Episode 6 transcript

The Disabled God

R = Robyn King
S = Stephanie Shockley

(Opening theme music)

R: Welcome to The Accessible Altar, a podcast of conversations at the intersection of faith and disability. I'm Robin King

S: And I'm Stephanie Shockley

R: We're your hosts.

R: Today we are going to introduce you to disability theology. And we're doing that beginning with one of the foundational classics of the field, The Disabled God: Toward a Liberatory Theology of Disability written by Nancy Eisland.

[music interlude]

R: I'm going to hand this over to you Stephanie, but just very briefly, Nancy Eisland wrote this as her Master's thesis and it was published in 1994. It is really, I think, fairly broadly understood as one of the first works of disability theology.

S: Yeah, I have heard people repeatedly talk about it as sort of a foundational text of disability theology, certainly in the United States, and certainly since the disability rights movement, or disability justice movement. And unfortunately it was not necessarily the beginning of a flowering of disability and theology writing. It is still one of not many.

R: Yeah, it is not a huge area of published books. There's some work out there that's not published in book format, but in terms of the more accessible corners, this is… it's a short shelf.

S: Yes, exactly. We are starting to see, at least I am, and I'm not sure if it's because I'm paying attention more, but I'm starting to notice a little bit more writing and discussion coming into the mainstream conversation in the Church. But not necessarily in theological books or book format. So to give you an example, the Episcopal Church publication Earth and Altar has been making what looks to me to be a real intentional effort to include articles about disability.

R: I'm really hoping we're going to get some of those authors on the podcast. I was reading, and rereading, because I've read large sections but not all of it… I've now read larger sections. I focused on the parts I thought we were going to talk about today. And I noticed several times she makes comments like "this work is not going to do 'that' because it was a master's thesis, it's not like a extensive compendium of disability justice and disability theology. And so she'll say "I'm not going to do that, but I hope someone else will." And sometimes I'm like "someone else finally did!" and sometimes I'm like "I don't know that anyone is actually doing that yet."

S: Right. Yeah, it is a beginning, it's a good foundation. It's certainly something that if you want to know more about disability and the liberation theology take on disability, disability theology, I should say, it is a book you need to read – it's probably the first book you need to read. But it is really only, it is really only a beginning.

R: I also want to tell you that this is not the book to hand to someone who is recently disabled, or has a new diagnosis.

S: No.

R: Because it, it is, the parts of it we're not going to talk about talk about disability justice and advocacy history, and sociology, and it can be a bit of a slog if you do not love that. But if you work with people, and work anywhere where faith and disability overlap a lot, it's probably worth poking your way through.

S: Yes. And there are bits of it that don't really hold up because it is from 1994, but it does hold up as well as could possibly be expected. Lots of it holds up. And a lot of it was way ahead of its time. And, you know, I was thinking, when I was looking over my notes for the book, I was thinking, you know, we did not cover this in seminary.

R: I was about to ask you to share where you first encountered this book.

S: So I told a… and that's a great question Robyn, thank you. I told a story in our second episode about how in seminary, in a class on Christian ethics, I was in a group that presented, actually, on this book and on disability in the church. And it was the first time I'd really ever publicly spoken about disability in front of my classmates, as opposed to, you know, private conversations, but in a class setting or presentation type setting. And I was not the one who found the book. It was actually a colleague of mine who was part of the presentation group who found the book and actually really read it and explained the basics of disability theology to the class. That was the first time I ever encountered it. Um, Robyn and I went to the same seminary as we've mentioned before and where we went to seminary was very committed to sort of what I would call, sort of the classics, like the foundations of the little "o" orthodox, the orthodox Christian faith and Anglican tradition. And really didn't cover some of the other perspectives. So we didn't talk about disability theology in any way. We didn't extensively cover other kinds of liberation theology or other points of view – womanist theology, queer theology, just being an example. I recently learned also that there is a whole bunch of different kinds of theology that groups have now been writing and reflecting…

R: We did not talk about!

S; That we never talked about! There's, um, I just picked up a book on Palestinian liberation theology, right? We didn't talk about these things. So, chances are, if you're listening to this, you may not have either. So, again, this was all new to me, even

as a person with a disability, it was completely new when I first heard it in… 2000-whatever-that-was, 2008, 2009. And I picked it up again recently.

R: We're skipping sort of chapters 1-3 because that's the terms, that's the lived experiences, that's the sociology, that's the history. And we're going to talk about the disability theology sections in 4, 5, and 6. And I got there this time and I was like "I wish the first time I had picked this up I had been like further into my 'you don't have to read a book cover-to-cover' journey, you can just start in the middle if that's the relevant section. It's really good stuff in the first part, but what I needed the first time I found this book starts in chapter 4.

S: Right, and I think that her unique contribution is most found in that section. I mean, the things that she says before that are said in a lot of other places because she's coming at it from, looking at it from partially the secular point of view looking at the sociology and the statistics and legislation and all that. But where it really gets interesting is where she, when she does a lot of work around the history, not history per se but the tendencies of the Church around disability and how we can look at some of the core tenets of the Christian faith through the lens of disability.

R: Yeah, and I don't… I completely understand why that first part is there. It's the context for everything that happens, and she's writing a very contextual theology, so she needs that, but if this your lived experience, you, to some extent already know that context.

S: One place it might be really good to start as far as her discussion of the theology is to talk about the ways, and she says there are three ways in which the Church understands disability.

R: Yes. These would be like the three, and these are the words I would use, they're not the words she uses precisely, the three traditional and problematic ways. That is sin and disability conflation, and we've alluded to that before and we will talk about that more, especially when we get to some sections where we

talk about disability in the bible and how that is viewed as disability as a sign of sin. That's not precisely what the bible says, it is more complicated, but that is, that concept that the Church has hung on to is a lot of, is what she is referring to there. Virtuous suffering, which is my… if I was going to rank these, this would be my like, personal least favorite. [laughs]

S: I was going to say… yeah. This is Robyn's favorite, and by favorite we mean she hates it more than all the others.

R: Yes. So virtuous suffering is an idea that I still encounter regularly. Drives me up the wall every time. I have not reached any sort of like, place of, yeah, no. You'll hear the… this is not what I believe… you'll hear this talked about as "in your suffering you become like Christ in his suffering, and therefore your suffering brings you closer to God." Which is, really harmful. Suffering and pain are not good. They are signs that there is a problem.

S: Eisland describes them actually, this concept of redemptive suffering, or virtuous suffering, as, actually, she uses the word "dangerous" for the disabled.

R: Yeah.

S; She's not mincing words here… the word dangerous.

R: She's right!

S; And she says it encourages, and I'm obviously paraphrasing, excessively, um, she says it encourages acceptance of poor treatment, of injustice, it encourages people to be passive and basically tells them that they're dealing with suffering in this life because somehow it will help them get rewards in the afterlife.

R: I am shaking my head so hard because I have nothing I can add to that, but yes, all of that is true.

S: And the thing about…

R: um…

S: Oh, go ahead, I'm sorry.

R: So, there's a great book by a Elaine Scarry (Scarry spelled with two Rs) called "The Body in Pain" (Note – full title is The Body in Pain – The Making and Unmaking of the World) where she talks about the experience of pain through the lens of torture. And how pain is isolating, and it separates you from everyone, including in the specific cases she's talking about of torture, from your torturer, even though that's your only connection. And I think that's some useful understanding to bring to this concept of virtuous suffering. Like, it isolates you even as you are being told it is "for the good" of your faith. It isolates you from the church community and the faith community.

S: I think one of the keys to this particular issue is that you can find meaning in things that you go through in life – BUT nobody else gets to decide how that mean-making goes for you, and there doesn't have to be meaning.

R: Yeah.

S: Sometimes things are just awful. You are not required to find redemption in your suffering or to find some kind of meaning or whatever.

R: Yeah.

S: Sometimes things are just terrible, and that's it, and it's… if you wanna, if somehow down the line you see it in a different way, that's ok, but that's not for other people to try to tell

R: To proscribe. And I think that one of the ways we get into a lot of trouble in this is that I definitely know people who have come through terrible things and will talk beautifully about how that was terrible and they have found deep and important meaning in

that. But when someone is in the middle of great suffering and pain, trying to explain to them that that is what will definitely happen – because it might, or it might not happen, does divorce us from, separates us from that person in suffering and separates them from us. I'm thinking of Job and how his friends were doing really well. They came, and they sat with him, and then they started talking, and it all went downhill. [laughs]

S: Yes

R: 'Cause they tried to find meaning in his suffering.

S: So, to do what we so often as humans do, to sort of make themselves feel better.

R: Yeah, it brings us comfort, because your suffering discomforts me. And it should, but sort that out on your own time.

S: Keep it to yourself, that's right.

R: Well, yeah

S: I mean, share with someone else outside of the situation.

R: Yep. And then the third one is segregationist charity.

S: And then this is probably my…

R: I was going to say, this is going to be Stephanie's least favorite.

S: favorite pet peeve, this is the one, it's my favorite, and by that I mean I hate it the most [laughs] of the three.

R: So, I'll give the brief description and then you can talk about why it's terrible. So, segregationist charity talks about how the Church and faith communities have historically given money, built hospitals, built institutions to help people with disabilities but in doing that we have moved them away from the community of

faith. So we have been very kind and generous to those people we have kept over there.

S: Right. This is about individualized acts of charity apart from, I would say, apart from any power analysis, or understanding of systemic injustice.

R: And, increasingly apart from any conversation with people with disabilities.

S: Right. This is very much about things that serve to make the able-bodied people feel virtuous. Like they're doing a good thing. This is kind of adjacent to what we've mentioned briefly before – inspiration porn. The thing where…

R: Yes, there's a direct…

S: of some poor disabled person having some wonderful thing happen to them and it's just to make you feel emotion – some kind of emotion – or to make you feel really good for supporting that cause, or, perhaps to make you feel that "gosh! I need to count my blessings! Because I could be little Timmy getting a wheelchair accessible van, but I'm not" right? So I feel like it's adjacent to all that, that kind of mess. But this is, yeah, the opportunity for charity, as opposed to people being part of the community, as opposed to being in conversation with people. And, this also, I would say, encompasses all the situations where people decide what disabled people need, without asking them, and sometimes not even listening to them when they're told. A lot of it comes down to not listening, and being more interested in feeling good about doing some sort of charitable act than understanding what people need. And it also comes down to making everything individualized, rather than looking at systemic injustice.

R: Well, and being really grounded in relationship and community. Which grieves me particularly in the Church because our whole thing is being in community with God and one another.

S: And all of these things, all three of these things, like you talked about before when you talked about suffering somehow being required, by some people, to be redemptive, all of these things just shut people out of the community.

Going, I just want to go back for a second to this conflation of sin and disability. One of the ways that this shows up – because… The reason I bring this up is, um, I'm sure most people listening, most of us would say "well, oh my gosh, I'm not walking around saying this disability happened because of sin, I mean that's, that's barbaric, I wouldn't say something like that." But let's say that most of us listening to this would never say that, we're not thinking that. But there are other ways of, um, of sort of saying that. For example, refusing to use the terms for disabilities that people ask you to use.

R: Refusing to use the microphone when you're speaking in a large room.

S: Exactly. Refusing to discuss disability, refusing to use the word disability. Acting like it's dirty. That's a way of saying that you think something is wrong, that someone did something bad, without saying that somebody did something bad.

R: I'm going to say something that is going to make people mad.

S: Go for it.

R: A lot of the phrases that clergy use in the best of intentions to make worship accessible – please rise as able, stand in body or spirit, all of that, is actually doing this, because you are still prescribing a normative action, and then saying, well, if you need to do something else you can do it, but we'll know.

S: Yeah, and when we get to the Eucharist we're going to talk about that a little more.

R: Yeah. Yeah, we'll talk about that whole thing more another time, but I have OPINIONS [laughs]

Ok, so those are the three huge themes she identifies in the Church. And clearly, we could, I don't think we're going to, but we could spend a lot of time talking about each of those. We'll return to them as concepts in other conversations, I am quite sure. [laughs]

S: I think so.

R: Probably, certainly [laughs] Um, and clearly, just based on our personal experienced levels of passion for these, they are still alive and well. She wrote this almost 30 years ago now

S: Yep, almost

R: And even conversations about them, I find any time I engage in one of those I just take a deep breath and say a prayer and wonder if I should put all my accounts on lockdown, because it's hugely contentious, in my experience of the Church.

S: I run across ableist language, ideas, concepts, etc. in Church universe all the time, and I'm constantly doing a calculation of "do I say something?"

R: Yep

S: Or do I just go on with my day, 'cause I don't know if I have the energy to say something every time it comes up.

R: And this is something we just heard about in Pat. He goes through the same thing, and I would extrapolate that most service dog owners do too. Like, do I fight with you about my legal access to this space, or do I not. And we both know it happens all over in disability communities.

[Musical interlude]

R: Shall we turn to her, because this is what I love, I think maybe the most, for myself, it was what I needed the most, her

discussion of the disabled God. Which is where the whole book derives its name.

S: Eisland talks about wanting to create, to at least start, a liberatory theology of disability. And in doing so, she says that we have to remake, redefine terms, and symbols so that they are grounded in the body and incarnational. So she talks a bit about the, and I've thought about this a lot, she talks about the transformative nature of the cross as symbol. So we all talk about this a lot if we are preachers in the Christian tradition. I actually am the priest in charge of a church called The Church of the Holy Cross, we just had our patronal feast day, so I just talked about this a lot – we're recording this in September – so we talk a lot about the conversion of the cross from a symbol of curse and torture and suffering and isolation into a symbol of life and resurrection.

R: And it's a conversion that is an ongoing conversion because the Church has not always done that.

S: Right. So she talks about the cross and the image of God on the cross as being, and a god that is wounded, and resurrected, and remains wounded, as being liberatory for people with disabilities.

R: So here is, it's a little long, but she has this whole section where she talks about the woundedness of Christ and contextualizing that in the context of disabled bodies that are also not perceived as normal. And this is the closing paragraph from that:

"Here is the resurrected Christ making good on the incarnational proclamation that God would be with us, embodied as we are, incorporating the fulness of human contingency and ordinary life into God. Presenting his impaired and feet to his startled friends, the resurrected Jesus is revealed as the disabled God. Jesus, the resurrected savior, calls for his frightened companions to recognize in the marks of impairment their own connection with God, their own salvation. In so doing, this disabled God is also

the revealer of a new humanity. The disabled God is not only the one from heaven, but the revelation of true personhood, underscoring the reality the whole personhood is fully compatible with the experience of disability."

How many places have you been in, Stephanie, where this concept that full personhood is fully compatible with the experience of disability, how many places is that actually true?

S: Um, [laughs]

R: I was going to say, maybe in my house, when it is just like, my spouse and I.

S: I mean, I mean… public places? So I'm really… I'm being a little bit slow to answer because I'm actually digging around and thinking. Um, very few. Very, very few places. I can think of some social settings, um, you know when you hang out in a social setting with other disabled people, that's an example. It's not spoken, you know, we don't talk like that, you know

R: No

S: when you're hanging out with friends from a bunch of different places and industries and backgrounds, right? Like, you're not talking like that, but that's what the experience is. But yeah, it's not… there have been very specific places and times that felt like that, but they're kind of few and far between.

R: Yeah. Yeah, it, it blows me away that she was writing this in 1994. Not only that in 1994 because that was like 4 years after the Americans with Disabilities Act passes, like it's not the genesis of disability activism, but it's very early in it too. And she could claim that as a dream and a goal and a truth that should be.

S: Right.

R: Yeah.

S: So, I'm thinking again, I'm thinking back to, and I'm digging in my brain for both secular and, for both secular and you know, church related environments. I'm thinking back to the summer of 1991, I talked about it in episode 2, where I spent a month a Drew University with other

R: Mhmm

S: vision impaired and blind students, um, who were considered "college" bound, we were all… it was determined that we were in that category. Um, and that's one of the things about that summer that was so freeing, and so confidence-building was the feeling of deep, uh, I can't think of a better word, normalcy. Because you were among peers and living on this college campus, and just getting to be teenagers. But even there, and this is a secular setting, but even there, part of why you were there, you weren't just there to have fun, you were also there because college was going to mean having a lot of skills and advocating for yourself and they really wanted us to be prepared. So there was a lot of work they were doing with us. Because there was a world that we were going to be entering into, you know, we were going to be growing up, going away to college, and there were a lot of skills we were going to need to survive. So, you know, you couldn't escape it. It wasn't an escapist thing, it was this is delightful, for many reasons, but also, you've gotta figure out how you're going to do a research paper, how you're going to handle this, how you're going to handle that, away from home without the supports that many kids were used.

That's one place I think of. Another place I think of is the parish I grew up in.

R: Mmhm

S: School was rough for me, often, I was certainly the only kid with low vision in my elementary school. And school be really hard. And there was a lot of bullying and a lot of wrangling with, about accommodations and things like that. The parish I grew up in was really accepting, in a lot of ways. Really, really accepting.

And, you know, I got to do all the things, I was an acolyte, from as long, you know, as soon as I was old enough to do that, and I just kind of was me, and everybody was just like "yeah, that's Stephanie." It was always just fine.

R: You were a person first.

S: I was just me, yeah, right, I was just me, I was just part of the community, I always, always felt part of the community in the parish in which I grew up. Having said that, when I talk about the lectionary and different stories about healing and disability coming around in the lectionary, that's the parish I'm talking about. And I would sit, and kind of cringe, because oh gosh, I know this is going to be preached incorrectly, at least from my point of view as a disabled person. And we had a wonderful priest, and it was a wonderful community, but it still wasn't aware, I guess, about that. So, it's complicated. There's nowhere that meets that paragraph, lives up to that paragraph that I

R: I can't think of anywhere either. I mean, like you, I can think of a few places that came close, but, also struggled in really important ways that I was very aware of being in them. I can also think of a lot of conversations I've had with people who were like "oh you should go do this!" and I'm like no, that has all the signs of being a really ableist space and I am not going to do that to myself. And I'm not advocating for that… sometimes the right choice is to go be in the space that is not yet welcoming, but also, if that was the boundary I drew, and I remember having people who were really puzzled about that.

[music interlude]

S: So when she's talking about the image of the disabled God, and Eisland in particular talks about a vision of the disable God as a human being who is quadriplegic.

R: Mhmm. And she cites it as a vision. She's using religious language around that.

S: And you know, what I was thinking when she said that, I was thinking about how there have been a number different of images of, either of God or of the crucified Christ or something like that, that are representative of different marginalized groups.

R: You know what I thought of immediately? Is our discussion of Lindsay in Episode 3 because she talks about Jesus as neurodivergent.

S: Oh, that's… yes, yes. I thought of the big controversy around the big piece of art called The Christa. It was at the Cathedral of St. John the Divine. I don't know if it's still on display of not. But it's a crucifix with a female-bodied Jesus.

R: Which is a really historic way of talking about it… I mean, it's Julian of Norwich who talks about Jesus our mother.

S: Right, and there was a huge controversy around it, and around it hanging not in sort of an art gallery set up but instead as the cross in one of the chapels. And I thought, I thought about that. And I thought about what would the reaction be to the quadriplegic God, or some other visible representation of disability. Because there was so much backlash against, that. I mean in some circles even just depicting Jesus as a 1st century Jew becomes problematic [wry laughter]

R: becomes problematic. And, well, Katharine Jefferts Schori, while she was presiding bishop of the Episcopal Church got in massive trouble I think because she was in England and preached drawing on that same Jesus our mother image.

S: Mmhmm, yeah, yes.

R: Like, that's not just some, that's the presiding bishop of the Episcopal Church.

S: People acted like she had made it up, she just…

R: …created some brand new heresy, which, 1. That's impressive, if you can do that

S: [laughs] right

R: And 2. No! [laughs]

S: Right, yeah, they acted like that had never been a thing before, no one had ever heard of it, hadn't been said. And so I think about that when I think about Eisland and her re-imagining of Jesus or God as the disabled God or the disabled Christ. And how she talks about the imago dei, the image of God, is the disabled body.

R: I feel like she talks about the backlash she has gotten… yeah, she does, at the end of… this is, we're trying not to do a book report, so we're not giving you, like, page numbers for all of this…

S: Yeah

R: But yeah, this is a lot of the stuff she covers in chapter 5, and at the end she talks about, um, "the numerous objections she heard," to this whole concept of a disabled God, because it's too much of a challenge to the power structures we have assumed are correct. Paraphrasing greatly there.

S: Right. The thing that's funny, I mean, not actually amusing, but funny-odd about that, is that to me, this whole thing, what Christ is about to me is about challenging the power structure, powers and principalities, evil, all kinds of things that destroy people, that hurt people, that marginalize people. To me, that's what this whole project is about

R: Yeah

S: So… I tend to think that… I tend to wonder if not only are those people objecting to the disabled God, they're just missing the whole boat. I feel like they're missing the boat on the whole thing.

R: Yeah

S; That's, like, super-judgmental of me but that's what it feels like. It feels like they're missing the whole thing of this incarnate human being being tortured to death and then God saying "you know what, that's not the end of the story."

R: Yeah. I mean, I, I agree. Um, she has a line at the very end of this, and I'm pulling us there deliberately because she does spend a little bit of time talking about sacraments, and we are both Anglican/Episcopal type people, so we want to talk about the sacraments too. But she sort of wraps this up with this really beautiful, it's a like a two sentence sort of conclusion, but I really just want to read the last sentence of this because I think this is the heart of the theology she's talking about: "this God (meaning this disabled God) enables both a struggle for justice among people with disabilities and an end to estrangement from our own bodies." And if that is not the promise of salvation right there, and the call of the kingdom of God, I don't, I don't think I could get that down to one sentence that neatly.

S: [laughs] right.

R: Just as an aside, because I can hear the voices that I would raise – she does identify that disability justice requires justice for all people. If you are around the disability justice movement now you will know that things like climate change are tagged as a disability justice movement, so we're not trying to silo there, we're trying to broaden.

S: So, yes…

R: That takes more time than we have for this but just wanted to say that.

S: Yes, yes, I know, I just wanted to jump in for one second. I have this overwhelming desire to say this thing. [laughs]

R: Go for it.

S: Today is, as we're recording this, is the 10th anniversary of the beginning of the Occupy Wall Street movement. It started in New York City and spread around the globe.

R: Yes

S: And I was a part of that.

R: It was transformative for you.

S: It was deeply transformative.

R: In the best and worst meanings of that.

S: Exactly, yes, actually. And, the reason I wanted to talk about that is because Robyn's talking about everything, all the concerns and issues being interconnected. Eisland talks about that, she talks about interdependence and mutual care being part of this, of things that define the disabled God. It's not an overcoming, it's not the overcomer God but it's a God that survives and leads us into interdependence and mutual care. And at Occupy, they always said… Everybody thinks that the most important slogan is "We Are the 99%." Well, that's the slogan that sort of was the thing that the media picked up on. The most important slogan of Occupy was "All Our Grievances Are Connected." All Our Grievances Are Connected.

R: Mmm, yeah.

S: And was at Occupy, and particularly Occupy Sandy, when we were doing hurricane relief, that I learned about the concept of mutual aid. The concept of mutual aid isn't "I'm so sorry this bad thing happened to you, you poor pitiful person, but I will bestow my charity on you." The concept of mutual aid is that we are all interdependent. Today you have some needs, and I have some resources, and I will do my best to share them. Tomorrow it's likely to be the other way. But we are all in a community of care.

R: I just want to second that with two comments. 1. If you go to our website, we have a link in our resources page to disability justice resources and mutual aid is at the core of a lot of that as a sustaining movement. And 2. Acts talks about how the early Church gathered, sold everything, held all things in common, and gave to one another as they had needs.

S: Yes.

R: That is mutual aid.

S: And occasionally, in life on this earth, we are blessed to see that for a brief time, and humans aren't good at holding that together for too too long, but occasionally we are blessed to see that lived out well in person. And I've seen it, and I pray that you find opportunities to see it. It changes everything.

R: I have seen it and have experienced it, very rarely, but it is transformative. So…

S: Speaking of transformation, and that which is transformative, maybe it's a good time to talk about sacrament.

R: Yes. So, um, there is another podcast called The Accessible God that talks about this, and will put a link to that episode in the liner notes for this episode, because it is well worth a listen. I just want to identify that we as we will say often enough you will know this very well, are in that Anglican/Episcopal tradition, so we have all the sacraments and then other things that are sacramental. We are not going to talk about all the sacraments; that would be like a whole episode, which maybe we should do at some point in time because…

S: We'll add it to the list.

R: We'll add it to the list. If anyone wants to come talk to us about sacrament and disability and faith, send us an email.

S: Please email us, exactly.

R: We'll schedule that real fast.

S: Yes. But I think Robyn I'm so glad that you remembered that, because I made a mental note to mention and I forgot. Definitely go and visit our brothers in the Methodist Church over at The Accessible God. They have some really wonderful things to say about this in particular, but also about disability in general.

R: Yes, I really love both that it's two men, because disability spaces, for a bunch of reasons, tend to be really feminine spaces. They aren't – disability is not a feminine thing, but there's a whole thing that we're not going to get into there. But I also love that it's two Methodists, because they have their own perspective, which is delightful.

So, sacraments. She talks specifically about I think Eucharist and laying on of hands, I'm drawing on some old memories here.

S: Yeah, there was just a lot to talk about with Eucharist. And Eucharist, it's important in so many Christian traditions, but it absolutely central in the liturgical traditions

R: Yes

S; In a way that there's just… I feel like we have to talk about that more than anything else, because it is just so central for our worship.

R: So, let's just to do a second… if you are listening to this podcast because you think it sounds cool but you have never been to a liturgical church: Eucharist is the sharing of bread and wine usually, right now it's just bread…

S: In my diocese it's just bread right now as well, it's being done in a lot of different ways.

R: It's being done in a lot of different ways, but the most common historical expression of this is usually bread and wine that is shared with prayers either in memory, recreation, or - insert a whole bunch of liturgical scholars writing about this – in some sort of pattern after the Last Supper between Jesus and his disciples.

S: Exactly. And in the liturgical traditions it is the central act of worship. In some other traditions the preaching is the… they may have Communion a certain number of times a year (which is also another word for the Eucharist or the Lord's Supper) but they may have that particular ritual – sacrament – a particular number of times per year, but the preaching is more important in certain traditions. In the liturgical traditions, certainly in the Anglican tradition, the Eucharist is the most important thing in the liturgy. There is a sermon, but it's not the focal point.

R: Yeah.
I want to move us back to the book a little bit. So, how is Eucharist and disability complicated. Because I think complicated is the best word here.

S: So, first of all, I guess, the first thing I wanted to read that she says is, um, talking about sort of an ideal world, she says, of an ideal setting for the Eucharist, she says "who is it that we remember in the Eucharist? It is the disabled God who is present at the Eucharistic table, the god who was physically tortured and rose from the dead and is present in heaven and on earth, disabled and whole. So, that is sort of, I guess, the ideal for her of what the Eucharist is about. So God in solidarity with humanity, disability as part of the image of God, God the, the disabled God there, present, with us in that act.

R: I cannot find this so I cannot link it for anyone. I have looked; I am sorry, I will try again. So if I'm wrong, it will be in the liner notes, but I don't expect that I will be right. Rather, I expect that I will be right.

S: Um, we will find it.

R: This isn't in here, but I remember, one of the first times I raised this question of what is disability theology, having found the resources that do exist, I'm like how did nobody put these books in my hands? Separate thing. But someone pointed me to an interview with a priest who's in a wheelchair, who's a wheelchair user, and talking about really finding identity in the moment, in the Eucharist where we break the bread, it's a symbolic breaking of the bread because Christ body was broken for us, and saying like "here's the broken body, my body fits here too." Which I feel like is close to what Eisland is talking about.

S: Right. She, she talks a little bit, and I was just skimming a tiny bit, um, to try to find it, but she talks about this as a repudiation of the idea of disability as being entangled with sin.

R: Mhmm

S: Well wait, here's the broken and resurrected Christ, so that's obviously, obviously the view of disability and sin conflated together doesn't work.

R: But there are often logistical struggles.

S: I was going to say, here's where it gets complicated

R: Here's where it gets complicated. Our liturgics professor in seminary liked to say that the building always wins. And church buildings were built with stairs, and levels, and widths that are not accessible often. There are other lacks of accessibility in a church building, but it is often physically hard to impossible for someone with any mobility issues to get to the place where Communion is distributed, which separates them from the normative practice of receiving Communion. Many clergy, I don't think I've ever been in a parish where it's not offered that Communion will come to anyone.

S: Mhmm

R: But, it requires you to do something to receive, that other people don't have to do. So it is often the best available practice without, like, destroying the building and rebuilding it, which is expensive, and I get it

S: Right

R: But also, it's imperfect. It is an imperfect solution.

S: Um, yeah, this is very complicated. I'm speaking as someone that is in an 1869 church building, with a literal high altar, communion rail, a place where you, you've got to go up multiple steps, walk through where the choir sits, to get to the communion rail. Then you've got to go down other steps, around the organ… It is complicated to get to the communion rail.

R: Mhmm.

S: And of course we will bring Communion to you at your seat. But then, she says, on page 113, she says, talking about these kinds of situations, "hence, the Eucharist becomes a dreaded and humiliating remembrance that we are trespassers in an able-bodied dominion."

R: Yep.

S: Ouch. And this is real thing that plays out in my congregation certainly and in many others on a regular basis.

R: I… I was going to say that this has been true in most, if not all places I have celebrated Eucharist. There are, I'm assuming there is one or two exceptions, I had one congregation that met in a nursing home, so it was all on one level there. There were other accessibility issue there that weren't physical logistics, but most places. And it's ableist, there's no way around that, but it was also often meant to make what was going on more visible to people. Like, it was not done with malice, it was just not done in full conversation with the community of people who need to use that space.

S: Yeah. I'm thinking about how, at one point, during one part of the pandemic – gosh, everything is like a moving target, it's changed so many times…

R: [laughs]

S: But at one point in the pandemic, when we were first in person, I said, you know, we had all of these rules about distancing, and whatever, and I said "stay put, I'm going to come to you. I will bring Communion to you." And we were in our parish hall space at the time because it was a lot less complicated to get permission from the diocese to use that space; it took a lot longer to come up with a plan for our main church space. So, anyway, that was probably the only time when the Eucharist was, like, truly accessible, somewhere that I've been. Because I literally went around to each person, and everybody received in the same way.

R: Yep.

S: But people kept talking about, "when can we go back to the church, I want to come back to the altar rail, when can we go back to the altar rail, I want to kneel at the altar rail."

R: Yeah

S: So this is a complicated issue because there are people who want to be at the altar rail, they want to be close to the high altar, they want to have that experience of walking into, literally walking into and then kneeling in what they feel is the most sacred part of the space, closest to the altar. And yet, that means that other people aren't going get to receive in the same way. And I think…

R: I mean, we are not here to proscribe a solution to this, because I don't have one.

S: I don’t have a solution for my congregation so I’m not saying anybody might either.

R: I laugh a little bit because your solution of going around and distributing to each person is what I usually did back in the day when I could go visit long term care places. Um, it was proposed at my parish as a solution to Communion but our pews are not wide enough for me to safely do that. The space between each pew I couldn’t do that without basically being in every parishioner’s lap, as I’m stepping over them

S: [laughs]

R: And that is, there are many issues with that including that that is definitely too close to people in the middle of a pandemic.

S: That’s super awkward for a thousand reasons.

R: Thousands of problems there. And I was like, nope, I’m going fall and that will be a whole… yeah. So we did not do that. But it was an option, and it was like, man, it would be nice if we could do that. But I think that the ultimate solution is to really challenge what is that normative practice. And try and create, I think we’ve talked about this before. Try and create a community and a culture where it is not only appropriate but encouraged and there are many places to ask for things to work for you. So you do not feel weird when you come up and you’re like hey, could we actually do this, because that will make this more accessible to me, because that is a conversation that is ongoing in many ways. But it’s a lot of work. It’s work we should be, but even just changing to that culture is a lot of work.

S: And I know for me, as a disabled clergy person, which is, well, you know, we aren’t very common, um, I’m usually trying really hard to accommodate myself, like my own needs

R: Yeah

S: So I often don't do as good a job as maybe I could. Just, not thinking about the needs of other people because I'm just trying to keep my own accommodations on track. There's a… she notes, somewhere in here she tells a story of someone who was trying to be admitted to seminary, and was not allowed to be admitted to seminary until the proved they could perform the ritual of the Eucharist and I quote, or this might be a word I'm inserting, I'm not sure, "correctly."

R: I am really wishing I could be shocked about that.

S: [laughs] Right? What happened in my case is that just, people ignored it, nobody ever talked about it, and I didn't know how to bring it up.

R: Yeah

S: And I figured it out eventually, with the support, mostly of my husband actually, and uh, what was a really understanding field ed parish. But I got some pushback from others about it. And the other thing I've learned, is that just because I use very obvious – I talk about it in Episode 2, I guess – very obvious accommodations at the altar, and even all these years later I feel a little bit squirmy about my laptop on the altar, still not 100% always okay with it, that doesn't necessarily translate for other people to feel comfortable asking for what they need.

R: Yeah.

S: It's not, they don't necessarily, I guess, "do the math" in their head? They don't…

R: I mean, I don't think it's something that occurs to them, because we don't talk about disability in our culture. By the time this comes out, I'm currently finishing it, but I'll have posted an article on my blog talking about how I don't announce movement. The title I'm thinking of is somewhat inflammatory, like "I don't tell people what to do with their bodies in worship." So, I don't announce "sit, stand, kneel" which is really common.

S: Right

R: Because I have yet to find a way to talk about that that doesn't indicate a normative practice.

S: Right

R: But I stopped doing that for years before I started doing what I do now, which is I have a whole pre-worship announcement about it, where I say "hey, this isn't going to happen, here's why." And it was because I stopped, but the parishioners didn't, they kept doing what they have always done. Because, they didn't know there was another option. I don't know why, they didn't stop until I started giving them explicit permission to do what worked best for their bodies. Which is part of what I was thinking of when I said changing the culture so that is something people can have… It's a lot of work, it's a lot of work, because we're working against all three of those theological problems Eisland identified. "I can't say this because it will make me a bad Christian." "I can't say this because I'm just so glad to be able to come to church." "I can't say this because I should be brought closer to God in my sufferings." Um, and not like, "the way we're doing things is impairing my worship of God." Let's fix that.

S: Right, right. And it's really complicated, I'm telling you that I know how to help myself, but I don't know how to do this, I don't know.
I wanted to go back to something we touched on before, I think a little bit… she says earlier in the book, I don't know if we talked about it on mic or not, so I apologize, but earlier in the book she talks about this minority model of disability. So she talks about how people with disabilities have started, or started at a certain time to conceive of themselves as being part of a community, as part of a group of people that had some needs in common, that had some common experiences, etc., some common experiences of discrimination, and that they could be conceived of as being like other marginalized groups.

R: Mhmm

S: One thing she says about that, she says that unlike other groups that are marginalized, let's say based on race or something else, people with disabilities generally do not have the benefit of growing up in that community, within a family or culture where people are sort of helping them learn how to cope with the problems that might come up, because people have been there before. You know, you think about being raised in a family, they teach you how to navigate life.

R: Yeah. Oh, it's like the perpetual oldest child, first to go to college. What do I need to pack for college? Do I need this, do I need that? Nobody told me how to do that.

S: Right.

R: I asked people, but like there wasn't a pattern I had been able to observe and adapt for myself. But in every area of your life.

S: Right. And so what happens with disability, especially when children with disabilities are not necessarily mentored by adults with disabilities. I mean, if they're lucky they run into camp, and other kinds of programs where maybe they are. Before Pat, who we interviewed for the first portion of this [this is an out of order reference to episode 4-5] before he was doing what he's doing right now, he was running a mentoring program for high school and college students who were blind and low vision, and it was run and, almost completely by successful adults who were blind or have low vision. Most of the program staff, all of the program mentors, who were people who came in from, you know, for just a few hours a week, who were successful in other industries, um, but that's the exception to the rule, that people have that kind of exposure, and often when our parishioners, our family members, our friends, our neighbors become disabled later in life, they don't have the benefit of really having been in contact with anybody who can show them the ropes.

R: And even if they have it may not be someone who lives with their exact or even their close experience. Like, oh, your knee hurts, well my back hurts. Well those will have overlapping things, but they'll also have things that are really different where they might be like I need this kind of thing, and that has no relevance to what you need, and I don't know how to help you navigate that because I am fumbling through this too.

S: Yes. And the other thing that they deal with, that people deal with, is that the only people they might really be talking to about the issues they're having might be medical professionals, who are pretty much wrapped up in what we would call the medical model of disability. Meaning they look at disability as something that needs to be fixed. And…

R: The goal is to return you to a medically "normal" – normal is in air quotes that nobody can see –

S: Right. Often they themselves don't know a lot about the lived experience of disability, and it's very rare that they suggest that you seek community or some kind of solidarity with other people. So people really, sometimes they don't even know what to ask for because they're been given this idea that they're just supposed to struggle alone, and just kind of, you know, keep trying to do this thing as long as you can. Keep trying to get to the communion rail, keep trying to hear the service, or trying to read the bulletin, don't, you know, maybe don't complain because this is your individual problem.

R: Yeah

S: The society doesn't give them the encouragement, church doesn't give them the encouragement to think that maybe there's other options.

[music]

What I did like about this section about Laying on of Hands is that she acknowledges it as a hugely embodied moment which can be really transformative or can be really terrible.

S: Yes

R: She does, she spends significantly less time on it than she does on Eucharist, which I have no issue with, both because I don't. Maybe she had something else to say? She did not live terribly long after writing this book, so I mourn the possibility of that, I guess. But I did want to acknowledge that that's how she talked about it, as something that can be very isolating or deeply connecting.

S: Yeah, and it was something I didn't engage for a very very long time. Certainly growing up I avoided it at all costs, but… It was something they did on, you know, Wednesdays, Wednesday morning there was something, I don't know, whatever. Something I just avoided. I didn't know what that was about, I didn't want to know.

R: This is, I think, this is the tension I live in. I believe both things – I think it can be an incredibly transformative time, I think it can be a deeply pastoral time, people will sometimes mention things in this sort of context that will never be talked about in any other context, because we're full of shame about a lot of what our bodies do and don't do. But it can also be deeply, deeply abusive.

S: Yeah. It's something I had to come to terms with a little as a chaplain, because I did it over and over and over again. And then I had a rabbi teach a workshop on how to talk with patients and their families to help them reflect on what they wanted you to pray for with them, so that you weren't putting your own stuff into prayers that weren't about you. And that helped immensely, and it changed things I was saying, and then I started to see, that people, if it was done sensitively, people just saw it as a sign of care, and God's presence, instead of "you better get better!"

you know?

R: And that's exactly the dichotomy Eisland talks about. She talks about it can either be done setting up this future failure, which is almost guaranteed if you live with disability or chronic illness. I believe God heals, I am firmly aware most people are not healed. But if you then fail to get healed, we sort of go back to that conflation of disability and sin and like "well what did you do wrong that this failed."

S: Right.

R: But she also talks, I'm going to read a couple sentences here: "In a rural North Dakota parish I experienced the body care of several elderly nuns schooled in physical attendance as nurses and touched by the Spirit as Christians. Their touch and tears were the body practices of inclusion. My body belonged in the Church." It can also be that, it can also be "I'm not scared to touch you, I am not scared of you or of what you represent. You are a part of us and this is one of the ways we can care for you." Some parishes practice this a lot. For people who are wondering what this is, because some parishes never practice this, I don't think I, I think I had been seriously involved with the Church for three or four years before I really encountered this on any sort of level at all. Not even significant, just any level at all, and it is the practice of usually prayer with laying on of hands with consent. Sometimes just holding someone's hand, sometimes touching their head, sometimes, when appropriate, touching the body part in particular that you are praying for, for healing or wholeness or restoration or a sensation of pain.

S: I mean, at least I do, use oil.

R: Yes. The oil is not essential, but it often accompanies it. We like our outward and visible symbols in the Anglican tradition.

S: Right.

R: But again, it can be deeply, deeply abusive and as we have discussed, I think earlier in this episode, don't pray for people who do not want you to pray for them.

Is there anything else you want to touch on on this book?

S: The one other thing we would probably be remiss if we did not mention when talking about this book is she is one of the first people to talk about the concept, at least in a theology conversation, the concept of being temporarily able bodied.

R: Yes, that was a huge contribution of hers.

S: Yes, I'm not sure… I think it probably came up in the disability justice movement prior to this. But she brought it certainly into the Church, into conversations in the Church. So, that is something that she does speak about in this book a lot, the understanding that if you are not now disabled, most people if they live long enough will experience some kind of disability. And that that's part of what it means to be human. It's not a failure of being human, it's not a

R: And I mean her other distinctive introduction here is that it's not a only not a failure, it's a part of humanity that God himself, herself deliberately entered into.

S: Yes, yeah, exactly. It is part of imago dei, the fullness of being in the image of God. And that the body is in the image of God at all times in the life cycle, in all different situations, etc. So no matter your age, or what body you live in, you are part of that image of God. And as I said, it was really key for her to say to people "you are, we are all only, if we are able-bodied, we are all only temporarily able-bodied."

R: I was really struck, especially on this pass through the book, of how attentive she is to the parts of the disabled community she herself was not a part of. I'm not going to get this right off the top of my head, but she had a visible disability that impaired her mobility.

S: Yes, and I don't remember all the details, but

R: I don't remember. I will link the, I think there's a New York Times obituary of her that goes into some of those biographical details we have paid no attention to whatsoever. So I will link that in the show notes. But as someone who does not share those experiences of disability I felt very included and deliberately included in how she treated disability and theology.

S: Yeah, I think so, and she was really clear on her parameters of what she was able to address and what she was not able to address. So there was a lot that's, that is not addressed.

R: Mhmm. But her acknowledgements ends with the fact that this is an invitation to further work by people with disabilities and "a call to all others who care to engage with people who have disabilities." She knew she was not doing definitive work. She was doing a work, that would hopefully lead to other things.

Yeah, I am both saddened and surprised by the fact that this is still the foundational text and a part of me looks forward to the day when somebody picks this book up and is like "I can see why this began it all, but wow, have we spent a lot more time on it since then."

[music interlude]

R: Thank you for joining us for this conversation about faith and disability. We encourage you to find local conversation partners and to pick up some resources about faith and disability. You've heard a lot from us on The Disabled God, we do want to point you to our show notes with links to some other podcasts and some other sort of introductory material about The Disabled God and disability theology. Thank you very much for joining us.

[music interlude]

S: You've been listening to The Accessible Altar: a podcast at the intersection of faith and disability hosted by Robyn King and Stephanie Shockley. We record on the tradition land of the Leni Lenape and Treaty 6 territory.

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