Matthew Flanagan - Feb 10 2020

**SPEAKERS**

Molly Joyce, Matthew Flanagan

**Molly Joyce** 00:02

What is access for you

**Matthew Flanagan** 00:07

So, I think access for me is interesting because I live in two worlds of disability, I have a very physical... very visible physical disability and that I'm a wheelchair user, but I also have peripheral blindness due to degenerative retinal disorder. So, access for me includes physical spaces and what that looks like. But also, there is the invisible this invisible disability in physical spaces. So, like, not only can't my chair get through space isn't as equitable for me. But is the lighting right for me? Is it safe for me? Right? So just going into I think the misnomer is that, well, you have a chair, you won't fall, and you won't do X, Y, or Z. So, like physical access, can be interesting. But then it's also in terms of that visual disability, it's web access. It's, it's when spaces include physical or web access, what that looks like for me. And like how intentional or unintentional people have been about those spaces, because I think it goes on a continuum from "we didn't know", all the way to, "it's not a priority". And then to "Well, it's an inconvenience." But I think there there are more important questions in terms of access, it's not just about getting into this space, it's about what's there for me to thrive in the way that I define it in those spaces. And having conversations with people so they can understand what that means for me, rather than them deciding for me. Because I think that's something as people disabilities we're always fighting for, at a minimum for people to presume competence, that we have the capability to know we want to be self determined. So I guess that's where I sit with access I... With that perspective, it's still and being a professional in the field. So like, my background, is I come I was originally a special education teacher, in New Jersey, taught students with a broad range of disabilities and moved into doing what's called technical assistance in states working with them to improve systems. For young people with disabilities, I have a pretty big interest in supporting young people with physical disabilities for obvious reasons. So with all that professional knowledge, I at times don't feel like I'm any better equipped to fight particular barriers that the young people that I work with face. And I think the only difference is, I know it can be different. And I don't think they always know that. But a lot of the times, it's, I mean, like I tell them all the time, I became an expert in certain things, and access and support by going through them and fighting through them, probably right before I met them. Like that day, like that morning, I was probably fighting with this and figuring this out. And I go there not because I read it in a book, but because I'm like, and that's kind of where our conversations go like, well, this, this problem you're experiencing right now is not internalized. This is not something that's that comes from you, it comes from the environment, it's a social construction.And I was just dealing with it too. And even though I was dealing with it, my experience, that my social construction of disability is completely different than yours. So I think I think access is equal parts like us, the social constructions and then the interplay between them because those two things look totally different for one or two people like our... how disability is constructed for... on society and then placed on us are two very different things depending on the way that we look in the way that people perceive us. Yeah.

**Molly Joyce** 03:59

What is care for you?

**Matthew Flanagan** 04:08

So care has been interesting in that I've done a lot of experiences and done a lot of long stays in hospitals of my life from my, my physical my disability that the reason why I use a wheelchair is I have a normal neuromuscular disorder. And that has lent itself to really long four or five months stays in hospitals and care for me has been advocating for what care means. So I've had an uphill battle for a decade now. Which is when my my, my disorder kicked in. My rental disorder I was born with a form of both of them are both genetic, but my retinal disorder I've had has kicked in like when I was born, it was right away and my secondary my neuromuscular kicked in when I was in my late teens. So being a teenager, and going through from now to being 28, care has been fighting against doctors and medical systems. And really, I wouldn't even say doctors or medical systems, just the medical perspective disability, and them thinking that care is being in a nursing home, which has happened multiple times, successfully and unsuccessfully fought that. And care has look like well, this is the space that we think will be safest for you, that you should be in versus what are your goals? You know, what are your goals, forget about like, this whole thing of like care is "you need to go to physical therapy every single day" and fit some normative model of walking or whatever it is, which has led me to learning how to walk against my own self determined beliefs, I don't know how many times I've learned how to walk different ways. None of them were what I wanted to do. Ranging from using almost full body braces with metal and you name it feeling like a robot, and loft strands and walkers, and you name it. And it's funny because people in like in the medical field they consider care, like getting you as close as possible to being able bodied, whatever the heck that is. But for me care and ability is using my chair, my chair is the most liberating tool that I have in my disposal, not that I won't use braces or, or lost strands, or canes or whatever, or walkers or rollators. But it's it's about that I choose that it's that day that I say that I want to use that and then there's no discussion about why I'm using one one day or another day, what my rationale behind it, I shouldn't have to explain the way that I feel that day that I need to do it. It's just that's my version of care, I guess, my care for me is, is kind of you can't parse it out from like, self determination, at least, that's probably mostly due to the how many times I've had to fight this uphill battle with systems of putting me in nursing homes with 85 year olds, and leaving me there for, you know, three or four months at a time. So yeah,

**Molly Joyce** 07:25

 it was amazing. I was so excited to like, score these or, you know, put them all together. What is control for you?

**Matthew Flanagan** 07:38

Yeah, I guess, not to like wrap them all together. But control? It's a good question. Because I feel like it's easy to say that it wraps them to the whole medical, but it's so much more than that, like control is also it's not just about like, where you go and where people let you go. But it's like how people perceive what you do and what you're capable of. Like, it's little things like my fiance, and I go into a restaurant and asking him, what does he need? Or what would be best for him? And our response, Usually, I'll catch her before she even says it is. I can tell you, you know, like, you know, so it's it's just funny that there's no presumption ever like, "Oh, I might be speaking to a doctor or professor, someone who is working nationally, right with disability rights movement. Oh, no, I'm just talking to someone who's and this is the term that I hate. Like in a wheelchair, I'm just talking to someone who's in a wheelchair. And this is probably their caretaker, who's making decisions for them." That's where their control sits. So it can be little things like that, but can also be like, control over like, the, like the identities that people put on me. My fiance and I were talking about this recently about like, it's not only it's not only ability, but it's like the secondary things where people feel like you shouldn't have control over your not only your professional career, like the spaces that you go on, but like your sense of self and your sexual identity. And like D... The depersonalization and the sexualization of people with disabilities is something that I definitely experienced constantly, like how could people who use a wheelchair be attractive? How could they feel attractive? Like what does love look like for them? How can they control that? I think those are questions that look really different depending on what disability you have. So I know, like the young people that I work with intellectual disabilities, that's a significant, social, socially constructed challenge that they have to face. Like fundamental questions like, like people, people without disabilities, questioning. Whether with people disabilities have any say or control over like love and the ability to do that, which I think are are dangerous, scary, fundamentally dehumanizing things that we know over time that when we don't advocate for control, people with disabilities now and to this day we continue to be placed in the Borderlands. And sometimes that looks societal, but sometimes that means we're in institutions, or we are euthanized at birth. I mean, people think that happened in the 50s. That, but it's, it's the reality that in 2020, some people with disabilities don't even have control over whether or not they're born. And if I were born in, you know, instead of the early 90s, I was born in the 50s. That I may not have been. It's something that I definitely think about that if I was born in the eugenics movement, they would, they would say, so this, this kid is, so I was born legally blind, and gain more vision through surgery. So this kid's legally blind, we already know that he won't be able to have control over this, this, this, this, this and this life. So therefore, your two options are X, Y, or Z. And I think without saying we kind of know what those are. So yeah, I think

**Molly Joyce** 11:27

What is weakness for you?

**Matthew Flanagan** 11:38

I think weakness for me is internalizing what other people think I'm able to do. I don't know how many times a day, a week, a month, a year. People say like, you're such an inspiration for doing blah, blah. I'm like, I'm such an inspiration for being on the sidewalk. Like, that's how about I'm an inspiration, because I persevered through an educational track and went on to do X ,Y & Z and build this professional career like why isn't that inspirational? So can you hear me the question again?

**Molly Joyce** 12:20

What is weakness?

**Matthew Flanagan** 12:22

 Yeah. So yeah, so weakness. I feel like weakness for me is this ongoing thing of like how much I let those external dialogue permeate how I feel about myself, I don't feel like Personally, I don't feel like I. And it's not a it's not like a confidence or an ego thing. There are always things that we can grow, there are things that I'm not good at, but I don't consider that a weakness. I consider that, like an area have to give attention to in my life, but none of those things that I consider, I'm not going to have to do with the fact that have a disability. It has to do with the fact that like, Oh, I need to go more training or do this or do related to my field, or, you know, and I don't see like disability in any way, wound up in like, character flaws that we all have like, like, whatever, like, yeah, so just being humans, like obviously, we're all far from perfect, but I don't feel like that has anything to do weaknesses of myself have nothing to do with my physical disability, but I feel like it's other it's harder for others to disentangle those, they just kind of see one box, and they put everything inside of it. And I think weakness for me is. So like, it's not only how much you let the outside world and narratives and dial-dial discourse permeate you, but then it's like, what you do with it. So like, if there was a weakness related to my disability, it would be like me being lethargic about not pushing back on it and like, having people say these things and press these or reading about these things, or seeing these different things and being like, well, I guess that's just the way it is versus like, No, fuck this. That's not the way that it is. This is it can't it can't. So I think weaknesses is probably also wound up in self advocacy, which I feel like is also wound up in care and everything else. And it's probably just because we're constantly in this like, in this state of pushing back. That if we like, it's impossible to think about the other categories without i think i think it's impossible to think about the other categories in a way that pushes us forward as a community, people disabilities without thinking about self determination, self advocacy, all of them Because I think they've been redefined for us. And we need to advocate for ourselves to redefine them before like, we really start to unpack, like, we can't even unpack what they are. Because we need to, like, define them first. And we haven't been able to do that.

**Molly Joyce** 15:18

What is strength for you?

**Matthew Flanagan** 15:37

It's interesting. That's, that's the hardest one to say. And that's probably...that we're so like, having two disabilities and advocating, it's like the conversations ever about strength. It's always about like, bringing back to baseline, like, having conversations to save to show people that you're not here, and I'm here that we're here. And like, then there's no more breath left in the conversation. So like, well, I also do these things. By the time we've talked about, like deconstructed all the things that you set all the ablest things that you thought about me, then I'm like, well, no one, there's no room in the conversation for, like, the things that would people would consider strength, like, I also go to the gym, and I'm on a power cycling team. And then then you have to say, like, Oh, you could go to the gym, or you can be on a paracycling. That's so inspiring. Like, no, I'm just, those are things that I do. And then like, talking about getting through doc programs in and building a career and doing all these different things. And like, yeah, it's, it's so interesting to think about, like, in the, in my work, I do so much, so much work with supporting young people in figuring out what their strengths are. And we kind of have like processes or like experiential opportunities and learning to do that. But it's makes me this question makes you realize, like, how often do I think about what strike means to me, like, as an individual, I guess the word strength in in my daily life is like, is helping others figure out what that is, and helping them set plans and work towards that. And that's probably out of not having a lot of opportunities with people with disabilities. Who could do that for me. I'm the only person in my family who has any disabilities. So definitely the black sheep in that regard. So strengths for me, no one had that experience. So they really didn't know how to help me define that. Yeah, it's an interesting question.

**Molly Joyce** 18:04

Okay, it's interesting, it kind of turns into the hardest question. And

**Matthew Flanagan** 18:08

Yeah, it is. And it's just speaks so true to like, even though we fight constantly about this, like this disabling construction, and like that big web of everything that goes into it, like we really don't spend any time talking about our strikes, as people.

**Molly Joyce** 18:30

Like without relation to it, not to say,

**Matthew Flanagan** 18:34

Right. And then like, it's interesting because like, imagine if we could just talk about strength, and disability without the ablest construction, like there's nothing fundamentally wrong ever with having a disability. Like identify as disabled and with with disability culture, the only thing that are wrong with it are what ablest culture puts on it. So like, we'd almost like don't have any conceptual understanding of like, what strength is in disability, because strength is just taking everything back to basics like that back to baseline thing for for me,

**Molly Joyce** 19:12

like doing ablest actions. Yep. It was kind of a controversial question. I definitely don't have to answer. So. What is cure for you?

**Matthew Flanagan** 19:25

 Huh? No, I definitely. For me, cure doesn't exist. Because I think it's unnecessary. I think any efforts to by external forces, whether it be people you know, whether medical or society To bring me to some ill conceived notion of what they think, you know, an able bodied person is, and their rationale why that needs to exist is just I think it does our society no good. I think that the more diverse we are, the more equipped we are to modify our world in a way that it reaches its fullest potential. And I think when you have a society that its primary focus is on cure to bring everyone into some specific form, then we don't maximize the potential of the environments that we live in, I think. And I think that when you go on these cure, I don't even know what campaign like but societal medical campaigns, you it's funny because cures always put towards people with disabilities in and it's for people with specific disabilities to, not to spike it and and, and most definitely, those efforts are disparate towards particular groups and others, including disability culture, but if you remove it's like the stupid things to like, if you remove all people with disabilities, and the efforts that we take to, to support inclusive environments, then you're you're kind of by proxy making those environments less equitable for people without disabilities. So people who are elderly people with who are pregnant people with whatever work that whatever is not considered disability, so then what do you cure them to? How far does the cure go? What what's your end goal? It just seems so short sighted. And I think, I think our when we think of cure, the second thing we need to think of is how do we remove that narrative from our culture? Because people would say, Well, okay, well, cure looks different than it did in the 50s. It doesn't mean lobotomizing people anymore, it doesn't mean sterilizing people. So well, they're still sterilizing people in 2020. Well, it doesn't mean mass genocide. Well, that and that's the thing to people don't even remember that. And, you know, in Nazi Germany, and in Europe, cure meant the mass extermination of people, with people with disabilities, millions of people with disabilities were killed systematically because on the sole purpose that they did not fit a normative profile, they were not able bodied. And therefore, not only were they not worthy, but they were uncurable. So I think cure is also wrapped into like, if you say cure, then you have to also make a decision, like who's incurable and what you do with them. And who gives people the right to make that decision. And it's definitely not people with disabilities, we have no, we have no stake in that game. Because structures are built and have been maintained that prevents us from getting into professional policy or leadership roles that allow us to make fundamental changes to those any of those hegemonic structures that would help us to eliminate this idea of cure. And I think you see this in some organizations that call themselves advocacy, but people with disabilities really pushed back on him I think about so like, the autistic community now pushes back heavily on Autism Speaks for their emphasis on cure. And you see the language interestingly, now their language has pushed away and they started talking about it, you can still hear cure in it, but it's but it's more along the lines of like, living something along the lines of like living today and what that looks like and maximizing that and then like for brighter tomorrow, but it's even that like, it's almost like ableism light, rather than saying like, Cure was evil like, but think about down the road or like a better tomorrow. And then it's like, well, who gets to decide what better tomorrow is? Yeah, I just think fundamentally cure is such a dangerous word. And I think it's been used in my life by by the medical field in society to suck up a huge amount of my time that I could have been putting proactively towards my career and things that I wanted to do that I will never get back. And I think the only reason why that happened is because care was in their mind. And I think it was in my family was in the systems that they put me in. And I think it was Yeah, it just sucked up so much. freewill. And I would hate to, and I would hate, I hate to I hate knowing and I hate knowing that that's other people's experience. And I also hate knowing that that will be people, young young kids who are born now with disabilities, it'll likely be their experience to remove care from the conversation.

**Molly Joyce** 25:22

What is interdependence?

**Matthew Flanagan** 25:33

Boundaries. I think interdependence is boundaries between like, what people normally think and I feel like I think of interdependence among relationships. So like a setting a boundary between what everyone else considers and like pulling what they think like that caretaker role is out of it, getting that the hell out of it. And then just only talking about interdependence in terms of like the society and social capital, and removing that like, the even the any presumption that like, because I'm engaged, that it's like, I rely on that person, more than they rely on me always that there's not a pendulum which always exists in relationships, and not even between my fiance and I, but anyone else. And I think interdependence for me is less about my relationships with people and more about the tools that I use or have access to, I don't feel like I'm a dependent on people, I feel like I'm, I depended on systems that give me access, I'm interdependent on them, that give me access to being able to use different tools that I want to use. So if there's anything I would say that I'm interdependent on my chair as a tool, not as a place, or my Walker, or whatever I use as a tool. But I don't consider myself into interdependent on people. Yeah,

**Molly Joyce** 27:17

that's another place what is the assumption for you?

**Matthew Flanagan** 27:22

Assumption is my whole life, past, present and future, but I don't think that is any different from people without disabilities. I just think that there are different assumptions that were assumptions right. And I think that goes into the like, the responses and conversation we have all gone through this that it's, it's like not even a s...assumption. assumption gives me the gives me the feeling that like people have to see you in order to, to think about what you are and what you believe in what you do what you can and can't do. But I think it's like for people disabilities, it's presumption, like you don't even be in that space don't even know you exist. To know, to have this clear, I know, it's clear from talking to people, I'm breaking this down that like, they don't have to even know that I exist in this 6 billion people in the world. It's just like, doesn't matter you're you're in a wheelchair and God forbid, I'm a wheelchair user, you're in a wheelchair so I know exactly what you can you can't do you know what your life is going to look like they make they make presumptions across my entire lifespan that while you're you're in a wheelchair now so your life is only going to get more difficult as you go on meanwhile I'm like, I'm pretty sure that being in you know, using my wheelchair not being in a wheelchair is increasing my quality of life throughout my lifespan, but I think it's not even like I said it's not even assumption it's like presumption not even exist like I feel like you like we're so a more like people disabilites so amorphous to people without disabilities that it's like and I guess that goes for other disenfranchised groups too. Like I'm I'm sure having no experience like no, I don't claim to know that experience but like, from talking to people and learning about that through other people's experiences that like other disparate groups also talk about this feeling of like, you're You don't have to be in the room for kind of your whole life to be laid out for you already.

**Molly Joyce** 29:34

Yeah. And last one, what is difference for you?

**Matthew Flanagan** 29:51

I guess dif-...got thinking about strike like difference is strength. Difference is Innovation. Difference means that I'm not lesser that I comment situations in an alternative way that you may not have been able to look at that situation that way. And because of us being there together, we're able to construct something that otherwise something positive that couldn't have otherwise existed. And I think that I think that difference has been weaponized. In our particular, in our current societal socio political climate, I think difference is seen as weakness, rather than strength. It's very hard to, to talk about difference and not and not talk about all the things we've talked about, like social construction and ablest and defeatist and deficit perspectives, it's so hard to do that. It kind of goes back to like, like, defining strength and like, it's hard to define that. So it's easier just to, just to think about it's, it's like, underlying structures that we use to, to define strength, I don't know. And it's interesting, too, that that just like strength difference is so hard to define. And that's probably because despite best efforts that even though we constantly push back on these constructions of ourselves, no matter what we do, they're internalized in us, which kind of shuts us from even thinking creatively about what could be. We're like, so stuck on what is that we can't we, like the most we can do is think about like, what is and then like, what works well, and it's so hard to move into a place of like, capitalize on, like, what works well, in terms of like all, like, what works out work, what works? Well, is all difference and the full continuum have that. And then like, we can't even do that. So how do we go from like, all difference works well, and how do we capitalize on all difference? Like we're not even in the we're like in the dirt? We haven't even built the foundation yet to move to a place where we can start building like levels of what that looks like. So yeah, it's a complicated question, for sure.