Episode 1 full transcript

Speakers are denoted by their first initial. In this transcript, S = Stephanie Shockley, and R = Robyn King.

[Introductory music]

S: Welcome to The Accessible Altar: a podcast of conversations at the intersection of faith and disability.

R: I’m Robyn King

S: and I’m Stephanie Shockley, and we’re your hosts. Today for our first podcast we’ll be having some conversation together about this podcast and our experiences.

R: And specifically, you spent some time interviewing me about some of the reasons and inspirations that brought me to the point of calling you and starting all of this.

S: Exactly. We’re going to get to that interview in just a moment. And, in the second half of today’s episode, we’re going to talk about the name The Accessible Altar, and how we chose it.

R: And what we like about it.

S: Exactly.

R: I really love our name, so I enjoyed that conversation.

[music interlude]

S: The first question I have for you is… I’m wondering if you’d like to tell me about your formative experiences related to the topics of illness and disability.

R: Hmm… I'm just trying to figure out how to start now [laughs]. So, the part that I'm most public about it I had three brain surgeries between university and seminary. And the part that I tend to now generally assume everyone knows - and everyone doesn't know – is my mother was diagnosed with brain cancer when I was 9, so I have these, like, relatively young memories of, you know, my father fighting with insurance companies and my mom being in a different city for radiation and chemotherapy treatments, and that really changing everything about how our family worked. And then she had a period of remission, and then was re-diagnosed and died. So, there's a lot of also family trauma related to that, which definitely informed both some of why I came to really love the church, because our church was lovely and really showed up for us in the middle of all of that, but also informed my own approaches when I was like, barely 19 and being told I had a brain tumor, and suddenly had more specialists than I'd ever seen or knew existed.

S: So, what happens in a family that's already been through a trauma related to a brain tumor… now, just to back track a little bit, my understanding is that your mom's condition and what happened to you are medically completely different…

R: yes, very different, yeah, different on every level.

S: Okay. But it seems like, I mean, that trauma in your family of your mom getting sick, and then you mom dying, it seems like that's, I mean, in time, if you think about loss, that's really fast, that's really close to

R: Yeah

S: …you having your own medical situation, and kind wondering what that's like for a family and even for a church, and for you… I mean, that's just…

R: I don't know if I have a good answer to that, because it's one of the many traumas my family tends not to talk about. What I noticed is that it sort of deepened everyone's response to my diagnosis, because it automatically wasn't just about me because it was so easily connectable to this relatively recent trauma we'd gone through with Mom.

S: Going forward a little bit, so you know, you have this really traumatic experience, you and your family, when you were relatively young, and then you had your own situation, which is different but obviously very serious, like, you know, not a small deal, if I understand correctly…

R: Yeah, so I had a pituitary adenoma, which is the fancy medical term for a not cancer growth on my pituitary gland, which is sort of at the bottom of your brain. Which, um, and people can look a little shocked when I say this – in the world of brain tumors, it's like, the good one to get. They're very rarely cancerous and they tend to be very slow growing.

S: I laugh a little bit about that only because, you know, people sometimes, when they haven't been through a thing, they don' realize there is a whole universe of "oh, thank God for this diagnosis because the other options are much scarier."

R: Yeah

S: There's kind of a scale there sometimes.

R: So yeah, so that was sort of like the initial diagnosis, and I mean looking back on it, even at the time I knew it was kind of funny because doctors kept saying things like "well, just in case let's do this other test" and then it turns out that was exactly the test they needed to run and I actually had to go do more tests or more blood work or whatever. And then they found that, I finally had the imaging done that really definitively showed that, and all the sudden I'm like "I have a specialist, and another specialist, what city would you like your specialists to be in" because I was in university and the time. It was really happening too fast to try and process any of it, it was more like trying to keep numbers straight and information straight and learn, you know, more biology than I thought I would need in my adulthood in like, days, and hours.

S: In the middle of undergraduate…?

R: Yeah. Actually, yeah, it was the summer between my freshman and sophomore year of undergrad. I had been planning to have like, I mean, except for the terrible pay, a fairly idyllic summer working at our church camp on a lake with my friends. And now I was, you know, travelling to see doctors and scheduling brain surgeries and leaving early so I could have brain surgery before I went back to university. Yeah.

S: And so, I know you said earlier in the interview that this happened, having to have surgery happened three times, and um, for those who don't know and are listening, they might think "oh, it happened three times in the summer, or whatever" but there was a period of time between each one.

R: Yeah, so the first, between my first two surgeries it was a little… now I have to do math in my head [laughs]

S: [laughs] they said there'd be no math in the podcast, I'm sorry…

R: It's okay, I know not to believe such promises these days [laughs] there's always math.

S: there's always math.

R: Yeah, it was a little under two year, and between my second and my third surgery it would have been right around three years.

S: So, we fast forward a little bit, and by the time you find out that you have to have surgery for the third time, you are not only in the ordination process, the process of being ordained to the priesthood in the Episcopal Church, you're in the middle of seminary.

R: Yeah, not just in the middle, it was my, um, last semester…

S: I'm sorry, you're not in the middle, you're at the end of seminary, right

R: [laughs] the end is almost in sight. Yeah. That was weird. I mean, seminary… you, we… we went, we overlapped at seminary, so you know what I mean when I say seminary was so weird. Because it is, I think just functionally has to be, but yeah, that was weird. That was weird even for seminary.

S: What that was like, to be in the ordination process, or to be in seminary, and to be navigating that world, which you're right, is, for lack of a better term, weird, um [laughs] and to be navigating these two things at once? You were a young ordinand…

R: Yes, yeah, I was one of the rare ones who went straight from undergrad to seminary.

S: Right. So you're a young ordinand, which also makes it weird, weirder

R: mm hmm

S: You're in seminary, you're dealing with these health issues.. how does that all fit together, or does it?

R: I don't… I mean, I think it does in some strange ways, and it really doesn't. I mean, I don't think it's a surprise to hear either one of us say that the Church doesn't always deal with this stuff well. If it did we wouldn't need to have a podcast about it. [laughs]

S: [laughs] Right.

R: But I think one of the advantages I had was, because a lot of this was seen as, you know, basically, acute medical care, and not, what wasn't seen, were some of the chronic conditions and disabilities that were either, I hate the term side effects, but sort of side effects of staying alive, or were being discovered through this, and if this was a medical podcast we could get into that, but it's not, fortunately…

S: Right

R: So, I think to a lot of people I looked like someone who was just having a rough go of it for a few years, and I was at least marginally aware that this was all like life-changing, and health-changing, especially by the time I got to surgery three. I was more aware that, like how my body functioned had dramatically changed, both in ways that affected me more or less. I developed migraine after my second surgery, which wasn't super great and never went away. I also got secondary adrenal failure for a couple of years, which I don't recommend, and I worry about with all of the current stress in the world. So I know I spent time in therapy and spiritual direction talking about, you know, like, all of this is changing everything and it's all relatively unseen. I'm trying to figure out how all of the beautiful theology and liturgies I was also studying and loving and experiencing.

S: And I think that kind of dovetails into another question that we talked about before we started recording, which is, what happens to… you know, it's interesting like you said, you're kind of, you have this situation going on, and to people who aren't in the situation, it appears like "oh, you know, Robyn had a surgery, or whatever, you know, she has some health issues…" They just don't really, you know, none of us can read anybody else's mind. So we don't, we're not part of all the different things that are happening, and all the things one might ponder when something changes everything.

R: Yeah

S: So, what about, and I’m sure this is a complicated question, what about your experiences, whichever ones you want to talk about, with illness, with the sort of side effects of surgery, you know, all of this, what affect did it have on your faith? How did it affect your faith? Was it helpful, was it not helpful, was it, did you think of things in new ways, was it detrimental, was it a mixed situation?

R: Yes??

S: [laughs] I know, it was not a very well-phrased question, I’m sorry

R: Well no, but I think it… it was all of those things. And it sort of depended on the season. I know I had sections of life where I was like “um, the discipline of taking meds every day has this weird parallel with the Daily Office.” [laughs] And it’s like, “okay, well I can do one, I can do the other, sure.”
But then there are stretches of life when it’s like “I would give anything to not have to deal with this today.” I think it also meant I cared more about some of the weird and arguably never perfectly answerable questions, you know, that whole where is God in suffering, and how do we make sense of this, and how do we talk about things like pain and suffering. I remember sitting in one class and we were reading some mystic, who I love, but the mystic was, you know, sort of writing rhapsodically about how all of this suffering had brought her closer to God, because of course it was a woman… My class was like “this was such a beautiful transformative experience” and I sort of took them all to task. I’m like “pain is bad, stop saying this!” [laughs]
And to their credit they were able to hear that, but you know, you’re sitting there and you’re like, “you guys don’t know what you’re talking about right now – never say that again, just don’t!” [laughs]

S: [laughs] right!

R: You’re missing, the fundamental issue that pain is there to tell you something is wrong.
So, I mean, we have a friend who has said for years and years and years that like, bad theology kills, which is true.

S: Yes! And it does!

R: And it does!

S: Yes!

R: And if you want the summary of it, all of this sensitized me to some of that in a way that I probably wouldn’t have been otherwise.

S: And do you think… [talks over Robyn] oh, I’m sorry

R: And seminary was really my first personal introduction to the concept that Church is literally inaccessible sometimes. Because, so part of the surgery is they do a graft site on my leg, which is overall pretty fine, but it makes hard to walk for a little bit. I still remember I had had surgery over Spring Break of my senior year of seminary, which, yeah, that was weird, don’t recommend it…

S: I mean, these are the things that we do sometimes that later you look back on and go “ok, I don’t know that that was wise, but it happened…”

R: Well, and to go back to a question you had asked earlier, at the time I was really glad, because there were two dates my neurosurgeon was mentioning as possibilities, and the other one was the day my mom died. And I was like, I can’t do that to my family, there’s no way.

S: Right, right.

R: And the other date happened to be in Spring Break. So it wasn’t like I planned it for that, it just was the better choice for so many other reasons. And of course, because at seminary, Spring Break is not that close to Easter, so I was still in recovery at Easter, and I wasn't like an invalid, but everything takes a lot of energy after surgery. I had been debating if I could spend the energy to go to any of the Holy Week services, and I was like, well, I think I can get to Maundy Thursday, which is just one of my very favorite services in the Church year… I have a lot of favorite services in the Church year, but it's one of very favorite ones. And I was really excited, and I was like, I know I should expect not to be able to go up and get my feet washed, because that's actually going to be a lot of work for me right now, but I got to the chapel, and all of the foot washing stations require you to go up stairs.

S: I remember that.

R: And I was just like, "oh, ok, well, I knew I wasn't going to do it, but now I can't." And that was hard. Yeah. So it was very formative, in a lot of different ways.

S: So, as you went, you eventually graduated from seminary, and go out into the world, and begin ministry, get ordained to the transitional diaconate, and the priesthood, which usually for most people is a whole story in and of itself… but, um, you've been in ministry for quite a long time now.

R: Yes.

S: These formative experiences, I mean, there's no way you could have all of these formative experiences and then just sort of go about your ministry and not have them influence you, I would think. So, day to day… you've been a parish priest for a long time… How have your experiences influenced your ministry?

R: I remember, I was doing an internship, and I sitting down with someone, and they were sort of like, laying out some of their approach to hospital ministry, and such, and it was, it was like a weird power dynamic because they had been ordained for years, and I was working for them, and they get to a point where they're like "Does that make sense?" They were asking for my validation, because I had had so much more experience being on the other end of this. Which is just to say, I do think it makes me think about what questions I ask. I know there are questions I will ask people who are in hospital or contemplating procedures that I wouldn't ask if I didn't know what it was like to be a patient. My two favorite ones that I just increasingly routinely ask anyone who is dealing with medical stuff is "Do you like your doctor, and do you trust your doctor?" and if they're in the hospital, "tell me about your nurses" because nurses are the backbone of hospitals. I hope it has made me more sensitive to people for whom the way church has happened isn't working any more. I mean, I've been doing this long enough that I'm sure there are people out there who would tell you that is true and people who would tell you that isn't true. But I hope it has. I think it has made me a little more willing to say, well, if that's not working, we'll just do it differently. I was reflecting the other day that one of the things that I've started it took me years to do, but one of the things I have started doing at the beginning of services is tell people I'm not going to tell them when they sit, stand, or kneel, that everyone is going to do some things, and not everyone is going to do other things, and they're going to make choices, and we're going to trust their choices, and I really missed that part of the service. Which is so small, but like, this ability to you know, sort of verbally mark this as space where it is safe to just exist with your body, however that is working for you, I miss that, because I think it's a fairly radical approach to space and communal actions.

S: Yeah, I agree with that. I think particularly in a sort of um, Episcopal, or Anglican setting, where we even have jokes about the different movements that go with the liturgy, traditionally.

R: Yeah.

S: I mean there are even memes and jokes about pew aerobics and you know, sitting and standing and kneeling and do you genuflect or do you do this or do you do that.

R: Yeah. What is the appropriate thing to do at this time, what is the acceptable thing to do at this time, what should you definitely not be doing at this time. I'm really over all of it people.

S: [laughs]

R: And I invite you all to join me on this side. Like, do what works for you, if it's not helping you authentically worship God, you don't have to do it. You just don't. And no one should tell you you do.
I think it's also made me a little more comfortable saying, "look, there are questions that we don't have answers to, but here's what I believe about it." I don't believe God is punishing you, I don't believe this is some cosmic lesson you have to learn. Sometimes things are just terrible, and God is with you in that. I believe that.

S: It sounds like that almost goes back to that experience in the classroom where people were talking about the pain being meaningful.

R: Yeah

S: … for this mystic, and you said, actually, hold on

R: no, this is just terrible, you can find meaning in it… I do believe you can, what I tell people is I believe that God is the ultimate creative, and will waste nothing, which includes our pain and suffering and misery, but that God doesn't create any of that, God responds to that creatively, with love and generosity. And that's easy for me to believe. Not every day, but that fits with the God I see in Scripture.

S: That seems like a good segway to a question that brings us to the present, which is, with all of that background, you know, it sort of seems like, it seems natural that you might want to start a podcast to talk about illness and disability, but what was it in particular that made you decide this was something you wanted to do?

R: I forget what going on, but I was dealing with some health-related thing, and I was sitting down with one of my mentors, and complaining [laughs] because sometimes you need people you can do that with. They looked at me and they said "somewhere in this is a great testimony that is being shaped in you." And I remember in the moment being like "well, yeah, but right now it sucks"

[both laugh]

S: right

R: Like, my response to this wasn't "oh YEAH!" it was like "yeah, no, I want it to not suck." But I kept seeing the Church struggle with things, I mean really everything from like all of the conversations about marriage to some of the liturgical debates that I just don't have patience for anymore, to, I'm in Canada now, so we had a whole medical assistance in dying conversation, and one of the things that kept coming back to me is that how I approach these so shaped by having been the person in so much pain that no medication will touch it. Or with the condition that is not responding to any of the conventional treatments, or whatever story would flash through my head. So some of it was that through line, and some of it was watching people in the pews struggle with the same thing that my body was struggling with at that moment. The people who need us to talk about this better aren't like, some outreach population, they are the people who are actively in our pews that we are under serving, and they're our clergy. And I sat with that question in different ways for years. And I'd think "well maybe I'll do this" and I'm like that's not going to change the thing I want, that's not going to change

the thing I want to see being different. And then I bumped into, I think through Disability Twitter, which is an underrated resource, in the world, um, a list of principals of disability justice, and the concept of disability justice communities, and I was like, this is brilliant. And one of the things on there is you don't do anything alone; you have to do it in community and conversation with others. And I sat with that for a little bit, and at the end of it I was like, ok, so part of what I have been missing in all of my other like ideas that weren't going to work out the way I wanted them to was I didn't have a conversation partner. I didn't have community around this yet. I started asking, instead of what's the thing I could do, who are the people I could do it with? And that's when you came to mind, and I was like, someone who, we're not like in lock step, we don't agree on everything, and we come from different places, but we often arrive at similar places with, is Stephanie. Let me call Stephanie, and see what she's into.
[laughs]
And now we have a podcast.

S: And now we have a podcast… and the rest is, potentially history.

R: Yes.

S: I think the last thing I want to ask you, or just pick up on, from the things you were just talking about. I think, and this is not just the Church, this is not just to blame the Church or whatever, but I think you mentioned disability justice. In the world, and in the Church, in many places, including sometimes places that perhaps should know better, there's a sense that illness and disability, and all of those things, and the things that are sort of adjacent to that, that those are very individual things. That whatever it is that's happened to you is for 'you', whoever you are, to struggle with, kind of on your own.

R: I mean, not just on your own, but quietly, out of sight, so you're not inconveniencing other people.

S: And “it’s a shame, but what can we, what can you do?” right? I feel like I am kind of hearing that through this, that’s it’s the discovery of Disability Twitter, which is, like you said, an underrated resource with a lot of energy and a lot of information, um, the discovery of Disability Twitter is really important. And the realization that there’s an entire community, an entire universe of people that might be experiencing some of the same things, that it’s not just “oh, it’s a shame that this happened, shrug, we can’t, there’s nothing we can do about the problems that brings up.”

R: And for me, I mean, that sort of realization was in some ways a return to like, undergrad Robyn who was, you know, alone in her dorm room often, frantically googling things and trying to find people with any level of similar interest. This is back in the early days where people had anonymous blogs, and wrote true things on them that were hard about their lives. And finding people who had all sorts of other health conditions or disabilities, it was like “oh, these people are the people who get it.” So Disability Twitter for me is like this return to this early community of people who made me feel not alone. Yeah.

S: And Disability Twitter is FIERCE. [laughs]

R: Oh my gosh, I love them and I fear them…

S: [laughing] I know! But it, you know, it’s people who refuse to be put in a little isolation corner, and you know, what is the tagline of disability justice, “nothing about us without us.”

R: Yep

S: Yeah.

R: Yeah. So that was sort of, I don’t if inspired… inspired is probably the right word, I should not underplay that. But that was the process that led to both of us sitting here.

[Music interlude]

S: You know, when we were putting this together, when we started talking about this, we spent a long time looking for a very, I don't know, like, a sexy title or a very spiritual title or a really snappy title for our podcast.

R: We wanted a title that would fun to say, and communicate what we wanted to talk about.

S: Right. And we spent hours with an open zoom channel…

R: [laughs] trying to find something that connected, like, disability and church, Jesus things…

S: Scripture maybe… the Book of Common Prayer…

R: [laughs] and things were either not universally applicable or attractive to both of us, and the one we picked may not be universally attractive to you, so, sorry? Or had already been taken. And we wanted something that made it easy to find us.

S: Right. And oh, so many good, all the good stuff… so many good things were taken. So many different biblical illustrations were taken. All kinds of random things too.

R: Yep.

S: Yeah. You know knew what it be, it would be really funny when you started googling. And then there were other things we started thinking about and they just, honestly, just were snarky.

R: And while we can both be snarky, we're trying to not live in that space, because we want this to be a little bit more helpful, and accessible than snarky can sometimes be. [laughs]

S: Yeah. Some of those things, as fun as they might have been to say on an open zoom channel between New Jersey and Alberta…

R: [laughs]

S: …we realized quickly that we wouldn't want to say them over and over again, and we wouldn't want to talk to people at a diocesan convention about our podcast on XYZ, and it was very clear very quickly that they might be funny but they were not productive.

R: No, they weren't helpful funny.

S: Right.

R: And then I think the phrase we lifted the title out of is something I have memories of you saying for years and years and years, I might be wrong about that though.

S: Which was?

R: The Church isn't accessible until the altar is accessible.

S: Right, ok. I'm, I'm not sure that I can claim that. I may have made that up, someone else may have made that up. Or that might be a riff on something else from another part of society. I do not, I truly do not remember.

R: I was going to say, I can't… but it's just tagged in my head as a very Stephanie thing. And I forget how it came up, but I think we were in the phase of just writing down anything that seemed reasonable, not necessarily even good, just like, plausible. And we came back to it, and we were like "The Accessible Altar"!

S: Yeah. I feel like, and it's falling out of my head right now, but I feel like that's a riff on, again, other things, from other parts of society, basically like "this is not accessible, such and such is not accessible, or such and such isn't fair, or such and such isn't equal if so-and-son isn't at the table, or isn't in leadership, or whatever. " So it morphed from other things that people have said. Also the classic disability justice slogan of “nothing about us…”

R: “nothing about us without us.”

S: Right.

R: Yeah.

S: Yes. And if you’re new to disability justice issues, that is the first thing to sort of carve into your brain. You know, if this is something you’re learning about for the first time.

R: Yep.

S: Nothing about us without us is the slogan of disability justice.

R: And if you are… so we are both liturgical Christians, and we both have hung out in fairly high church parts of that, so a lot of the ritual and things that can go with that. So for us the altar is often a core symbol of what it is to be the Body of Christ in worship together.

S: Yes, I think that’s really important thing to include. So, because we’re both out of the Anglican tradition, because we both went to a higher church Episcopal seminary, for us…. you know, we can have conversations about the priesthood of all believers, and the ministry of all the baptized, and all of that, and the way in which God works in all the people in the world. And that’s critical, and that’s very important. But in our tradition specifically that symbol of leadership in the worship service is the priest at the altar, or the bishop at the altar. Visually, if you’re sitting in a pew, and you’re looking at the front of the church, when you’re in a church,

R: one of our churches

S: In one of our churches, in non-COVID times

R: [laughs]

S: if you’re looking at the front of the church, what do you see? You see the priest at the altar, and they are doing the liturgy of what we called the Eucharist, or the Holy Communion. And that’s such an important symbol.

R: Yeah. So, we’re both very aware that that’s not how every church is set up, but that’s the imagery that the title is based on.

S: Right.

R: The core thing that we do together, made accessible for all the people. So we can actually do it together. And we picked the name with both the recognition that the altar is often, is usually, not fully accessible to people, and the hope that the work we’re going to do here and in conversations and the people we’ll be able to engage with, can help make more altars more accessible.

S: Right. And I think part of the reason the name works, at least for us, is that when we talk about something being accessible, it refers to literally accessible – can you physically get to a location in space. Most, like Robyn just said, most altars are not accessible to everyone. Many people are not physically able to get up the stairs to the altars in many churches. And I do understand the reason for that – in order for people in an assembly to see, things were traditionally elevated. But…

R: Well, and it draws on all the sort of Isaiah imagery of the altar and God lifted… yeah, there’s beautiful theology to that. But it’s not accessible theology.

S: And sort of practicality of what people have always done, if you want to see somebody speaking you put them up on place. All those things. But there’s also the figurative issue of the altar being accessible. So that’s when we talk about who gets to be in leadership and who doesn’t get to be in leadership.

R: And what, I mean, ableism can be internalized like so many other isms. What is the theology and goal and how is that applied to the Church, and to how ministry is being carried out. Because there are times when that can be done with great intention, and work towards accessibility even in horribly inaccessible buildings. And there are times when all of the physical accessibility in the world isn't going to change a theology that is very ableist. So trying to find a better world in both of those realms is, I don't know, a dream, a hope.

S: Right, right. One of the things that happens with ableism and people who, maybe otherwise are quite informed on a lot of topics… one thing that happens is that they have an unexplored idea of what's possible for people. So there's a lot of, "common sense" about "well people with xyz disability, well we know they can't do such and such." And it's just an explored, unquestioned "common sense." And in many cases, that's not correct. It just a lack of experience, or a lack of education, or perhaps maybe not being introduced with that disability. Or people who have had a particular disability for a long period of time. If you're newly… if you have a new disability, and you're adjusting to something, what you're going to be able to do may look very different because there's such a steep learning curve. It may look very different compared to someone who has a had a disability for a longer period of time. So if you suddenly, your vision, for example, has suddenly changed, you've got a learning curve that's very steep and challenging. It's going to take you a while to adapt to that and to learn, you know, adaptive technology and adaptive techniques. Somebody who has had that level of vision loss for decades isn't going to necessarily have the same experience. So, so much is dependent upon, for the average non-disabled person, so much is dependent upon who you've met and whether "common sense" really is common sense…

R: [laughs]

S: or whether it’s just like, not having ever known, and not having a chance to be educated otherwise.

R: To go back to that concept, one thing we’ve talked about off mic, and I don’t think we want to share all of these stories on mic, we’ll talk more about some of the things guiding that decision in our next episode, I think is where we have that slated… is when you hit these things, you often, you don’t always know that it’s not just you, that individual barriers or complications or inaccessibilities you’re encountering or engaging with in the Church at all or in being part of Church leadership are part of a larger systemic inability to grapple with ableism and accessibility. A lot of this podcast will be interviews and conversations with people to raise the awareness that there is a community of people who hit those issues, and none of us are alone. We might be individuals, and on different levels, but we’re not alone in trying to struggle to be faithful in community with accessibility issues.

S: Right. And I think it’s our hope that we can introduce a number of concepts that maybe people haven’t run across before. There is an entire universe of concepts around disability, accommodations, disability justice, what is disability, the theology of disability, the sociology of disability… I could go on…

R: Yep.

S: But there are a number of concepts that, again, sort of, turn that so-called “common sense” about what disability is and isn’t, and what it means, and what kind of capabilities it represents, it turns all of that on it’s head. There’s a lot out there.

R: Well, and even at a level below all of that – who disability touches. Again, I think that conversation is coming up. But when we talk about building accessible theology and practice, that people who are impacted and need that are not just people with disabilities. They’re often the people who know us and love us and listen to us go on about it at other times and places. [laughs]

S: Yeah, I think that’s really important, and there’s an interview coming up in another episode…

R: Yes!

S: …where we talk about that a little bit, which I’m actually transcribing right now so I’m being reminded about it. But, the point being, that when an organization, an organization in general, but the Church specifically, because the Church claims to at least try to speak for God, when the Church makes certain things inaccessible, to certain people, whether that’s because of disability or some other reason, it does impact not only those people but the people they love and care about because it becomes painful.

R: Well, and it has an impact on the people who don’t know they’re being impacted either. I mean, both disabled people, and the people who know and love them usually have some level of awareness about that, maybe, not always, but usually. But it also impacts people who are deprived of the ability to see and understand that the beloved children of God come with a range of bodies that work in a range of ways. And… we’re veering straight into the theology of disability here, on a very introductory level, but the God I love and know and understand loves that about people. And the Church should represent that better.

S: Exactly. We’ve talked off mic, off the recording about the ancient concept of who is the default human, the Aristotelian concept of, you know, the male in the “prime” of their life, the cis male in the prime of their life being the “default human.” And all of this is about a different vision of humanity, and the broadness of humanity, and the image of God.

R: Yeah.

S: So we are jumping right into the theology….

R: [laughs] right into the theology! And I'm going to go a little bit further. When I teach Genesis 1, and talk about it with people, I always make the point that this was not meant tot be a like, list of things that got checked off, but that it's a poem meant to represent the breadth of everything they could think to name and categorize that was created in the likeness and with the blessing of God. And that includes all range of people, people with disabilities, people without disabilities, people who live with an assortment of disabilities… they're named good. And we want to reclaim that, and do some of that naming of good, and seen, and beloved.

R: What are things you like about the name that we picked?

S: Oh, what are things I like about the name that we picked? [laughs] You're going to laugh at me, but the first thing I thought of is, I really like the alliteration!

R: [laughs]

S: [laugh]

R: It's something I remember, both of us being like "AND IT'S ALITERATION!"

S: It's alliteration, yes!!!

[both laughing]

R: Yes, we're geeks, we know that.

S: It made me very happy! I do, actually, like… that was a good question… I really do like the fact that it has multiple layers, and that, it's not exclusively Episcopalian/Anglican, but it definitely has an Anglican feel to it. I like that too.

R: Yeah. I agree, I like that it has multiple layers. So we've lived with it, sort of privately, for several months now. I've enjoyed the slight flip in my head that has happened, where it’s still tied to that, you know, the Church is not accessible until the altar is accessible concept, but it’s now also tied to the hopes and the dreams that we’re hoping to further through this work. That the altar can be, and will be, more accessible, and the Church will therefore be more accessible, and more welcoming, and more open to the beautiful diversity of the people of God. And I’ve enjoyed that, like, flip, and so I hope that happens for a lot of other people through this too.

S: Yes. I think that we are living in a time where we’ve seen renewed calls for justice for so many people. It’s so important, and I like the idea of helping to further that conversation by helping this group of people, which is such a wide and diverse community. I like the idea of helping to further the conversation about this group of people being included in those conversations that people are having that are maybe new to a lot of people, talking about systemic injustice. I like the idea of this getting… of being part of people who are working to make sure this is part of that work.

R: Yeah.

S: Because it’s SO important! And this is tied into all of the other… like, we already talked about this, Aristotle’s, this Aristotelian idea of the “default human”, right?

R: Yep.

S: There is no such thing a default human, right?

R: No.

S: And this work is tied into all that other work that is saying there is no such thing as a default human, and that people of all races and genders and backgrounds and origins and faiths and everything else… sexual orientations… everything else… that all of these people represent… that we all are a default human. There is a no such thing as a default human/we are all the default human.

R: We are all beloved Creation.

S: Right.

R: Yeah.

S: So this is part of it, this is part of making sure that when we're having that conversation we're not leaving anybody out.

R: Amen! I think that does a beautiful job of it for me.

[Music interlude]

R: Thank you for joining us for this conversation about faith and disability. We encourage you to find local conversation partners to talk with about your experiences of faith and disability.

Before we conclude things, Stephanie, are there any highlights from either talking with me or talking about the name that you wanted to go back to?

S: Hearing your story, of course, and everything that you've learned along the way. And the other thing I liked and that I wanted to highlight is that in the section about how we chose the name, we talked a bit about how this is one part of including everybody in the conversation, and I think that's really important. I think that's a key to why we are doing this. We want to bring people into the conversation that have not been in the conversation before.

R: And I think both the conversation about faith, which has often excluded people with disabilities, and the conversation about disability, which people who understand themselves to be able bodied don't always seem to see themselves as being part of.

S: Exactly.

R: Yeah.

S: So I hope you enjoyed our episode today, and I hope you'll join us next time.

[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.

R: For additional information about anything we talked about in this episode, as well as a transcript of the show, and show notes, check out our website: www.accessiblealtar.com

S: We are on twitter and instagram as @accessiblealtar. And join us on our Facebook page at The Accessible Altar.

R: If you have questions, feedback, or ideas for future episodes, email us at: accessiblealtar@gmail.com.

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