, you're wrong!" [laughs]

CHERYL: Right. Yes. I like to try to be careful to never forget the people who came before me. And at the time that we started using person-first language in the community, that was a time when disabled people were not widely considered human. They were not--they would be human, but they weren't considered people. They weren't consider to have the potential--which is a nasty word--to have the potential to contribute to society or be worth much of anything. And so there was so much more institutionalization back then. And so I like to always remember to honor those incredibly hard-working, hard-fighting civil rights activists who came before us who championed person-first language.

SARAH: Yes.

CHERYL: You know, I am not "the amputee in bed 18." I am not "the head injury in room C." I'm not "the cripple." I am a person with a disability. And I love that! And now that, let's be honest, it's still a lotta institutions. And there are still ways that we institutionalize people informally and segregate them.

SARAH: Yes.

CHERYL: But we're in a place where disability rights is at least in the conversation worldwide.

SARAH: Yes.

CHERYL: Not in every country, but it's in the conversation. And that's the point where I have also made the shift. And I don't know how to always make sure that my elders understand that I respect them, and I respect their use of person-first language. But we are a different point in time. And we're in globally and economically, we were in different positions. And we are a point where we can say the imperative around person-first language used to be that. It was we need to be de-institutionalized because we are PEOPLE with disabilities. But what's happened now is now we've got all these clinicians who are using it in the way that you're talking about, which is "Oh no, no! You're not negative! Let's not look at your disability. You're a person with a disability. You're not disabled." And so it's shifted in its use. I believe that it's no longer such an empowering term. Now it's a disempowering term because it does create that attitude that the disability is bad, oh it's just a little thing, we can be separate from it. So now you've got the activist communities saying, "I embrace it. It is something to be just as proud of as my other pieces, whether that's my gender identity, my sexual orientation, my ethnic heritage." And it's only thanks to the people who came before us who championed person-first language. It's because of them that we

can turn around and say, "We have a new term that we find more empowering. And that is now we can embrace it because you showed that it's positive."

SARAH: That's such an excellent point.

CHERYL: I wanna champion non-person-first language. I wanna champion identity-first language. But I wish I had a sign that I could hold up to all the civil rights activists and say, "But I LOVE what you did!" Because we get into fights about language all the time. So I'm with you on that idea that each person's personal preference about how they wanna identify is really what's key. So I think when people get on their high horse about language, you have to stop and think, it's really the ideology behind it.

SARAH: Yes.

CHERYL: Because when you use your person-first language, but you still demean me and belittle me and demand to know personal details about my disability, what was the point of using "respectful language" if you're disrespecting me?

SARAH: Well, yeah. Exactly. It's the intent. And I think for discussions like philosophical discussions or whatever, I like the idea of declaring a language amnesty and saying, "OK. We all have a lotta different ways of saying this. But let's not have the big discussion about terms of reference right now unless it's being used in an obvious demeaning way. But let's accept that we don't always use the same terminology and just kinda go from there. Otherwise we'll never get anywhere! [giggles] We're going to be arguing this forever and ever. And we'll never get to any other issue."

CHERYL: Right, right. I mean, of course Sarah would be the best way to refer to you. [laughs]

SARAH: Well, yes. Yeah.

CHERYL: Right.

SARAH: Call me by my name. [laughs]

CHERYL: Right. And then beyond that, I like to know. Do people want to be referred to as "disabled" or "person with a disability" cuz I'm gonna do what I can to honor that when I can because I know that I may hear one term. But I don't ever truly know what you mean by it until I get to know more about you. You talked a little bit about this before, but when you were in high school, you were matched up with a woman, an intellectually disabled woman, for this program. You were volunteering. It was kinda like a structured friendship program it seemed like, from what I read.

### **Having friends in the disability community before becoming disabled**

SARAH: Yeah. They don't do it anymore. But they were trying to get people involved in the community more. And they were trying to increase people's numbers of natural supports more. So I think they called it Circle of Friends or something like that. And they were trying to get volunteers from the community to spend time with the people that this agency supported. And I decided to get involved, not knowing anything about disabilities at the time. They matched me up with this great lady. And we



turned out to be wonderful friends. And we're still friends today. That is a friendship that really has changed my life. And I probably wouldn't have gone into this field if it hadn't have been for her influence.

CHERYL: It's nice to hear that she had an influence on you as a friend, and also ideologically, I think.

SARAH: Yes.

CHERYL: And You wrote on your blog that you felt like having known this woman and having been such good friends with her that that helped you adjust to your life with disability.

SARAH: I really think that she did cuz, well, being involved with her and getting to know her and other people that were supported by the agency too, I could see that--and again, my disabilities after the stroke are very different from hers and from her friends, but--I could see that these were folks that are disabled and yet were out in the community and working to the extent that they could, doing volunteer work, had friendships. Ivy today still has a better social life than I do. [laughs]

CHERYL: Nice.

SARAH: And do need support, yes. But being a part of that and seeing that disability didn't mean a life of being stuck in a room and life kinda ending. I think that that really did have a positive effect on me. I mean, some of these people came to see me in Toronto when I was sick. And I think that Ivy and I had traveled together already at that point. There was nothing stopping them from having normal lives.

CHERYL: Yeah.

SARAH: Yeah. So really, what was to stop me from eventually [giggles] having a quote-unquote normal life. Normal, I don't like the word normal. And here I have used it twice. Having a fulfilling life and being part of the community again, you know?

CHERYL: Absolutely. And what's so interesting is that earlier we talked about when you worked in the transition program, even though your disabilities may be very different from those students', you could be in some ways a role model or a mentor. But years before that, Ivy was showing you that. It sounds like it almost was something that came full circle.

SARAH: It did. It worked out really well. [laughs]

## **What can you tell non-disabled providers to enrich their work with disabled people?**

CHERYL: Earlier, we were talking about how you've kind of been on two sides of disability: working with disabled people and then becoming a disabled person yourself. So looking at people who work in disability services and rehabilitation--people who are not disabled--what ideals and concepts would you want them to know about that could enrich their work with disabled people?

SARAH: I remember, actually, doing some writing about this for a friend who was a physiotherapist and the company that he worked for. And I remember the two things that really came up for me when I did it were--I don't know. Do you get the emotional lability thing with uh, um? Yeah. Yeah. [laughs]

CHERYL: Yes, I do. I have some problems. Yeah.

SARAH: I remember when I was in rehab, most days I worked really hard at rehab. But I had this terrible day one day when I just couldn't stop crying. And I'd stop for a minute. And then somebody would say something, and I'd be off again. And I really didn't wanna do it that day. I just did not wanna do it. And the social worker there kept trying, she kept coming into the room and saying, "Well, you have to get up and do your rehab. This is what you're here for. You have to get up and do it." And eventually, towards the end of the day, I think I did. I think I got to one session. But I remember wanting to say to her, "You know, maybe I'm crying because just everything's messed up in my head. But I don't know. But maybe I'm crying because I'm just really overwhelmed, and I just need a day." [laughs]

CHERYL: Yeah.

SARAH: "And I'm just trying to tell you that I'm sad, and I'm scared, and I just need a day. And tomorrow, I will get up, and I'll be fine. And then I'll wanna do everything. But can you just leave me alone for a day?" And I think I titled that essay "Just Listen To Me." Don't make assumptions. Just listen to what people have to say. And you'll be amazed at how much you actually find out! [laughs]

CHERYL: You know, we actually can be reliable reporters about our own experience! Isn't that amazing! Uh-huh, uh-huh.

SARAH: And that's a theme that keeps on coming up again and again in my writing too and in other people's writing as well, I've noticed. People make a lot of assumptions about people with disabilities, whether it's the assumption that because you have a physical disability you must also have a mental disability. People have assumed that about me. Or whether it's the other way around. The assumption that it's OK to ask you personal questions. There's just a lot of assumptions that people make. And for a while there, in my writing, it was just kind of a mantra: ask, don't assume. [laughs]

CHERYL: That's great.

SARAH: And I think that most physiotherapists are kinda trained to look for that. But the other things, some students aren't. Or they don't realize that they have to cuz the other thing that I wrote about for this person was there was a student physiotherapist at, I don't remember which rehab center it was. But she got far too close to me far too quickly. And that just set everything up. I didn't want her anywhere near to me after that. And this has happened in non-therapeutic instances too. People assume that it's OK to touch you. Or people assume that it's OK my cane. The kids at school and I had to talk about this a lot. They would just pick up my cane and play with it. And I'd be like, "No. You don't do that. You don't just grab people's canes and play with them. That's not appropriate." [giggles] And I've heard people in wheelchairs talk about it too. You know, people will just rest on their wheelchairs. Or if they're not in the wheelchair, people will sit in it. That's an extension of that person's body. And it's a very private

thing, you know? That's how they get around. Again: ask, don't assume that it's OK to touch somebody or to touch their mobility aid without asking permission. [giggles]

CHERYL: Yeah. Again, it's so objectifying.

## What blogs should people check out on social model and medical model of disability?

CHERYL: Are there writers or bloggers or media representations that you feel really good about and would like other people to check out?

SARAH: [Renee Salas](#)'s blog on Autism.

CHERYL: [With A Little Moxie](#) is one I know you highlight.

SARAH: Yes, I like that one. Yeah. And [Ellen Seidman](#), the one about her son, Max. Andrew Pulrang's blog, [Disability Thinking](#). [Bad Cripple](#), I think, is always good for--well, sometimes he's very serious. And sometimes he's very funny. [laughs]

CHERYL: I noticed in your blogroll, you've got names I recognize and names I don't recognize. But they're very identity-focused: disability pride and disability identity. For instance, Lydia Brown's [Autistic Hoya](#), [Bad Cripple](#), [Emma's Hope Book](#). There's a lotta stuff around empowerment. There's a lotta stuff around identity and pride. I also see on here a couple of things that sound like they might be medical, like [MyCerebellarStrokeRecovery.com](#).

SARAH: Yes, there's some stroke resources on there as well.

CHERYL: So you have a blend of sort of social model and maybe medical model stuff?

SARAH: Yes, it's fair to say that, yeah. Yes, I've never really looked at it that way. But you're right. Well, I think sometimes because I'm on the blogroll as a stroke survivor for a lot of other people who've had strokes for their blogs. And I wonder sometimes when they come and check it out. They'll wonder why I rarely write about my stroke, rarely. [giggles]

CHERYL: Oh, interesting! I'm so glad you said that. Lemme ask you a question. I was recently talking to someone. And she was curious about how I got my brain injuries. And I told her, "Well, I don't really need to talk about that. There's other stuff I wanna talk about." She's in the clinical world. And her response was, "Well, I've always learned that the most empowering and most important thing you can do for a brain injury survivor is encourage them to tell their story." So my response to her was, "You have to understand that for some people 'my story' is to tell you what day of the week, what time, what year, what intersection I was at when I got hit by the car and then how long I was in the hospital and what impairments I had. That's their story. My story that I like to tell is about why I dropped out of cognitive rehab."

SARAH: Right.

CHERYL: "So you have to understand that 'my story' is gonna be different from someone else's 'my story' and that some of us don't want to talk about how it happened and the aftermath of it. But what we do wanna talk about is just as legitimate."

SARAH: Mmhmm. Definitely.

CHERYL: That is an absolutely reasonable response that people don't need to get defensive about. If you put your boundaries up and say, "I don't need to talk about my stroke" or "I don't need to talk about how I got the brain injury," that's respectable. This demand to hear the details--

SARAH: No!

### **I'm not a fan of the word "recovery" and other politics**

CHERYL: I've noticed from reading your blog that you're not a fan of the word "recovery" in terms of your own experience. And I will tell you that I am not a fan of that word either, for my own experience. At the same time, I think you and I both enjoyed that we've made improvements since your strokes and brain surgery and since my TBIs. But neither one of us likes the word "recovery." So I would love if you tell me a little bit more about your opinion on that word around your personal experiences.

SARAH: OK, yeah. I'm certainly glad that I've gotten the return I have in my movement and everything. I mean, I still can't use my left hand. I don't have much movement in it. But I've done pretty well everywhere else. I still use a cane when I'm outside, obviously. But I don't use it inside. But I feel like the constant focus on recovery in rehab, in the medical community in general, among anyone who's--it's hard to talk about this without saying "recovery--"

CHERYL: Yeah, it is.

SARAH: --among anyone who's trying to get over a brain injury or some sort of injury like that in general. I feel like if that becomes too much of the focus, and the other side of it--kind of staying in the now side of it--isn't introduced, then people start to put off living their life until they're recovered or until they get their life back. And while I think it's always, if there are things that you can be doing to, like if there are things that I can be doing to get more function back in my hand, great. But in the meantime, I don't wanna be putting my life off until that day happens.

CHERYL: Yeah.

SARAH: And I think in that, we're running into some of the attitudes that we've run into before in that, being disabled is negative. And I don't wanna remain somehow flawed or somehow less than fully what I was. I'm just kinda surprised when I hear other people talking about being in rehab. And then they'll come out, and they'll say, "When should I start using my other hand?" When I was in recovery, they taught me how to start using my right hand, because my left hand is my dominant hand. They started teaching me to use my right hand to do things right away, how to write and how to eat and everything. So there was this kind of acknowledgement that there may be some improvement in the left hand, and that's great. But this is kinda your new now. [laughs]

CHERYL: Yeah.

SARAH: You know, and you have to live with it. You're gonna have to feed yourself. You're gonna have to learn how to write. So live in your now as fully as possible and learn how to do those things. And from talking to other people who've had strokes, I don't feel like that's present in all rehab programs, necessarily. And I think there's kind of a loss when that focus on this could be your new now, and you'd better learn to live with it isn't there. Does that make sense?

CHERYL: Yeah, that makes wonderful sense. I think it might be something that's very specific to the acquired disability communities, that we do have different from communities of people with lifelong disabilities--

SARAH: Yes.

CHERYL: --or disabilities that weren't acquired rather suddenly. Is that we can spend time thinking about the past and what can I do to get the past back, here in the future, and get all normal again? I feel like something that you're advocating is let's get some accommodations and access and compensations in place ASAP and get inclusion going.

SARAH: Yeah.

CHERYL: Right? I mean, you can still have a bad attitude and wanna stay in bed and not get out there and do anything, right? There's no imperative that you get out and learn to ski on one leg just because now you've got one weak leg. So just get out there and learn new things! But it's about if we can get past the idea that disability makes you less of a person, then you can get ready to say, "It's time to get going. I am ready to do things. So I've gotta learn how to do them in a different way." One of the reasons that the recovery imperative is so strong is because we have so much ableism, and we don't have real equity and inclusion. And people believe that the worse your disability, the worse your life.

SARAH: Yeah.

CHERYL: And it's not linear like that. Nobody is who they were yesterday. I don't in any way mean to trivialize anything when I say that. I mean I changed in some ways for the better and some ways for the worse. But nobody is who they were before. You wouldn't be the same person anyway because of your other life experiences.

SARAH: Right.

CHERYL: And so, I think when we start to see disability as identity and culture and life experience, we can move forward the way we move forward with other life experiences.

SARAH: Mmhmm.

CHERYL: I don't feel like I know a lot of people in the TBI community who really share a lot of my politics and ideology and stuff like this. Do you feel like you know a lot of people in the stroke community who you share your ideologies and politics with? Or are you kind of a weirdo like me?

SARAH: I think so. Usually cuz well, I thought it was because I was so young to have had a stroke. But I'm finding out that lots of young people have strokes. I know that in the older stroke community, I'm definitely an outlier for sure. But I think that yeah, I think that in the younger stroke community, I'm definitely an outlier as well. I think that if I went back to some of the groups that I was in and said, "You know, well, my hand's probably never gonna be 100%. But you know what? I'm OK with it." I think that yeah, that would probably raise some eyebrows.

CHERYL: Cuz they want you to keep fighting?

SARAH: Yeah. Well, if you can get some improvement back, why wouldn't you go for it? Like, have you considered some people get Botox to relax their hand. And I don't know, it's been--how old am I? [both laugh] It's been almost 15 years since I had my strokes. So I'm pretty good at living one-handed now. [giggles] And that's kinda the point where I am with it right now. So I mean, yeah, it'd be nice to have the other hand working a little bit better. But it's not going to be the end of the world if it never does. [laughs]

CHERYL: Yeah! I'm with you on that.

SARAH: And I used to say this to the kids at the school that you have a disability. It doesn't make you any better, it doesn't make you any worse.

CHERYL: Oh, but it does make you better. Because it makes you more enlightened and inspiring, and you're going to heaven first!

SARAH: [laughs] That's right.

CHERYL: Yeah, this conversation has been extremely inspiring.

SARAH: [laughs] Oh, I'm so glad.

CHERYL: You've done your job in this lifetime. You can quit all your work and just lie around now. You've accomplished what you needed to accomplish: you inspired me. But I have to say in complete sincerity, this conversation and reading your blog is very inspiring for me. And what I mean by that is inspiring in terms of I read what you write, and I'm having this conversation with you, and I'm thinking about things in a different way. And I'm wanting to do things and take action. It's not the inspiration of "Wow! Oh well," that you often see. Or that inspiration of "Gosh, if she can do it, I'm just a lazy jerk for not trying harder!" That's not inspiration.

SARAH: Thank you very much.

CHERYL: Yeah, I've really enjoyed reading your blog. You're an outstanding writer. You're so thoughtful. I appreciate your politics. And I just appreciate what you're doing.

SARAH: Thank you so much.

CHERYL: Yeah. I do wanna thank you so much for taking the time to talk with me and share your perspective and share your experiences.