

Disability Visibility Podcast

Episode 53: Disabled Editors

Guests: Elsa Sjunneson-Henry and Dominik Parisien

Host: Alice Wong

Transcript by [Cheryl Green](#)

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Introduction

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

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

ALICE WONG: Hello, hello! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong.

Editing is an artform. Whether you're working on something of your own or for a publication, there are a number of choices on what to leave in, what to leave out, and who you decide to highlight. Today's episode features a conversation with two disabled editors and writers: Elsa Sjunneson-Henry and Dominik Parisien. Elsa and Dominik were guest co-editors in chief of *Disabled People Destroy Science Fiction*, an issue from *Uncanny Magazine* published in 2018 featuring work by disabled writers. Elsa and Dominik talk about their experiences collaborating and editing this issue together, how they approached and worked with disabled writers, and why having disabled editors in publishing matters. And by the way, full disclosure: I have an essay in this fantastic collection. Call me totally biased. Are. You. Ready? [electronic beeping] Away. We. Go!!!

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

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

ELSA SJUNNESON-HENRY: Yeah, we're absolutely thrilled to get to be here today.

ALICE: And why don't we just start with some introductions. Elsa, would you like to go first and then Dominik?

ELSA: Sure. Hi, my name is Elsa Sjunneson-Henry. I'm a partially deaf-blind speculative fiction writer and editor. I was the non-fiction editor for *Disabled People Destroy Science Fiction*. I co-guest edited it along with Dominik. And I've also done work that, write a lot of non-fiction. Places I've been published includes the *Boston Globe*, *Fireside Magazine*. And I do a lot of grassroots disability activism, which includes work with New Jersey 11th for Change.

ALICE: Great. Thank you.

DOMINIK PARISIEN: Hi. My name is Dominik Parisien. I am a French-Canadian disabled bisexual writer, poet, and editor. I edited fiction for the *Disabled People Destroy* issue. My poetry chapbook *We Old Young Ones* is forthcoming from a Canadian chapbook publisher, Frog Hollow Press, through their disability series. They have a dedicated disability series that

they started this year. I've written fiction, poetry, non-fiction, some of it published in *Quill & Quire*, *The Fiddlehead*, *Uncanny*, a variety of places. I also work with queer elderly folk and just other elderly folk in general. And those are a lot of the intersections that I work with.

ALICE: Wonderful. Thank you.

Getting involved in *Disabled People Destroy Science Fiction*

ALICE: So, I was wondering if both of you could tell me how you became involved with this *Disabled People Destroy Science Fiction* issue of *Uncanny Magazine*. And what were your roles and responsibilities as editors in chief? Dominik, do you wanna go first?

DOMINIK: Certainly. So, I was approached by Lynne and Michael Thomas after working on *The Starlit Wood*, which was my anthology with Saga Press. They really enjoyed the material in that, and they thought that our interests were quite similar. I'd also written an essay for them on a strange condition called Alice in Wonderland syndrome or Todds syndrome, which is something that I have. And my essay intersected with chronic pain, with insomnia, with a number of my intersections for disability because they usually overlap with Alice in Wonderland syndrome. And they published that, and we talked at length about disability, both within the context of that essay and outside of it. And when it came time for *Disabled People Destroy*, they immediately approached me for that.

ALICE: How about you, Elsa?

ELSA: So, I wrote an essay for them called *Act Up, Rise Up* the people at *Uncanny*, Michael and Lynne. And it's about being a disabled activist and about my father's legacy—he was an AIDS victim, and he was also an activist before he died, and about sort of the role that he played in raising me as an activist with a disability. And they said, "Hey, this is a really great essay. We really love this. Do you have any experience editing non-fiction?" And I was like, "Yes. Some." I had some suspicions about what was going on, but they didn't explicitly say it. And then they sent an email offering the non-fiction position, and I was thrilled because this is the kind of work that I'd been wanting to do for a long time. I think that disability-specific science fiction and fantasy projects are really important because our genre doesn't always include us.

ALICE: Yeah. One thing that I was really delighted about is that very often, there are special issues or disability-focused issues that'll have all disabled writers, but very often, they're not edited by disabled people. And I think that really matters.

[funk music break]

The collaboration process, access, and ableism in publishing

ALICE: Could you both tell me a little bit about the process of how you collaborated with your colleagues—and feel free to give shout-outs to the folks that you worked with on this issue—and what the process was like putting this whole thing together?

ELSA: Sure. So, it was actually interesting. We, Dominik and I, talked a lot about how to work together as a team because one of the things that's consistently true in any disabled-focused project is that somebody's always going to be having some kind of medical thing going on. It's just true. So, we had to balance: when one of us was having a bad day, the other one would step up and do a lot of the legwork. When I was having an ocular migraine, I was like, "OK. You need to take over the emails for the next day. I'm gonna go bury my head underneath some blankets." And we would just trade off and support each other. And I think the level of

communication that we had during the project was really high, and that was with both of us. That was with our co-editors. That was with our authors. We were really engaged with the people we were working with and making sure that everybody was able to do the task. And if there was something that somebody needed help with, we were able to step up and do it because of that intimate communication style.

ALICE: How about you, Dominik?

DOMINIK: Yeah. I do love that collaborative aspect. This, more than anything I've worked on, felt like a community project in that sense. A lot of it was as much about the project as it was building the relationships that are evolved around it. So, like you asked for some of our other people involved. So, we had Judith Tarr on reprints, we had Nicolette Barischoff for personal essays, and we also had S. Qiouyi Lu for the poetry. And Elsa and I worked a little more closely because we were overseeing the project, and at the same time, we had the general angles on everything. But we were checking in regularly with everyone. And Elsa's absolutely right that there were days where either one of us or another member of staff wasn't necessarily able to function on that specific day. There were times when I was messaging Elsa, and I'd had a violent convulsive episode the day before. And looking at my screen was virtually impossible, and I had to rest for a long time. And we would switch off on those things, and not just those bad moments, but at the same time, because we were all aware of the things that everyone was dealing with, we were checking in regularly whether it was a good day or not, just to see how things were proceeding and if we could do anything for anyone. And that kind of proactivity often doesn't happen with people who don't understand what disabled people are faced with.

ALICE: Yeah. I think this is what a writer named Mia Mingus calls "access intimacy." It's the idea that disabled people just, we understand each other's needs, and we recognize the interdependence that we have with other people and that it's not a big deal if you're having a bad day. I will lift you up because I know you will lift me up. And I think that's something so beautiful about our people and our culture. And I think it shows, also, a great lesson for how people think about work. Because there is such a rigid idea of how work has to be structured. I mean, could both of you either share about in terms of publishing and being a writer, how the work of writing is itself somehow ableist in some ways, or at least publishing?

DOMINIK: There's definitely a lot of glorification of individuality in publishing and writing. There's a lot of that perpetuation of the idea that you shouldn't rely on others, either in terms of aspects of mentorship or aspects of just vulnerability with others. There's that idea of the—less and less, I think because community has become such a topic of discussion—but a lot of it, there is that kind of glorification of that person who's able to isolate themselves and write these genius pieces, not just without the input of others, but without any support of anything. You know, that idea that oh, they pushed away their family and their friends and all of these things, and they did it on their own. And that's an extremely limited idea because that's very much not a reality for a great number of people. So, I think it's definitely an issue in our field, but I think that's also just in the arts in general.

ELSA: You know, it's kind of funny that you bring this up because we just started working on the science—I'm a member of SFWA, the Science Fiction Writers of America, and I'm currently working on creating a committee for disability within the structure to create resources for disabled writers to have support because there's a lot of things that matter that we don't often think of in publishing. I was talking to a friend of mine who's a wheelchair user who wants to write a book, and in their sort of thinking about how the life of an author would work for them, they were like, "But I don't know if I'll ever get to go on book tour because I don't know if there

are any accessible bookstores.” I was like, “Well, we could have a database.” So, that’s something that I personally am working on because I see a lot of ableism in publishing. I see a lot of expectations put on writers and on editors about how the job gets done. I see a lot of expectations about what an author looks like or what an author must do. And I think that we need to start shifting those expectations to include more people.

[funk music break]

Challenges of co-editing this issue

ALICE: I was wondering if the two of you could also share maybe some of the major challenges you faced as co-editors in chief of this issue. Like, what was difficult about putting together a massive issue like this?

ELSA: You know, it was interesting. I think the biggest challenge that we faced was during our submissions period because I specifically—but I know Dominik had to do some of this—was I had to do a lot of emotional labor to convince people that they were allowed to submit. So, a lot of people would send me Twitter DMs or emails saying, “So, I have such and such disability, and I don’t know if I’m disabled enough to submit.” And then I would have to talk to them and figure it out, and it was really stressful. And we also didn’t initially have enough submissions, so we had to extend our period because disability time. Not everybody can work as quickly as an able-bodied writer, so we just needed to give people more time to get work in. But I think really, it was the submissions period that was the hardest thing.

DOMINIK: Yeah, that was definitely a genuinely challenging aspect. Elsa’s a little too humble to mention this, but she had an essay on tour on *You Are Disabled Enough* that essentially, at first, we went into extended dialogues with writers and people online in a variety of ways, having discussions about why yes, they should be able to submit. And eventually, by the end, we were doing it so much that we were frequently linking Elsa’s essay because Elsa’s essay perfectly encapsulated everything that we were trying to talk about being disabled enough for the— Sorry. That wasn’t on tour, right, Elsa? That was on *Uncanny*. It was your personal essay.

ELSA: Yeah, it was *Uncanny* ‘cause that was, we published it with personal essays. And that’s in the final magazine.

DOMINIK: Yeah, sorry about that. But yeah. It was put up before the submission period was open, but it encapsulated a lot of the issues that writers have in relation to disability and community where self-exclusion is such a major element. And that was the recurring problem throughout a lot of it. I mean Elsa and I had talked about it: I myself had those difficulties ‘cause for years, I didn’t identify as disabled because I didn’t think it qualified. And especially—I’m Francophone—and in French, almost everyone still uses the word “handicapped.” And it was one of those things where because I didn’t have a mobility disability, everyone I’d grown around with, especially in a small town, knew I had a very serious medical condition, and I couldn’t drive, and I couldn’t do a great deal of things. But because I didn’t have that specific language, and I didn’t have community, that wasn’t accessible for me. And I think that’s the issue that came up with so many of those writers who wanted to work with the project. So, it was quite a barrier for a lot of them, and that’s something we had to work at actively.

ALICE: Yeah. I think sometimes there’s also hesitation because when you read about a call for stories, call for submissions, and it’s about disability-centric, I mean specifically calling out for disabled writers, I think there’s the fear that oh, do I have to write about my experience with disability, or do I have to center my story necessarily all about disability? Versus just a regular

science fiction fantasy piece. I think that itself is another, probably, hesitation that a lot of writers have that either they don't wanna be pigeonholed, or they may feel like they have to kind of fit their submission, their story to a certain topic. Did either of you get those kind of questions or concerns?

DOMINIK: Yeah. We definitely— Our guidelines were very clear that we encouraged stories—I'll just talk about the fiction specifically, and Elsa, if you want to jump in after—yeah, we were very clear that we were very welcoming of stories that dealt with disability specifically, but they didn't need to. Provided that it was disabled writers, that was the qualification for it. Otherwise, we were very happy to have stories that didn't necessarily deal with disability because disabled writers always bring their perspectives to their stories, regardless of whether the story explicitly has a disabled character in it. But I will say that frankly, about 75% of the stories that we received did explore disability in pretty specific ways, and I think that pointed to the lack of opportunities for those kind of stories, or at least the perceived lack. Because people aren't necessarily encouraged to write them, I think a lot of folks are intimidated submitting it to writers or to editors and magazines that don't necessarily showcase it or ask for it explicitly.

[funk music break]

Response to the issue

ALICE: So, this issue of *Uncanny Magazine* came out in September 2018, and I'd like to ask both of you what's been the response, especially from the science fiction fantasy community?

ELSA: So, it's been interesting. The response to certain essays has been huge on Twitter. I've seen a lot of people retweeting specific essays, and it's hard to really predict which essays are going to be the ones that people get excited about. But I was really happy to see that *teri.zin's* essay about the science fiction genre and blackness has been really well received. And A.J. Hackwith's essay about anxiety was very well received and so was Fran Wilde's essay on empathy. And I've been really happy to hear from disabled people within my circles have emailed me to say that they were really excited about the issue. But I have not heard as much as maybe I'd hoped to about the non-fiction primarily because people don't really review non-fiction that often. So, it's a little bit more difficult to track.

DOMINIK: Yeah, the response has been good. Elsa's point is also one that I felt where I had hoped that there would be more critical engagement with the essays. There's been a lot of interest and fascination online with the essays, but there's frequently a lack of discourse in long form about non-fiction. I think that's always a little unfortunate, especially in this context. Generally, we've seen a couple of reviews pop up—we had one in *Locus* and a few other places—and they've been good. Twitter has really been the place that we've seen the most engagement with stories and the most enthusiasm and the most conversation.

ALICE: And you two co-authored a manifesto in the issue that talked about the fact that there is no one monolithic disability experience or narrative and that this issue of *Uncanny Magazine* is part of an ongoing conversation. So, what challenge do you wanna give readers, publishers, and other editors out there as an editor, through your experience on this issue?

ELSA: Yeah. So, I'm gonna try and cover for the editors because I feel like, especially able-bodied editors, don't often get disability narratives, and so they're tough on them because they're either afraid to touch them, or they don't wanna get, you know, smacked by somebody who doesn't agree with the story. And I feel like able-bodied editors need to get over that. We need to be seeing more disability stories out there, and the only way that that happens is if

publishers and editors are willing to take them on. There's not always going to be a perfect situation of two disabled editors editing a special issue on disability and science fiction or fantasy or horror or something else. Sometimes you're just gonna have disability stories in your general publication, and that's OK. And actually, it's great because it means that we're mainstreaming, and we're not just doing special issues.

ALICE: Thank you, Elsa. How about you, Dominik?

DOMINIK: I recently had an essay with *Quill & Quire* that was discussing specifically that— Our manifesto said the same thing, that special issues are important, and they are extremely valuable in terms of creating conversations around each other. But at the same time, if those are the only contexts in which not just disability but any marginalized identity is featured prominently, then it makes it very easy to segregate those things and not to have them appear alongside the other fiction, making it feel like either the quality or the importance of that fiction is not equal to the others. And I think that we genuinely do need to see more of that type of fiction in general within contexts. And I think that, specifically for publishers, they do genuinely need to look at their editorial teams and with an eye for diversity in general, and that also includes disability. And I think disability is one of those things that is frequently forgotten in conversations when we talk about disability and—sorry—diversity and decolonization of working environments.

And also, quite seriously, I mean Elsa and I are both white, and disability is frequently discussed within a white context. And that is genuinely one of the things that I think needs to be done better in a lot of conversations about disability, is looking at the variety of intersections of disability. I mean I'm white and disabled and queer. And I know that frequently, it's a specific approach to disability that's discussed, and there's a lot that's missing from the conversations, even in special issues and even in general. And I think that's one of the tremendous challenges facing representation in the field, is to ensure that disability conversations are intersectional.

Final comments

ALICE: Yes. Is there any final comments, anything you'd like to share with me before we wrap up? Elsa?

ELSA: Well, I would just say if you're looking for people to edit things about disability, both Dominik and I are great people to talk to because we may very well have availability. I would certainly love to edit more, and just look for other people besides us too, though. Look for people of color who are disabled. Look for more queer people who are disabled, because I'm also queer. But think about how to engage with our community and find more people and really listen to us. And don't forget to pay us.

ALICE: Yes, always! Always pay us. How about you, Dominik? Any final comments?

DOMINIK: Yeah. Just the same kind of conversation about finding more disabled people: not everyone is always directly visibly disabled or will necessarily be talking about it. Again, in terms of challenge and the like, I would definitely challenge editors and publishers and people out there to, when they look at this specific project, it'd be great if we see more of these names in other venues. But I would also like some of those people interested in projects like this to reach out to us and to others and ask who the other voices are, the people who either didn't make it into this project or weren't able to contribute in time, so that we aren't perpetuating the same voices all the time. Because that tends to happen within these projects. You know, someone becomes the one disability writer that publishers, editors, and other writers know, and they're the only one that others can point to. And that's kind of the danger of those projects. Yes, we

want—Elsa and I want—to be able to pay our bills, but also, please hire other disabled editors so that it is a variety of perspectives and not just our takes on disability.

ALICE: Well, Elsa, Dominik, I just really appreciate spending time with you today, and thank you so much for sharing about your experience and all the labor of love that you put in this issue. I just feel like this is something really special that is gonna really last, and it's such a gift to the world. So, thank you both!

ELSA: Thank you so, so much for having us, Alice.

DOMINIK: Alice, thank you for everything that you do for our community: these kind of community building and putting disabled writers in conversation with each other and disabled artists in conversation with each other has an absolute impact. So, thank you for this. It's a pleasure being here, and I think it's tremendously important work.

Wrap-up

[hip hop plays]

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

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 Elsa and Dominik's work on our website.

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Thanks for listening, and see you on the Internets! Bye!!!

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