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Transcript for "in STEM" series, Episode 04: Disabilities in STEM

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All 0:17

Welcome to STEMculture/podcast.

Dani 0:18

Oh, I fucked up!

Zach 0:23

Alright, we have an intro.

Dani 0:25

You guys, it's so warm in here!

Brooke 0:27

Welcome to STEMculture Podcast. Today we are talking about disabilities and learning differences. This is your host, Brooke and Dani so this is our first in STEM episode where we hear people's stories, especially those stories we don't hear often and this episode goes out to all the people who have ever been told that spelling and perfect grammar is the only way to heaven.

Dani 0:52

Damn straight

So we have a disclaimer this episode like all episodes and

The disclaimer there's just there's literally not enough hours in the day for us to cover every kind of disability or learning difference. So that means that will eventually be doing a follow up episode for this. So if you would like to be a guest, please send us an email at stemculturepodcast@gmail.com. That's all one word or hit us up on Twitter at STEMculture. Also, one word Facebook at STEMculture Podcast, just search us or Instagram at stem culture, podcast also all one word if you're in doubt, all one word.

Also, if we make a mistake, which I promise you we are trying very hard not to do so everyone can save their emotional energy for other things. please do let us know we're really open to it. And we do want to be better.

All right, y'all. So this topic about disabilities and learning differences in STEM is a hugely broad topic. So in order to understand the interviews that we're going to have later, we're going to give some background and a

Lot of this background is actually news very new to me and new and in part, I think with Brooke.

Brooke 2:07

So first today we're going to talk briefly about person first language or identity first language. So person first language would be saying a person with a disability versus identity first language, that saying a disabled person. And so if you ever have questions on how to address someone, always just ask. And so you'll hear us in these interviews that are coming forward in this episode that we're asking each person what they would prefer.

So the reason why this is so important is just like other groups of people with disabilities, not everybody has the same types of disabilities and everybody has their personal preference on how they want to be addressed. So it's always important to make an effort to ask the person especially if you're referencing

their disability for something.

Dani 3:03

And so if you want to read more about person first language and identity first language we have referenced and linked a few articles for you

one by Emily Ladau from Think inclusive, called why person first language doesn't always put the person first. And the second is from Stairway to STEM called autism one to one. And they give a great little chat about autistic culture and what identity first language means to some people who are autistic.

And they'll be linked in the show notes.

We wanted to learn more about how accommodations are provided to those who needed on campus. So we ended up interviewing one of our local accommodations officers to learn more about disability student services. We have a disclaimer for this because obviously this is our accommodations office at our university. And so there may be some things that we say that aren't 100% correct to your university and we did make an effort to try and

figure out, okay, is this specific to our university? Or is this nation wide? And where we can we make that difference? but really to figure out how your university does things, you'll need to go chat with your disability student services, or they might call themselves an accommodation office.

Brooke 4:19

So

So first and we wanted to understand how somebody applies and who is

is

available for services. And so one of the things that we were told right off the bat is that if your university accepts federal funds, they have to provide accommodations, it's the law and if they don't, is a civil rights violation. So that was really good to know that this is a nationwide

law. So then we were really curious about

how somebody would go about applying for services. And first thing that they told us was that you have to self disclose. They can't go out and say, "Oh, you look like you have a disability". That is a huge No, no to do for obvious reasons. And so it's really important that if you know you have a disability, that you can identify yourself to the office, and then you can show them in some manner, whether it's with current medical documentation within three years, or you'll have to go get a psycho educational evaluation.

And usually that evaluation looks like

two or three sessions with a psycho educational evaluator. And the biggest issue I think, is that it might not be covered by insurance, and so a rough estimate would be anywhere from \$300 to \$1,000.

And that's a lot of money. If you are,

you know, you're going in, you're asking for help. And then you realize, okay, now I have to go and pay out of pocket. That can be a huge roadblock for somebody. But unfortunately, there are not services that are out there that can help that we know of. If there are let us know we can put it in our in our website to let other people know.

Dani 6:28

And I think the main thing here is that if you have documentation within three years, you can use that but they do ask they do let you know that the psycho educational evaluation is something you can do and it's so thorough and essentially it makes it so that they can give you the best service that they can because you will have been evaluated in so many different ways and they'll know how to accommodate your needs the best but obviously, if you can't pay for that you have your own documentation and that is going to

help you too.

Brooke 7:01

Yes. And another thing that was mentioned to us is that the more you have on your evaluation, the better accommodations you can get. So let's say they have, you know, this person needs extra time in

this room, they'll be able to give you exactly what that psycho evaluator tells you to do. But they can't do anything more than what the psycho evaluator says. So if you were having excess absences, and you needed it, for some reason, you just need to have that in writing. And they'll be able to give accommodations regarding absences like that, just as an example.

Dani 7:42

Yeah, and when we were talking to the accommodations office, they mentioned that people with ADD and ADHD people with learning differences and anybody with a psychological disorder, they're really the most common students that seek out accommodations so let's say if you have a

psychological disorder your psychologist or psychiatrist really should write down not necessarily

your what the name of your disorder, your diagnosis, but they should be writing down what accommodations would be most useful for you, because that helps the accommodations office the most it really goes a long way.

Brooke 8:20

We were really curious about if there's a difference in accommodations for undergrads in compared comparison to graduate students because I think some people who have accommodations in undergrad might not realize that they can have accommodations in graduate school and that's really important. So a lot of the same accommodations apply. So if you have that same documentation, you can still get the same

accommodations when you come into graduate school in regards to

a class room environment so

some of the accommodations that

graduate students might have are

well, you know, some of the common things that we have in graduate students are in graduate school are in class exams, take home exams, final papers, final projects,

but you can get extra time on exams and take an exam in a private room. You can also have a note taker or a special reader. Or there are websites that as long as you have

a letter of from a psycho evaluation that

you can get textbooks that are read to you just like audible.

So that could be really helpful as well. Also, you do get you can get preferential seating preferential parking you can get exceptions to missing classes.

And if you have a physical disability and the building that you are schedule your classes scheduled in, you can have it changed to a different location if it's an accessible to get to. But I think it's really, really important to contact the disability office or the accommodations offices as soon as possible so that they understand the things that you're facing and have plenty of time to make sure that they take care of everything that you need.

Dani 10:35

Yeah, and then one of the kind of Hot Topic things that's going on right now is a lot of students are asking for more time on assignments. So let's say in the syllabus it says something's do a couple months into the semester and students are asking for more time. If that's in the syllabus, you're unlikely to get that

and

and let's say that

they assign something for a week later and you want more time on that it can be part of the conversation. But it's just not something that accommodations offices currently offer. But it's something you should definitely talk with the teacher about, if you're worried about it.

Brooke 11:12

Yes, yes. Very good. And

And

I think, you know, we've we've said this already, but I think it's worth saying, again, if you don't know where to start, find the Office of accommodations at your school. That's really the first place to start. Even if you've not had an evaluation, they oftentimes know of places in the area that you're in who offices who do offer evaluations,

you know, they're really going to be your number one resource with all of this.

Dani 11:47

Nice, yeah. And then one of the things that they'll they'll tell you a lot is, is you need to discuss and pre arrange

Brooke 11:54

Yes.

Dani 11:54

So what that means is if you want accommodations or you think you might want

Accommodations go to your accommodations office at the beginning of the semester, that is, one will be able to help you the most.

And then because the problem with signing up mid semester, it makes it harder for them to help because you're already partway through and they haven't had time to discuss anything with your teacher or with you and they haven't had time to prearrange any of the accommodations that you might need.

I will say though, of course,

we're saying this with a caveat. There are exceptions to this, but if you can discuss a pre range and in terms of discussion, not only discussed the accommodations office and your teacher, but it might be worthwhile talking with your TA as well.

Brooke 12:45

Yes, Yes, for sure. I think your TA is are

really, really it's important that they know what's going on as well. Sometimes you just tell the professor but you don't fill in the TA and and there can be a miscommunication.

Along the way, if that goes on.

Dani 13:01

Yeah, or your TA, like me, goes to the final exam day. And five of my students are missing. And I go, how did five of them miss this? I'm so worried, and I'm emailing them. And then finally, I realized that they were they had accommodation. So they were taking the exam elsewhere.

So

So, but that being part of the conversation is important.

Brooke 13:24

Yes.

So

So, um, the last thing I think that we're going to address with what the accommodations office told us is talking about service animals versus emotional support animals. And so we wanted to kind of explain what the differences are between that and a service animal can only be a dog or a miniature horse.

Dani 13:48

Which I love.

Brooke 13:48

Yes, yes, absolutely. These animals provide service so a seeing eye dog,

I know that there are service animals that warn of

seizures or low blood sugar,

and

and they are legally allowed to go everywhere. And now an emotional support animal can be any type of animal and they don't necessarily provide a service. So they're not trained animals and

and

Dani 14:23

Not necessarily trained.

Brooke 14:25

Right. So I would say they're not trained to the point that a service animal is trained for, you know, service animals are trained for a specific job and and so

that is

And and so

that is

they, they also they the accommodations office here wanted to make it clear that those animals do not have public access rights at the same level that a service animal does.

So service animals can go to classes with you and into labs.

But emotional support animals cannot.

Dani 15:03

Yeah. And so since service animals can go into labs with you, there's a couple things that need to be discussed. So first is, will the health of your service animal be affected by being in the labs? That's a conversation you would have with your PI or your lab coordinator, etc. And then the second question is, will the outcome of the experiment be affected by the service animal being in the lab? And both those questions are a discussion.

So I'm going to interview Brooke now because Brooke

Brooke 15:38

That's me.

Dani 15:41

Brooke has some things about her that she wanted to share for this episode. So like with all of our other interviews, we're going to start off first and I'm going to ask her, Brooke Do you prefer identity first language or person first language

Brooke 15:55

I'm so glad you asked me.

Dani 15:57

Hehe.

Brooke 15:57

But I also want to say that I

honestly didn't think about like one I didn't know that there was a difference, a different way of addressing this. And so growing up not knowing I had a learning difference. I wanted to hide it. And so I when I started addressing the fact that I had a learning difference, I was a person first. And so I never really even started thinking about it until we started exploring doing this podcast and I really love that there are people out there who really embrace their difference and feel that that comes and plays into like every part of them because thinking through my life I really think that I am where I am because of my learning difference. But growing up I tried to hide it so well that that it was

was always something that I looked at as like a bad thing. Society doesn't like these learning differences because nothing I went through in school growing up really was set up for somebody like me. So I would try to fake it as much as I could. But I love learning that there is a different way of approaching that. And so I think after learning that there is a difference. I love saying I am a dyslexic person. I think that's really powerful. And then being a mom of a child who has a learning disability

I think I fall into the my child, you know, the same thinking because I am his spokesperson and so I'm you know, he's a person first and this is you know, I don't want the world to see him as somebody who has a disability, but that's 100% of his life experiences are as a person who is

is you know dyslexic, and has dysgraphia and ADHD and all of these things color every aspect of his life. So

you know, I guess I'm taking away the experience from him by saying he is a person with a disability instead of saying, you know, he is a neurodiverse individual. So that those are my thoughts.

Dani 18:30

Yeah.

So when did you find out that you were dyslexic?

Brooke 18:37

This is so

so

good this is a good question because you know there's always that little voice in the back of your head that says there's something wrong but I was it was never caught in school be and so that's something wrong. That little voice that was telling me this

made also made me feel like I needed to hide it and so I never

disclosed like, I'm having trouble. I'm having a problem. But the signs were all there. It just wasn't paid attention to. And, you know, just just so you like everybody knows I dropped out of high school because I was struggling so bad. And so I ended up getting my GED so that I could go to dental assisting school, and I remember being terrified that like, would I even pass the GED? I did. It was great. But

so going through going through most of my life, I didn't even acknowledge it to the forefront. It wasn't until I had a child that was very was struggling and I went to,

you know, speech therapy appointments, occupational therapy appointments, a lot of them and I started learning everything I could about him and realizing this is my childhood that I'm experiencing over again with

him and through him his experiences I'm learning about myself. And so that's when I started addressing it and really embracing that I have

a different way of learning.

Dani 20:16

And so was that by the time you're doing undergrad?

Brooke 20:19

Yes, that was when I was an undergrad. And really where it really showed through was when I was trying to learn French, you know, you have to take a foreign language in order to be able to pass

your your undergraduate and move on to another degree. And so

Dani 20:36

Which is not the case at all universities.

Brooke 20:38

It's not the case at all universities just so one that I attended. Well, I shouldn't say just the one that I but I luckily chose one that made me look at these things and realize that one if I can't spell in the English language, there's literally no way I can spell.

in French

Dani 21:02
I'm laughing

For our listeners out there Brooke and I are incredibly close. So I'm just imagining her like trying to write a word in a different language and just being like, what the fuck.

Brooke 21:12
Yeah. Yeah, that was pretty much me the entire time. And so that really helped push me towards the accommodations office and like, you know, what do I need to do in order to get help because I was such an advocate for my son and had never advocated for myself

Dani 21:30
Gosh, isn't that so hard.

Brooke 21:31
It is, it's so hard.

Dani 21:33
I'm really proud that you did that.

Brooke 21:34
Thank you.

You know, it was a good experience because it made me also appreciate that things that are hard, you know, those those are the times where you really see

where

it's great to put a name to something you've dealt with your entire life.

But also to look back and say, I wouldn't be here. If it wasn't for that.

Dani 22:05
Yeah.

Brooke 22:05
You know like that it truly is a part of who you are.

So I embrace it.

Dani 22:13
Yes, Queen.

So what kind of what kind of accommodations were you getting as an undergrad?

Brooke 22:20

I was getting extra time on testing. And I was getting

a

a private room for testing. So I would have extra time so I could really work things out. Because one of the things I wanted to kind of explain, and I'll touch on this again, but I really learned with my son with dyslexia is that people who have dyslexia need to file things in their brain in a different manner than people who don't have dyslexia. So

So

that's really important to

understand, because when you're asking somebody questions in class, a lot of times, neurotypical people can pull that file really quickly. But dyslexia people have to file it in multiple locations in order to pull it fast, because we have different pathways that we follow in order to get to those files. So one of the ways that I would cope with that is I would talk out my notes and I'd make sure I took handwritten notes because it files things in different in multiple areas so that you can pull it when you're under stress because the first thing that happens when you're under stress is like you're not pulling any files at all. But if you have them in multiple different areas, you know, your handwriting is going to be filed in a completely different spot then you're listening so you have to make sure that you're studying and and really .

preparing in the right way. So I'm also I would go to my professors at the beginning of every semester, and I would explain my situation. And I had a professor one semester who we would just go, and it was for French. And so he knew that I really struggled with it. And so he did his testing a little bit different for me, because you have to have this oral component where you're speaking, answering questions back and forth. And so he would just patiently wait no pressure on me at all. And I could just play through different sentence structures and he was very patient with me on that. Now that's not something he had to do that was because I went to him and I explained

why I was getting receiving accommodations and I explained to him my worries and I was able to articulate it in a way that he you know, felt like he could just

justify giving me the extra time

and I wasn't. I wasn't even asking for it. He it was something that he just said, let's do it this way.

Dani 25:08

Oh, that's cool.

Brooke 25:09

Yeah.

Dani 25:10

So now that you've been in grad school for a couple years, do you use accommodations or something else?

Brooke 25:16

So

So I'm really glad that you asked that question. Because up until last semester, I really didn't think that I needed to. And I kind of kicked myself because, you know, most of our grad courses have not had this same structure as undergrad courses. Until last semester. I took a stats class and it was structured very much like an undergraduate class

and I really wish that I had taken advantage of my accommodations

but this is where I have to self disclose and say, I didn't even think that I could have accommodations in graduate school so that's why exploring a little bit

background about this podcast really opened my eyes to the fact that I should have been asking. And this is where you look back and you go, Okay, I should have been asking this whole time. So to everyone out there, you have accommodations if you've had, especially if you've had them in undergrad, you know, utilize it. It's there for you for a reason.

Dani 26:22

Yeah, just because you're a grad student, doesn't mean you can't use the accommodations if you want them.

Brooke 26:26

Yes.

Dani 26:28

Nice. And thank you so much for explaining. You know how dyslexic people are pulling files from where they've stored them in their brain. I think that was a really great explanation.

Brooke 26:41

Well, on top of that, I I've read the book, I'm Dyslexic Advantage. And that is up on our website as well. And I that was kind of a

godsend for me when I was kind of trying to navigate

my journey and my son's journey at the same time. One of the things that they talk about in the book is how the brains are structured differently. It's not just the filing, but it's how the neurons are laid out.
And

Dani 27:16

So it was like a physiological difference.

Brooke 27:18

It is a physiological difference. And so they explain it as if the brain is modular, and that you have neurons that

carry information over long distances. And then you have neurons that are packed tightly together and are stacked on top of each other, and that people who have dyslexia have more of these long reaching neurons, and so they're filing things very differently. And then people with autism have

stacked neurons and so oftentimes that means that they can be really good at specific tasks and, you know, very skilled

you know, they're mastering specific tasks. And so you have these different brain types. But something that I had been thinking about for a long time is that that doesn't mean that this is a disorder that this is more of a phenotype, you know, that you have different brains that are structured differently, but that just means that we're just different phenotypes for different ways of thinking about things.

Dani 28:30

Yeah.

Brooke 28:31

and so, you know, I I'm very sad that it's thought about as a disability when we're just looking at different variations of human beings.

Dani 28:41

Yeah, yeah. Well, one of the things you and I have talked about before is and in preparation for this podcast is,

is,

you know, we don't often you know, people someone says, dyslexic or someone says, autistic and you're doing a word association.

Almost no one says successful and yet we know many successful people who are dyslexic or autistic or have other kinds of disabilities. And I wanted to ask you a little bit more about that. If you had any special or anybody you kind of follow that inspires you or that you think about.

Brooke 29:21

You know, I think

there are,

I think there's a lot of people who are successful out in the world that you wouldn't realize are dyslexic or autistic. And unfortunately, I don't think that's highlighted because that would really

help remove the stigma of it, but I think it gives I keep referring back to the Dyslexic Advantage book because it really does highlight that you know, people are able to solve problems.

in really spectacular ways when they have this different phenotype, and

And

I eat

I, there are a lot I keep thinking of,

Anne Rice. So I was a teenager when "Interview with a Vampire" was really, really popular. Everybody wanted to be a vampire.

Dani 30:22

That's come back now, though.

Brooke 30:23

Oh, right. Okay. Right. So I really love Anne Rice books. You know, I like blazed through them as a kid.

And so, which is funny because I'm dyslexic. But I read I skim read everything. So um, but anyways, there she was told as a child that she would never amount to anything and that she would never be a writer. She couldn't even you know, like all of her English report cards were just atrocious. And here she is.

Like. And this is actually the case for a lot of top bestsellers. New York Times bestseller list is if you went back into their childhood and looked at the report cards, a lot of them had, you'll never make it as, you know, X, Y, or Z. And here they are, because they can approach things in, in a way that's outside of the box thinking

for neurotypical individuals. And so that's what captures these incredible audiences that they want to read these stories because they're, you know, they're extraordinary. So, yeah, it's actually quite common that New York Times bestseller authors are dyslexic.

Dani 31:43

Oh, that's cool. I know that nice.

Brooke 31:46

I think it's really important that

we are highlighting dyslexia and autism because I think I truly do believe it, it's an advantage.

Dani 32:00

Yeah.

Brooke 32:00

You know, I think that

those are usually the people that I feel comfortable with and gravitate towards. Because, you know, they're really extraordinary people. So...

Dani 32:15

Yes, I can attest to that. Brooke is amazing.

Brooke 32:20

Thank you.

Dani 32:21

Okay. So my next question is, I know you have a so your experience as a kid growing up and not wanting to

kind of express that you were having an issue in school.

Brooke 32:39

I

I think that I felt that I was not normal.

Now, I embrace this. But I think I strictly felt that everybody else was getting it. And I wasn't. And so I just would hide the fact. But what's interesting about this as I would come up with these way workarounds

that

That would essentially be cheats on how to get to different stages where everybody else was because I couldn't get there the straight and narrow like the straight road path. And so I find these workarounds that I can figure out how to get things done without doing it, how everybody else did it. But I felt like a failure while I did it. But I mean, that's, that's why

neuro diverse people are really great to have be in these incredible roles is because they do figure out these workarounds.

Dani 33:39

Yeah.

Brooke 33:40

That's what makes them so

great at problem solving and, you know, doing really extraordinary things because they've had to figure it out their entire life.

Dani 33:51

Yeah.

Brooke 33:52

To not live in a or to, like, live in a neurotypical world.

Dani 33:57

Yeah, well, that makes so much sense to me.

Because my brother has ADHD, and he's like, he can MacGyver anything if you I mean, he's also a mechanic. I mean, that's where his interest lies. So he's a mechanic, he knows how to weld. He's just this incredible person that knows how things work. And it was really interested in how they work. And I can ask him, how am I going to do this thing? And within literally five seconds, he's already figured it out. And he's going to help me do it.

Brooke 34:25

Yeah, yeah.

Dani 34:27

So that that's interesting.

Brooke 34:28

Jaeric would love your brother.

Dani 34:30

Oh, my God, they would get along like,

Brooke 34:32

Yeah.

Dani 34:32

pair of thieves.

Brooke 34:33

Yeah, exactly.

Dani 34:37

And that's amazing.

So I have one last question.

Brooke 34:40

Yes.

Dani 34:41

What do you wish your peers or the listeners of this podcast knew about how you might like to be interacted with.

Brooke 34:47

I.

I, so my response is not completely on how I want to be interacted with but maybe a

being socially conscious of something.

There's a lot of people

On Facebook and

and

I think that I've interacted with over the years that will continually make derogatory remarks towards spelling.

And it might just come off as, like something

small or funny in neurotypical environment. But, as somebody who harbored tremendous shame throughout my entire entire life, you know, that could be something that's really hurtful to somebody who is dyslexic. So, I think that people do it unconsciously, but you know, not realizing that the huge emotional impact that somebody carries with them when they feel like they're not normal or they're not, you know, that something as simple as spelling you making a small comment or even people like attacking a comment that somebody makes not

on the content but on maybe a spelling choice or like not putting a correct grammatical

comma in where it should completely discredits everything that that person just said. And I think that that

I would really love for people to be socially conscious about that.

Dani 36:24

Yeah and fucking stop it.

Brooke 36:25

Yeah yeah

Dani 36:29

That's my translation.

Brooke 36:31

I like your transition.

Dani 36:34

Well and I want to share this little story before we end it was one day I was trying to find you and you were telling me what lab to go.

Brooke 36:43

I remember this.

Yeah,

Dani 36:44

Yeah, you were like it's 365. And I was like, tight and I'm looking for 365 can't fucking find the room and I'm telling you Are you sure it's 365 and you're like yeah, yeah. And then finally

you took I think took a maybe a little bit more time.

Time to why the fuck isn't Dani here?

Brooke 37:01

Yeah.

Dani 37:04

And, and you're like, oh, oops, I'm at 356. And so I came like coming in, like, what the fuck? Like, how could you get that wrong? And then you're like, I'm dyslexic, get over it. And I was like, Oh, right. Like, you told me that before. And so then I just started cackling. So that's what I do. I'm being a fucking idiot.

But I remember that very fondly. And I just how forward you were with me. I was like, Oh, I'm being an asshole.

And so that helped me self reflect. And also just remember, like,

since I know that you're dyslexic then there's times where I don't even have to bother asking you Are you sure about whatever right because I can just be like let me just check that's each other thing..

Brooke 37:45

Yeah

Dani 37:45

Because I can't find

Brooke 37:46

I'm so glad that you do that.

It helps me so.

Dani 37:51

That made me really happy. Okay. End of the interview. Love you.

Brooke 37:55

Love you.

Dani 37:59

All right.

So we also wanted to talk a little bit about ableism and what that is

so ableism is a discrimination against disabled people or people who are disabled again that depends on if you prefer identity first language or person first language and honestly I thought one of the articles that we got from Stairway to Stem called "Autism 101" put it really well so I'm for the next paragraph going to quote them

quote,

"Much as racism is part of the daily life for people of color ableism is part of daily life for disabled people including autistic people. This includes internalized ableism or feeling as if we should be doing better at fitting in, not needing commendations or support not being disabled. Ableism can take the form of micro aggression in the form of compliments, such as you don't seem autistic to me, or you must be high functioning, or even you're so inspiring and so articulate.

If these seem far fetched at All these and more are set on a fairly regular basis to both myself and my students".

and quote,

so

So like with many things, if you recognize that you've done or said any of those, the first step is recognize that you're doing it. And so I'm going to give a little example of ableism that I've seen my mom experience. So my mom had a spinal cord injury when she was 15, and we've interviewed her for this episode. And as a result of that accident, she ended up in a wheelchair and she identifies as a woman who is quadriplegic but also as a bunch of other stuff for so you'll hear that later on, but as a kid, we would go to restaurants and frequently or maybe not as a kid I mean, we went to restaurants this I definitely started noticing this once I got a bit older, maybe 15, 16 and

Many of the hosts would look at me and ask how many people we had where we wanted to sit, etc. And I learned to just stare at them and not answer

because my mom would be like, "Hi. You can talk to me".

Brooke 40:17

Wow! That's

I'm just kind of flabbergasted.

Dani 40:22

Yeah. it's really frustrating.

Brooke 40:24

Yeah, yeah.

Dani 40:25

And when I was older, I definitely would be like, Oh, you can ask my mom.

Brooke 40:28

Right.

Dani 40:30

She's right here.

Brooke 40:31

Yeah.

Dani 40:32

She's the head of our family. So you can ask her.

Brooke 40:35

She's our pack leader.

Dani 40:38

Exactly. Don't fuck with her.

Brooke 40:39

Yeah.

Dani 40:40

And for the most part, I mean, you could tell people didn't mean ill by it. But it would happen almost every time we went out to dinner and said I could see that that was really wearing on my mom. And so sometimes she would handle it with a lot of grace and other time she'd be like, hey, you can talk to me.

Brooke 40:56

Right.

Dani 40:56

I'm right here. Thank you.

Brooke 40:58

Yeah.

Dani 41:01

My mom never sounds like that. That's just me interpreting her tone.

All right. And so a little footnote here, too, because I'm likely to get some questions. So in case anyone is wondering, yes, my mother physically birth me and my brother and little science lesson, perhaps what's super cool about the endocrine system and reproduction is that even when someone with a uterus can't physically push during birth, the brain is sending oxytocin to the uterus anyway. And that hormone oxytocin is going to cause the uterus to contract, which helps push the baby out. So yes, my brother and I really came out of my mom's vagina, and I don't care if I'm over sharing because a lot of women with spinal cord injuries to this day are told they can't have kids and it's a fucking lie.

So if you're out there and you want to have babies, just because you have a spinal cord injury doesn't mean you can't.

Enjoy.

Hi everyone. I'm Danny here with my mom, Deborah who had a spinal cord injury when she was 15 years old, which is now almost 50 years ago

you might hear a motorized something happening every now and then. And that's my mom's cushion. She's a cushion that will change the pressure on her seat so that she doesn't have more pressure on one side or one part than any other. So hi mom.

Deborah 42:28

Hello Dani.

Dani 42:30

So first Mom, I wanted to ask how you prefer me to reference her disability Do you prefer person first language or identity first language?

Deborah 42:39

Well, you know, I've thought a lot about this over the years and I would be I would prefer to not be identified by my disability

as many others would not like to be defined by their

gender or

Some other specific thing about them

I once did a presentation where I said for some a person, then I'm a woman

and somewhere in there

there is a recognition that I have a disability. I'm not a disability but I have one and when you talk about disability, I don't like that. That because that almost sounds like unable

interesting in Spanish one would say disability incapacitado and that means incapacitated

so and there's a lot of definitions that go into things like disabled if I had a preference and even when I talk I go back and forth between disabled person in person with a disability my preference if I had only those two choices would be person with a disability but

I don't want to be defined by my disability. I don't want to be defined by limitations.

And so I would just like to be seen as if I were going to be identified by anything. Maybe by my profession,

maybe by the fact that I'm also a mom.

There are other ways to identify me that I would like to come first before

before the fact that I have a spinal cord injury, okay, which does not make me disabled

so to speak. And

you said this, my mom, she has a spinal cord injury. It was like mom came first. That was great. And the very next thing that came was spinal cord injury. I think over the length of this conversation, you'll see that maybe you'll see that

that the disability is a very little teeny part of my life. Yeah. And I met and I really want to say and I really want to stress that if you have a question about that, how to refer to someone ask that person.

Dani 45:13

Yeah.

Yeah,

Deborah 45:14

Ask that person because we're all different.

Dani 45:16

Yeah.

Deborah 45:17

We're not just this group of disabled people that all think the same. And back with spinal cord injury. Oh, my gosh, one millimeter of difference where that spinal cord injury occurred along the spinal cord can make all the difference in in what your limitations are your abilities and so we're all different. Absolutely. So as the person how they would like to be identified.

Dani 45:37

Yeah.

Yeah. Okay. That's wonderful. Alright, so when I was going to say, I don't know if you ever knew this mom. But growing up I never told people that you were in a wheelchair like my like my friends. And it's not because I was trying to hide it. I just didn't see how it was important to whatever story I was telling and so

friends would meet you and they'd be like, I didn't know. You know, whispering to me, I didn't know your mom was in a wheelchair. And I'd be like, Oh, well, it wasn't important. Any of the stories I was telling and they weren't about the wheelchair is about her. Did you ever know that know?

Unknown 46:14

know

Deborah 46:15

No, that and that makes me feel really good inside because. Because it's like,

because I always wondered as a mom,

how that might restrict you

as my child

and and also if you might be a little embarrassed...

Dani 46:37

Oh no way.

Deborah 46:37

...with me, you know, picking you up at school or, or whatever. And so that makes me feel really good inside that that again, the disability did not come first.

Dani 46:50

Oh, yeah. Mom, I was proud as hell of you. I'm I'm sad. I didn't say that more as a kid for you to know that but I was super proud of you. And I loved it when you came to pick me up.

At school, I just felt like I felt super cool. Like my mom's coming to pick me up. And her van is like this cool Cyborg situation.

Deborah 47:08

You remember when when your friends would like to ride on it go up and down and up and down?

Dani 47:13

Yeah.

Yeah,

Okay. Cool.

Okay. So obviously, I know the answer to this question, but the listener as well. But how did you get injured?

Deborah 47:23

I was 15 freshman in high school. It was my mother's birthday on March 22, 1969.

begged my mother please, please, please, please, please, please, let's go to the beach the next day. So she reluctantly said, Okay, and so we went to the beach and

and this little place called Little Corona. And so there's this rock jutting out in in a little Corona and on this rocket says no jumping or diving, but there's a whole line of people up there jumping and diving off of this right.

Rock and I had done it many summers before my brother had done it.

And so I was up there again ready to dive off me and a friend of mine Melanie

Unknown 48:15

and

Deborah 48:17

and I wasn't super aware that the tide was out and that the water was very deep. And I

Unknown 48:23

And I

Deborah 48:26

was the kind of person that if someone said to me you can't I was going to show them that I could .

Dani 48:33

Oh that's where I get it from.

Deborah 48:36

So I was standing up there and these two scuba divers came up to me and said you know I wouldn't dive from there by where you because the water is only coming up to our waist so I dove in and something about the dive either I whip flashed in the middle of the dive or I hit the bottom of the water of the sand below and

Unknown 48:57

And

Deborah 48:59

at that point, and I didn't know that time, but I broke my neck

and the bones that broke, splintered and they cut into my spinal cord and so it paralyzed me instantly from about the chest down. And that included, as weird as it sounds, that included although I could move my arms I had no function over my hands making me what's called a quadriplegic quad meaning for so that my four extremities were affected. My legs were completely paralyzed, my arms were paralyzed, my arms were not paralyzed, but my hands were as opposed to a paraplegic meaning to pair meaning two that means their legs are are paralyzed only but they have full use of their arms and their hands. That's the way I became injured

and spinal cord injury does not only affect a mobility and the fact that

sensations over the majority of my body I can't feel normally

it affects my bowel and bladder.

It affects my ability to feel or not feel

sex.

It effects

my temperature, I cannot temperature regulate.

Dani 50:22

So now that we talked about how your spinal cord injury affected your life, I'm curious how it affected your education.

Deborah 50:28

So really good question.

I remember I was 15 of the freshman in high school, believe me, I did not want to leave my house. I did not want people to look at me. I was freaking out because I was disabled. Basically. Basically, I wanted to die and that's the truth. So my mom had to fight the school system because there was no mainstreaming he didn't get to go and be with other students who didn't have

disabilities, you had to go to school where everyone was disabled. So it was time to go back to school. And I said, I'm not going

and she said, Oh yeah, you're going. And my mother always knew this about me that I prided myself on my independence more than anything, probably. And she said, So I'll push you and everybody see that I'm pushing you or you can go on your own. Which way do you want it? Oh, she had me. And so I went to high school. They said, if you go to school with her, they said that to my mom, do you go to school with her that will allow her to come back? Okay, now imagine this. I'm in 10th grade, 10th grade high school and my mother is in the class with me.

I know that was so hard. That was so incredibly hard, but at the same time,

I probably wouldn't have gone if she wasn't there just by myself.

side the hallway, there were no accommodations. What then happened in 11th grade, they allowed my brother I could be in classes with him. And and then by the time senior came around, they allowed me to go to classes on my own. I didn't have to have anybody with me

and and that gave me the confidence to know I could do be on my own. So mom said, you know your plan before you're interested, go to college, and there's no difference. Now you will continue to go into college. And so I went to a four year university then in high school, you know, really thinking about what do you want to do? What do you want to do? What do you want to major in

Unknown 52:42

and

Deborah 52:42

and everybody looked at me and said, well, you can talk.

Dani 52:46

Assholes.

Deborah 52:47

Why don't you major in psychology. Want to be a psychologist before my injury. I loved animals and I want to work with animals. I want to do something with animals and they're saying now well, you can talk

So why don't you be a psychologist and work with people and I just, I felt deflated. I felt like this balloon that was going up, up up in the air. Somebody just pumped it burst it. And my dream was over. I majored in psychology,

I got a scholarship, a full year scholar, a full four year scholarship to go to

this university because of my grades in high school. Everyone always assume that

Wow, she got good grades and she's disabled.

Like people with disabilities

can't

there's already this thought that you you can't do well.

Dani 53:46

Hmm.

Deborah 53:47

So if you do anything just normal like other people, they think "Oh, that's awesome". Like that was a surprise to them, that they that one can be disabled and still be successful.

That was like, wow. And so I later resented those kind of comments.

Dani 54:05

Yeah. So What year is it when you started college?

Deborah 54:07

I started college in 1972.

Dani 54:09

Okay. And at this time did you have your splint?

Deborah 54:12

I have a hand splint and the hand split. It allowed me to hold the pen to hold a toothbrush to hold a makeup brush so that I could be more independent. And my really my hands and my wheelchair

were the two things that increase my independence so that I didn't need to rely on other people. So I was able to write independently but when I went to college, there was a what's called a Disability Resource Center

and it was really interesting. First of all,

I refused to identify myself with this disabled group. And part of it was I was incomplete denial that this disability was going to last which is very common. When you become disabled when you have the significant loss you just deny that it's

going to last. And so I sort of have this friend to this day that says basically, you know, you are a bitch

Unknown 55:21

and

Deborah 55:22

and you are hard to get to know you snub this, you were rude. And later on as that part of me gotten softer and softer and I began to talk to these other individuals. It was so refreshing because I needed that I needed their support I needed to know about their experiences and and so I got better than that and they were going well at last and it was where I was also being more accepting regarding my spinal cord injury.

You know, they say that that you

you go through denial, you go through bargaining, like "Please, God, make me make me better". If you do that, I'll do this. You go through bargaining. You go through, or you go through anger. And, oh, I had anger big time.

Unknown 56:14

And

Deborah 56:15

And but at the end, apparently, you go through something called acceptance. Acceptance is different for everyone and I refuse to accept it. And bottom line for me is that

if I think about it, I think about the fact that I was healed and I wasn't healed so that I could walk again. I was healed so that

I still had power as a person with a disability. I had power I could do things I could make choices. When I was undergraduate school, they had something called a Disability Resource Center. And it was great because if I had a physical need, say the bag I peed into because I have

a catheter inside my bladder and so my bag might fill up

I could go in there and they would empty it for me because I didn't have

I should say I needed care.

Someone to bathe me and dress me and help me with my bowel bladder care, get me up in the morning get me in my wheelchair. Put me down to bed at night, position me so quite a bit of care went into that but I didn't have with what was called an attendant. I didn't have an attendant the whole day and when I was in school I did not have somebody with me going around with me to all my classes I could now independently wright with the help of my hands but but they did provide in the disabilities or centers they provided note takers and so that meant that they would actually employ someone in your class who who you might think

good notes and they might,

I might suggest to them could you be my note taker, and that the Disability Resource Center has funds and they will pay you to do that nice. So they had note taking, they had an end it just began to be we talk about culture, it it just began to be a place that you could also just hang out and that have a learning

disability center there as well, where they could do testing to see if there might be something causing your limitations to learning.

And they had

that they had part of it was maybe like a career center, but it all was surrounding disability. And this center itself provide a sort of a haven like if you were out there feeling like you're really being stared at, and it was uncomfortable, or you could go into this Disability Resource Center. And it's like, Okay, everybody hears, you know, got the same sort of thing going on. And we all understand each other. And, and it was, it was comforting, it really was comforting, but they provided a lot of services and, and accessibility boy, that campus was

just perfectly accessible. And it was not say, for instance, you cannot get to a class because there were stairs in there. No elevator, the Disability Resource Center was a, you have to move the class. Nice. And so it it was very accommodating at that university and and that was in the that was in the 70s

Dani 59:46

Nowadays is like testing accommodations where if you need it, you can get time and a half or maybe even twice as much today did they also give you that?

Deborah 59:56

In fact, I was in a class where I'm was not doing well, because I didn't know how people did it. But in their exams or final exams, or whatever. And these people were writing a mile a minute, I cannot write that fast.

Dani 1:00:11

Okay.

Deborah 1:00:11

And so, but I was determined to be like them. And I wasn't going to ask for extra time, because I thought it was cheating.

Dani 1:00:20

Mm hmm.

Deborah 1:00:21

And so that this professor of mine knew that I knew the answer is, but I just couldn't take it. I would not take the time he goes, Deborah,

I insist that you ask for more time, and you will be given it. So I took more time. And my grade back came back A he goes, I told you so. So since then, since then, yeah, they would give you more time for exams, you could record lectures, you could anything that would make it easier for you, they and if there wasn't this specific accommodation available, they would make changes. So and that was part of the reason why my mother chose that university for me to go to

Dani 1:01:10

Oh, cool.

Deborah 1:01:12

So what happened in college, I started out as a major in psychology.

I'm sorry, for all those people that love psychology. I was bored to tears.

And then I took this class called social behavior of apes. I think it was

it changed my life. I wanted to be the Jane Goodall I wanted to travel the jungles and observe the animals. And, and now I can't do it. But when I took that class, I realized that I could observe animals anyway, I could observe animals, zoos. And my big thing was sort of animal welfare. And, you know, I really, really thought I knew and Jane Goodall prove this without a shadow of a doubt that animals feel they have mental health, I could still study animals, I could observe them, I could, I could be a scientist. And I could do more than talk.

And I began to take classes like that. And I had one teacher, one mentor, who just she said, you know, part of her class was to go to zoos and take take down data. And I just wanted more and more and more of that. So it was time. So I changed my major from psychology to a double major called psychology and psycho biology. It was wonderful. It was, it was just what I wanted. It was, it was a way we talked about identifying myself, it had nothing to do with disability. It had to do with, like, what I thought of myself as a scientist.

Oh, every part of me, just like, like, right now, I'm talking about, I get goosebumps, so. So then I went on to grad school.

Dani 1:03:10

So I was curious at UC Riverside, which is where you went to undergrad. Right?

Deborah 1:03:15

Yes.

Dani 1:03:16

I was wondering how difficult it was to set up your accommodations today require a lot of work for me, or was it fairly straightforward,

Deborah 1:03:23

It was fairly straightforward, didn't didn't take much effort on my part at all. I just needed to be able to say, this is what I have any trouble with. Sometimes that was hard to identify. But that's they had questions and I was able to answer them, and they told me what their services entailed. And so it was pretty straightforward.

Dani 1:03:43

Did you choose UC Riverside for any special reason?

Deborah 1:03:47

Actually, my mother chose

UCR because she talked around to universities it wasn't that far from where we lived and it turned out to be a really great fit

because of its accessibility and because of the Disability Resource Center and because they also added an additional service and that was that students that might want to be an attendant applied and you could go through that their applications to see if there might be somebody there you might want to hire

Dani 1:04:20

You said you went to grad school and you have one masters and then another masters abd, which means all but dissertation. Can you tell us a little bit about that, and what kind of accommodations you received for that at those universities

Deborah 1:04:34

That was another commendation. But the Department of Rehabilitation, which was this state run program, paid for education as an undergrad as a graduate student. And the idea was to make you employable, and they were going to pay for my graduate program. However, this is one area in which unfortunately, I made a mistake. I said, I wanted to get a Bachelor's a graduate degree in psycho biology, they said, nah, we don't think you can be an employee employable as a psycho biologist. No,

we don't think we can pay for that. But they said, but because you like science, and you like people, maybe you'd like to be a medical social worker, and we will pay for that.

And I don't know what happened there because I needed the funding.

I didn't

say no. And so I went to San Diego State University. Again, the accommodations there for people with disabilities were very wonderful, what they were wonderful, very accommodating. And by that time, I knew what to expect. I knew what I could have, if I needed it. I knew to ask for it. And I did. I started graduate program in social work as San Diego State and the year into the program. I knew it was not me. And so I began to explore the university and I found out that there's something called a special masters. And so I began to combine biology, psychology and anthropology to develop a master's in animal behavior. And I felt alive again, I was almost not going to finish the master's program. But I thought, well, I started it, I'm going to finish. So I did finish it and

Dani 1:06:35

The masters in social work?

Deborah 1:06:36

The masters in social work. And I did have a computer but nothing sophisticated, like what they have now

I could not talk and it would just right for me, which is like, wonderful

Dani 1:06:48

By the, you met dad at UC Riverside, right? During your undergrad.

Deborah 1:06:52

Right.

Dani 1:06:52

Okay. And so by the time you started at San Diego State, how soon after you started your masters of Social Work? Did you have Alan,

or did you have him during your

Deborah 1:07:04

Okay, so after I graduated as a social worker, I began to work as a social worker. And with that money, I began to pay for a second Master's in animal behavior that I created in the special master's program.

Dani 1:07:21

Okay.

Deborah 1:07:22

And that was from 1983 to 1986, I did all that. And in 1984, and 1983, I pregnant with my first child, and he was born in 1984,

I'd finished all the classes and everything like Dani said, all the thesis or dissertation except for one class by the time Dani was born in 1987, and that one class took me because now he was this new mom trying to figure out

as a mom with a disability because my major thing was that whoever was caring for them, would that person be their mom? How could I be their mom, if I wasn't changing their diapers? If I wasn't, how do you identify what a mom is, and I really, my studies were almost secondary. But even through all that, I applied for PhD program at UC Davis in animal behavior. They accepted me into psychology, again, with an emphasis in animal behavior. And they said, after a year, if I didn't like the psychology program, they would transfer me into the animal behavior program. I was ecstatic.

But for many reasons and majorly because I struggled, I struggled with the whole thing. Parent versus PhD and, and everything else I had to do. And, and I took a break from the graduate program to be a mom to work as a social worker. And I didn't go back I wish I had, and I wish at that point,

Dani 1:09:07

I'm sorry, never went back.

Deborah 1:09:09

I am too. It's the major regret of my life.

Dani 1:09:13

I love having you as a mom,

Deborah 1:09:16

I love being a mom and I tried to be a good one.

Dani 1:09:19

I think you were.

Deborah 1:09:20

Thank you.

Dani 1:09:22

How do you think overall stone culture can be improved today?

Deborah 1:09:26

I would say exposure

to the possibilities and reach those people maybe new with their disabilities or at campuses, you don't have to isolate out disabled groups, but make sure they're part of that discussion. But I think overall, I was exposed to two professions where I could talk, no one even move me out of that category, into the category that where I could be a scientist, or where I could work in, in technology, or, or engineering or any of that, that that that wasn't brought to me as even a possibility, you know, so I think including all of that, not limiting, again, not limiting what we can do. Because someone looks at us and says, oh no, you have a disability, you're not capable, you're not going to be able. So I think exposure,

let's expose

individuals to that. That's graduate students. I felt very isolated,

and there were no specific support groups. And in graduate school, I don't know, I think that the assumption is that you're going to be able to do this on your own. And so the accommodations,

they probably were there, but I use them less because I just thought

now, and because of my experiences, before that, I could do this on my own again, there's that part of me that just wants to be, you know, independent, I want to be

like everyone else.

The Department of Rehabilitation said, No, you cannot be employed in this science field. They made this decision, they made that assumption. But as a social worker, you could be employed that changed the direction of my life forever. So not to make assumptions not to stop as before we even get started exposure.

Dani 1:11:58

Yeah, well, we're really

hoping this episode will help other people hear stories that they haven't heard before. But also maybe we can hear more about this conversation. Thanks mom.

Deborah 1:12:11

Thank you. Thank you for the opportunity to get this out here and get this message out there.

Dani 1:12:16

Yeah, well, duh.

I think you're awesome. So I want everyone to hear about you.

Okay, love you bye.

Brooke 1:12:26

next we have our interview with Patrick. Patrick is a psychology graduate student and he is also autistic he prefers identity first language but he's going to explain that in the interview and he explained it so amazing that we're going to leave that up to him

but we connected with him thanks to an interaction that we had with Stairway to Stem on Twitter. And they are amazing. That's their twitter handle is Stairway to Stem, and we will also have them linked in our show notes. But we really want to thank Jessica, who helped us connect with Patrick.

Dani 1:13:11

Hi, Jessica. Thank you.

Brooke 1:13:12

Thank you. Thank you. Both so much. Stairway to Stem is an organization that really strives to help autistic students transition from high school into college. And so we really want you to go check them out. But here is Patrick.

Dani 1:13:31

Alright, so the voice you're hearing now, this is Dani.

Brooke 1:13:37

This is Brooke.

Patrick 1:13:39

Hello.

Brooke 1:13:40

Hi.

Dani 1:13:42

So then it started with this interview. And so first, we wanted to ask you, do you prefer identity first language or person first language?

Patrick 1:13:50

Well, I prefer identity first language. So for a long time, people in the disability world would always say a person with a just a disability like a person with autism. And the idea behind that is we're putting the person first and thereby helping to avoid stigma, remembering that people are people first and not defined by their disabilities. But then some autistic advocates, Jim Sinclair was a real pioneer in this area started to think we'll wait a second, we don't do this for pretty much any other thing, right? Like, we

don't do this for our nationality. We don't do this for our ethnicity. We don't do this for our sexual orientation, or gender identity.

What we do do this for things like person with anger management problems, or person with substance misuse problems, things that we would probably think of is very negative. And so the argument is that actually person first language is kind of stigmatizing and reflecting a negative view of autism and disability, but we should take pride in our identity is and put the and basically comfortable identifying with them.

Dani 1:14:58

Well, thank you so much. I read some about this beforehand, but I hadn't gotten that viewpoint yet, which I think is really great to have kind of that history behind it. So thank you so much for that.

Patrick 1:15:10

Great question.

Brooke 1:15:14

So and I'm wondering what type of research that you do?

Patrick 1:15:19

Right, so I'm kind of sort of on the periphery of STEM in that I'm in a psychology program, but actually doing a lot of autism research, which, you know, is just reflecting my own interest as an artistic person and a member of this artistic community. More specifically, I'm interested in sensory processing and autism, something that was very difficult for me when I was younger, and the heterogeneity and sensory processing and autism. So we're recording brain activity electrically in response to these different sounds, and then trying to use clustering techniques to identify subgroups of autistic and typically developing kids based on their sensory processing pattern.

Brooke 1:16:06

Wow, that sounds really interesting.

Patrick 1:16:09

Well, I certainly think so that, you know, it's pretty hard to research something if you're not interested in it. So

Dani 1:16:16

Oh, yeah.

Sometimes you think you're interested in it, and then you start diving into it, and then minutes ends up nothing interesting.

Patrick 1:16:26

Yeah. Yeah. And that is a danger because how one learns about things in the classroom and how one actually does research in the field is not always necessarily exactly the same thing, right?

Brooke 1:16:42

Yeah, yeah, very true. True.

Dani 1:16:47

So we're curious and you'd actually brought this up as a great question to ask. But when you decided to attend graduate school, what was your decision process on disclosing whether or not you're an autistic student?

Patrick 1:17:00

Yeah, and that's a really difficult challenge that we face whether or not we're going to disclose, I specifically decided that I was going to disclose because like I said, I am actually interested in autism research, it's pretty difficult to explain why I'm interested without revealing the fact that I'm autistic is sort of central to my decision process.

And as well, there's the additional advantage of disclosure that it allows you to sort of sound out how accepting a program might be whether people are open minded toward autism and disability. So those are advantages. But on the other hand, there are a number of disadvantages.

There's a lot of similar autism. And then just there's the fact that I'm familiar to a lot of people. And, you know, if you're a faculty mentor, and you're looking at potentially getting another graduate student, you're looking at several years of your time spent on this mentorship and it might be frightening or off putting or creating a lot of uncertainty. If you're looking at somebody who has a different neuro type that you're unfamiliar with. And if there's a lot of applicants that might create a lot of pressure in favor of selecting a safer neurotypical candidate if that makes sense, which is very unfortunate, because, of course, that's discrimination, but there's little bit we can do about it. So I disclose, but, you know, I'm certainly not saying that everybody should disclose or recommending it, I think people think long and hard about what's right for them in their particular context.

Dani 1:18:45

Yeah, yeah, you did mention the term neurotypical a few times and I was wondering if you could define that for our listeners?

Patrick 1:18:54

Yes, good point I can easily slip into my jargon. Neuro typical means somebody who is typically developing meaning that they're not autistic. And they also wouldn't have any other sort of divergent neuro type.

So an neuro divergent person might be an autistic person, but also maybe a person with ADHD. Both of those are neuro divergent where some of these neurotypical doesn't have any of those diagnoses.

Dani 1:19:21

Okay, and can I ask you about another word that I learned about recently that's related to neurotypical and neuro divergent?

it's the term neuro diverse Have you heard of that term?

Patrick 1:19:34

Yes, yes, I actually am very interested in sort of the whole neurodiversity movement and paradigm. My faculty mentor and I are co organizing and their diversity summit at UC Davis on May 31, we're bringing in a scholar is autistic and neurotypical from the Starways, the UK will have all sorts of panels, it'll be really interesting. I think,

as far as neuro diversity is typically it's like the plural form of your divergents. So a neurodivergent person is like a specific person who's autistic or ADHD or whatever. And diverse is referring to a group of people maybe including neurotypical maybe not who are different, their minds are different from each other, their brains are different from each other.

Dani 1:20:24

Okay.

Okay. Thank you. And Patrick, do you mind after our interview via email? You could I get that those conference details? Because maybe that's something if you would, like we could advertise?

Patrick 1:20:37

Oh, absolutely. And it'll all be filled as well. Even if people can put him in person and a service pretty. So yeah, I will send you the fire.

Dani 1:20:44

Okay. Wonderful.

Brooke 1:20:45

Thank you.

Patrick 1:20:46

No, thank you.

Brooke 1:20:49

So we're also wondering what your experience in grad school so far has been like being an artistic person. And if there has been a huge difference from your undergraduate

degree and being an undergraduate student has to be in a graduate student?

Patrick 1:21:07

Right. So I think I was hinting that the sort of differences between an undergraduate and graduate degree before in that it is very different being in a classroom having very explicit structure, very specific expectations, and then going into graduate school and being expected to work more independently and autonomously.

There is some overlap because there are certain expectations that you might have some research experience, maybe volunteering in the lab as an undergraduate or working as a lab manager between your undergraduate and graduate degrees. So that was kind of provide a bit of a bridge there, but certainly they they look very differently. And as far as being an autistic students specifically,

well, it's complicated because often it's not just autism, I'm very privileged in that I more or less than just just autistic I don't have additional co occurring challenges. Some of those products that a lot of people, you know, maybe there's the CO occurring ADHD, maybe there are specific identity intersects with

something like a non binary gender identity or a minority racial group or something. A lot of people probably most autistic people are really struggling with mental health as well. So all of that creates additional challenges in terms of whether it's easier or more difficult to function as an undergraduate student versus a graduate student is it's very variable, because graduate programs there's

more more flexibility, which creates more opportunities sometimes for people to design their own environment to make sense for them and work for them, but also their lessons about explicit structure. And

there is therefore more opportunities to have for things to become more challenging, and for them not to be an easy solution. So hard to say,

Dani 1:23:19

Oh, no, I I really like that answer. And, and really, it just shows how, you know, if your artistic or neurotypical, we all have the same challenges when it comes to grad school, you know.

Patrick 1:23:31

To a large extent, yeah, yeah, a lot of the things are overlapping. Because autistic people might have some additional challenges

as well. But most of the challenges will be the shared, they just might impact people more severely. So for example, there might be, you know, somebody might have a sensory sensitivity, or they might really struggle with networking and small group discussions, fast moving rapid pace things. And those are very specific challenges that would be more likely to happen for an autistic students. But something like mental health is something that probably all graduate students struggle with a greater or lesser degrees, but maybe if you have those additional challenges that come with being autistic, that might then increase your stress levels and aggravate the mental health problems, which is why they be so much more common among autistic students.

Dani 1:24:26

Yeah, yeah. And thank you for that clarification. I realized, I said, we all have the same struggles. That's not not quite right. So thank you.

Patrick 1:24:34

Well, yeah, I mean, it's kind of a controversial controversial point, because people worry that if we move away from recognizing the validity of disability, then that could be a negative things. So these are such complicated questions, though, and there's both overlap and dissimilarity.

Dani 1:24:55

So what do you see as the cultural aspects of graduate school, and how might that relate to receiving or acquiring accommodation?

Patrick 1:25:03

Right.

So there is this pressure in graduate school to publish or perish, right, that's the phrase that we use. And that creates this situation where people are really expected to go off and be autonomous and complete high quality independent work.

And we may talk about the need for like workplace balance, and we might talk about the needs be accepting of diversity. But there are these structural factors

that sort of create stigma against anybody who is not like a proper super hard working graduate students who, like them eat or sleep or have a life in the way, it's very difficult to balance all of that for anyone, especially if there is a disability, that is maybe going to mean that you have less energy to get things done, you have more stress in your daily life.

And so even if you don't require explicit formal accommodations, then there is this immense pressure that people are under

I mean, to end on a positive note, there is also the flexibility that comes with independent work, and it makes it easier to sort of structure things for yourself. But a lot of graduate students with disabilities, I will probably want to find a program where those cultural aspects are as minimal as possible, where there is a more flexible and open and understanding culture.

Brooke 1:26:55

And so something that we were wondering is that did you how or have you experienced any type of roadblocks or barriers in graduate school that a neuro typical individual would not have experienced?

Patrick 1:27:10

Right, right. Well, we sort of hinted at this already, like I was talking, for example, those the difficulties that come with networking, because a one on one conversation is difficult. In the US, you're expected to deliver answers instantaneously, you're expected to show reciprocity, you're expected to monitor the other person's facial expressions on their feedback in their behaviors, you're expected to show interest in them and think about what they're thinking, and you're expected to do all of this at once in a period, that's just a few moments. Or maybe if you don't have a brain was explicitly designed to do that, that's difficult. And then you throw in a small group conversation where you have to do this with several

people at once and monitor turn taking a try and find your place to inject yourself into the conversation. And this is getting really, really complicated, right,

that's just one example of something that would be very difficult for for many of us, and I have certainly had difficulty with in the past is networking, which is very important for graduate students, if we want to be getting to know people in our field. And it's tough. I mean, I have my coping strategies, I go to explicit events where there's like meeting a visiting professor and I try to talk as much as I can to make sure that I'm remembered. But these are things that are difficult for a lot of people.

Dani 1:28:33

And when you say that kind of your coping strategy to go and talk to the professor, is that when that professors alone?

Patrick 1:28:42

No, not generally, like the generally in the visiting lunch, they'll be a bunch of other graduate students. So

it's a question of talking enough that I remembered, while, you know, not being like obnoxiously over participating. It's such a difficult I practice so that I've gotten better at it. But when you try and break down all the steps to go into social interaction is usually incredibly complicated, astonishingly, so. And you wonder, how on earth do I do this from day to day basis?

Dani 1:29:15

Yeah,

Thank you so much for that. Because the way you broke that down and talk about, you know, how complicated is because it is, and it's something, you know, I think, a neurotypical person does have, I know, fairly easily.

So I think the way you broke that down was really great.

So coming into a graduate student community to do you have a hard time with interpersonal relationships. And I guess this gets a little bit, you know, kind of repetitive with our conversation about about networking, but maybe with other graduate students.

Patrick 1:29:53

I can make it interesting.

So this might be a slightly longer philosophy, rising answer, but...

Dani 1:30:02

We're here for it.

Patrick 1:30:03

Okay. Well, I think it's interesting to think about how our society works, compared to practically all other societies. Because generally, people have lived in these very small communities where there's a sort of a network of acquaintances that are chosen to them, maybe they live in a rural area, and they're just limited to those people who live in rural area. Or maybe they live in a very stratified class society. Or even though they're in an urban area, they have certain acquaintances, they're really picked out to them and their family, and that aren't going to be very variable. So people are more or less stuck with certain friends,

for better or worse. But that's not how our society works. We have the giant urban centers, we have all this mobility, people are moving around, people are totally free to hang out with whomever they please. And this has the positive and the negative aspects. The negative aspect is that there's a lot of competition that goes into friendships, because you have for way people to hang out with you, which is difficult the positive side on the other hand, is it creates more opportunity for people to hang out with people who are genuinely similar to themselves to actually find people with from feel a strong sense of similarity, not just people who coincidentally happens to be born in the same social circles, people who have similar interests, people who might share our disability identity. And I think that actually just the problems that undergraduates and hang out of them can be very useful for creating these sort of sort of relationships. So no, I was coming into Davis, probably your community, I've grown up in Victoria in Canada with my whole life, and then they come down to grad school, and I don't know anybody, but I actually

found some other autistic students and we actually set up peer support community for autistic students and other people might, you know, find a club that is based around some some interest, but there's that sort of thing. Another thing too, that I should probably mention on this question is the lab culture is very important as well, whether there's a lot of collaboration between graduate students or if it's a more competitive atmosphere. So if you're looking at graduate programs, and going around and visiting people, then I really recommend asking people who are already in the program or the lab and question to get a sense of what the culture is like. It's really helpful if you have a collaborative spirit.

Brooke 1:32:38

Yeah, that's a really great point. Great point.

Dani 1:32:42

I asked how you might word an email like that, that you would you have to disclose in order to ask that question, or would it be more broad

Patrick 1:32:52

I think a lot of neurotypical students asked that question about the collaboration and the competitive atmosphere, it might be something even that's easier handled and person because a lot of the time generally in psychology people will visit graduate programs that they're interested in and go around and actually meet graduate students who are already in the program. And I think it's a natural question to ask, well, what's the culture like, do you collaborate with a lot of other graduate students are people in this program friendly and helpful,

but if you can't do that, then

you can just send a polite email, you could even ask if the graduate students was already in that person's lab has time for a video call it delicate though, because, of course, the graduate student who's going to potentially report back anything unusual or weird. So their faculty mentor, but I think that enough neurotypical students have asked that question that is not not unusual.

Dani 1:33:59

Yeah. Okay. Thank you. Thank you.

Brooke 1:34:05

So I, what would you wish that your peers or the listeners to this podcast knew about how you would like to be interacted with?

Patrick 1:34:16

So that's an absolutely excellent question. But I think I'm going to tweak adjust a little because I am, I am one autistic person. And we have this saying in the autism world, that if you've met one autistic person, you have met one person,

we are so incredibly different from one another. That was is true of me, may not be true of somebody else. But one thing that I think it's important for everybody to know is that there's some studies that really emphasize just how much sort of automatic

discriminatory negative judgment is applied to autistic people. These are studies they're being done by people like Ruth Grossman and Noah Sasson

where they are just taking these still images of autistic people are very short video clips,

as and showing them to neurotypical people and also showing these people, images and clips of neurotypical individuals. And remarkably, just this still image or short video clip is enough to elicit a very negative judgment. So there's something very subtle about how people look how we carry ourselves something about our style, not substance of what we say they actually could not just there was no negative judgment applied to the content of what autistic people were saying, when it was transcribed. It was something about the delivery. And you can imagine that whether it's trying to navigate our competitive friendship society and identify friends, whether it's trying to interview for some position, whether it's the grad school position, or some other position, whatever it is, that's going to create a lot of automatic discrimination against autistic people, and maybe people with other disabilities as well. And I think that's fine. That's important for people to mind was so that they can be aware when they're doing this and work to override this automatic stigma.

Dani 1:36:32

Yeah, thank you so much for that I hadn't, I hadn't heard of that study. So I really appreciate you bringing it up. That's very new, very recent. I think just in the last two or three years, as we've started seeing these studies,

I'm going to follow up with you after and see if you can help me find that study. I think it would be great to put in our show notes for anyone that's interested.

Patrick 1:36:55

Oh, absolutely.

Dani 1:37:00

And then, Patrick, we just wanted to finish up with one last question, because we love talking about success. We wanted to know, what are your successes in grad school?

Patrick 1:37:13

Well, let me my second year, so I don't want to be overly presumptuous and like declaring victory or whatever. But, you know, I think I've

done various things that I'm pretty proud of,

I put them to various posters are

currently doing some interesting analyses where I was talking about earlier with the clustering of those electro physiological data.

And

I am looking forward to at some point in the future company, being able to publish some of those results. I think they're very interesting.

I've also I think been able to keep the reasonable balance, you know, remain true to my sort of identity as an autistic person and incorporate that as well into what I'm doing. So I mentioned that there's that peer support group and the neuro diversity summit and other things. I also finally finally started writing a blog, which is like on my list of goals to do at some point for ages. I started that a few months ago.

Dani 1:38:28

Great that is that the artistic scholar.org, is that your blog?

Patrick 1:38:33

Yeah, autistic scholar.com.

Dani 1:38:36

Oh .com my bad.

Patrick 1:38:37

Yeah, that's the one I started in August, I think.

Dani 1:38:42

Well, that's amazing. Congratulations on starting that. I know some for me, also, the idea of starting something and then actually starting it somehow....

Patrick 1:38:52

Yeah.

Dani 1:38:52

...are separated.

Patrick 1:38:54

Yes. Yes. Very much. So. Well, thank you.

Dani 1:38:59

All right, Patrick. That was all of our questions, um...

Patrick 1:39:03

Yeah, thank you for for having me. And I look forward to seeing what comes out of it.

Dani 1:39:11

Thank you all so much for listening today. Next time we'll be starting a new series called work and life and balance. The first episode is going to be called Work, work, work, work, work, work. And a na na na ba ba ba meh meh, meh, meh...

Brooke 1:39:28

Meh, meh.

Dani 1:39:30

What? What is yours?

Brooke 1:39:31

I don't know. I was just dancing.

Yeah, work work work work work you can't quite like distinguish what she's saying. You just write

[gibberish singing]

Dani 1:39:44

man. Yeah,

I just don't know I'm words to songs. Anyway, we will discuss time management as it relates to your PhD in campus life. In the meantime, let us know your favorite way or perhaps a useful but hated way to manage your time.

Brooke 1:40:01

You can find us on Twitter at STEMculture one word or email us at STEMculturepodcast@gmail.com. If you like what we're doing, please rate us on iTunes to help more people interested improving stem culture. Find us please, please, please, please, please, if you'd like to support us, you can find us on our Patreon on our website, plus show notes, articles to stimulate and links to our YouTube channel of transcribed shows at www.stemculturepodcast.com.

Dani 1:40:36

And if you'd like to interact more with our guest speakers, you can check out our website for their bios and contact info under the tab nicely labeled as guess until next time, don't forget to consensually hug grad student or at least buy them a coffee or tea or more coffee.

Brooke 1:40:54

Lots and lots of coffee.

Dani 1:40:55

Yeah, we're caffeine tablets. Hmm, maybe not.

Brooke 1:41:02

What does DNA stand for?

Dani 1:41:05

Deoxyribose nucleic acid

Brooke 1:41:07

National Dyslexic Association.

Dani 1:41:17

I really like that.

But the N came

Brooke 1:41:25

Exactly.

Transcribed by Brooke & <https://otter.ai>