



Episode 42- Empowering Individuality with Inclusive Style

May 22, 2024

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest Family of Content. I'm your host, Mindy Henderson. Together we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them. We are here for you, to educate and inform, to demystify, to inspire, and to entertain. We are here shining a light on all that makes you you, whether you are one of us, love someone who is, or are on another journey altogether. Thanks for joining. Now, let's get started.

Yasmin Keats is the Executive Director at Open Style Labs or OSL, a national design, award-winning nonprofit organization. Initiated at MIT in 2014, OSL is dedicated to making style accessible to people of all abilities. Yasmin comes into this field with her own experience of living with a physical disability and has a background in graphic design, architecture, and creative learning. Such an interesting background. Yasmin, thank you so much for being here with me.

Yasmin Keats: Lovely to be here, Mindy, and thank you very much for having me.

Mindy Henderson: Absolutely. We've been talking about doing this for a while and I'm so glad to get a chance to sit down and chat with you a little bit. You have such an amazing organization. I know MDA has worked with you all in the past on projects and things, but before we jump into a lot of specific questions can you just tell us a little more about Open Style Labs, what you all do, what programs you have, and just kind of the mission of OSL?

Yasmin Keats: Yeah, of course. So Open Style Lab was started in 2014 out of MITH Lab, and with the real mission of how do we educate the next generation of designers to know how to do inclusive design with people with disabilities, and not for them. Our foundation is in education and we run a program which is around six to 10 weeks long, it can vary, where we bring occupational therapists, people with disabilities or elderly, designers from all different backgrounds and engineers together to design functional wearables, garments, clothing, products, experiences, but with a focus on style, and beauty, and how these products can do something past just function, which I think we all feel in our day-to-day. The way that we use an iPhone or what we choose when we go on a date or for a job interview, that it's not just the clothes that we wear but it integrates into our identity and our style and who we are.

Mindy Henderson: I love everything that you just said and I particularly love that you talked about creating style and fashion, not for people with disabilities but with people with disabilities. I love that perspective and it's sort of that nothing for us without us kind of mindset. I think that that's so important because you have people all the time who I think are maybe well-intentioned but they don't know what they don't know. And, I feel like inclusive design in any industry, it's so important to include the people that you're actually designing for to make sure that you cover all the perspectives. And so, I just had to stop and tell you how much I love that. So tell me about your role with Open Style Labs as executive director, what do you do?

Yasmin Keats: I joined Open Style Lab three years ago, originally as a researcher. I always say it was such a wonderful way to come into the organization because my job for the first two years was just to talk to people with disabilities from all over the world about their experience. I think I was at a stage in my life, I was late twenties or mid to late twenties, where I was starting to figure out how to feel comfortable and to talk about my own disability so in a way it was very healing and it was also very humbling because you started to see across the board all the different challenges, which made my own look very small.

It gave me that foundation, which I think makes Open Star Lab what it is, which is the community. So, then I went on to work as the educational director where I ran the summer program that we did in 2022, which was a really wonderful experience. Last year I was very honored to take on a position as executive director and what that's shifted in my day-to-day is, I think I'm a lot more focused on where do I want Open Style Labs to go and it's been wonderful to also have the support of the Board. It's like having three mothers.

Mindy Henderson: Yes.

Yasmin Keats: And, really thinking about how do we expand Open Style Labs mission and create more impact and bring more people with disabilities on board in this journey as well. I have amazing team. I guess I'm doing less of the interviewing one-to-one of people, which I really loved from the research, so I kind of made it a rule of I'd love to set aside some time once a week just to talk to at least two

people in the community so that it never loses that groundedness, but, yeah, a lot more administration. But I do love it and I love the team and it's really exciting to think about what is the future.

Mindy Henderson: Yes. Well, and I feel like I've known you for probably about a year, maybe a little bit longer now. You're very humble and I know how fantastic you are and what you bring to Open Style Labs. So you're wonderful and you've shared with me some of the vision for how you're expanding and some of the things that you're doing and it's all really, really exciting to hear about. And, you mentioned a summer program, and if I'm not mistaken I think MDA participated in that a couple of years ago and members of the neuromuscular disease community were invited in or maybe applied to be part of that program. They actually, I think, got to bring one of their visions to life and actually create some things in an adaptive way for the style world and see what that process was like, I think, to actually get to have an idea and bring it to life.

Yasmin Keats: Very often when we do a summer program we'll team up with a non-profit and it was wonderful to be able to team up with MDA. And I think you brought your community and we brought the designers and different participants together around focusing around how can we make ... That particular year was around clothing, and style, and fashion, which I think is the main crux of Open Style Lab. We started in style and clothing, I'd say style and not fashion because fashion is trend.

Mindy Henderson: Oh, okay.

Yasmin Keats: And we feel style is more about linked to identity and the way in which you navigate the world and express yourself. But yeah, we started in style and clothing because I think no one was doing it really 10 years ago, where it was very, very rare. And unlike a wheelchair and a staircase where when you see that it's quite obvious that mismatch as you're aware, Mindy, you don't watch someone get dressed in the morning. Unless it's you personally or a loved one, it's a very rare act to witness and to understand. It's those daily acts, daily routines, daily practices of just putting on clothing that can be a real barrier for many, many people in the community. And, not even just putting things on and off but also choosing things and being able to have access to items that can fit your body and also not cause you harm, a lot of the time.

Mindy Henderson: Yeah, and one of the things that you also mentioned a few minutes ago that I think is really great is you said that you involve and work with occupational therapists, which is great. You're getting so many different perspectives from the community itself but then also occupational therapists who part of their job is helping people learn how to do things in their daily life. And so, they're of course very familiar with how a wheelchair user, for example, may put on a pair of jeans and what the struggles are and those sorts of things so I love how broadly you look at the style world and try to solve the problems. It's all very interesting.

Yasmin Keats: We absolutely love OTs.

Mindy Henderson: Yeah, they're so good.

Yasmin Keats: We really do appreciate them because I think OTs, we've identified them as people within the professional community that look at the holistic view of the person, and the aim is not to fix, it's to enable you to do the things that you want to do.

Mindy Henderson: Yes.

Yasmin Keats: And so, they are a slightly different breed.

Mindy Henderson: It's true.

Yasmin Keats: I just call them and they really ... We also say they're the original hackers because often they have had to hack on the fly and repurpose and redesign things to get something to work with their client. And so, they understand the importance of what we do so there is a mutual appreciation, and when OTs and designers come together there's a lot of magic.

Mindy Henderson: I bet, I bet. One of these days I want to be a fly on the wall and be part of one of those sessions it would be so interesting. Let me pause for just a second and there's so much to talk about with you, but I do want to ask about ... We've mentioned that you also live with a physical disability. Do you mind just sharing a little bit about that? Of course, so many of our listeners have their own disability and so I ask for a couple of reasons.

First, I think that it probably lends some additional expertise to what you do because you really understand, you get it, the landscape. But also, I always love to ask successful women a bit about their journey and how they got to where they got to today and what they had to ... In a lot of cases, the challenges that they faced and had to overcome in order to reach a level of success for them because, again, there could be young women listening who are just starting out their careers or maybe they're still in school. I love sharing those stories.

Yasmin Keats: Definitely. As many of our listeners will know, it's part of you.

Mindy Henderson: Yes. Not all of you, but part of you, yes.

Yasmin Keats: Exactly. I'll talk a little bit about that later but how much it defined, I'm doing quotation marks. Or, was part of me or accepted part of me or not accepted part of me has changed over time and morphed in different ways and I'm sure it will continue to do that, how my disabled identity interacts with the way I do my work and life. But I was born with ... My mother had chicken pox when she was pregnant with me, super rare, and actually my symptoms are kind of quite similar to polio, it's often been compared, where I have nerve damage in the

whole of my right leg and my lower back so it had affected whatever was growing at the time.

And so, I wear a leg brace and I walk with a crutch and my right leg has very little feeling and is a lot thinner and atrophied than my left. So that's a kind of overview about my disability. But also background, I came from a very creative family so my mother is an architect, my grandmother was a sculptress, and her mother was a painter. I was in and out of hospital a lot when I was a kid and in out of different wheelchairs and mobility aids, and it was something that we always really cared about was how can we make this beautiful or how can we make this experience a little bit more joyous or colorful or ... I'm coming up with different solutions.

I also, from having months at a time where I couldn't go to school or things like that, it actually also gave me the space to learn to sew, to paint, to have those creative outlets so I did see how the space that the disability life gave me allowed me to go into those fields or harness those things and my family. And then when I was 18, I would study architecture and I was the only physically disabled person in the whole school, and that is very primarily due to the school was not accessible in any way. It was an old, Georgian building in London, which if you've ever been to one is just narrow corridors and stairs galore. You couldn't even get into the front door if you were in a wheelchair.

Mindy Henderson: Oh wow.

Yasmin Keats: At age 18, I didn't have the language. I didn't have maybe the confidence to ask, and so I just went along. And, the toilet was either on the very top floor or the very bottom floor so every time I needed to go to the toilet that was also a half an hour excursion.

Mindy Henderson: Oh, good heavens.

Yasmin Keats: And actually bad. I ended up ... I now see that it's really shaped my view about what we're doing at Open Star Lab because we're looking at education. I even gave a talk at university a couple of months ago and I even went back to my old university after 13 years and, still not accessible. And another place I went to they couldn't even get the lecturer, a friend of mine who is in a wheelchair, who uses a wheelchair even up onto the lecture hall so because the elevator was broken. So, kind of iterates our mission, which is if you can't even get people with disabilities in the door just to talk to the [inaudible 00:17:37], how are we going to get people with disabilities to become designers in these institutions or give them the confidence that they can access those spaces. And I have seen wonderful examples of more and more spaces that are being more accessible as time has gone on, but there's so much work to do.

Mindy Henderson: There's so much work to do. And yeah, thank you for sharing all of that and I think your advice is wonderful. If there are young women listening, I think it's so

important to know that you're allowed to ask for what you need and I think that if you've got ambitions and goals and dreams for yourself, I just never want to see someone back down from their goals and their dreams. And I think you're right, I think it's about finding the confidence at a young age to be able to almost kind of advocate for yourself and make it known. And, if you advocate for yourself it's only going to benefit other people down the road as well.

Yasmin Keats: Definitely. And I know this is probably for a lot of listeners as well. Disability, I think it's the only minority that you can be born into without anyone close to you also having this.

Mindy Henderson: Yes.

Yasmin Keats: And so, I actually didn't really know anyone close to me that had a disability until I was a lot later in life. I think it made it harder. It made me feel like I just wanted to not make it a thing, which looking back I would never give myself that advice. I don't believe it anymore but I know there was that struggle when I was a teenager in my early twenties on how much this "defines me" and how much it is a part of my life, but also not. And it took me a while even to get into this work because, yeah, I was worried about it becoming my whole identity but, at the same time, it is a part of life and it's a part of everyone's life.

We all have bodies, we're all going to have challenges with our bodies. And also, through integrating and talking and being part of such a wonderful creative community, you also see how so many people that you meet with a disability, they've had to become so resilient and problem solve in a way that you never would've thought of. It's such an exciting space. Regardless if you have a disability or not, it's such an exciting space.

Mindy Henderson: Absolutely. Yeah, and I will say that I personally feel like adaptive style is having a moment. I feel like just the awareness, probably thanks a lot to what Open Style Lab does, I think that so many more people are aware of the needs of a bigger community than style and fashion has ever designed for in the past. I personally am starting to see more and more stores carrying things, more and more designers and brands who are making it cool and are designing really beautiful quality things.

I think it's really exciting. And, in fact, I also just have to mention really quickly, I think it was, was it last year that Open Style Labs did the first of its kind fashion show that included the SMA community, spinal muscular atrophy community, and all of the clothes were designed by Open Style Labs with people living with SMA. The models were people living with SMA, and that was really exciting to see. I think it was during Fashion Week, if I'm not mistaken.

Yasmin Keats: Yeah, I think it was the first runway show that was just dedicated to this community in New York Fashion Week. I think it was in Spring Studio so it was

an amazing production which matters because I feel it needs to have the same quality in that way.

Mindy Henderson: Absolutely.

Yasmin Keats: Or, it's important to have that. And it was such a wonderful year. This was 2022, that was my first year as educational director, and we had fashion designers from all over the world come with the SMA community from SMA My Way, which was showcased, I think, in New York Fashion Week and it was in New York Fashion Week Calendar as well in the center of New York City, so.

Mindy Henderson: So cool.

Yasmin Keats: It was a great moment.

Mindy Henderson: I know, I wish ... I'm just going to put it out there. I wouldn't mind if you did it again because I live with SMA and I would love to design some clothes and come be in the fashion show, but let's ...

Yasmin Keats: Well, I will keep you in mind for future.

Mindy Henderson: Thank you, I appreciate it. So let's talk about some more of the thing. Like I said, there's so much to what you all do. A large part you've mentioned gathering research and using that research and expertise to educate, design schools and brands. Can you talk a little bit about the research process and then the education that you do and what that's all like?

Yasmin Keats: Yeah, of course. So we've been doing research on a number of different things and then either creating resources that we can bring all that together and give back to the community. A lot of it goes on our Instagram so kind of research of what is different adaptive brands that are out there or bags or tips around Halloween costumes or ... A lot of what we do, also you'll find a lot on our Instagram. We also create journals which are a combination of many different subjects. So we've done one on work wear, we've done one on pants, on undergarments, on media representation.

It's our way of trying to bring in secondary research and our research together as well as different things happening within the community into a concise way that then can be resources to design students or different designers or people within the community to learn more about what's out there. Because we've found that there are very little resources, especially around this subject, and told and produced in a way that is accessible from an educational point of view as well.

Mindy Henderson: And you are going directly, I know, to the disability community for your information. In fact, you've approached me a couple of times and I think we've put your surveys out there in the hands of the neuromuscular disease

community to give feedback on, like you said, things like shoes and what their challenges are and those sorts of things. And then, do you mind talking a little bit about more on the education side? Do brands and design schools and things, do they come to you seeking the information or do you have to do a lot of outreach to get them to listen? Or do you find that they're really wanting more and more of the information?

Yasmin Keats: We find that they're wanting more and more to work in this area and it's been wonderful to see that there has been this kind of organic interest in inclusive design and working with the community. And so, it's all been organic and so that's been wonderful to see ...

Mindy Henderson: That's so exciting.

Yasmin Keats: How that has evolved. And yeah, we hope it will continue to grow and I think it's also, it's a way of, I think, seeing where the industry is going in that way and I think we see it going in a positive direction.

Mindy Henderson: That's fantastic, so let's talk more about that. My next question I wanted to ask you was the sorts of innovations that you're seeing show up in industry as a result of people listening to this community, innovations that you're seeing or new trends for function. Anything that really particularly excites you that you're seeing start to emerge.

Yasmin Keats: Because there's many different ways, I know that you'll understand this as well, Mindy, is that it's not just doing one thing in this space. You've also got to look at the shopping experience, the way that people with disabilities are represented.

Mindy Henderson: That's a great point.

Yasmin Keats: Education of designers, so there's many different waves in that sense. I think we saw a lot maybe more representation in advertisement five years ago or whatever and more recently, or 10 years ago. And then, now it's more we're seeing actual products that are coming out. And so, you start to understand that that's deeper work within an organization that they've done that. I think what I'm excited about is just that it's being normalized, just that it's becoming a thing and it's not like that ...

Mindy Henderson: That gave me goosebumps.

Yasmin Keats: You're not thinking this is ... I think the less excited we get every time we see a new brand bringing something out, that's better in some ways that it's just a given, that inclusion and inclusive fashion is part of their line or part of their way of designing. And, that with the diversity, equity, and inclusion awareness, which has been so wonderful to see, I know that the disability community often felt like we're the last ones or we've been kind of left out of the conversation a

lot of the time and it's wonderful to see that it's becoming more and more. I think what I'd just say is just normalize, let's just normalize it.

Mindy Henderson: Yeah, I agree with you. I love that, and I think that you're right. I think more and more we're seeing people with disabilities in advertisements and we still need more of that, like you said earlier, there's still work to do. But it's becoming a little bit more common to see that in advertisements and on television and to see people considering, like you said, the shopping experience in retail stores and things like that. I think that that's so exciting, in addition to the fact that this is an industry where you get to a person, disability or not, gets to express who they are in such a personal way. I think it's an industry where it's so very important.

Yasmin Keats: Definitely, and I think clothing is the closest thing to our skin, one of the first things that people see. And so, it does have a lot of effect on not only how we feel, how we're able to move through the world, but also how other people see us. And, it has a real ability to change stigma, I think, within around disability. Clothing is very powerful ...

Mindy Henderson: It is.

Yasmin Keats: And it's one of the basic needs. We need food, we need clothing, we need shelter. Fashion is not frivolous, it's not at all.

Mindy Henderson: It's not. It's not an extension of ... I mean, in addition, like you said, to being a basic need, it's such an extension of who we are.

Yasmin Keats: Completely, and it's also very linked to social inclusion as well. Like when you think about going to a wedding or being part of a uniform or a job, or these moments in your life are often celebrated by clothing and being able to take part in those moments as well to the full.

Mindy Henderson: So true.

Yasmin Keats: I'm just going to say one last thing, which is what I've often heard as well, is that often with a disability you are put in situations where you don't have so much control around things in your life so I feel like a lot of what I've heard is that clothing, and fashion, and style has the ability to help you control your narrative or give you that autonomy of how you want to be represented.

Mindy Henderson: So good.

Yasmin Keats: Not always but it is just a tool for that.

Mindy Henderson: Right, right. Oh, I love that, that's so insightful, I've never heard it quite put that way. I do want to ask you, and I wish we had two more hours, but I want to ask you, I think, two more questions before we have to wrap up. I want to talk just a

little bit about the future of Open Style Labs. Can you tell me a little bit about how you're expanding or what accomplishments you're most proud of or what you're looking forward to in the next year or two with Open Style Labs, or are those top secret?

Yasmin Keats: Not top secret. So we're opening a branch in London, which is really exciting, and it'll be wonderful to see how the two cities can work together as well and what they have to offer. This summer, we're doing our summer program around footwear, which I'm really excited about because we've never done that before.

Mindy Henderson: Oh, great.

Yasmin Keats: We have a few projects in the work thinking about just how can we expand our program and how can we get it to more places, more people, through many different means, and continuing to have that mission of awareness. And, for me, it's also very important that we leave those spaces for ... We have a workshop on Saturday, I don't know when this is going out but this Saturday on June 1st, on Dining with Style and Dignity. These are workshops which also call out to anyone in your community. We hire people with disabilities to run the workshop if they have an idea and want to bring something that they think they want to talk about that they think is important or often not talked about.

And so, this one's going to be run by an amazing woman called Monique Stemp, and she's bringing on two friends of hers. One is a chef and one is a sommelier, and are both wheelchair users, and talking around designing a fine dining experience or the dining experience and what that means as someone with a disability and how to do it with dignity, and not just from an accessibility point of view but further that.

So I want to say I'm also open to different topics, different collaborations on what to focus on next. We know we've done a lot in clothing and fashion but there are a lot more areas that have the same texture in terms of look at style and self-expression that maybe isn't just focused on fashion but is maybe focused on performance and many different areas in your life and how style integrates into that.

Mindy Henderson: That's wonderful. That's so exciting. And, of course, we're going to put information in the show notes about how people can get in touch with you or Open Style Labs if they do have ideas for you, so that will all be in the show notes. So last question. What is your hope for the future when it comes to access to ... Let's focus on adaptive apparel for those living with a disability, or should we focus on apparel? Maybe we shouldn't.

Yasmin Keats: You are the change makers. You are the most untapped resource of creativity and the problem solving skills that you have, the way that you ... We constantly need to adapt to situations that aren't designed for us and be creative. I guess I'm just trying to say is that you are part of the solution and I don't think settle

for being made for anymore. It's about being part of the conversation, and that's what I hope. I hope to see more disabled voices at the table leading the conversation. But also recognizing that disability is, and what I hope for for everyone else is to recognize that disability is not something separate, it's a part of life. And so, it's not about designing for people with disabilities, it's about designing for all of us and for all of our futures.

Yes.

Mindy Henderson: And how do we bring people along on board with us on this journey, not alongside us but not like a separate [inaudible 00:37:32] either. Start the conversation that I'm going to say, again, normalizes it. It's about this is just a part of life and working in inclusive design practice and methods just produces better design. We've seen it again and again, an out of the box thinking and innovation. And in a world where I think a lot of the design industry is grappling for meaning, especially in the fashion world, this is a way in which you can look at innovation in a completely different way just through collaborating with this community. Yeah, I see a lot of possibility and excitement for the future of this but people with disability need to be in the room.

Agreed. Oh, so well said. I can't think of a better note to leave this conversation on. It's always such a pleasure to talk to you. I know that we'll be working together again so just thank you for your time and for being here today and sharing more about what you do and creating some excitement for our community.

Yasmin Keats: Thank you very much, Mindy, and it's always lovely to talk with you too.

Mindy Henderson: Awe, thank you.

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