

**Audio Title: Mary Fashik**  
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## Transcript

**Rebekah Borucki:** Hey, friend! I heard you were looking for our spot and I'm here to help you.

So, you're going to go past the corner bodega and down the block from the fresh cuts barbershop, and there you'll find a brick row house at the intersection of Literature Place and Social Justice Blvd. That's where you will find the stoop.

Our host Amanda Lytle will be there to welcome you to the conversation. *The Book Stoop* is the place for the hottest takes on book culture, nerd culture, current events, with best-selling authors, change-makers, and risk-takers, our favorite kinds of people.

I'm Rebekah Borucki, President of Row House Publishing, and this is season two of our podcast. Thank you for listening.

Now, I'm going to let you get to Amanda.

**Amanda Lytle:** Thanks Bex. Hey friend. Let me be the second to welcome you to our spot, *The Book Stoop*. I feel incredibly honored to be the host of this podcast and I'm so grateful to have you here.

Today on *The Book Stoop*, I'm speaking with Mary Fashik. Mary is a Lebanese born, queer disability rights activist, author, public speaker, and workshop facilitator. In 2019, Mary founded Upgrade Accessibility, a movement designed to challenge today's accessibility standards. The movement has grown to include disability rights, intersectionality, disability justice, equity and unequivocally supports Black Lives Matter and Black Disabled Lived Matter.

In the conversation today, Mary shares the backstory to Upgrade Accessibility and the where and the why to where *Mary Mic Drops* have come from. We hear about why so many disabled people have neglected medical care during the pandemic as well as some personal experiences of Mary's during the last few years.

Mary also tells us about a very exciting project coming up next year with Row House and Wheat Penny Press and why representation is so vital.

Before we jump in, I want to invite you to share *The Book Stoop* with your community. If you're loving this episode, grab a screenshot and tag us on Instagram, @rowhousepub. Every share, five-star rating and written review helps us find more listeners and climb the charts.

So we're super grateful for your help. We start our chats on *The Book Stoop* with a rather fitting question. So what are you reading these days?

**Mary Fashik:** Well, right now I am busy reading content to help prepare for workshops that I'm doing with businesses, organizations, and nonprofits. I would love to have time to sit down and just pick up a book and read a book. But unfortunately, I don't have time to do that right now.

**Amanda Lytle:** You know what Mary though, knowing that you're reading more stuff to just enhance and increase just the caliber of your workshops now having sat in on, what, six of them, you're doing incredible work with your workshops. If you want to take that as an invite, I would love to know how the workshop stuff even happened or maybe you want to take us right back to the foundations of Upgrade Accessibility.

**Mary Fashik:** So Upgrade Accessibility and this is a story that I think I've been telling for the rest of my life. You always hear celebrities tell these stories and you're like, "OK, that's interesting," or you're more than [0:03:34] *[Indiscernible]* to the story. Well, this is how I feel with the story. This is prior to the pandemic. I was at a local grocery store, and I went to use the restroom and I'm a wheelchair user and I went to use the accessible stall and my armrest on my wheelchair was pressed right up against the door.

As I'm sitting there, I'm wondering, "Who decided that this is accessible? Who says this is accessible? How can a non-wheelchair user or non-disabled person ...?" because most likely it was a non-disabled person who designed this stall. How did they know that this was accessible? And I came out of that stall, and I looked at my best friend and I said, "Accessibility needs an upgrade."

I said I'm going to start a hashtag "upgrade accessibility". So on August of 2018, I started the hashtag and, you know, I posted a few things and then my life got in my way as life tends to do. Then in December of that year, I had my access needs denied and it caused me *injury* [0:05:12] *[Phonetic]*.

I took my anger and I said I'm going to use this hashtag and make it a movement. That's exactly what I did and initially it was to amplify voices that had not conditionally, conventionally been amplified before. I would just DM people and say, "Hey, do you mind answering these questions about your daily life and the lack of accessibility in your life?"

I got a lot of nos. I got people who will not respond to my DMs. But I was persistent and that's how it started, and I've grown with my movement. I *[Indiscernible]* about disability justice, disability rights and so, so much more. The workshops began because I was working for a nonprofit last year in 2020.

As I am one of the only disabled employees, I'm starting to realize the amount of ableism that was in the workforce. I always experienced ableism but what surprised me about this particular workplace was that they worked with disabled individuals on a daily basis. I'm a disabled employee and I am experiencing ableism and I couldn't wrap my mind around that, and I said, "Let me come in and explain to nonprofits who do work with disabled individuals why their

thought process is outdated, why their language they are using is harmful to the people that they are serving.” This is how the workshops began.

**Amanda Lytle:** So for anyone listening who may be ableists or ableism is a new term, can you put that into your own words? What does that mean to you?

**Mary Fashik:** There are many working definitions regarding ableism. I frame it as systemic discrimination against disabled and chronically ill individuals and that goes for government and society. In the United States, the government aims to keep the disabled poor and uneducated because if we aren't empowered and we are uneducated, we cannot fight the system.

**Amanda Lytle:** That's actually a perfect segue into *Mary Mic Drops* and I'm going to use that as a the segue because a lot of the things that you have come to say and that I've heard in our own conversations but also through the workshops that you've put on for Row House is, you know, you and I kind of had this joke about the *Mary Mic Drops* and I was like, “Mary, you have so many mic drop things that you say that are so powerful and impactful,” and you're like, “Amanda, there's a reason that they are short and concise and to the point.” So can you speak to that?

**Mary Fashik:** Of course. So as you said, this was like a joke between you and I. You said, “Oh, we need to start a hashtag *Mary Mic Drops*,” and I said the reason why I speak concisely even in written word is because growing up, I was told that no one wanted to hear me speak because of my impaired speech or that no one will listen to me, at least not for an extended period of time. So I learned that once I have somebody's attention, I had to hurry up and say what I want to say before they stop listening.

**Amanda Lytle:** Even in the posts that you have, I mean some of these are such powerful takeaways. How has the response been for people either in your community or that are just coming on to your page or people that you know?

**Mary Fashik:** So I get a mixed reaction as you know. Some people do not necessarily agree with my format and often ask me why do I not address certain aspects of what I'm talking about.

But then the positive response is thank you for taking something so complex and making it to where I can understand it, where other people can understand it and as you know, we live in a society where people want a soundbite and that goes for written word as well. They want a soundbite.

So I'm going to give them that soundbite that they're going to remember. They may not remember word for word, but they will remember the idea.

**Amanda Lytle:** That makes me interested in what your favorite area is to educate about. Like do you have a specific thing that you just love to drive home?

**Mary Fashik:** I think it really changes depending on what my community is experiencing at the moment. So for the past almost two years now, it has been the pandemic and that seems to be the biggest thing I talk about that gets the most reaction, the most response is what disabled and chronically ill individuals have experienced, myself included, in the past almost two years.

As you know, except for doctor's appointments, I have not left my house since March of 2020. That takes a physical, emotional, and mental impact on an individual. So many in my community, myself included, have neglected medical care for ourselves because if we seek out either routine or emergency care, it could put our lives in danger.

**Amanda Lytle:** Can you elaborate a bit on that? Because I know the story but anyone listening might not understand exactly what it is you're up against.

**Mary Fashik:** So I can only speak for myself. I am only speaking for myself. This is a criticism as you know that I get very often that I'm trying to speak for the entire community. I'm not. I'm trying to represent my community. We can [0:13:14] [*Indiscernible*] speaking for them.

I was speaking to my personal experience. I am highly immunocompromised. I have had pneumonia five or six times in my lifetime. Not the last time I had it but the time prior to that, my doctor neglected my pneumonia to a point that I now have scarring on my lungs from that bout of pneumonia.

What do most people get when they have COVID? Pneumonia. Of course not everyone but the biggest thing is pneumonia. So if I caught COVID pneumonia, it's so much worse than "regular pneumonia". It could be fatal. It could kill me. My life is really in danger with COVID and I'm not saying that for attention. I'm not saying that to be overdramatic. That is absolutely the case and can firmly support that.

My primary doctor refused to give me antibiotics in July for a sinus infection because they did not want to lower my already compromised immune system to where I could – if I caught COVID, I would not be able to fight off COVID.

**Amanda Lytle:** I remember something that you've said in the workshop about how the neglect from the medical practitioners and healthcare providers almost killed you and has almost killed you in the past.

You know, we've had discussions at length about me being in Canada and you being in the States and me being non-disabled, and you being disabled, and I'm white, and you're a Lebanese woman, and, and, and, you know.

That there aren't many parallels. But when it comes to the heart space and me sinking into like my heart just aches for you. So can you share a bit about that, just that experience? Because I remember just our own conversations at length about this where when you share that and even as you did in the workshop, that that in itself is such a powerful takeaway to sit with.

**Mary Fashik:** So I'm currently working on an Instagram post that talks about how being disabled and chronically ill is difficult and yes, that's partially because of the physical toll it takes on my body. But also because of the ableism and mainly because of the ableism and the ableism being that non-disabled individuals do not understand the scope of what that means to be disabled, immunocompromised, chronically ill.

They do not understand, and I've been told so many times, "Well, why don't you just do one? Why don't you just take this pill, eat more fruit, do this, do that?" and no one understands the complexities of my body. Not even doctors understand the complexities of my body. Why am I losing weight and why am I losing weight only around my waist and not my entire body?

I don't know how sick I am currently because I do not have the medical care that I need because I live in a small town where there is one rheumatologist. There is one this, one that. There are no options. Getting a second opinion is a privilege and getting adequate medical care – notice I didn't even say good medical care. Adequate medical care is a privilege at that.

**Amanda Lytle:** Hey friend, we are coming straight back to *The Book Stoop* after a quick break.

When you said about the second opinion being hours away, you know, and then that is another hurdle. Like why is that there? Well, we know why it's there but that's another thing that you would have to take on in order to seek that. So ...

**Mary Fashik:** It would be and guess the toll it would take on my body. I had to drive – or be a passenger for two plus hours up to four hours away one way. It would mainly do more harm than good to my body. I would need a week to recover from one doctor's visit.

**Amanda Lytle:** Yeah, all for a second opinion because you've been denied access to one of the physicians that's local, which is heartbreaking.

OK. This is actually – not that this is a perfect segue but I think that this is a great opportunity to segue into an upcoming project and before we get too excited about it, I will tell you why this is a perfect segue because the conversations that we have, the workshops that you put on, your *Mary Mic Drops*, your Twitter posts, everything that you're doing online is so geared towards educating awareness, advocacy, activism.

Like all of these things that are disrupting and creating change and now we have the opportunity to talk about a very special upcoming project, which you are going to take it away for us because this is big news.

**Mary Fashik:** I am so excited to announce that in 2023, Row House Publishing and Wheat Penny Press will be publishing my first children's book.

**Amanda Lytle:** Yes, Mary! Well, tell me about it. So what is it going to have in it? What's it going to be about?

**Mary Fashik:** I am so excited because I have had this idea for years to the point where when I had the initial idea, I remember I went up to a lady I saw in Walmart with her young kids and I said to her, “Excuse me, ma’am. I’m thinking about writing a kid’s book. I was wanting to know, can I talk to your kids and ask them what do they want to know about disability? When they see me, what questions do they have?”

So this was like seven, eight years ago. So this idea has been blooming quite that long and the story is going to be about a little girl who is new. It’s like the beginning of a school year and she’s new at the school and she’s disabled. She’s a wheelchair user like myself and she’s going to have cerebral palsy because I want to speak to the disability that I know and not something I don’t know.

So she’s going to have cerebral palsy. She’s going to have impaired speech because this is vital. Representation is vital. I can’t imagine what I would have gone or as a little girl, thinking why as a little girl if I saw a book about a Brown little girl in a wheelchair who had impaired speech, that would have empowered me so much.

We don’t see characters in books that have impaired speech. In movies, like only so they can be made fun of. So this little girl is new in her school, and she befriends a non-disabled girl. They become really good friends and the non-disabled girl is having a birthday party and wants to invite the main character, but their house is not accessible and then it becomes the conversation with her parents about how to make this birthday party accessible for her friend.

The parent builds a ramp to their house so that her friend can get in their house and also they talk about making their party games accessible, making sure that the table is not too high. All of these things that I didn’t get when I was a little girl because I couldn’t go to a lot of parties for that very reason. At the very end, just a little sneak peek, at the very end, it’s going to be – the overall message is that accessibility is for everyone. Everyone, disabled and not, benefits from accessibility.

**Amanda Lytle:** I can’t stop smiling. You must be so excited.

**Mary Fashik:** I am. I’m nervous.,

**Amanda Lytle:** Yeah, of course you are. That’s OK.

**Mary Fashik:** Yeah. But I’m going to tell you I want to see – like this is huge and also speaking of accessibility, the best thing to come out of this book is how accessible this book is going to be. I don’t know if you heard but we are going to put image descriptions on the illustration for children who are low vision or blind and not just for children and adults who are low vision and blind. How many of us, when we read books with kids, we describe with pictures? Well now, it will be on the page.

**Amanda Lytle:** That's incredible. This is a game-changing book already and it hasn't come out and when it does, this is going to be a massive educational tool. But now I'm actually curious about braille. Will there be braille as well?

**Mary Fashik:** We are looking into that. I really want this book to be in braille as well.

**Amanda Lytle:** Wow, Mary! I'm also so excited that I get to witness this journey.

**Mary Fashik:** I wasn't going to do this if it wasn't going to represent me and my community in the best way possible and Row House and Wheat Penny Press are giving me the opportunity to do that.

**Amanda Lytle:** Oh, yes, yes, yes. OK. Now I want to come back to something that you've just said about accessibility is for everyone. In some of the workshops that we've done together, we've talked a lot about this, about Bex, you know, and she calls her [0:25:16] *[Indiscernible]* and about how she watches TV with subtitles or other people may choose to watch something in mute and require image descriptions or the alt-text as readers. So can you speak a little bit about the importance of creating – if you're saying that you're intentionally doing something, to actually follow through and how social media is so inaccessible at this point?

**Mary Fashik:** So there are a lot of discussions about accessible social media, and I've always said that if businesses and organizations realize that disabled individuals are viable consumers, that they would make their content accessible.

But we are not seen as viable consumers, so they don't bother, and the average person doesn't see the importance of doing image descriptions or they think, "Oh, this is hard. It takes too long." But at the same time, they say, oh, [0:26:30] *[Indiscernible]*. You know, I – but you're not. You're not because you're excluding one of the largest – or not one of, the largest minority group in the world, which is disabled and chronically ill individuals.

We make up a quarter of the world's population and you *[Indiscernible]* because you see us as burdens or as an inconvenience and we're not. There's no reason why social media should not be made accessible and that you should not take the extra few minutes to write an image description, to caption your videos. That is the number one thing. Caption your videos and write image descriptions.

But I do want to speak to a point that has come up within my community. Many times, those of us who are chronically ill do not have the ability or the energy to make content accessible. We are speaking to those who are not disabled because if more people did, then you won't *[Indiscernible]* you're going to do it. If I'm not capable of doing it, there's a reason. But if you're not doing it, it's probably just because you don't want to. You're making up excuses.

**Amanda Lytle:** Yeah, that's a great point. I want to come back to one more thing that you've said here about captions because this was a huge thing for me to learn and it was all because I didn't realize that there was the captions available. So as my own personal experience, I had

taken an accessibility workshop – like I don't know. It was the second half of 2020 and I had taken this workshop and it was really great and I had taken away some image descriptions and alt-text stuff and captions and whatever.

But I had been typing out my captions and then a girlfriend of mine was like, “Mandy, you don't have to actually type those out. There's a captions thing.” Well then of course which I can admit to now is that the ease of that just far exceeded just what I was putting into the effort.

So I thought, “Well, I love this. This is great,” and that's what I stuck to. So one of my biggest takeaways of something that is easy enough for me to do and why it actually matters is that – I already know that I speak quickly. It's when the captions come up on the screen and they are autogenerated is that they are not accessible because they're too quick whereas if it has been physically typed up on the screen, someone can hold their thumb on the screen, and they can read it in time and that it allows someone to process the content. I remember that even in your workshop, just being one of those takeaway moments that it is so easy for me to do.

Why am I not doing that? So thank you. I have so many thank-yous for you always. I just remember that was just – if you're going to try something to do better, that is such an easy place to start.

**Mary Fashik:** So I'm going to give you a mic drop moment because I know how much you love those. So I'm going to give you one.

**Amanda Lytle:** Yes.

**Mary Fashik:** So two things. Yeah. I always say one, not all representation is good representation and two, not all accessibility is actually accessible. So the auto-generated captions that come up as you speak. They seem to be accessible. Overall I caption my video. Yes, you get *[0:30:26] [Indiscernible]* accessible because anyone – and that includes a disabled individual, but most people speak a lot quicker than people read. So you are having to keep up on the screen with how fast the person is speaking and then you have to go back and watch again and captions, if you're a mom and you're trying to put your child down for a nap and you want to watch somebody's story, captions help you. Accessibility is for everyone. It works for everyone. Everyone benefits from accessibility. But again, not all accessibility features are truly accessible.

**Amanda Lytle:** Mary, I want to be mindful of your time. So I've got one more thing for you here. If you were to give a shoutout to an account, a person, an organization, a disruptor, activist or change agent, who would it be?

**Mary Fashik:** Absolutely. I want to shout out Catalina Bliss. Catalina Bliss is a Latina disabled ballet teacher. Catalina is amazing. She offers adaptive ballet classes. I took her class this summer. She offers an adaptive ballet class for Camp Access, which is a virtual camp that I started online last year for disabled and chronically ill adults.



Catalina came in this summer and gave Camp Access the best adaptive ballet class. She adapted in the moment. If there was something one of us could not do, she said, “Try this. Let’s change this up.” Catalina has faced ableism and racism and has not been able to be hired fulltime as a ballet teacher like she deserves. She’s currently offering classes on Patreon. The link is in her bio, and she offers not just adaptive ballet classes but disabled [\[0:33:06\] \[Indiscernible\]](#) she offers ballet for everyone, and she also is big in disability justice.

She and I have had many talks about disability justice and how ableists [\[Indiscernible\]](#) the dance world and the ballet world is. I highly recommend following her and sign up for her Patreon, classes for all ages. And who doesn’t want to take a really cool ballet class? I loved it and I’m not one for ballet or yoga or anything like that. Zumba is more my pace, but I love her class. It was amazing.

**Amanda Lytle:** Mary, that – what a conversation! Thank you so much for everything that you’ve offered here. Thank you for pointing us in the direction. I’m totally going to check this out right now. Thank you so much for being a guest on *The Book Stoop*.

**Mary Fashik:** Thank you so much for having me, Amanda. It was a pleasure like always.

**Amanda Lytle:** Thank you so much for being with us. Please be sure to follow us on your podcast app and leave a rating where you’re able. Written reviews help us reach more listeners too. Be sure to check out the show notes for all the links and share *The Book Stoop* with your community. Talk soon.

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