Accessible love

An interview with Darla Schumm

Editor's note: Darla Schumm is professor of religious studies and associate provost for curriculum and faculty engagement at Hollins University in Roanoke, Virginia. She is the co-editor, with Michael Stoltzfus, of four books, including *Disability in Judaism, Christianity, and Islam* (2011) and *Disability and World Religions: An Introduction* (2016). In September 2024, *Vision* co-editor Jackie Wyse-Rhodes sat down with Schumm to discuss her current work on intersections between religious studies and disability studies. At the time of the interview, Schumm had just finished a book manuscript, tentatively titled *Healing Ableism: Stories about Disability and Religious Life*, that explores the experiences of people who are disabled in their religious communities.

Vision: Tell us about your work, your research interests, and your academic journey.

Darla Schumm (DS): I'm starting my twenty-fourth year working at Hollins University. For the first twenty years, I taught religious studies. Now I am the associate provost for curriculum and faculty engagement.

I am a Goshen College graduate, where I focused on psychology, history, and women's studies. A couple of years after college, I went to Berkeley and did a master's degree in social ethics at the Pacific School of Religion. Later I did a PhD in religion, ethics, and society at Vanderbilt University. And that's where I met my husband, who is an Episcopal priest. I identify as a Mennonite Episcopalian (whatever that is!).

I describe myself as functionally blind. I have a guide dog. I can see a little bit but not enough to get around without some type of mobility aid. Disability studies, as you probably know, is a relatively new field. Toward the end of my time at Vanderbilt, I happened upon a book called *The Disabled God: Toward a Liberatory Theology of Disability*, by Nancy Eiesland, and I started thinking a little more deeply about the intersections between religion, disability, and my own experience. That book introduced me to the idea that disability could be a site for theoretical as well as theological exploration. I discovered feminism in college, and so I was already familiar with, and a champion of, theorizing from personal experience. But I had never thought about it through the lens of disability and from my personal experience before reading Eiesland's book.

In graduate school, I co-authored a paper with a friend of mine, Dr. Jennifer Koosed, exploring the use of the metaphor of blindness in the Gospel of John. That was my first publication in religion and disability. We went on to publish three more journal articles together over the course of the next twenty years. I also started co-writing with another Mennonite scholar, Michael Stoltzfus. We published a couple of articles on religion and disability and then planned to do an edited collection, but we got so many submissions that we ended up publishing two books. At that point, in the early 2000s, the Bible and disability was a growing field, and there were a number of texts written about Christian theology and disability, but Mike and I edited the first books specifically on world religions and disability.

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About ten years ago, I decided to do a project interviewing people with disabilities about their experiences in religious communities and organizations. Originally, I framed it as an academic monograph. Simultaneous to the COVID-19 pandemic, I started getting involved in more public facing scholarship. I finally realized that the book I wanted to write was not an academic monograph but a book written for a general audience. A year ago, I pivoted the project, pounded out a new book proposal, and found a new publisher. I sent my manuscript off two days ago.

Vision: What does this new version of the book look like?

DS: The working title is *Healing Ableism: Stories about Disability and Religious Life*. The book is a blend of reflection on my experience living with disability and other disabled people's experiences, and I'm putting all of it into conversation with some theoretical concepts from critical disability studies. I am trying to present an honest overview of the experiences of people who are disabled in their religious communities.

Experiences are mixed, but they are often hard, ableist, exclusionary, and inaccessible. My overarching argument is that it is not disability that needs healing; it is ableism that needs healing. The message that most of us with disabilities hear from most of our religious communities is that we need to be healed. I'm pushing back against that and trying to say that disability is one form of human variation—and often a celebrated one. That was what I heard from other people with disabilities.

I wrote one chapter in which I introduce the idea of the misfit as a positive and capacious image of disability. In another chapter, I challenge the definition of normalcy that a lot of religious communities hold. The book also addresses how a lot of religious ritual is embodied in a way that keeps people with disabilities from being full participants in the ritual and, therefore, from being full participants in the religious community. I also explore time and the future—particularly the notion of the afterlife—through a disability lens. And in the last chapter, I home in on the idea of "accessible love" as one way religious communities can engage in the work of healing ableism. In no way do I believe that religious communities perpetuate ableism intentionally or maliciously. But it's happening, and we have to deal with it.

Vision: Who do you hope reads your book?

DS: The people who are going to be the most interested will be those who have some kind of connection to religious community. But I have discovered that I'm writing a critique that could be applied to all kinds of institutions. For example, many of the things I talk about in the book also apply to higher education.

I hope people with disabilities will read the book and discover that they are not alone, if they don't already know that. But it is also geared for the able-bodied world and for religious leaders, practitioners, and congregants. My hope is that people who don't necessarily identify as religious would also pick it up and apply it to their workplace or organization.

Vision: You began doing more public-facing scholarship during the COVID-19 pandemic. Now that we are four years in, what impact do you think this pandemic continues to have on people with disabilities?

DS: I wrote a piece at the beginning of the pandemic called "The New Normal?" In that piece, I talked about how this "new normal" that everybody was freaking out about—feeling vulnerable about their health and not being able to move through the world in the ways that they were accustomed to or wanted to—this was "same old, same old" for a lot of people with disabilities. It always bears noting that disability is an incredibly large category, and it is not a monolithic group. We have to talk about disabilities as opposed to disability. If we think about "disability" as both a physical impairment and the social and cultural conditions around us, we can see how things like COVID impact people with disabilities differently. A lot of people with disabilities are also immunocompromised. I have disabled friends who are still totally isolating. For them, it's not about choice; it's about survival.

At the height of the pandemic, when medical resources and hospital beds were limited, there was quite a bit being written about the allocation of resources and deciding who to prioritize when you have limited resources. Do you prioritize a ten-year-old child or a ninety-year-old adult? Do you prioritize someone who's healthy and probably going to recover fully if treated or someone whose health is fragile? These are complicated questions.

Vision: When religious leaders read your book, what do you hope they prioritize in the work for disability, justice, and access in their own congregations and communities?

DS: I want them to prioritize accessible love. I certainly also want them to prioritize access and inclusion, but what is tricky is that access and inclusion involve much more than accessible bathrooms or braille worship leaflets or ASL interpreters. I want religious communities to have all those things, but what I heard repeatedly in my interviews is that when a community has those things, often they think their work is done. It is usually much harder to figure out how communities can practice access and inclusion in such a way that people with disabilities feel as though they belong, not just that they are tolerated.

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A lot of congregations have pew cut outs for wheelchairs, but often they are located at the back of the church. What that communicates is that we have a place for you, but you're on the periphery—literally in the back. If a few cut outs were in the second row or even in the middle, that alone would symbolize that somebody using a wheelchair is in the center of our community. That is seemingly a small thing, but it's a significant shift.

In the book I also talk a lot about sacred texts and the messages they communicate. If you look at the Christian Gospels, any time Jesus encounters a person with a disability, he heals them. They are only ever welcome into the community once they have been healed. It's problematic. From a pastor's point of view, it raises the question of how to address these texts in an inclusive way when they show up in the lectionary.

A common slogan in disability activist communities is this: "Nothing about us without us." I want communities to include people with disabilities in the conversations about access and inclusion. There is always a balance. In anti-racism work it is not incumbent on people of color to come into a space and help white people fix their racism. This is also true for people with disabilities. At the same time, it is also annoying when able-bodied people decide what's best for us. One of my favorite things to say is that two things can be true at the same time. It can be true that I want able-bodied people to seriously do the work of undoing their ableism *and* that I want them to talk to people with disabilities about what that looks like.

Accessible love is not a formula. It is about communities figuring out what access, inclusion, and belonging mean in their context and seeing those things as justice issues. Hopefully, communities ask these questions for any non-normative body that enters the space. How do we build a community that helps people feel that they are welcome and wanted and that they belong?