Down to the Struts

Season 8, Episode 2: Renegades with Day Al-Mohamed

Host: Qudsiya Naqui

Guest: Day Al-Mohamed

Transcript by Qudsiya Naqui

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**Introduction**

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Welcome to another episode of Down to the Struts, the podcast about disability, design, and intersectionality—where we uncover the building blocks for a more just, inclusive, and accessible world. I'm your host, Qudsiya Naqui. Today, you'll listen in on my conversation with Day Al-Mohamed. Day is a lawyer, a writer, and a filmmaker committed to designing laws and policies that ensure access and inclusion for disabled people and to bringing disability history and culture into our collective consciousness. Day

and I talked about her approach to transforming social and cultural attitudes about disability as a central tool that walks hand in hand with advancing policies that ensure rights and legal protections for disabled people. Day wants people to see disability, culture as cool. A worthy objective, I think.

Okay. Let's get down to it.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Day, it's such a pleasure to have you. Thank you for joining me.

Day Al-Mohamed:

Thank you. I am super excited to be here. And hello everybody.

Qudsiya Naqui:

You are so many things. You are an advocate, a policymaker, a filmmaker, an author. Can you introduce yourself to our listeners and tell us about the journey that led you onto all of these paths at once?

Day Al-Mohamed:

I worked in disability policy for a long time in a variety of kind of legislative and executive kinds of arenas. I've done employment, I've done education, I've done accessibility and technology. Done healthcare and a lot of it relates to disability, some of it on race and ethnicity in general. A lot of the work has been kind of support for marginalized populations. I even spent part of a summer working at the un, the International Criminal Court for the preparatory commission that was designing it, and it was working on on plans as it relates to reparations and victims of genocide. I most recently completed my tenure as the White House Director of Disability Policy, and I currently work in the Occupational Safety and Health Administration, OSHA, at the U.S. Department of Labor. I'm a big believer when it comes to making change, right? So policy is one way. The other is when we talk about impacting culture, I. You can write all the laws you want in the world, but we still have to have people to be willing to follow them. And so I'm a big supporter of things that impact culture and being a little bit of a nerd and a geek, a lot of that is focused around fantasy and science fiction. And part of that also is because the idea that science fiction in particular as a genre is very much about social critique and does it in a way that allows people to think about what's right and what's wrong in our society in a way that puts it almost a little bit a step away, so it's easier to see. I'm a regular host on Adobe Radio's Geek Girl Riot with an audience of about a hundred thousand listeners. I do a lot of writing. I also started moving into film. I'm a founding member of FWD Doc, which is documentary filmmakers with disabilities. And I am currently working on a docuseries of Disabled Leaders for American Masters PBS, and I'm also the proud producer of the feature documentary, Unseen. And other than that, I'm in live in Washington DC uh, with my wife, N. Renee Brown.

Qudsiya Naqui:

I had the great privilege to work with you on Unseen as the Impact Producer and got to see some of your brilliance at work. You are both a lawyer and a media maker. You were talking about how culture is important to policy because policy can't exist in a vacuum on paper and it requires people to implement it. Can you expand a little bit more about how the law and media, together and separately, can be used as tools to dismantle ableism and other types of marginalization?

Day Al-Mohamed:

There's a study done several years ago in the UK and the idea was looking at how do you remove stigma around disability? And it found the number one way to help reduce stigma around people with disabilities was one, for them to spend time around people with disabilities, right? Because if you're with somebody, it helps allay fears, it helps disperse with some kinds of stereotypes you might believe, things like that. The second most effective way to address stigma was through media, because. Uh, if you can't be with somebody with a disability or meet with them, guess what? What you see and what you learned from media is the way you will see and perceive them, and that's what will shape what you think about folks. So the thing is, if you are exposed then to stereotypes and to these ideas that devalue the lives of people with disabilities, then your views are gonna be that. And I think one of the things that brought that very much home was in the last few years with COVID. in so far as we are in a global pandemic, we have, we have hospitals that are short on resources and the general idea is, hey, folks who need care should get care of course. And there are protections that have been put in place, right, that, that make sure that folks with disabilities aren't discriminated against. However, during this time of pandemic, what was happening is that, that there was this belief that folks with disabilities lives were less valuable. They were more pitiable, it was less, they were less successful, and so they were given less care, less quality of care, denied care, like to the extent there are folks who had to file lawsuits to get themselves seen and of course, and on the streets gonna be like, yeah, they're folks with disabilities.

They're actually more likely to die. And the the truth is, depends on the disability. So there are folks who had disabilities that had absolutely nothing that would impact their ability to survive COVID. Yet they were being denied care. Why? Because the idea is you have a disability. Gosh, oh my gosh. You are deemed as a less, you are less valuable to society. You are pitiable, you are. This whole idea, and these are. These are folks who are doctors, nurses. These are folks who supposedly have spent years of their lives studying the human body. They're learned, they've gone to college, they've gotten advanced degrees, and yet they are falling victim to the belief in the same stereotypes.

And that, and the direct results of people believing these myths about disability was that people with disabilities died. For me, that was a straight up example of where, yes, we have laws in place that you can't discriminate against somebody with a disability. Because of the cultural impact, folks with disabilities still died.

And so that in many ways is one of the reasons why I think that more inclusion of disability within media and more representation both onscreen and actually behind the camera, makes a difference because the more folks within a broader culture, non-disabled folks actually see representations of disability that are.

Authentic, realistic, and place value on individual human life, then, then that is the best way we have to actually really address some of the discrimination and bias that we're seeing.

Qudsiya Naqui:

I'm curious, for you, Day, in your own personal story, in your own journey with disability, was that true for you? Was there a point at which, in your growing up, in your sort of origin story where stories of others with disabilities started to reshape how you thought about your own disability and was there like a turning point for you?

Qudsiya Naqui:

In that regard, I don't think I have a turning point. I'm still looking for it. I think I'm still looking for those pieces and those stories and I'm not seeing them and so I wanna make them or I talk to other people who are working.

I'm like, that's a great story. The world needs to see it. In many ways I, I think the idea was it's not seeing a story that became a turning point. It was seeing the lack of stories that became the turning point, and I'm not sure that was any one individual moment. I think it just slowly started growing.

When I was in law school, I got the opportunity to intern at the Missouri State Legislature for Representative Bill Boucher, and he was putting forward a piece of legislation around the employment of people with disabilities. He was a non-disabled man, retired electrical engineer who was elected to office.

His wife was a school nurse and he thought, this is, this is a great idea. This is the right thing to do, but you know what, I should put my money where my mouth is. I should walk the walk. And so I should get a disabled intern. And this man didn't know anything about disability, but he wanted to do it right.

And so I became his intern through luck and circumstance, and it was wonderful because I learned so much about policy from him. And in many ways, I think he learned a lot more about disability and what folks with disabilities are capable of during that time. And I think from that point on, I got really excited about policy. I think that's one of the reasons, even though I have a JD, the idea of practicing law wasn't what interested me. 'cause to me that I looked at that and I was like, but that's trying to resolve a problem after the problem's already occurred. You can only come up with the best answer in a bad situation. If you're working on the legislative side, you are actually developing the policies, and if you do it right then there should be fewer of those problems that arise.

Qudsiya Naqui:

Is there a project that you worked on that recently you feel really shifted the narrative about who disabled people are and what they have to contribute?

Day Al-Mohamed:

Unseen, which is a featured film directed by Set Hernandez, and it follows aspiring social worker, Pedro. The restrictions he faces as a blind, undocumented immigrant on his way to get his college degree and be licensed and go on from there. And I think the toughest thing is in that film has been the idea of how this young man can follow his dreams, right? It's what everybody wants to do. And at the same time, obstacles that come in the way based on the way our society is built itself, some of that is, is because of his undocumented status. Some of it is because of his visual impairment, but. The issues that arise. It's about the community that's built around that and how he builds himself. And then also, one of the things somebody says, the story seems to meander almost the way his life does. And it's because he, he's been forced to find these other ways of doing things. And I really love the idea that it's not a story that follows the traditional. The moment you do an immigrant story, the moment you do an undocumented person and the undocumented person story, and the moment you do a blind person story, everyone assumes it's an overcoming story. Here's this person, and they have these big obstacles and they overcame them. And rah rah, isn't that great? And the fact of the matter is most of us are pretty regular folks who are just getting by just like everyone else. And there's good and there's bad, and we all figure out ways to work through it. In many ways the story is so much more authentic because it, it very much Hughes closely to that truth. And I think one of the things that the director did was, was to make sure that, to tell the story, one you wanna, he wanted to make sure he worked with the protagonist. So he worked very closely with Pedro, but two. Was to make sure that the folks on the team, our producers, our camera folks, our editors, everyone in many ways have an authentic understanding.

So there are folks on the team who are blind. There are folks on the team who are undocumented. We have a lot of LGBTQ folks on the team. And actually, I believe the team is majority people of color. And the idea was to offer the kind of nuance to the storytelling versus the kind of flat stories that usually make it, this made sure we could actually capture that in a way that's meaningful.

Qudsiya Naqui:

And what was your role specifically on the film and how did that bring meaning

for you?

Day Al-Mohamed:

So I and Felix Endara our two of the producers on the film. We started real early. So one of the things, as the producers, you end up covering a lot of ground. So we worked on things with distribution, we worked on things with regard to paperwork and some stuff with contracts and making sure people are protected. We did some line production type work, which is logistics and making sure that everything is set up well for everyone. I know one of the things that I was wanted to make sure was a big part of what we did is we made sure that anything we did did not put Pedro at risk.

And so whatever we could do to provide as much support in that regard as well. There's also the creative elements of, uh, working through with the film and the story, also looking at staffing and crew. So in many ways, one of the nice things about being a producer, even though most folks don't hear about it, as much as you get to see a film all the way, almost from an idea stage all the way through to the end, until it is on the screen and beyond, sometimes. So it has been fabulous working, uh, with this team and, and I think Set really went out of their way to make a really good vibe and that everyone feels heard. And the idea is we try to make sure that we work very well through consensus. So it's a very different way of working on a film, and I think it's one that I would encourage more crew and more team to teams to take on.

Qudsiya Naqui:

I always wondered what exactly a producer does. So given all these diverse experiences you have had in your career, both as an artist and a filmmaker and a lawyer, what advice would you have for young disabled folks who are trying to pursue their own paths?

Day Al-Mohamed:

Share the candy, right? When good things happen, if you can, you share the experiences, you share opportunities with other folks in your community, particularly those who are, might be younger, who are still working their way up. Also those who might be willing to share back with you. I'll give a example where this idea first started for me. There are very few black men working on the Hill as legislative staff, and the story I heard was there were two young black men on the hill, and one of the things they did when they first got started was when one of them was invited to a reception, um, he'd bring the other as his plus one when one was invited to write an article, if he was too busy, and couldn't, he'd say, Hey, I've got this other person who's great, and make sure the opportunity passed to the other. And the idea was, you're not giving up your opportunities, but the idea is when you have an abundance, the idea is, oh, I know this person. You should talk to them. Or if there's something that's not quite right, rather than taking it or doing it or just saying, I'm sorry, I can't. Passed on, and between the two of them doing that back and forth, both of their stars began to rise because both of them were in the stream of opportunity.

And so I'm a strong believer in share the candy, right? So when good things can happen, you wanna be able to work with other folks, because what happens is by doing that, more folks from our community get advantages. But also, honestly, it's also good. It's good for you because it can come back and it can lead you into paths that you didn't have before.

Because one of the toughest things about for many of us with disabilities and actually for many other marginalized communities, is we don't necessarily always have as broad a network into as many places as we would like to. And the moment we start doing something like sharing a candy with somebody else, we have, then automatically that network gets larger.

Especially if it's somebody who's who, like I said, they have to share the candy back with you. But the idea is that's one of the biggest benefits. The second thing that I would say, I. Is, find something that you like to do that you love, hobby-wise, or whatever else that has nothing to do with disability.

I think one of the most frustrating things for me, particularly with young folks, very young folks with disabilities, was to get very excited. I'm like, I'm gonna be an advocate and I'm gonna make all these changes around disability and accessibility, and everything that they wanna do is around that. And I, well, what do you do for fun? And they didn't usually have a good answer. And I think that bothers me because when the whole rest of the world is reducing us to nothing more than our disability, we shouldn't be doing that to ourselves, right? We should be well-rounded people. We should have things we like to do. Go hiking, play video games, watch films, write books, whatever.

It doesn't matter. But you know, have things that you love to do that have nothing to do with your disability. So those are my two little pieces of advice.

Qudsiya Naqui:

Those are great pieces of advice. Share the candy and have hobbies. Can you tell us about your newest project, Renegades, which is going to air on PBS next year, and share about how it came to be and what do you hope to achieve with it?

Day Al-Mohamed:

My first documentary was called The Invalid Corps, and it was about disabled civil war soldiers. I was fortunate to have it screened at Superfest in San Francisco. It was amazing to see your film in front of an audience, but, and while that was cool and exciting, what caught my attention was folks afterwards who said, I had never known this about disability history. I'd never known this about our community. And one of the ideas that I had been playing with previously had been about more broader knowledge of disability history. This was Civil War, disabled Soldiers. But how about something. One in four adults live with disabilities in the us, but despite its prevalence, disability, disability history is this like marginalized topic and it's both underrepresented and misrepresented. The Annenberg Inclusion Initiative shows that only, I think 1.9% of all speaking characters shown in films have a disability. That number hasn't changed in the eight years they've been analyzing films, and if we talk about disability history and culture, a survey of educators at K through 12 schools across the country, more than 50% of them said that in 2021 and 2022, they had never taught a lesson or part of a lesson that directly addressed something about disability history. Uh, another 36% said we did it maybe one or three times last year. And I'm like, so basically you covered Helen Keller and FDR. That's probably who they did. And if they got somebody modern, maybe it was Stevie Wonder, right? That gives us the Holy Trinity of disability. And of those folks who did teach disability history, 80% said they had to write their own lessons. And so just from that experience with the Invalid Corps and from looking at what's happening in both film and in education, we are missing a large part of American culture and history. The disability community is missing a huge part of our history. We see things like Crip Camp, which is awesome and amazing and this is great. This is the protest movement. This is disability history and disability rights, and I'm like, we were around a lot longer than then, so there's this audience that's basically hungry to hear more about themselves. What I wanted to do was to develop a series of documentary shorts showcasing the lives of the little known, uh, historical figures with disabilities, like all the way from the very earliest days of America as a country all the way to today. And I wanna talk about, uh, these folks, their impact and their contribution to U.S. society.

Not just that they live, but how they are driving and they were transforming American society. I want it to be a chance for us to look at disability culture and bring it to a broader audience. I think the joke I tell folks is I want a non-disabled kid watching a digital short about a disabled historical figure and go.

I don't want them to think about the person being having a disability. I want them to look at it and go, oh, that person's cool. I want disability to be cool. And so three years ago I had put together part of a pitch deck and this idea of saying, here's what I wanna do. This is loosely what the budget would be, and started trying to find someone to pick it up and this is where that share the candy does come into play. And while, and I had worked with other folks and someone had passed along that pitch deck and I started having a conversation with American Masters about a series of digital shorts, about folks with disabilities. And it sounds like this, oh, it all happened as magical. I'm like, no, we had to start early on to go, Is there interest in this? Does it work? There's a series of, uh, posts on the PBS main website and their profiles of three different folks with disabilities and history, and it's just a little bio snippets of them just to see is the audience interested, do people like reading it? And what was great was it proved that, look, people are reading this. Actually the readership for those posts was higher than some of the regular posts put up on their site. So it's look proof. And then in 2021, they provided funding saying, okay, it looks like there's interest. Let's film a pilot. Uh, that year I set out to write and direct, and I brought on Amanda Upson to produce a series, and our executive producer was Charlotte Mangin, who American Masters introduced me to. That way we'd have somebody who had a lot of experience producing to help make it happen. Between us, we decided we would do a short biography of Kitty O'Neill and I'm like, we wanted to find someone who was exciting and interesting and vibrant, and so Kitty O'Neill was a race car driver and a stunt woman. Her claim to fame is that she was the fastest woman in the world. She was in a drag, so she raced across the desert and she broke the women's land speed record. And it was awesome. She didn't just break it, she broke it by more than 200 miles an hour, so she blew past it so fast. They were afraid she would break the men's record.

And the problem is, right when you do that kind of racing, it's expensive. Those kinds of cars, like the fuel they run on, it's, you know, a thousand dollars a second sort of a thing. That's how expensive it is. So they'd contracted her to beat the women's record. But they contracted with the someone else to beat the men's record, and they couldn't have a woman be the fastest person in the world.

And so they pulled her from the car and they wouldn't let her race it again because they were too afraid that she would beat the men's record. And I was like, it's this amazing, almost a little bit heartbreaking story. And sadly, she did never get the chance to go back and try again. So she actually turned towards doing stunt work and she was known for High Falls, was her specialty.

And she also did a lot of things where you set yourself on fire, which we say back in the seventies was pretty, uh, dangerous. And not that it's not dangerous now, but back then I'm like, I'm imagine much more so. And the fun thing is she was the stunt double for Linda Carter who played Wonder Woman, and for Lindsay Wagner who played the bionic woman. Here's the thing. Kitty O'Neill was deaf. So a deaf woman is both Wonder Woman and the Bionic woman, and yet nobody really knows her story. And so we were so excited to be able to say, let's tell people about this stunt person who's Wonder Woman, you know, and held the land speed record for more than 30 years who has a disability? The fun thing is part of the episode focuses on Kitty's story. That coolest fact of her. The second part actually has a, a deaf expert, Dr. Rezenet Moges-Riedel, she actually talks about the concept of death gain, the idea that everyone thinks about hearing loss, but the thing is, within the community, there's this idea of deaf gain and what is gained from that. And so what it is, is we wanted to bring some ideas that are common to the community to a broader audience. And so that was the other thing that we did with that episode. And like I said, we want it to be light, we want it to be a fun, we have a fabulous host, Lachi, who's an EDM musician, and we want it to be, uh, as a, have a host to be able to act as our guide along the way who will ask the same kind of ridiculous questions we all ask. And when we get, she got a chance at visiting with, with a good friend of kitty's who had the dragster that she won some of the land records in and he said, oh, do you wanna sit in it? She was like, I can sit in it. And was super excited because I'm like, yes, because that's what we'd all wanna do if we were right there in the moment. Can I get in the car? We'd be the first thing we'd ask. And so we've got this mix of like history and disability culture and just a little bit of fun. And so that's our, was our goal with Renegades and the pilot. The pilot was in the top 15 of all the videos on PBS's American Masters YouTube account. We picked the idea of Renegades because we wanted to recognize how often folks with disabilities were accomplished or successful, did so operating outside the mainstream cultural and societal expectations is a chance we can kind of examine these fundamental concepts like identity or community or normalcy from a disability culture perspective, these are folks who actually were really awesome and they deserve to be a part of everyone's history. The stories that make it into history books and that make it into documentaries tend to be told by the dominant culture. And so this is a chance for us to tell our own stories. One of the, the flat out requirements we made is that it'll, it's disabled documentary filmmakers who are going to be telling the stories. Each of these episodes has a disabled team with writers, producers, directors, who all have disabilities. That way we make sure we capture that nuance and that we get a chance to authentically tell our own stories.

Qudsiya Naqui:

What happens next?

Day Al-Mohamed:

Well, I think that's the fun part, is you just heard the idea, this isn't this fun, and PBS just made the announcement. But the, but here comes the now comes the work. Now comes the, we're building the teams. We're selecting the profiles of who we're going to profile. We're looking at, alright, where do we wanna shoot?

Because if you think about profiling somebody, do you do it where they're born? Do you do it with somebody who knows them well? Which is what we did with Kitty O'Neill. Do you do it where their home is? Do you do it at a museum that might have a lot of their materials? Who do you wanna interview? Do you where, which experts are the ones who are best?

And how do you like connect? What disability cultural issue do you think is best reflected by this person's life? So we could have talked about Kitty O'Neill and we talked about it and the idea of death gain. Another story that we didn't go into, which would've been great, which is the difference between.

Black ASL and white ASL because at one point in time in history, just like regular schools segregated, so were, so were schools for the death. And then later on when the big push came towards Oralism and speaking, only many folks within the, the white community were pushed that way and many lost access to ASL, Whereas, the black community can trace their sign language. All way back without kind of an interruption. So there's this interesting story there that we didn't get to cover as much in a 10 minute short, but because we found the idea of death gain was a tighter connection to Kitty's story. So figuring out what is the element we wanna put forward is another piece of that. It then comes the building, the schedules, building the budgets, and then actually going out and going into production. So we are just at the beginning of what is probably almost a year long project.

Qudsiya Naqui:

That's incredible, Day. And I wish you and all the teams all the best and. I have spoken about this and discussed this issue with so many of my guests on the podcast at various points. This lack of this absence really of disability, history and culture in what we teach our children, in what we teach ourselves, and that has disadvantages and damage, both for non-disabled and disabled people alike because we lose these essential elements and these important characters in our collective story. When you have a shared identity and shared history with people, that is tremendously powerful and it's galvanizing. And I'm really hopeful that this project that you're embarking on with so many other disabled folks is going to do that for so many people, for whom, who have never saw themselves in the stories we tell about our country, about our world. So I am personally really excited for this project to release and excited to promote it and share it in whatever way I can through this platform. Where can our listeners find you, Day?

Day Al-Mohamed:

So the easiest place to find me is actually@dayalmohamed.com, so D-A-Y-A-L-M-O-H-A-M-E-d.com. I do have a link there to some of the film work.

If you look for Kitty O'Neal, PBS, actually it will show up on a general Google search and we have an audio described version. We have a captioned version, and we even have ASL. If you have an interest in science fiction, I would urge you to pick up the Labyrinth’s Archivist, which is a science fiction novella.

And this is one of the reasons I love my, my publisher, Falstaff Press, because they said they were looking for, for a science fiction novellas. And I sent a note back going, I have a murder mystery in a fantasy setting. The main character who is our detective, who's solving the mystery is queer brown woman.

Who is also blind, and they said, send us, send me the first chapter. And I sent them the first chapter. They go, this is great. We'll send you a contract. Finish the book. And so there's a novella out there with a blind detective. There are no superpowers, no fancy figure out. It's the way, as blind folks, we actually operate in the world and guess what? We could still solve a, a mystery, which is what this is. The main character, Azulea lives in the Great Archive, which is modeled off the great library in Alexandria. So there's a lot of more like Middle Eastern style fantasy as she tries to discover who murdered her grandmother.

Qudsiya Naqui:

Thank you so much, Day. It was such a pleasure to sit down and chat with you and get to know you more.

Day Al-Mohamed:

Thank you. This was great and a lot of fun.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Thanks for listening to Down To The Struts. This episode was produced by Ilana Nevins and me. Our social media manager is Avery Anapol, With special thanks to Claire Shanley for designing our logo, and to Eiffel Gangsta Beats for our theme music. For more about the podcast, visit us at downtothestruts.com,

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