

STAY Tuned Episode 22: Living With a Disability- Work, Life, and Self-Advocacy with Destiny Maxam

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Emily: Welcome back to stay tuned, supporting transition age youth. This podcast is brought to you by the Transitions to Adulthood Center for Research at UMass Chan Medical School, Department of Psychiatry, and in partnership with our research sponsor, the National Institute for Disability, Independent Living, and Rehabilitation Research. I'm your co-host, Emily. And I'm your co-host, Mei. Today, we are joined with Destiny Maxam. Destiny, would you like to introduce yourself?

Destiny: Hi everyone, I'm Destiny. Thanks for having me today.

Emily: Oh, thank you for being here.

Mei: Um, so we've gotten the chance to talk a little bit about your lived experiences before, and if you're comfortable, we would love, um, for you to share your story with our audience, um, and to know like what coping mechanisms helped you overcome the challenges you faced.

Destiny: Yeah. Thank you, Mei. So my, my story is definitely, um, one that's a little out [00:01:00] there. Um, I guess I'll start off with, I am somebody that has a genetic condition that is known as vascular Ehlers Danlos syndrome type four, which is a mouthful for basically my body doesn't know how to hold itself together, um, anymore.

So it's a connective tissue disease, but what happens is. 80, uh, 80 percent of your body is made up out of connective tissue in case you didn't know that. And my body produces faulty collagen and, um, that causes my organs to spontaneously rupture. It causes dissections and aneurysms to form. I've had multiple bowel perforations.

And when I say multiple, I mean over 10. Um, I now have an ileostomy, um, which is a bag that holds my output, and I also have a urostomy because my bladder ruptured three [00:02:00] years ago, and I'm also fed by a feeding tube because my stomach is paralyzed. So I have a GJ feeding tube, which means that I'm fed into my intestine, but I have, um, A essentially like a bag that's connected and puts out all the bile so that I don't constantly get sick from what my body produces.

Um, so it's a progressive genetic condition, um, that will get, you know, a little bit worse as you age. I'm 31 for context now, and I was diagnosed when I was four after my dad gave me a hug that ruptured my bowel, and that's what led to my diagnosis. In addition to that, um, I got a little bit of a genetic lottery.

I also have epilepsy. Um, which has impacted my life, um, severely. And when I was 18, I was undergoing, um, open heart surgery to have [00:03:00] an aneurysm repaired and a nurse forgot to put up the bed rail after, um, my surgery. And I had a seizure coming out of anesthesia and I fell out of the bed and I severed my spinal cord.

And that led me to being paralyzed from the waist down. So I'm now a wheelchair user. I'm a paraplegic with a, um, it's an incomplete spinal cord injury is what it's called. And yeah, that it's really changed. It's changed my life, um, in a really huge way. I previously lived in Wisconsin, but after that, Um, accident.

I refer to it as my accident. Um, I wasn't able to go home. I had to live here in Massachusetts because back home I lived on a farm and that was just not accessible for a wheelchair user. So, I moved my entire life here to Boston. I became pretty [00:04:00] sick after my spinal cord injury due to the combination of my injury and my vascular Ehlers Danlos syndrome, the, um, they didn't know how the two would go together because VEDS is commonly referred to, um, is very rare and, uh, was one of the first, I think I was one of the first and still am one of the very few people with a spinal cord injury that have VEDS and, um, That led to a lot of, a lot of serious complications that I wound up in a nursing home where I spent five years of my life, um, and it was really difficult, um, but I, I did eventually through a lot of self advocacy get out of that nursing home and I moved into a group home where I spent another four years and then I learned about self advocacy.

MRC services, and I was able to move into my own apartment the day before the world shut down due to COVID. And I have now been in my apartment for the past [00:05:00] four years, and I'm married and I have a dog. I'm really happy with my life currently. But yeah, that's a little bit of my story. Um, and when it comes to, you know, coping mechanisms with it, you know, to me, support is the biggest thing.

Um, I wouldn't have made it through anything that I've gone through without the support of my VEDS community, as well as the support of my family, um, and friends. They definitely got, got me through, um, everything that happened to me. They visited me almost daily when I was at Spalding rehab. And then

when I was in the nursing home, they always, always made sure that I was never alone.

There was a rotation of, of friends cause they knew that I was really, really struggling, struggling with my life changes. Um, so the first thing to me is support, you know, and then not being afraid to, you know, seek outside, you know, resources and help speaking to a therapist, you know, um, antidepressants, anti [00:06:00] anxiety medication, because things were really hard for me, and I needed to, um, I needed to grasp that situation, so I had to, I had to admit to, not just myself, but to the people around me, like, yeah, this is hard, and I think I need some help, um, so I utilized those, and, and now it's just, um, continuing to, you know, monitor, you know, mood fluctuations, um, Utilizing medications as needed when needed, um, and continuing that support, support base and immersing myself in things that I enjoy, um, those, those things may look different now than they did, um, before my accident, but I'm still able to enjoy them just as much now as I was back then.

Mei: thank you for sharing. I think I can speak for both of us. Your story is so incredibly inspiring and like I've talking to you before you are just like a sunshine human. [00:07:00] Um, I think you radiate a lot of positivity and, um, I guess my question, my follow up question is for those who may not have a strong support system, like how did you, how do you go about building that for yourself?

Because I agree, I think a support system is, is so essential for anyone who might be struggling, um, in any sense, or even if you're not struggling, I think just having a support system is so important. So how did you go about building that?

Destiny: Yeah. Um, that's a, a very good point. Um, so my dad was the biggest supporter in my life and unfortunately I lost him, um, to pancreatic cancer.

And when I lost him, I felt like I had to rebuild, um, a lot of my support. Um, and how I did that was through social media. Um, at the very beginning was I, I, Well, at first I created, um, a social media group because there was nobody out there for VEDS specifically, um, [00:08:00] there were things out there for Ehlers Danlos syndrome, but not for my subtype.

And so I couldn't find it. So I created one for myself. And, you know, I, I reached out to people that I knew that had this condition. I added them there and we just kind of slowly built a connection with one another and expanded. Um, So I would say utilizing social media groups is the first thing. If you have

support groups, you know, join those support groups, make a post, um, you know, look for the Inspire, you know, threads, which is another, um, resource for people with, you know, invisible disabilities or, you know, any chronic illness, you can go there and start there.

Start with the people that have the same condition as you, because you don't feel as alone if you don't have that in person support. There's, there's so much, um, support that's offered on the Internet these days. And then from there, you'll actually have a chance to perhaps identify some people that, you know, live near you and you can, you know, start these a regional [00:09:00] group of friends.

That would be my first suggestion. But if you're able to, you know, getting out, putting yourself out there with your hobbies, the things that you like. I love dogs. Um, I'm an all person, animal related so that when I got my puppy, I started going to dog, um, dog parks, even though I hated the idea of dog parks, I went there because I was surrounded by other people that liked dogs.

And I'd see one that's like, Oh, they have a chocolate lab. That's. That's something that's like me, let me introduce myself and that was a connection that was a support, and then they slowly got to know me and we exchanged information and now one of my best friends was somebody that helped me pick up dog poop at a dog park because I couldn't reach it because I was in a wheelchair.

I mean, and this is a friend that I've now had that's You know, been for seven years that I never would have had had I not gone and had that opportunity of just putting myself out there, even though I wasn't comfortable, I definitely stuck out like a sore thumb, but it was, you know, the way that [00:10:00] I was able to make that support.

Mei: That is that is awesome. Yeah, I think that's a great tip is choose what you love to do and then seek out communities that also share what you love to do.

Emily: Yeah, I think that's great that you were able to, like, especially form that community online, um, when, like, you didn't have anybody else with VEDS online that you were, like, able to connect with. I think that's great that you were able to be the one to, like, start that, and I'm sure that was very helpful for a lot of people.

And, like, speaking of support systems, I know that you had mentioned earlier, Um, a little bit about the MRC, which is the Massachusetts Rehabilitation

Center. Um, could you maybe talk a little bit more about like those resources and what, um, I know you had, I don't know if you had mentioned the waiver in this episode, but I know like before when we met with you, you talked a little bit about the waiver that helped you like get an apartment.

Um, could you maybe [00:11:00] talk about that and like how that was really important for your journey too?

Destiny: Yeah, of course. So, MRC played a huge role, Mass Rehabilitation Commission, that is going to be rebranded to MassAbility soon, and that will make so much more sense than what they currently stand for, um, is a huge component as to, uh, where I am.

So for so long, MRC has, is a state funded agency, um, first and foremost, and their primary goal is to provide people with disabilities, um, various resources around employment, around home health services. Um, vocational rehab. They have so much that's available to them. It's hard to tie down one specific component for MRC.

So I'll focus on the thing that they helped me the most with, which is their waiver program. Um, for me, they took specifically, I was able to move out of the group home and into my apartment and how they [00:12:00] did that was something called the waiver program. Um, so waiver support services. And the MFP program, which is the Moving Forward Plan, is a specific, um, program that's for people that have spent at least 90 days in a nursing facility, um, and they're eligible then to qualify for so many resources, uh, for medical equipment, for, um, assistive technology.

There's. You kind of name it and they they can provide it for you at this rate. So at my apartment, they helped me find the apartment. They helped me fund the apartment and they also helped me get it. Um, I quit because I'd never lived on my own before. So I had no furniture. I didn't have anything really to my name.

Um, so they helped me make it my own, including like, you know, the paint and all the fun stuff that, you know, is involved in it, which is to me, what was the most exciting part of the whole thing was [00:13:00] furniture, shopping and decorating. I mean, we get down to it. That's That's what I was the most excited for when moving in, um, but they also provide, help me provide services for, you know, my PCA program for home health, a home health aid, um, for homemaking.

So I have two different aids that come in and a nurse, um, that comes in to help me meal prep, that helps me clean, that helps me do my laundry, that helps me get ready for, um, the days ahead. Um, whether that be with, uh, all daily living skills or ADLs, um, or various things. And then another fun component that the MRC specifically has is you can hire somebody to just be a buddy.

Um, so you can come in, they can play cards with you. They can go on walks with you. Like their whole thing is to just kind of have fun. And that was what kept me sane. Um, as I mentioned, I moved, uh, The day before the world shut down from COVID. And so I was very isolated. I was very alone. I was terrified [00:14:00] because I'm very medically fragile and I didn't know if I was going to be able to succeed in where I was living, um, on my own.

And the idea of having to go back into a nursing home was absolutely terrifying to me. Um, The MRC kind of had, uh, uh, another support where they had somebody just come in to like, chat. We played games. We went on walks. We, you know, did all sorts of activities together that wasn't focused on just my disability.

And it helped me like, see more of myself rather than just like, The medical component of me, and she's one of my best friends, you know, to this day, we still hang out and she's not even employed by me anymore. She's now in nursing school and she's moved on so much further in her life, but she was a big part of my, of my life through waiver.

And now I have, let me see. Um, what [00:15:00] else do I have? Oh, there's, um, a bunch of assistive technology that they helped me be able to, um, Utilize in my home to make it easier. So as I mentioned earlier, I'm a wheelchair user. Um, so they have automatic door openers. So I just have to simply like press it and my own home doors in my apartment open.

So I'm not constantly like getting stuck in the door or ways anymore. They were able to help me. Um, The bathroom in my studio apartment is kind of in a weird angle. And so they helped like put a barn door over there so that I was able to go in and do that. They helped you do the renovations. Um, I use all the smart home technology and that's something that was funded through MRC.

Um, they actually have someone come in, they talk to you about all your needs with your disabilities, and then they think with you and they brainstorm with you. Um, Um, things that you can utilize and they can provide those services for you. [00:16:00] Um, and if you have medical changes, you know, say I got all

this done, you know, two years ago, but I had a really major surgery, which for me I did.

Um, and this unfortunately happens to me quite frequently where my medical changes. You know, have significantly, um, changed and I need, you know, a new level of support or I don't need as much support and something my social worker is able to come in or my case manager is able to come in and we brainstorm again.

And we just add things onto my medical supply or add things into my durable medical equipment and they cover things that my insurance would not cover. So there's so much that's available under MRC. I'm also now part time employed through MRC under a contract as a disability inclusion leader, which is a really unique component that was just added, um, through the Learning and Community Engagement Office at MRC only three years ago.

Um, we heard from the community that they wanted more voice from [00:17:00] those who are disabled. Um, because they were constantly making decisions about people with disabilities without asking them like what they could benefit from. And so the commissioner, Tony Wolfe, actually took, you know, that initiative on.

She's like, well, let's hire people with disabilities. Let's hire the family side. Let's like, Get their perspective on the things that we're doing. And so that actually launched three years ago. And I'm a part of that now. Um, I co team leader with my, my other deals and we have 10 people on there now, and we've been a huge part in the decision making process.

And it's been amazing to see my voice and my, my team's voice be heard, um, and see like the changes that MRC has been, has been making. It's, It's insane. Um, and my quality of life is just so much better than, than it once was. I went from, you know, feeling quite isolated and, and sad and alone to, again, like I said, I'm married and I've got, you know, a job that I'm happy in and that [00:18:00] I'm passionate about and, you know, life is, life is really good.

Through waiver.

Emily: That's amazing. Yeah. Thank you for sharing about those resources. Cause I'm sure like, like I had never heard of that. I'm sure that a lot of people had never heard of that. Um, and I think that's really important and, and a great resource for people. Um, and I think it's, it's good too, that like you are now employed by them and that they made that, you know, Yeah.

They took that initiative to actually get voices of people with disabilities because that's such a common thing where, you know, higher ups and people like in charge of these types of things just aren't actually listening to the voices that they're directly impacting. And so, I think it's really great that you're able to like, you know, provide that for them and, and, you know, stand up for yourself and, and get your own needs met.

Cause I think, you know, so often that just goes overlooked. So yeah, it's really, it's really great.

Mei: [00:19:00] Yeah. Yeah. I think what's more is like to actually see the change that you are invoking is, is so cool. It's one thing to share feedback, it's another thing to actually see it come to life.

And that is so cool. Um, like I'm hearing it's, it's comprehensive. It's flexible. They involve like peer work. Like I it's checking all the boxes in my brain. Like this, are you sure this is real?

Destiny: Is I wouldn't have believed it unless I was a part of it. And it's just. It's so much. Um, there's so much inclusivity around it.

And, you know, there's constant changes to the team where we're implementing new, new voices as well that are being heard so that the different parts of the disability community are constantly being represented each year, which is the fun, fun part to see.

Mei: Yeah, yeah. And what you said about, um, having like a [00:20:00] buddy to come, come in and like actually just hang out with you and probably just.

remind you like you're just you're a human trying to have fun too. So speaking of your job, um, we were wondering, so we know that you, um, had gone to school to be a therapist. And so, we were just wondering, like in your, in your eyes, like what strategies helped you succeed in school? Like how did you, how did you cross the finish line?

Cause for a lot of people, like that is, that's hard and that is a huge accomplishment.

Destiny: Yeah. So for me, um, I realized that I wanted to go back to school when I was still in the nursing home, um, that that part of my life kind of felt unfinished and I was doing so much better physically, but mentally, I just felt like I was declining.

Um, and I knew from early on that Psychology was the path that I wanted to take if it wasn't going to be nursing, it was going to be [00:21:00] psychology. And I knew that I needed a little more physical ability to be in the nursing field. So psychology was the next natural thing for me to do. And so I went back to school and immediately, you know, just focused heavily on

how I, how I could help other people. So like, I had a lot of, a lot of issues and barriers growing up with, um, with my own psychological, you know, issues with, um, depression with VEDs and the acceptance of, you know, uh, my, my Accident and everything that I had that going on. And, um, so therapy and counseling psychology was just, you know, the next natural step for me. I had nothing else to really do in the nursing home. Um, so I really put a lot of my. My focus into school, but I guess what drove me the most was I just didn't want any other person to have to [00:22:00] go through the stuff that I was feeling.

And I had this drive, you know, this passion to work with, you know, youth, um, who had chronic illness and to be able to, you know, have that voice to be like, I know what it's like, because I feel like I've been through school. Plenty of therapy, um, talking to someone that, you know, Oh, I understand that. I hear that, but they don't, they have no real-life experience.

And I always felt that kind of like hesitancy to be able to really talk about it, um, to a therapist that didn't truly understand. So, I wanted to be that person to so many people in my specialty. So that's kind of what drove me, um, to get through school is like, I want to be that person that wasn't. That I didn't have, I guess, um, was the way to, to really focus on.

And, um, you know, for me again, I utilize a lot of the support network. Um, I thrive off of lists and organizations. So, I always just, you [00:23:00] know, had my, my list for the week, um, balanced with a lot of self-care, obviously. But yeah, I really, really enjoyed doing it just with the knowledge of. You know, I'm going to be able to help somebody the way that I would have wanted to have been helped in my past.

Emily: Yeah, yeah, that's, that's great. I, um, because I know for me too, like, I, I just graduated grad school to become a therapist this, um, I mean, this year, like this spring, and I know it's a very common thing. You know, there's, there's the whole, like, quote, unquote, like, wounded healer. Like, a lot of people come into this field because, like, we didn't have the support that we needed, um, during a certain point in our life.

And so now we want to be able to give that back to people. And so I think that's really great that you're working with kids who are going through similar, um, similar things. And I. You know, I'm sure that you're going to make a really big difference in their lives. Um, but like that being said, like I know like this [00:24:00] definitely isn't always an easy career.

Um, so I was wondering if like you could maybe share some challenges, but also like some positives of your career so far as a therapist.

Destiny: The biggest challenge for me is not taking my work home with me. Um, because I was just similar to what you just said, that wounded healer. That's definitely, definitely the role that I envisioned myself in.

Um, and if there's a kid that's really hurting and, you know, I can see that leaving that at the office and then coming home at the end of the day and living my life is really difficult. And that was something that I didn't always succeed in in my first year. Um, I definitely had to learn the hard way.

And when I say learn the hard way, I'm talking about burnout and compassion fatigue. And, you know, I just. And the lack of balance in my life and my home life, that was very apparent, um, for me. So I think that was my biggest learning curve [00:25:00] was how to leave my clients behind in the office. And, you know, to me, I had to physically kind of do this thing of putting their files down and saying, and this is my plan for you tomorrow, you know, in my head, like I put it down and just be like, I'm going to deal with this tomorrow, but right now this needs to stay here.

And that...to me, the physically putting the file down is what helped me. I needed to put a physical, um, action to it rather than just saying, you know, okay, mentally I'm leaving because I'd still find myself churning about it when I got home. So that physical action of putting it down was really helpful.

Um, but that being said, too, some of the cases that I took home are the ones that I also learned the most from, um, they're the ones that have the most positive impact on me, they're the ones that I learned so much, so much from what not to say. to clients what never to say again. Um, you [00:26:00] know, that silence is also critical, that silence can be healing, um, that you don't have to fill every, every seconds with chatter.

I mean, there's so much that I learned from, learned from those moments, uh, to as, as a positive, um, from those clients, as well. Um, and I just laugh because I'm replaying some of the ones in my head that used are very blunt. You know,

you talk too much. Why can't you just sit there with quiet? You know, it's like that mirrored face back at me.

Um, the ones that kind of stick with me that that critique at the end of the day, like, yeah, I need to work on that, I guess. Um, but you know, that's, it's also the favorite part of my job. Um, you know, the, and that's, that's, um, That's the thing is a lot of the clients that I have had, you know, have taught me so much about who I am as a person, the things that I need to work on my character defects that are, are the ones that I should do with, but also about resilience.

Um, my [00:27:00] accident happened when I was a little bit older when I was 18, and it was a big life change. Um, but my VEDS diagnosis when it was, when I was four, but some of these. people that I work with, you know, it happened much younger and they just accept everything that comes their way. And the fact that they're able to do that has taught me, you know, that not every single thing needs to be challenged, that some things you can just, you know, quietly endure and you'll make it through.

You know, you don't have to make everything a battle when your life is so much struggle and hard. You don't have to battle through every single thing. And I'd say that was probably the biggest, biggest thing that I've learned through.

Mei: That is like a beautiful chunk of wisdom right there that, yeah, that's, that's definitely resonating with me right now.

Um, I was laughing earlier too because I was remembering something I had a psychiatrist tell me. I was basically telling her, like, I've been really struggling with, [00:28:00] um, like doom scrolling and just like telling myself, like, you need to go do the thing.

I don't even want to be on my phone at that point. Just like put the phone down, but I can't. And she said in response to that, have you ever considered just like trying a little harder? And I'm like, at the time, I didn't, I didn't even think anything of it. I wasn't offended. I was like, Oh, I'm trying a little harder.

I logged off that session and I, that whole week I lived with the mindset of like, I can do it. Just try a little harder. And so I came back the next session the next week and I was like, Um, I need to tell you something. You said something that really helped me. And she was like, Oh my God. Cause in my head, that was like the worst thing I could have said to you.

And I had a lot of anxiety about that, but it ended up being exactly what I needed to hear. And so I just think about that a lot. And that's what came up for me when you, when you said like a lot of some, [00:29:00] some parts of your job involved, like learning what not to say, but.

Emily: Yeah, that's so

funny.

Yeah, and it's like it clearly resonated with you, but she was probably like freaking out like, oh my god, why

did I say that?

I feel terrible.

Mei: So hopefully that gives you some peace of mind if you ever say something that in your head was a little Maybe I shouldn't have said that. Maybe it resonated with your client. Who knows?

Destiny: Thank you. That's good to hear.

Emily: Um, I also, I really liked that tip about like the physically, like putting the file down.

I feel like that's something where when you think about it, you're like, oh yeah, like that makes sense. But then like, To actually do it, to make that sort of like part of your routine of like, okay, like these physical things, like, okay, I'm leaving the office, I'm leaving everything in the office, like physically, I feel like that's a really good tip to like, you know, kind of connect the two, like the mental and the physical, like, okay, it's staying in this file.

It's staying in this room. I will deal with it tomorrow. I feel like that's a really good tip. I'll [00:30:00] definitely keep that in mind when I start practicing too. Thank you.

Mei: Which is soon, Emily! You're literally ...

Emily: yeah, I don't know when, like, this episode is gonna come out, but this week we're recording, like, a bunch of different episodes, and one of these is gonna be my last one, so.

Mei: It's funny that you brought up, um, leaving work at work and then, you know, having that work life balance because we were just talking about that yesterday, actually. Um, and how that's It's hard.

It is hard to feel all the emotions and expect to just like cut that part of yourself off at work and then come home and deal with your life. But I think one thing that's important to remember too for listeners is you have to fill your cup up first in order to help other people. And It's easier said than done, especially when chances are, if you're in a field that is [00:31:00] mental health related, it's cause you care a lot.

Um, and so it's, it's hard to just cut your emotions off, but not that you should be cutting your emotions off. That's probably the wrong phrasing of that. Um, but to just have some, I guess, boundaries surrounding what's work and what, what is like your downtime to just, You know, focus on yourself and your self care.

Destiny: Definitely learning the lines of balance between work and home and Yeah. It, it really is. And that's why, you know, I really had to, I can't stress that physical, that physical action to go with it. Um, cause it's one thing to just mentally say, I'm leaving it here. But then, you know, you start thinking of, of thinking of somebody that something said and then you're ruminating the next thing, you know, that note comes up and, Oh, I wonder.

And then before you know it, three hours have passed and you're still, you know, your husband's still waiting for you to talk to him after dinner and, you know, things, you know, haven't happened yet. So. [00:32:00] Yeah.

Emily: I think too, especially like for those of us who work at home, like for me right now, like I'm sitting at my desk, like my bed is like right there, like I'm in my little bedroom, which is like my whole life, you know, so my like physically, you know, logging off of my computer at the end of the day, like shutting off my laptop, like that is like the physical like leaving work.

And so I feel like, Especially for, um, you know, people in the mental health field, that can be really hard if you are working remotely and you're just kind of like, okay, I'm done. And then you just look around, you're like, okay, I guess now I have to relax. I feel like that's a really hard thing to manage to that balance and like that, you know, those boundaries, like the work life balance and everything, because sometimes there isn't that, like there, there's such a fine line between it.

Destiny: When I worked from home, um, what I would do. As I would leave the apartment when I was done with [00:33:00] work and like go on a walk with the dog or, you know, go get a cup of coffee and then come home. And that was my reset. I'm off of work.

Emily: That's smart.

Destiny: I had to not just move because I felt like I was still at work.

So I needed to do an action of just like shake off the day doing something different and then reenter my home space. You could take home. Um, you know, that's. That was really important to me and something I still do as a disability inclusion leader when I log off, I need to kind of go out, do something with the dog, then come back and be like, okay, like now it's my now I'm off work and I can go do X, Y, and Z.

Mei: That is so smart. I should. Incorporate that I'm going to try that out today.

Emily: Yeah, no, that's reminded me of when I like did my internship this past year and One thing that I just noticed was really beneficial was as soon as I got home, like the first thing that I would do every single time before I like ate dinner or anything, like I had to take a shower and I [00:34:00] feel like that was just kind of like literally like washing off the day.

And it wasn't even something I was like, you know, doing as like a conscious sort of ritual. But then over time I realized like that's what it was for me was like, okay, before I do anything else, I have to take a shower. And then that's like the start of me being at home for the night. And I feel like that's another like kind of smaller thing like that, like taking a walk or like taking a shower, like those little things can really help in your routine to just kind of like bridge that gap from like work to home, especially if you.

Already are home. Then you just like go in a different room or you go outside for a little bit. I feel like those are really good techniques to implement.

Speaking of, tips and tricks and also, like, resources and support and everything, um, are there any resources that, like, you wish you had known about earlier or that maybe could be helpful for some listeners?

Um, and kind of going along with that, like, What are some common like mental health impacts that you've noticed about like not having as much

independence [00:35:00] and are there ways in which providers can help better support their clients through those?

Destiny: Yeah, um, I was reading this question and it was the one that I had to put the most thought into, into my answer with because there's, I feel like there's so much packed into there and I feel like they're all different, you know, answers.

I'll focus on the, um, more resources. There are so many more resources than you could ever imagine, you know, out there. If you're thinking of resources for, you know, people with individual, individual disabilities, you know, you want to look towards what's geared towards your community. What are you eligible for?

I spoke about MRC Connect, um, or MRC. That might be one thing that you were eligible for. I spoke specifically about waiver. Um, probably very select few in the audience is eligible for waiver, but MRC has so much that they can and do offer. Um, they can help fund [00:36:00] for college. They can help you go back to school.

There's Employment options that you can do through them. The best place to start through there is MRC Connect or 1MRC. And I can, um, you know, say that. The link to do that, but it's, um, it's a survey, not a survey. It's a website that you fill out an application and, um, see what you can benefit from and what you are eligible to receive, and you can kind of go from there.

Once you fill out the application, it's a bit of a wait. They do say around 45 days for a process time. We hope to get it lower than that, but unfortunately, with where we are right now, that's where we are. That's what exists, um. As far as other resources, you know, I'm thinking along the lines of, you know, individual supports that you, you may have looked to your community.

So, I mean, if you are a church member, go to, um, the pastor, you know, ask [00:37:00] them, you know, I'm struggling with this. Is there anyone in the, in the church that might have, you know, resources available? If you, you know, um, go to the library, look at those little information boards. There's so many flyers that are always there.

It's kind of the small things that are overlooked that people dismiss sometimes, um, as kind of being like, Oh, that's not relevant or up to date, but you'll find a lot of information. You know, just there the Internet's at your fingertips these

days, too. So if you just type in what you're struggling with, you'll oftentimes find a long list.

Um, support groups are a great place to also start, um, either online or in person. Uh, the online ones, you can narrow it down to such specific filters. Um, but you can also ask your doctor, ask your therapist about, you know, group group settings that you can go into to meet some meet some people, the importance of, um, connectivity and being able to talk to [00:38:00] others that, you know, might be going through the same thing as you and what has worked for them, you may find, you know, beneficial, uh, to you as well.

So that's the big thing that I would, you know, offer to take away, stop trying to deal with everything on your own because there's so much out there. And as far as the mental health impacts of the lack of independence. There is so much there. Um, I think it's very common when somebody hears that somebody is disabled, um, especially in a care setting, the immediate response is, let me do this for you because I'm going to make it easier for you.

But in reality, you're not giving that disabled individual a chance to try. Yes, it may take me 10 minutes longer than it would you but the sense of accomplishment that I'll feel having done it for myself is quite big, you know, and so rather than just taking over, you know, ask the person. That's such a huge thing.

Um, you know, there's [00:39:00] a lot of people that think that they're helping and I'll use this as an example of, you know, opening doorways or Opening doors for you are moving a chair or something, but in reality, they're often standing in the wrong spot. And I end up having to, like, do a lot of extra work on not running over their toes.

And I know they're trying to be helpful. They're really not being so rather than say, would you. Rather than just doing it, would you like me to open the door for you? Would you like me to do that? So, don't try to take away the independence. Just ask if they want assistance. And I think that's the biggest thing.

Treat them like you would any other individual. I mean, you don't have to see the disability first. See the person first. Because that's what we are. We're all people. You know, just because I use a wheelchair, just because someone else, you know, is blind, or somebody else has, you know, um, disability.

Difficulty with hearing that doesn't make them any less of a person see the person underneath the disability and then you don't have to take away that that [00:40:00] individual, um, independence. And that's the biggest thing that I'd say that you could take away from anything because the more that you try to do to help.

Sometimes you're not helping. Um, you're just making it a little more. A little more difficult. So just offer how, how can I help? Don't just do something first.

Emily: That's great. Thank you. Yeah, I think that that's a really important thing to hear. Um, especially like for us who are, you know, more able bodied, like, it really is important to remember that you're not always being as hopeful, even if that's your intention.

Um, and yeah, I think, yeah, just, just asking what you can do and if you can do something, if not, then that's fine.

Destiny: I heard at a training at work, and it's really helpful as intention versus impact, even though you're not intending, you know, to, to [00:41:00] cause an issue, you know, you, you may be. So just, you know, consider that, um,

when you're,

you're interacting with people with disabilities.

Mei: Thank you. Thank you for that piece of education, too, because I know it's, it's, you know, not necessarily your job to educate others, but it's so important that there are people like you advocating and speaking out. Um, and I, I can imagine it gets tiring to talk about it, but, um, just, I can't thank you enough for speaking out and even being here today, um, as a guest on our podcast so really, really appreciate it.

Emily: Yeah, and thank you for, for joining us today. It's really great to like hear your story and hear about all the resources available and I'm sure that's going to be really helpful for a lot of listeners.

Destiny: Of course, thank you so much for having me, and if there's anything that I can, I can do to help further, let me know.

Mei: If you would like to contact us, you can email us at stay tuned at umassmed.edu and check out the [00:42:00] Transitions ACR website at

umassmed.edu/transitionsACR. Thanks for being here and be sure to stay tuned for next time.