Mary Silayillah Cook 0:01

At first she said that I need to go find something of my faith, but then it became mandatory that I went to church. I felt totally out of place, and it was kind of scary.

Raisa Habersham 0:20

Welcome to Hidden Voices, I'm your host Raisa Habersham. Join me on my journey to learn more about the experiences of Georgia residents with developmental disabilities guided along the way by my co-host and mentor, Derona King.

My conversation with Ayah and Autumn Baskins left me feeling a bit hopeless about Georgia’s so-called special education system. But what really broke my heart was how Autumn described the reality of Ayah’s future, a future shared by so many other students with developmental disabilities. I can’t fathom the thought of “better not dream too much,” as Derona put it. That idea speaks to the low assumptions assigned to people with disabilities. But it also speaks to the non-inclusive environments people with developmental disabilities often find themselves in. Hearing Derona talk about the segregation in schools made me wonder - are there any places where people with developmental disabilities feel fully accepted? I personally believe in God and grew up going to church, and I’ve seen how places of worship can offer refuge for people from every walk of life. But I also understand how religious spaces can be a place of trauma for those who don’t fit a certain mold. I have witnessed this with my own friends in the LGBTQ community. They were shunned for going against the word of God as their church saw it, when all the while they were just looking for a place to belong. Knowing this, I wondered how a person with a developmental disability might be treated in a faith-based community.

So you know, you brought up this conversation about who gets to sit on the Pew versus who doesn't. And that never crossed my mind that there were conversations about just who gets to lead.

Derona King 2:24

We mentioned some about even what accessibility looks like. If you think about the historical, physical structure, say, of Jewish temples or Christian churches, based in some of the historical narrative of ascending up to Jerusalem, that edifices themselves have typically been inaccessible, because you need to climb to the holy place, you need to ascend to the holy place to be close to God.

Raisa Habersham 2:55

You know, where is this idea of needing to heal someone with a development mental disability come from? Is it still pervasive in faith today?

Derona King 3:07

I think there's still a lot of it in faith, but the perversion in the teaching is that well, you must not have enough faith are you that that that all, all sickness, or what might be considered disability must be associated with some sin. And so that connection between whatever is perceived as, as a disability, just is just suddenly ingrained. So you get people who get sometimes paid, you know, to have these healing services, or to convince people that if they just, if they just believed and had enough faith, they, they would get up out of that wheelchair, instead of the reality of us all being created in the image of God, that we all have gifts, the capacity within each of us if we believe that we have this connection to God, is his full faith for some people is different.

Raisa Habersham 4:08

And people don't necessarily lean in on faith because, you know, think it will fix them. They want something to believe in. And I think that often with my friends who are LGBTQ, and, you know, they lean into faith. And they do that, despite the fact that there are so many people who use you know, scriptures to tell them that you're wrong. Or to say that or if you go to church, you can somehow mythix you will be quote straight. And it may not be for me to understand, but I've never understood how, you know, my friends that are LGBTQ are able to lean into faith despite the negative messaging.

Derona King 4:55

Yeah, the fixing is significant. I think many segregating and dehumanizing practices have been justified from the segregated Sunday school classes, which many faith communities still practice right? To people being made the mission project of the Sunday school class or the mission or service community. These very practices continue to perpetuate these hierarchical differences. And this class Stratus, this group of people, they're so broken, they're so far removed from what we consider holy that they have to be over here or over there, apart from us more holy, whole and perfect people.

Raisa Habersham 5:48

I spoke with Mary Silayillah Cook about her personal experiences with faith. Mary, who prefers to go by Silayllah, is a creative spirit and has quite the green thumb. She paints what comes to her in her dreams and manages the garden at her local church. Sillayillah was diagnosed with chronic depression and anxiety when she was 12. Silayillah is someone whose experiences with mental illness began as a young child and those experiences significantly impacted her development and interrupted her education. She was raised practicing Islam, but was forced to go to a Christian church when she lived in a group home.

Mary Silayillah Cook 6:27

In my group home, at first, she said that I need to go find something of my faith, but then it became mandatory that I went to church. There was people that was disabled, there was people that wasn't disabled. She saw a lot of potential in me, but I didn't really like how it was done. I felt totally out of place. I felt uncomfortable. I had to go to a Christmas party, I had to go. I cried so hard. Because it wasn't my thing. It was a Santa Claus that was in red, all red. And it was kind of scary.

Raisa Habersham 7:07

I was disheartened by Silayillah's experience. Being forced to attend a place of worship is wrong, especially one that is not of your faith. I asked her if there was anyone who knew about this or was an advocate for her during this time.

Mary Silayillah Cook 7:23

I made friends and the Holy Comforter, where the friendship center was. One time I left, and I left for a long time. And I came back, they were so happy to see me. And that's a church based place. But I'm not, I'm not Christian. So it was it was really beautiful to see people care about me and they know that I'm not their faith.

Raisa Habersham 7:53

That's very encouraging. I'm glad you have such a strong support system in place to have helped you. And I know that you also garden, can you tell me a little bit about your gardening endeavors?

Mary Silayillah Cook 8:06

Oh, um, I work there. That's at the friendship center. It's for people with mental health or any type of disability. So they allowed me to work there. And I became one of their top gardeners. Nowadays, I've been working there for, I think five or six years. And I, I love gardening. I love nature. I have plants pictures all over my wall. And I feel like I sometimes represent a garden a lot.

Raisa Habersham 8:43

And I understand you so you're are through Synergies Work. Can you tell me a little bit about Synergies Work and how you got involved with them?

Mary Silayillah Cook 8:51

Well, Synergies Work is a place where you can become, become an entrepreneur. And so, your artwork or whatever you may do, that's fantastic. And I sold eight paintings last year.

Raisa Habersham 9:08

Can you tell me a little bit about your dance background as saw that you performed at the 2019 Georgia Disability History Symposium? Can you talk a little bit about that dance that you performed and you know, what story were you trying to convey in that dance?

Mary Silayillah Cook 9:25

Um, okay. So I was with Francie Wallace. She, she basically let me tell the story of a girl who was made fun of and disabled somehow. And the part that I remember the most was when we danced together, she was the angel. And I was the little girl who was heartbroken. And I remember the song, "Don't Stop", by Jon Batiste. I love that song. And it just like, it inspired me to be able to make up that part. Because I do believe in angels, and angels speaking to us and talking to us, and trying to lift us up and give us hope.

Raisa Habersham 10:14

Who's that little girl representative of?

Mary Silayillah Cook 10:17

Well, it was actually me. And any little girl who felt like they weren't enough. I always felt like I wasn't enough. And I'm, I'm 32 learning that I am enough. But I'm still learning that and sometimes, I have to build myself up, sometimes my friends have to build me up. But I'm still here. I believe in Islam, I'm Islamic, I was raised to believe in Allah. Allah has always saved me from a lot of stuff. I'm very grateful. If it wasn't for Allah, I don't think that I'd be here talking to you guys now. My faith is my everything.

Raisa Habersham 11:12

Can you go into deeper detail on some of the things that he's saved you from?

Mary Silayillah Cook 11:19

Well, I was diagnosed with chronic depression, when I was 12. And there were times where I tried to hurt myself when I was younger, and I'm still alive. I'm still here. I know that I'm supposed to be here. I know that it's Allah that's always helping me.

Raisa Habersham 11:43

I wanted to go back. So I know you said that you tried to hurt yourself. Can you talk a little bit more about that? And how Allah kind of helped guide you away from further harming yourself?

Mary Silayillah Cook 11:58

Well, he would guide people in my life, to let me be with them. Or sometimes he would say himself. Don't. Don't do that. Don't, don't take those pills. I mean, a lot of people hear the spirit talking to them.

Raisa Habersham 12:21

You've mentioned pills, and correct me if I'm assuming too much. Was this a suicide attempt with the pills?

Mary Silayillah Cook 12:29

Always.

Raisa Habersham 12:32

Can you talk about I guess the first time you attempted and just at what point was it where Allah said, No, I don't want you to attempt suicide. Or you know, how would you phrase what happened?

Mary Silayillah Cook 12:48

Well, I mean, to be honest, he, okay, like the way he said no, was I would take the pills, and then it would come back up. It would all just come back up, and I'll end up going to sleep. And then I wake up, fatigued, but I would still be alive. Nobody would know about it. It was like he had my back.

Raisa Habersham 13:19

Despite being Muslim, Silayillah has been attending an Episcopal Church, because she felt more of a sense of belonging.

Mary Silayillah Cook 13:27

They actually supported me in being Islamic. They just accepted me. And I liked that. Macy, she would tell people who are judgmental. Well, she's my boss. You would tell them Muslims are very good people. So don't judge. I respect her for that. But I wanted to be a part of that community because there was so many people that love me there. You know. And when I did come out of telling them that I was Muslim for my whole life, a few of them didn't really understand. But Macy had my back. And then my friends had my back. I'm just happy that they accept me for who I am.

Raisa Habersham 14:13

I wanted to ask you and you know I mentioned church earlier, but do you attend a mosque?

Mary Silayillah Cook 14:20

I do. I attend the one on 500 McDonald Street, Masjid Al-Farooq. And I said my Shahada. Um, I learned a lot of the prayer in Arabic. And then I also had some friends. They taught me a lot more of the prayer, along with the Koran teacher, and I really love them. I love them with all my heart.

Raisa Habersham 14:50

Did you find the church more accepting of your disability than the mosque?

Mary Silayillah Cook 14:58

I found it more accepting because I didn't tell them exactly what I had I told them a little bits and pieces. But I didn't tell them everything to church. They were full of people that were disabled in every way. So I did feel more accepted there with my mental health.

Raisa Habersham 15:22

Like many people COVID has kept Silayillah from being around people she loves, including her citizen advocate, Sheri Mann-Stewart.

Mary Silayillah Cook 15:32

We met through Derona through Citizens Advocacy, we just hit it off. We did. We went to I think it was a coffee shop. And the vibes were good. I just love everything about her. It's like, I saw me in her a little bit, there are only little few differences. She's like, who I want to be when I get older.

Raisa Habersham 15:57

I love to hear that. I think that's something we kind of look for in people we meet someone kind of just like us. I wanted to ask you also, you know, you mentioned earlier about your spiritual gift, you know, how do you want to use that to help others?

Mary Silayillah Cook 16:15

The Koran is, is a good message. The religion is absolutely beautiful. But sometimes, I had to tell people, that you can't let people deter you from what you believe in. You have to follow the religion and the book. Because people are different from the religion itself. And don't give up on yourself just because you may have a disability because everything happens for a reason. There's always a purpose for it.

Raisa Habersham 16:54

You know, you're very accepted in your religious community, at least you still accepted in your religious community. But what would you say to anyone listening who has a disability who may be searching for belonging and acceptance, you know, someone who doesn't think that they are enough or who doesn't feel love? What do you say to them?

Mary Silayillah Cook 17:16

You are loved. Whatever you believe in, they love you. Allah has multitudes of names. I believe that the Creator, they love you. Believe in yourself, brush it off and keep it moving, and move with your head up high. Because you're here for a reason. You are absolutely loved.

Raisa Habersham 17:49

Silayillah’s story of finding acceptance in religion stayed with me because she’d found a place where she could almost be her whole self. Almost. She does hide her disability from her mosque to feel more accepted. But if Silayillah still has to hide parts of herself to feel included, is there a specific church or faith-based person out there to advocate on behalf of people like her? I found answers to that question after talking to Mark Crenshaw, the Director of Interdisciplinary Training at Georgia State University. He has dedicated his career to community building and inclusion for people with developmental disabilities. Mark, who has cerebral palsy, also works to mentor people with developmental disabilities with the expectation that they, too, will become leaders in disability work and beyond. Mark grew up in a small congregation in a small town in Oklahoma. He always wanted to work in the church. When he got to college, he studied theology and found more resources for people who, like him, have a developmental disability. What he ultimately found was the realization that he deserves to be loved...and fully accepted.

Mark Crenshaw 19:00

As a person who identifies as a person with a disability. You know, I grew up in a small congregation in a small town in Oklahoma, and I needed more resources to think about myself as a person with a disability before God, than I got in Sunday School growing up. I was also sort of growing up interested in working in the church and so sort of grew up with a vision of myself, potentially, as a church pastor, but it really sort of comes back to sort of my sort of self understanding of myself as a person with the disability and sort of wanting to gain more resources and ideas for understanding who I was before God and the study of religion and theology, gave me resources to think about myself differently, to think about myself positively, to understand that I was a person who was fundamentally loved and been fundamentally gifted and So, you know that that's really what brought me to the study of religion and theology.

Raisa Habersham 20:07

Despite his love of the church, Mark experienced early on how faith based communities can make people with developmental disabilities feel isolated or rejected.

Mark Crenshaw 20:17

As a preteen and teenager with a disability, I did certainly feel a need to feel love and acceptance. And so I didn't from a young age, sort of understand that there was a problem with who I was, as a person with a disability. I, I didn't necessarily always understand myself in the church to, to, you know, I didn't have questions about whether I was acceptable to God, as a person with a disability. As I grew older, in the church that I was a part of, there were questions about that, that were put in my mind, by clergy, and later in leadership within the church. I've come to believe as an adult, that sort of those, those folks were sort of doing the best they knew how, but at the same time, you know, for a long time, it caused me to have some doubts about my relationship with God. And I've been to lots and lots of therapy about that as an adult.

Raisa Habersham 21:18

When you were approached by clergymen, you know about your disability, and they put thoughts in your head that there is something, you know, wrong with you, because you had a disability, how did it make you feel in that moment?

Mark Crenshaw 21:34

Oh, it was devastating. It was absolutely devastating, it really struck at the heart of my understanding of myself as a whole person. And so you know, back to this journey to then theology school to seminary, and that sort of set me on a path to sort of reclaim who I was, and gave me lots of lots and lots of energy to re engage in a conversation about who I am as a person with a disability and, and therefore sort of what is possible, when we engage differently with the stories of our traditions, and with our histories and that sort of thing.

Raisa Habersham 22:18

Was there anyone who offered support to you when you were, you know, having struggles with your faith? And how people at your church viewed you? Did you have any support system there to help guide you through that?

Mark Crenshaw 22:32

I had certainly had supportive friends in my youth group and my parents were pretty supportive and have always been a source of support. But for the most part, I remember sort of that part of my journey, as a person of faith is pretty lonely, and really, really very, very hard.

Raisa Habersham 22:57

There goes that we're lonely again, disability exclusion is something Mark is all too familiar with.

Mark Crenshaw 23:04

I approached this part of the conversation to say, to live with a disability in modern day America is to navigate a world that wasn't meant for you. But what I'll say is, you know, lots of folks think about barriers to access related to physical structures. If the congregation's entrance has one step, it's one step too many for someone in a wheelchair. If the community isn't open to the participation of individual thoughtism, in religious service, you know, there can be disruption that happens in the context of religious service that can make the congregation and the leadership uncomfortable, and you know, that person then becomes a problem to be fixed rather than a member of the community to be welcomed and to be embraced.

Raisa Habersham 23:58

When you talk about inclusivity, for religious places, what does that look like for you?

Mark Crenshaw 24:04

Yeah, I think that's a great question. So I think inclusivity in religious places looks like people being welcome. I think it means that people are connected, participating in all the ways that are meaningful to them, whether that's as a worship participant, as a member of the choir, as a lay reader, people want to worship, people want to study, people want to serve, people want to lead. And so I think it's really important than when we engage religious communities, faith communities, churches, in these conversations to say, inclusion looks like opportunity to participate in those ways, and to take seriously all of them. To say, you know, I used to I used to say, when I was talking to congregations for the first time, about sort of this journey toward inclusion. How do you know when you're welcome someplace? Well, you know, you're welcome some place when they trust you enough to give you something to do. And so, and it might mean that a person with a disability that the doing looks different than it has before, right? So, my friend who was a member of a Baptist Church in metro Atlanta, one of the ways that she first got to contribute to the church was by being a sponsor for the middle school youth group in the congregation, you know, she was an older woman with, with a disability who used a wheelchair used a letter board to communicate. One of the things that she loved to do was to send email. And so she was in charge of making sure that she sent emails to the youth and their parents letting them know what the, what the group was going to do the next week. And so the church had to work with my friend, with Betty, to figure out what she wanted to do to figure out what was important to her to figure out how she was going to do what she was going to do. And she also showed up every Sunday evening for the youth group meetings, and she ended up being a mentor to several members of the youth group, I think it's just just important to remember that inclusion of anyone who isn't there already, is about sometimes thinking outside the box, and being willing to, to do things differently.

Raisa Habersham 26:27

As his friend Betty Thompson did, Mark also spends time mentoring young people with disabilities.

Mark Crenshaw 26:34

I envision a world where people with disabilities are leading these conversations, where people with disabilities are trusted sources of information are engaged to lead in different ways. Right. So I think, I think the leadership looks like lots of different things, I think it looks like lots of different activities. And I didn't grow up in a community where I was expected to lead. So as I've come to adulthood, those relationships with other with other people with disabilities have become important to me. And I have a ton of privilege in my space, right. So as a white man with a disability, who's had the privilege of going to, and obtaining higher education, having friends and relationships, where people, you know, trust me, I have an opportunity to hold the door open for other people with disabilities. And that's part of why I'm passionate about mentoring. That's why I think it's the calling of my life is to create opportunities where people with disabilities are welcomed and respected, and their voices and stories are important. And their gifts and skills are engaged. If there's someone in my circle, if there's someone who I have a path and mentored who can make an even stronger contribution than me I want to sort of clear the path for them.

Raisa Habersham 28:05

I connected with what Mark was saying about mentorship. As on this journey, I have begun to understand what it means to pass the mic, to give others voice. I asked Mark what he would say to someone with a disability who may not feel accepted by their church or place of worship.

Mark Crenshaw 28:21

I think that response has changed over time. You know, I think I want to have a conversation with that person about why the community is important to them, you know, what got them there in the first place? What's their interest in being a part of that community, and then we can create a plan moving forward, whether that's sort of approaching the leadership in the congregation, and explaining what this person's experience has been, and trying to figure out if we can create a situation by which they can feel, you know, increasingly safe and welcome. Because I think that congregations that faith communities, that churches and synagogues and mosques, what's really at stake for me at the at the heart of this conversation is I need for people with disabilities to be engaged in this in these communities, such that when they're not there, someone misses them. I know I belong in a in a religious community, when people call to check on me when I'm not there. And I get concerned about how people with disabilities can be isolated and excluded. And that, you know, aside from sort of paid service providers in their life, they don't have often people who will care enough to pick up the phone and say, or shoot a text and say, I missed you. Anything you need. When can I look forward to talk to you again, and if we don't have relationships between people with disabilities, people with disabilities and their families and congregations, we sort of miss a critical link in that The other way you know that your, that your presence and participation and the connections you made are meaningful is when people ask about you, when you're not there.

Raisa Habersham 30:12

Mark's words about a sentence stuck with me. Specifically feeling like you matter when someone calls you up if they haven't seen you in a while, I am so fortunate to feel valued in my life. And my friends and family make it clear when they miss me. I can't imagine how hard it would be to not feel or hear that, that only adds another layer of loneliness to what people with developmental disabilities may already be experiencing during this pandemic. I spoke with Dr. Rona about how I was feeling. Immediately I don't go to church while I pray. And I believe in God, I don't go to church. I've always been curious about how different people tie themselves to the church, a church or a religious building that doesn't value them. For me, it never dawned on me like why someone would fight through that, until I spoke with the Laila. And what I learned from her story, and marks to be honest, was, yes, there will be situations you'll find yourself in when you're not accepted. But go where you are loved.

Derona King 31:21

So Raisa, what are you unlearning?

Raisa Habersham 31:25

I don't know if I will call it unlearning as much as I'm learning, you know, in speaking with Mark, that, while my mind immediately goes to is a building ADA compliant, I don't often think about the attitudes in church, and how that can be a hindrance as well. Do I think about attitudes in terms of acceptance of LGBTQ communities? Yes. But I'd never thought about it in the perspective of a place of worship, and how there's this idea that you need to be fixed. And that's pretty dangerous.

Derona King 32:08

So what I hear you saying in regards to and I think we want to be clear, and we're talking about organized religion, and faith communities across the board, right, not speaking directly to any particular faith, there is something that feels uneasy about what we have seen the experience of people who are identified as unique or different from the dominant culture, in face communities. Are you saying that makes you feel uncomfortable?

Raisa Habersham 32:44

Yes, it makes me feel uncomfortable that there's this idea that people with disabilities need to be excluded. And then on top of that, they need to be cured. That's very uncomfortable for me. Because as a person, anyone shouldn't want to feel like they were born bad. Or they were born

Derona King 33:09

a mistake.

Raisa Habersham 33:11

Yes, that's exactly how I would frame it, that they were born a mistake. What I've heard from the Silayillah's story, and from Mark's story, it's just this willingness to belong and finding a place where you belong. And for me, it's just a matter of changing my idea of casting complete doubt, over places of worship. Because if I cast complete doubt, then I don't allow for growth in other areas, or I don't allow opportunities to find faith based entities that are welcoming. I cast complete doubt and I cast assumption that they're not going to be accepting. And that's not fair to that place of worship. It's not fair to me. And it's not fair to Soleil is a mark story. Because they have a strong community. And they deserve that anyone deserves that anyone deserves to feel whole, and to be a part of a community where they are welcomed and as marked put in, be a part of community where they call you up. After two days of not seeing you or even a day of that scene, you can say, Hey, where are you? Where have you been?

Derona King 34:27

We go back to thinking about how are we? If we look at how are we more alike than different? We need love. We need acceptance, we need welcoming. And so the answer to that is a big whited building at all. The answer is that are the individuals, the people that traverse those places, if we believe that everyone has something to contribute, and that's what faith communities should believe. Then not only will I come and see but You are benefiting at the body is benefiting from the gifts that I bring whatever that is. Whatever that is we talked about our mutual friend, Betty Thompson in her worship experience, that he lit up the room with just joy and love. And that was a gift because who doesn't need joy and love? Right? Who doesn't need someone to bring that into the space? Yeah. in faith communities, large or small, we're going to find good, bad and ugly, right? And what we want to bring attention to always just how do you how do you lift people's dignity? One of the ways that people are often just feel harmed is beat can being in these these large congregations of people all around them, and still feel lonely and isolated.

Raisa Habersham 35:52

And I think about how Silayillah has said, she talks to Allah a lot, especially now that we're in a pandemic, and we're physically isolated. And she's someone who seen physical isolation in different ways when she was in the group home. And now that she's living on her own, we're in the middle of a pandemic. And she's, like many of us was largely confined to her apartment.

Derona King 36:21

Yeah, the physical isolation is amplified in 2020. And it's the harshest example of that is what we're seeing for people with disabilities who are living in nursing facilities, where there was already isolation. So what would be your perception of a nursing home or nursing facility? Just, I don't know if you've had any experience visiting or being in a facility, what would be your perception now?

Raisa Habersham 36:53

So my grandmother was in a nursing home. She was we had to put her in a nursing Hall, unfortunately, when she was diagnosed with breast cancer, but it was a very somber mood.

Derona King 37:07

What it's strike you to know that young people with disabilities often end up in nursing homes.

Raisa Habersham 37:13

Yeah, that is very shocking. I mean, thinking about how I view nursing homes that's not good at all. If I have to be honest, it felt like this is where you go to die. Join us for the next episode of hidden voices, where we'll get an inside look at one of the most physically and emotionally isolating experiences possible for people with developmental disabilities. nursing facilities, a dire situation that has only grown more extreme during COVID-19 lockdowns. This episode is dedicated to the memory of Betty Thompson, who passed away in 2019 and is remembered as a bright light in her community.

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