

## Interview with Alice Wong

[00:00:09] **Kendra** Hello, I'm Kendra Winchester. And this is Reading Women, a podcast inviting you to reclaim half the bookshelf by discussing books written by or about women. And today I am talking to disability activist Alice Wong, who is the editor of *DISABILITY VISIBILITY: FIRST-PERSON STORIES FROM THE TWENTY-FIRST CENTURY*, which is out now from Vintage. For a full transcript of this episode, you can check out the show notes or head over to [readingwomenpodcast.com](http://readingwomenpodcast.com). And be sure you're subscribed so you don't miss a single episode.

[00:00:39] **Kendra** We actually recorded this interview on the day the Alice's book launched. So *DISABILITY VISIBILITY*'s birthday. And it was really a delight to interview her. And there was definitely an air of celebratory cheer. And at the time that this interview goes up, just as a heads up, Alice's launch party is going to be July 25th, I believe. There's a great event there. So I will link that in the show notes, and any other upcoming events that the publicist has updated me on will be in the show notes.

[00:01:08] **Kendra** I really enjoyed talking to Alice about this book and also getting some insight into how she really wanted to include disabled creators on all the different steps of the project. So, for example, many of you know, I primarily listen via audiobook. And the narrator, Alejandra Ospina, they narrated the audiobook, and they are also a person with a disability. So I really appreciated that and learning more about the process of how she brought together all of these amazing contributors for the essay collection. It's one of the most diverse and intersectional essay collections that I have ever read. There are disabled people of color and queer people and trans people, non-binary people. There's even an essay by a Muslim disabled person who is writing about the intersections of their religion and their identity as a disabled person. And I really appreciated seeing all these different experiences. Some were very similar to mine. Some were totally different to mine. There were also people with disabilities who had visible disabilities and people like me who have invisible disabilities. And I just was astounded by how great this collection was. And I didn't really realize how much I needed it until I read it.

[00:02:26] **Kendra** So a little bit about about Alice before we jump in to the interview. Alice Wong is a disabled activist, media maker, and consultant. She is the founder and director of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability, media, and culture. And it was created in 2014. Currently, Alice is the editor of *DISABILITY VISIBILITY*—the collection we're talking about today—which is an anthology of essays by disabled people, which came out on June 30th, when this was recorded. All right. So let's just jump into the interview of my conversation with Alice Wong.

[00:03:09] **Kendra** Well, welcome, Alice, to the podcast. I'm so excited to have you on today.

[00:03:13] **Alice** Oh, thank you so much, Kendra. I am delighted to be here.

[00:03:16] **Kendra** And today is the launch of the book as well, which I didn't realize until last night. But *DISABILITY VISIBILITY* releases today. So congratulations!

[00:03:27] **Alice** Thank you. It's quite a day. Just trying to process it here. Just trying to enjoy it.

[00:03:39] **Kendra** Yeah. I've seen so many great posts today, going around and just seeing it everywhere. And that's always a joy to see, I think. I think book birthdays are pretty special. The first question I had for you today is about the book. So the title of the book, **DISABILITY VISIBILITY**, shares the name with your Disability Visibility Project, which you founded. So what is that project and how did it come to be?

[00:04:05] **Alice** Thank you for asking. So the Disability Visibility Project started in 2014. You know, it's interesting that this—the timing of our conversation—because we're about to approach the 30th anniversary of the Americans with Disabilities Act this July. And I started the project actually as a one-year, oral history campaign to record stories by disabled people to lead up to the 25th anniversary of the ADA in 2015, July 26. So at that time, I think there were a lot of disability organizations getting ready to celebrate and do something to mark this occasion. And I was just, you know, one person. I just wondered to myself, like, what could I do? What's my contribution? And, you know, one thing that's always bothered me is that . . . number one, we don't see enough stories about disabled people by disabled people. And also, I don't think there's enough disability history that is known the general public. And I really wanted to do have an effort to think about disability history now, not just way back when. You know, and I think all of us are creating history every day. It is not just about these iconic figures or super famous people or big accomplishments. So I formed a partnership with StoryCorps, which is an oral history nonprofit. And I just started interviewing amazing friends of ours, you know, people that I thought are super cool and just wanted a chance to share a story with them. And I began to use social media, and I just encouraged people all over, and it kinda snowballed.

[00:06:22] **Alice** So I started in 2014, this project. It was just going to be a one year, you know, collecting stories. And it really resonated. People, I think, have a hunger to tell their own stories. And StoryCorps has a relationship with the Library of Congress. So each participant has the option to archive their story at the Library of Congress. So that's really exciting too, not just that we're telling our stories, but really a body of work that's going to be there forever for future generations and that could be accessed by the public. So as of 2020, we have approximately a little bit over 140 oral histories. In addition to oral histories, we are a online community dedicated to creating, sharing, and amplifying disability culture . . . through a podcast, through blog posts, Twitter chats, you know, all kinds of ways.

[00:07:37] **Kendra** Oh, that's really fabulous. And, you know, I really love the title of **DISABILITY VISIBILITY** because, you know—like you say in the very first paragraph of your introduction—that you don't realize what's missing because you don't see it. And you don't even realize that you're thirsting for your own types of stories until you read them. And that's something that I definitely felt when reading this collection. And I felt seen in a lot of ways that I had really never read essays like these before, and it just made me realize how much that was something that I needed to see. And I really love the idea that there's even more oral histories from from your Disability Visibility Project as well.

[00:08:25] **Alice** Thank you for that. And I feel my job, in itself, is not always. . . . It doesn't mean there has to be a bigger image. I think some people feel like being seen means a literal, exact shade to representation. And I feel like that's partially true. But I also think that being seen is also about this type of similar lived experience. I think people with disabilities, they range in such different types. You know, there's such diversity in the types of disabilities, just the ways people live. But I think some ways, you know, there's a lot of commonality in terms of just the, you know, living with a different way of being and how that really does challenge the status quo. They really deal with that, all types of people with disabilities, whether they have invisible disabilities or, you know, all types that are just,

you know. But then they read somebody in the book with or without their diagnoses or same kind of disability. . . . I hope they do find something there for them.

[00:09:39] **Kendra** Yeah. There's so many different kinds of representation in this book. It's one of the most intersectional essay collections that I have ever read. But how did you end up turning the Disability Visibility Project into an essay collection?

[00:09:55] **Alice** Well, you know, I thought, What are different ways of getting our work out? And I think, you know, I do have a blog. I have guest writers. I have a podcast. These are things that I could generate on my own or in partnership with other people. But I think having book is a little bit different as well as just another way to reach a different audience. You know, I feel like a book sometimes . . . I still feel a little conflicted about it, the sense of what does it mean to have a book? What is the privilege of having a book by a major publisher? I think this is, you know, this is another sort of step, I think, toward a extending, you know, of what I believe in and what I care about. I just want to kind of create very different forms and formats of ways of telling our stories. And books really do better. And I think having a book is significant. And that's another reason why I went this route in terms of just putting together a collection of essays that are either original for this anthology specifically, but also collecting work that's been published within the last twenty years because I really wanted to present a sample of what's the latest and really embrace a chapter in this moment.

[00:11:38] **Kendra** Yeah, and it's really interesting because, you know, I struggle. I can't really read print most of the time. And so I use the audiobook to listen to this book. And so even though it went to print, it also went back to audio as well. And the way that you're able to reach so many people with this collection because of the different formats . . . you know, I've listened to your podcast and listened to this essay collection. And there's just so many more resources. And for someone like me, who I feel like for much of my life was starving for resources, I appreciate having all of those different formats so that it is accessible in all of these different ways and all these different stories. And I think you really just made something really special. And I realize I'm just going to gush about this collection the whole interview. But it really is something.

[00:12:30] **Alice** It's funny because I just, you know, it's my experience. . . . But working on a book, I didn't really share too much or was very public about the process. You know, I just wanted to keep my head down and just work on it and surprise the world with it. And just, it's really nice to hear that because I think that, you know, I wasn't sure what the response would be. But I do know that, you know, this is a set of stories that I personally love. It reflects a lot of what I care about. It reflects what I think are important issues, issues and cultures and ideas that I feel really need to be amplified. And, you know, I want everybody to know about this. And I think that's . . . that was really the intention of how I selected these stories.

[00:13:31] **Alice** And, you know, just to get back to access. As a process with this book, I thought about what are some other ways of making this book accessible? And I just published today on my website a plain-language summary by a disabled writer named Sarah Luterman. I commissioned Sarah to write a plain-language version of the book because there a lot of people with different kinds of disabilities who process information differently. You know, self-writing can be very dense. And having clear language is a form of access that I don't think is talked about enough. And I've learned from other people. I've learned from people with learning disabilities, people with intellectual or cognitive disabilities that plain language is absolutely the key to reaching all kinds of people. So I'm

really excited to have this free resource on my website that any reader could access as well. So I guess I also have . . . thinking about this book . . . had to make the most of it, kind of just leverage this book to create more opportunities for conversation and questions. I have a plain-language version. And I also hired another disabled writer, Naomi Ortiz, to create a discussion guide. So I really do hope that these resources should help all kinds of people to really engage with the material. And also, it provides a way to . . . whether somebody can afford the book or not, they can also access the book in a different way.

[00:15:26] **Kendra** Those are ways to make the book accessible that I hadn't thought of, and I think that's incredible that, you know, this is definitely a group project. And so many people, so many disabled people are involved in making this book, whether it's making accessible or contributing or helping along the way. As you were gathering contributors for the essay collection, what were some of the things that you were keeping in mind as how you wanted the essay collection to look as a whole? And how did you find the different contributors who've come on board and written pieces or have pieces featured in the collection?

[00:16:02] **Alice** Well, you know, I think the original idea was 21st century stories. You know, I think what I've done just informally over the years has been reading a lot, but marking so many great stories that I just . . . you know, I'm a fan of. And I think this is just . . . at the heart of who I am is just a fan and a supporter of all of us in the disability community. I've just been. . . . You know, really the last five to ten years, seen this huge turnout, like growth and outpouring of writing by disabled people. And, you know, it's just been really exciting to see. Over the years, I've seen different essays, different blog posts, different kinds of work that I just feel really blown away by. It was hard to try to narrow it down to these pieces, but I feel like it's. . . . Also I tried to narrow it down to certain ideas and certain representation that I really, really wanted. You know, for example, I think, you know, readers can really see is that there are I think, you know, a significant portion of contributors who are disabled people of color, you know, marginalized, disabled people. And, you know, this just comes from my own experience as a disabled, Asian American woman in the sense that, you know, for so long the default, mainstream representation has been very white, you know? White, disabled . . . usually, they're kind of typical disabilities most people are familiar with. Like blind folks, deaf folks. You have people with, you know, wheelchair users. But this really is not enough. It doesn't really capture all the breadth of huge variation. And I think that's something that was really important to me.

[00:18:23] **Kendra** Yeah, and I was going through in my notes and marking just the different intersections that are covered a lot in each essay and doing like a little summary as I look back through, I can see that. And there are people of color. There are trans people, non-binary people, queer people. There's even an essay about a Muslim person who talks about, you know, how their religion interacts with their disability. And I was just so impressed with the wide range of representation and stories. And I think when you think about how more "traditional" representation are able-bodied people telling our stories, when you have all of these first-person stories from a wide range of experiences, it truly illustrates how there are so many different kinds of disabled experiences and such a wide range of experiences to listen to and to understand, but also to celebrate because there is such a wide range of creatives in here and artists and people doing all sorts of kinds of things. And I just really appreciated that each new essay brought something new to the table and made you think about something new and how disability is and how, you know, we've traditionally seen that kind of representation.

[00:19:44] **Alice** Yeah, and I feel like—I wrote about this in my introduction—but, you know, this is really not Disability 101. I just see in a lot of different kinds of work where there are stories where people are explaining their . . . what it's like to live with XYZ. And we see those kind of work. We read those kinds of stories. And I think those are, you know, clearly necessary. But, you know, I wanted to kind of raise the bar. And say like, what are people doing? What are they passionate about? What do they care about? And I really wanted us to advance the ideas of what disability stories are like or what disability culture is like. I mean, not everybody in this book is really going into details about their disability. It's about just their work, their drive. You know, just other things that they're doing. In doing that, that's also very important.

[00:20:51] **Kendra** And continuing in that vein, one of the things that I really loved about this collection is that it does a center the experience of people with disabilities. And you say in your introduction, "You may be unfamiliar with some terms or uncomfortable with some idea presented in this book—and that's a good thing! These stories do not seek to explain the meaning of disability or to inspire or elicit empathy. Rather, they show disabled people simply being in our own words, by our own accounts. DISABILITY VISIBILITY is also one part of the larger arc in my own story as a human being." And I really appreciated that because I think, you know, all of us with disabilities are constantly I feel like trying to root out our own internalized ableism and decentered the perspective of the able-bodied person and how we interact with the world. And I loved how the center of these stories is always the person with the disability and their life experiences. Can you talk a little bit about the importance of centering the stories of disabled people? And how, you know, in a sense that's revolutionary—though you'd feel like at this point in our series of events it shouldn't be, but it very much still is.

[00:22:09] **Alice** It absolutely is. And I think it's still a little sad that it's sort of seen as radical or revolutionary because, you know, I think we've seen a lot of efforts by all kinds of groups, all kinds of marginalized groups to really create themselves and celebrate themselves and center themselves. It's way overdue for so many of us. The challenges are still there because ableism is embedded in everything we see, everything we do. And, you know, it's very hard to try to resist those forces. And this is why I think community is so powerful in the sense that we realize we're not alone. We're a part of this bigger thing that's outside of our individual selves and that there is something about gathering together or having a space. And I feel like books are a way to carve out that space. In the literary world, it expands to a greater cultural, cultural spaces. And, you know, this is something that I think is part of a history of work by other disabled writers as well. It's not the first. But it's definitely in line with a lot of work that's been out there for the last 20, 30, 40, 50 years. But hopefully it's representing something that's unique to this time. And, you know, I think it is still. I don't want it to seem as an anomaly. I definitely want this to be, you know, I think we need more of this definitely.

[00:24:07] **Alice** And I think it's. . . . This is an exciting thing that hopefully people will see this book and, you know, they will be able to pay for more books like this because this is just the beginning. And I really do hope that anybody who's listening who's an editor or in publishing, who are producing media just think about this. The audience is. . . . Sometimes, I think as you know, sometimes people get told, like, there's no market for this. There's no audience. Don't be so narrow. Why make it just about disability? And I think this is where we have to challenge these assumptions because the people who are still in power, if we think about the traditional publishing world is still very much centered on non-disabled, white, heterosexist sort of place. And that's why in 2020, we do have so many people creating their own work, whether it's self-publishing, blogging, podcasting, that are

really not going through these traditional routes. And I feel like we could you do both. You know, we should do both. You know, we should have as many different options as possible. And also to push the people who do have the privilege, that do have the power to also try to wake up and to see what they're missing.

[00:25:48] **Kendra** That's definitely something that I've thought a lot about this year. On Reading Women, we have a yearly reading challenge. And since I have a disabling chronic illness, I've always included some facet of that on the challenge prompts. So this year is just a more general, you know, read a book by a woman with a disability. And it's been kind of shocking to see how many DMs that we've received, like, this prompt is so hard. You know, basically you could infer, like, why would you have this on there? And they don't assume that the person reading the message is the person with the disability, and that's why it's on there. And they don't even seem to think through that at all. They just assume that it's going to be another able-bodied person because I guess they can't imagine someone with a disability doing something. I don't know exactly what's going through their mind, but. . . .

[00:26:43] **Alice** Yeah. I don't know either. I mean, that's a thing too. That's kinda sad, right? I think there's also this weird assumptions about what kind of stories make good stories. You know, I think again, there's a lot of these tropes, you know, these inspirational, overcoming stories that are very typical. I think that that's a kind of typical story that you're going to find from disabled people. How did they overcome their disability? Or what kind of life lesson can a non-disabled person get, you know, to be more appreciative or to have empathy for the less fortunate. You know, these are just really kind of the things that I see a lot of publishers create because I think that's what they think, you know, non-disabled readers want. And I think, you know, again, they're not really going for the authentic . . . you know . . . what is that like? What do disabled people want from the stories that are supposed to be about them? And I think this is again why we need disabled editors, disabled people in publishing to really sort of have that eye for the work that's out there because, you know, there's just so much to us that's still unknown and undiscovered. And I want to bring in as many people, but again, centering it on us. But to bring in a steady stream of people into our world, into our experiences.

[00:28:32] **Kendra** Yeah, it's the whole thing of how the disabled person has to be an inspiration for all the non-disabled people. And, you know, I always read books, and if there is a person with a disability, they're usually to the side and, like, inspiring the main protagonist to be a better person and like all this stuff. But I really love the collection because it does have thirty-seven protagonists telling their own story and having these experiences. At the end of your introduction, you have a paragraph directed to the non-disabled readers of this book. And you have a challenge, which I really appreciate. It just says, "How many disabled creators do you know of? How can you support their work, whether it's a podcast, novel, play, video, or blog? How are you widening your horizons?" And I think that is an excellent challenge because I think oftentimes people don't realize that they aren't really following many people with disabilities in their social media, or they're not supporting content from disabled creators. And I really appreciated the way that you included that challenge because I think it's just something to start that thought process and kind of move them forward a little bit.

[00:29:48] **Alice** Yeah. I really want people to like. . . . I really want to encourage people to, after reading the book, to want to seek more. I just. . . . You know, this is not the big process of reading a book front to back, if they do read the book front to back. But, you know, I was also intentional of having a call to action. But, you know, at the back to the

book, I created a list of resources and additional reading because a lot of the contributors have published a lot of other incredible work. And I also, you know, clearly, because I can easily put in 1,500 people. But that's impossible. So, you know, I included other books that's been published recently or just books that I think it would be great to kind of follow up with. So I really do want to leave people excited and encouraged to seek out more. And I really want people to reflect. Think about, especially with the current conversations about Black Lives Matter and also the Reading Diverse Books Movement, everybody needs that, to analyze their bookshelves and really kind of think about why don't I read more works by Indigenous people? Why don't I read more books by Black or brown people? Why don't I have people with disabilities on my bookshelf? I think that's hopefully a good move toward a greater understanding that, wow, there are sort of different ways of being and understanding the world.

[00:31:39] **Kendra** I really love the resources in the back. And I have, you know, this "Authors with Disabilities" wishlist. And when I started reading your collection, I realized I was missing so many different things. So I actually went and spent a ridiculous amount of money buying all of these books. Not all of the ones that are listed, but a lot of them and especially ones with audio since I can't really read print. But I like to make notes in the print version if I can. So I like to use them in tandem, like I did this time. And it was a great resource. And I just went on, and I have a great stack of books. I'm ready for July. Impromptu disability reading list for July. So that's exciting.

[00:32:25] **Alice** That's what it's all about. You know, I think one of the things that I think is important to me is that this book doesn't just benefit me. It's just to also really put a spotlight on some really amazing work that's out there and that, hopefully, people will also support it the way you did. And I feel like this is just another reason why, you know, having a book is also this huge privilege and opportunity. And I just wanted to expand as much work out there that's out there, just to get more attention. So that's sort of the other agenda.

[00:33:11] **Kendra** While the week that this interview comes out—so if everyone's listening, the week that this comes out—over on our social media, we will be featuring disabled authors all that week in celebration of the interview. And I believe your book launch event online is also at the end of that week. Somewhere around there. So we'll make sure to include links to that in our show notes. But if you want more recommendations, definitely go check those out, because all of them that I looked up so far are in the back of your book. So I'm really excited about that. We're just gonna have a great week, really.

[00:33:47] **Alice** Well, thank you. And I think that's really exciting that you're having a whole series of different books you're highlighting that hopefully your audience will be super excited to get go on their own adventures and that we keep on moving this far. And we're doing it together. You know, you and I and so many other people, we're all doing this as a collective movement. And that to me is how we're going to change the culture. We're going to do it together, not by these individual acts, but in support of one another.

[00:34:22] **Kendra** Yes. And I feel like I could chat with you about these books and about all sorts of topics around disability forever. But I don't want to keep you too much. This is a day of celebration, and I'm sure you have lots of other things to do today. But before you go, I did want to ask, are there any books that maybe you're reading now or that you've had your eye on by disabled authors that you would recommend to our listeners?

[00:34:49] **Alice** Yeah, there's one coming out this October by an amazing artist. Her name is Riva Lehrer. She has a memoir coming out this October called GOLEM GIRL. I got to know Riva mainly through social media and appreciate her as a friend. But she is an amazing portrait artist, like portraits are her entire thing. And she has a great memoir coming out in October. So, you know, so definitely check it out, and maybe you can have her on your podcast one day.

[00:35:31] **Kendra** Oh, that would be really cool. I will definitely add it to my list to have. I have now this whole brand new shelf because of all the resources that you've put in the back of this book, which are again amazing. Yeah, so I feel like I am set for further reads. And again, I really appreciate you putting this collection together, which really in a lot of ways kind of jump starts your journey a little bit in reading all of these different . . . and listening to all these different voices.

[00:35:59] **Alice** Well, thank you so much for reading it and for having me on this podcast. I really do appreciate this chance to share my story.

[00:36:13] **Kendra** I would like to thank Alice Wong for talking to me today about her book, DISABILITY VISIBILITY, which is out now from Vintage. You can find Alice on Twitter (@sfdirewolf) and (@disvisibility) and on her website, disabilityvisibilityproject.com. And, of course, all of her socials and her website will be linked in our show notes. I'd also like to say a special thank you to our patrons, whose support makes this podcast possible. You can find Reading Women at readingwomenpodcast.com and on Instagram and Twitter (@thereadingwomen). You can find me (@kdwinchester). Thanks so much for listening.