



## Episode 7: Getting Active: What Did we Learn from the Experts?

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### Audio commercial:

Hi, this is Lindsay one of the co-hosts of beauties and head canons. Thanks for listening to the following broadcast on Public House Media.

### Audio Commercial:

Hey there, it's Rachel Mullins the host of hashtag. No Filter Friday on Public House media.

[Upbeat intro music] Disarming Disability

### Nicole:

Welcome back. We just went through an awesome chapter called getting active which we are going to talk more about and we're going to like talk through thoughts and decompress and just like talk about what we learned with each other. But before we do that, Sarah we really have to ask you the last time we were talking with you. You are going to meet a very special friend. Can you remind us of what that was and then tell us how that went.

### Sarah:

Absolutely when we had recorded Our Guest Becky who spoke about disability. And in the email she just said, hey, can we do a shout-out for Evie and her family that are living in Prescott, Arizona Evie has a hand that sort of It just has a hand difference.

Becky had met them on an airplane and showed them the American Airlines video that I had done and they just thought it was so cool. So they're like, hey, I actually get to meet Sarah and we're talking with Sarah. So can we just do a shout-out? Like hey Evie, you know, like look at this connection and then we brought back. I was like wait do you mean Prescott Arizona? Like, what would you mean in Prescott Arizona? I happened to be in Prescott right now. I'm I came to sort of help out with some things we're going on in my family.

So I was like, oh my God wait, I'm here. We have to meet up. So I was able to get the contact information for both Evie and her family and we met up we got some at this really cute little bakery. That is Jenny is the Evie's mother that really likes so she took me

out there like a little cinnamon roll all the girls got little yogurt bowls and she brought Evie who's our youngest daughter and then she has two daughters that are older than Evie so we had just went to the park and we just sort of sat and chatted and it just was really beautiful to see too see them and they were really excited to see me and just to be able to talk about all the things and of course Evie's younger. So she just like oh, this is awesome. I love it and it just was really cool.

And then just so validating to hear some of just what Jenni's experience because then and it's just like this is why the work that we're doing is so important, which is really fun. And Jennie is awesome. And I called my partner afterwards. I was like, oh my God like "Jenni is someone I'd like I'm gonna be her friend like we were totally be friends."

So then she a couple days later. She's like, you know, "if you everyone go get drinks, let me know" and then we did we went out last weekend and just me and Jenni and her wonderful, and her really good friend came too. It was just so nice to connect and then you know after we've been out for a little bit. There's lots of like "no you're amazing. No, you're amazing. You're so sweet." So it just was so much love and just so excited to be able to connect with them and to just be able to fit that fill that or complete that circle. and of course Evie had lots of questions and Evie had some questions and her sisters had some questions that and it really just like a cool hangout. So, you know fun for me to be able to see somebody with a limb difference.

That's absolutely something that I love and be able to connect and then fun for them to be able to see somebody of the limb difference too. And I'm just so excited and just sort of reflecting that the first time I met anybody with a limb difference. I was 19. So having to go through all that on my own. I'm just so excited for these, you know, they seem small but very important changes that were in the world right now where we can be connected through, you know, social medias and whatever and emails and be able to to make all those things. So it just was so fun and I'm so grateful and they have such a beautiful family and I'm so excited for them. And I'm just so excited for like these parts of the world that Evie can grow up in and and just trying to do right by her and instead of remembering her face and in the work that I'm doing and just trying to be the the

Brightest possible light for her and for you know, all the girls that are growing up right now with will different boys to you know, and whatever but you know, if pretty grown-up will different just so that we can create a better world so they can be proud of who they are.

**Nicole:**

It's so beautiful and so special. It's so special. I love it,

**Sarah:**

Right the Stars just aligned. So it was really wonderful. All right. So this is our chapter review of the getting active chapter and just as a reminder, we've had a really wonderful

experts for this section and we had Jay Ruderman from the Ruderman foundation. And then we had Danielle who is a casting director. And then we had Emily from Ada 25 Advancing Leadership. And then we had Becky from DisabilityIN which is a organization that is a Consulting organization that partners with with pretty prominent and pretty massive organizations as far as how they can make their their companies more inclusive for people with disabilities.

**Nicole:**

Yeah, it was great. So if you missed any of them, I mean we're going to talk about it now. So I guess in theory that would get you caught up but like these experts are amazing and I would really encourage you to go back and take a listen to what would be amazing things that they had to say.

Again. Just such like when we say the word expert we need experts these people are are doing the work day in and day out and they're passionate about it and they are thoughtful about it and they're in it for the long game.

So really they are building beautiful foundations and beautiful stepping stones for the Disability Community as a whole which is so cool and my favorite part like it's not it's not a short-term thing. It's not it a quick "This is helpful to me." It really is people who are thinking about the community as a whole and I think that's my first thought

**Sarah:**

And I think that like, these are our leaders that are creating actual. Right now like they are the ones who have been like leading and researching and studying and being, you know, like being a part of all these different groups, but they are the ones that are writing how we move forward with disability in our culture today and sort of in each of their different very distinct groups.

**Nicole:**

Yes. I I agree and I think that what was fun about this group is they are are changemakers from the inside. I guess is going to be the term that I use all four of them are working inside a system of sorts. And the inside this system they are creating relationships, they are creating opportunities, they are meeting with correct people in order to create change.

So you would be an activator outside the space. Right? You can be somebody who is not within the system who is asking for change, begging for change, demanding change. But then there are the people inside the activated space as well. And that's definitely what these four people were doing and it was fun to hear the different ways that they would about that.

Because for example, it was really fun. I thought to hear from Jay Ruderman who it's a Family Foundation. He is not every year, you know having to write some sort of Grant

proposal hoping that he doesn't say the wrong thing so that way he's not getting money. He he effectively, his foundation can do what they want when they want right?

I mean, of course it's you know more than that, but but really it makes it so he is able to be and he talked about this in our interview. He's allowed to agitate maybe say things that others may be wouldn't be able to for fear of some sort of retribution or fear of some sort of defunding or fear that you know, they wouldn't be able to continue on whatever for whatever reason that is.

And yeah, it was it was fun to hear how he understood and realized that and then the ways that he went about listening and too people with disability and having them on boards and using and they're their thoughts to understand the bigger problem to write the white paper. So he has the knowledge to back it up, you know, like really doing the homework, but also then saying I have the money to do what I want. Let's go.

**Sarah:**

Yeah. Yeah and just so thankful that he chose this and so thankful that he chose that he chose disability and is really intentionally being a huge support system and a really dr= big driving force behind a lot of the work that is happening right now.

And again just not having like, okay. Well we have to get this thing, you know, like sort of approved and maybe it doesn't fit in our financial budget this year and maybe it's something we believe in but there's other things that are you know that we need to get taken care of with this money. Like there isn't any of that so that that change can happen to faster and he's like consulting with really prominent leaders to to be able to write the white papers and and then they're building the 20-Link. I believe it's what it's called or Link 20.

**Nicole:**

Yeah, it is Link 20.

**Sarah:**

That is the organization of new, not new but like younger advocates so that they can have, you know be equipped with all of the information that is needed so that they can be change makers to and sort of integrate change making as they do grow into their professional careers, which is just so amazing. So it's not just like him, you know, I go look "I am fabulous" no, he's actually creating real change and he's making sure that the change is sustainable by doing things like Link 20 so that it can continue on and sort of has that backing in that sustainability.

**Nicole:**

I just I feel like you know as I was coming into my disability as I was coming into my Disability Pride a handful of years ago. I wish somebody had said start with here are for example, organizations of work that's being done and community that exists because I

just feel like these are spaces, these are these are the people I was working for initially and didn't know how to find them simply because it took me asking and talking to a million people to figure out what the culture at was and who the people were and what it was and of course, I mean that's the whole idea of why you and I are doing this like what let's bring that information from people most find it right?

And I think he's against for are just such good conversations of what actively is happening. You are not alone like I thought for the longest time my story was just in a vacuum. I knew so- meaning, I knew people paid attention to my story and you that I was special because people are paying attention to my story, but I did not understand the context of it.

I didn't understand the history of it. I didn't understand the social dynamics that came into play. Nobody taught me Disability Models. I didn't understand models existed and and so it once I woke up to that.

And I realized that these people in these places and these ideas existed like this is the work that I was so Desperately Seeking to find. So I guess I guess what I'm just saying is like look into these more because these are doing the work that you you think it isn't being done. It's be done! Guess what we need to talk about is being done. But we're talking about it might be done

**Sarah:**

and that within all of these faces like you can be a part of it you know? like you can you can apply to be on link 20 you can you know, like work through, you know, if you wanted to be an acting like you can sort of work with different casting directors.

Like there's spaces for all of you to be a part of this should you feel that that's what you want to be a part of a fear like, oh they have this totally fits on board with my personality in the things that I want in life and the types of skills that I want to learn and then the spaces that I want to work in and that there's absolutely space for you.

And in your if you're in the greater, Chicago the area I like you can be a part of the eight you like you can apply to be a part of the Ada 25 advancing leaders program and and be connected with that Network and you can you know, if you're somebody who is you know, recently graduating from any type of STEM curriculum that you can apply to be a part of DisabilityIN and that is really working to partner you with an organization who is really actively trying to build disability into their world and you can sort of have a supported setting and and practice interviews and do internships to really get involved

because I feel like the climate is really changing and really wanting to listen and really wanting disability to be finally a part of it. And these you know in this is this isn't just because now suddenly people decided like this is part of of you know centuries of work that has been doing to try to get society to space where this is the conversations that

were able to have, you know, I even think back on my own life and and just how powerful. You know like learning about 504 in that, you know, federally there should be no discrimination as far as you know, people being able to seek employment and housing and I know that you know, that doesn't always look like that in the landscape and stigma is still pretty heavy.

But but because of 504 like I'm able to be a flight attendant and I'm sure and I know that there's a lot of people that were unable to be a flight attendant based on all of the standards that existed in you know, the the 60s and the 70s, but just knowing that that piece of legislation like really gave me access to be able to apply and then get hired as being a flight attendant in you know, 2013, you know had I been alive or tried to apply to be a flight attendant in the 70s and had I met every other aspect or you know qualification for it, but they you know, that would have been it completely impossible for me because that was not protected under it.

So just knowing how that piece of legislature from that you know, whatever before I was born. Allow me to be in the space that I am right now and gave me that access and just like how profound a powerful that is and knowing that the work now that's being done. No worries and to know that the work that's being done now is really continuing to provide access even broader than that for so many people who identify as having a disability and even being proud of having a disability, right? I feel like I know both the Nikki and I we've both talked about sort of the the need to feel normal and then they need to really lose our disability identity or not even be able to take on that as a piece that would identify ourselves as being or even being proud of it because we were trying so hard to pass as normal to have it not be brought about because disability was not a conversation it was being had anywhere let alone a conversation that was welcomed or or you know, sort of a allowed to be in the space. If That makes sense.

Yeah, so I'm just super excited from where we've come and I'm really excited for where we're going. I know that there's still so much work that needs to be done. But I'm just really excited for all of these spaces that are opening up for everyone to get active and get involved in all of the different ways that that work for them and in the work for the week they want to.

**Nicole:**

Yes. I've nothing to add. Yes, that was Perfection. Yeah, and what you're starting to touch on is activism that we can be a part of we're seeing a lot of activated spaces now with the Black Lives Matter Movement, and there is a lot of activism that yeah that I think we can take notice of and it absolutely is not just a it's not about disability right now.

Although there certainly is huge conversations about intersectionality that need to happen in our company in right now. However, with that said, you know mindfully that the activism seem in real time the are things that we can take notes on and we can

apply to our own to our own version of rights that we're still fighting for because it's true we are.

**Sarah:**

People can get active so many ways like and I feel like there's very similar paths to activism that span across any, you know, all types of movements that are happening and that have happened. And when I was in my occupational therapy program, I took a course that was on sort of like Leadership and Management and one of the assignments that was required within the course was that we had to look up a bill that was either in the House or the Senate and we had to find something that was occupational therapy related and write a letter to our appropriate Congress members saying that we you know wanted to support this bill or didn't want to support this bill for these reasons.

And it was really cool because you know, I found a bill that it was something I really cared about and it just was really powerful to be like, "oh wait I can do this" and it doesn't take that much time and I'm sure it takes, you know a little bit more mental Clarity and energy to be in a space to sort of like dig around and look at bills, but I just didn't realize oh maybe because I don't exist in I didn't study politics or any of that type of stuff and that's not necessarily, you know, thinking of what bills are currently happening isn't something that typically is in my life to be like wait? I can actually look at what's going on.

So you can go to congress.gov and they have all of the different bills that are up you can sort of see where the bill has gone. You can click on the actual bill read the like actual verbiage as far as what's included in there and you know sometimes built tittles sound great. But then when you open them up, you look at the way they didn't think that these things would be included in there. And you know, if it's something that you really want, you can or that you really believe in whether supporting or not supporting, you know Congress members, like that's their job is to listen to the people and and you are the people it just was really powerful to be like, you know what you can't so also I hope that if people feel compelled where that's maybe where their voice is the strongest or something along those lines if that's what you want to do.

We can totally look up to see what that's happening which is really powerful for me and then similarly within organizations whether you're working in them or you're partnering with them, you know, people want feedback right? Like people want to be I mean generally I would hope organizations want to be organizations that are helpful for the people and that you can be able to submit inquiries about that.

I just uploaded a video on an Instagram platform and it took me like like no joke, like almost two hours to try to figure out how to get closed captioning subtitles on a like two minute video to accept Instagram just because some other closed captioning systems. It's little more automated but just it was so complicated to try to like get the transcript

of the video to then try to find like a you know, you had to go through one application to get you know, and these are all like third-party applications to get the transcript and I had to go to another one to like burn it into my video and then I wasn't able to edit it and it was just like wildly maddeningly frustrating.

So then I wrote, you know, like a suggestions and comments feedback saying like "hey, Instagram, you know, like please build closed-captioning component into your videos so that more people can have access to it and and something I found really powerful to was to look up mission statements for different organizations. If you want to contact them and sort of like really, you know, if what you want falls in line with the thing they have in their mission statement then sort of use that

And I believe Instagram's mission statement was like "sharing the world's moment" and you know that I sort of wrote that in my like, you know whole little form thing that I submitted just you know saying in order to like effectively share the world's moments. We need to make them accessible and you know, there's a 1 in 20 people identify as deaf or hard of hearing that would really benefit closed captioning and closed captioning not only helps our you know, individuals create access, but all so if you're in a space where you can't have a video you playing out loud, then you can just read the closed captions like that's creates access for people who don't necessarily identify with the deaf and hard of hearing community. So just these are like really cool small like, you know, very tangible action steps that that you can create advocacy and that way if you know sort of that like using your voice in submitting feedback.

**Nicole:**

Yeah, it's kind of I'm going to use these terms again. I'm totally making them up. But it's it's the idea of like are you doing work inside the system? Are you doing work outside the system and so are you kind of are you building the building blocks? Are you right? Are you writing the bills or are you writing letters to the people who are writing the bills are you marching to get the attention of the people writing the bills. Are you helping with verbiage and language on the bills? Are you consulting on the bills,

you know and that can apply to to not only politics it but to companies as you're talking about Instagram or two different organizations that we see like it applies in every single facet and I think it's really important to understand that those two pieces of work are both equally important and equally needed right we need to be activating our voice in one way or the other or whatever way we, you know feel comfortable in or maybe in one season of life. We're using it in one specific way in an another, you know a different way or maybe we're doing

You know 12 different not 12 different ways, but both ways in 12 different facets all the same time, you know, and and I guess so true and it's I think what I want to underline is just regardless of how you feel compelled to get active and and to connect like if something is important to you and as you're learning your voice is important and it's



important in spaces not only where you feel heard but in spaces where you don't feel heard. And that we need to be speaking in both and we need to be creating space and both and both strategically from the inside and push from the outside as well. We need the agitation in both places. Yeah, so we need we need that that activism to be to be it needs to be activated and we got to activate and members in both players

**Sarah:**

Yeah, and then talk about it.

**Nicole:**

I think it's important but else get active. That's that's that's how I feel. Let's find a way to start. I mean my the term I like to use is I like to yell into the void quote unquote and I just yeah, however, I'm feeling that day. I just yell so find your way to yell into the void. I love it.

**Sarah:**

Find way to yell into the void and it is here for you and we'll post those links and resources to do on this website as well. I'm sorry the disarming stability webpages Associated to this episode. But yeah, get out get active make change happen.

**Nicole:**

Let's create a better world guys and work with the world connect with the community. So important and disability as a whole and that's remembering that that yeah, we can be a community all together. Even if we have all these cool like flavors and facets and intersections that we still are one Community.

**Sarah:**

Yeah. We are We Are One community and you should be proud of that community. And also we're so excited to share that we partnered with Hannah and she is a really wonderful human and she is an artist and she makes stickers and she is she identifies as having a limb difference and she is starting an occupational therapy program, you know, so course I'm in love and she makes these really beautiful stickers and

and she partnered with us to create a "Be Proud" sticker and we're so excited to share that that has dropped this week and just really coming back to that that disability and your identity or things you should be proud of and and that we hope that everybody feels proud of sort of their all of their identities and that you know, it's not sort of be. I don't know stifled or ashamed of disability. I know I felt ashamed of my hand for a very long time but just sort of this like, we you know like yeah be proud of who you are.

So stickers are up there on her Etsy store will have a link in our website and we'll have them on our Instagram. They're durable. They're these really cute little hearts they "Be Proud" in the middle and there's flowers on the outside and the flowers are made with our season 2 colors. So it's totally on par and then with that we're splitting the profits so

and this is something that Nikki and I've been wanting to do for a while and we're still working through Logistics of what it means to actually start it, but we want to start a scholarship for disability, you know disarming Disability Advocates so that people who want to engage in anything related to advocacy whether it's going to a conference or taking a class or taking a workshop that these could be funds to help support people to do that because it totally falls on par of all of the things that we really care about, you know, we want representation and we want people to have connection to the leadership opportunities so that they really are, you know armed with having all the knowledge and resources to like get out and made actual change.

So please stay updated as far as what that looks like in the future and when funds will be available to be able to access and sort of what things people would be able to access them for. We're definitely a ways out. But this is just a street as seed to start that going so we're really excited to share. We're really excited for Hannah. We're really excited for the sticker. So please check it out be proud and get active.

**Nicole:**

Yay!

**Sarah:**

Thank you for spending part of your day with us. We want to give thanks to our Network Public House media for intro beads to Jason bars with cybernetics our local art. We want to remember Patrice. You can find his work at [normal person's.com](http://normalperson's.com).

**Nicole:**

Be sure to follow disarming disability on Facebook and Instagram and lastly be sure to check out our website [disarmingdisability.com](http://disarmingdisability.com) where you can find all 13 episodes of season 1 links to resources transcriptions and discussion questions for each episode and our blog where we feature amazing Disability Advocates. See you next week!