All Access Podcast

Niamh: Welcome to the all access podcast I'm Niamh and I'm with Tasha bringing you the access ability

Tasha: For our first podcast we are going to be talking about the diagnosis

Niamh: But first a bit about ourselves I'm currently the Accessibility Officer and I am going into my third year my degree

Tasha: And I was last year’s Accessibility Officer and I'm just starting my third year of criminology

Niamh: So to open up conversation why did you start the podcast?

Tasha: Well the reason why we started this podcast was mainly to just open up conversations on disability and Accessibility because we don't really talk about that much as a University right now

Niamh: Yeah and as the current Accessibility Officer I wanted to reach students and it's not just those with disabilities or Accessibility needs, it’s you know every-day students who are just completely unaware where it be lacking education or you know less exposure for those kinds of topics.
So firstly I am disabled and I identify as being disabled I have two conditions first of all I have a learning difficulty, I have dyslexia, which means that the neurons in my brain act slower so if I read something it will take slower for my brain to understand right, read, that sort of thing.
I also have another one which is where my feet can swell up, it’s called “**” so if I'm constantly walking and stuff it causes me pain swelling. So I have to take breaks compression socks all that sort of stuff but it is on and off temporary it's not a constant thing. And you what about you?

Tasha: I have, well I'm autistic which, people know what it means to be autistic but it means a lot of different things for different people - so like it's quite a wide spectrum. I'd say the main things that affect me as I have quite bad anxiety, I have quite a lot of OCD symptoms like for example I have to sleep with my door at 45 degree angle and it's really specific, or I cannot sleep. Then there's quite a lot of things like that that affects me and I also have hereditary neuropathy with liabilities that pressure palsies

Niamh: Please tell us what that is!

Tasha: It’s known as HNPP, most people have never heard of it, which is understandable and that basically it's just that (a bit sciency) but you have an Axon which is like your main nerve and then the myleen sheath around your nerves is to protect your nerves from like damage and stuff and my nerves don't really have much about protective coating and so they breakdown really easily I get a lot of nerve damage it can cause a lot of pain and paralysis and numbness in issues like that.
So yeah it’s not fun.

Niamh: I mean I'm just a quick one, do you identify as a disabled or person with a disability

Tasha: I personally identify as disabled I find that it's just for me personally that's why I prefer because, I don't really know how to best describe it, but it just feels like using with a disability kind of isolates that from myself been really nice basically my whole identity. I can't take those diagnoses away from myself without those I wouldn't be who I am so. Also, I just feel like disability and disabled isn't a dirty word, like I don't feel bad referring to myself as a disabled person, it doesn't make me feel shame or anything like that.

Niamh: Yeah I also think when people, I mean obviously people can identify as a person with a disability by all means, there's no judgement, but my personal view is that saying I am I am disabled its ownership of me. It's almost like saying if I'm a person with a disability that I'm not a person because I've got this like extra growth or something but this is ability you know it's this weird thing so I think I'm saying I'm a disabled question really does bring about it also show is that you're not afraid to say it to people as well.

Tasha: Yeah exactly, it's more a pride thing at that point like it isn't just like a 'that's my side identity I'm actually like that order Tuesday Thursday and Wednesday'

Niamh: Yeah like I'm at work sometimes and I said I'm sorry this is I'm struggling because of my dyslexia or my foot issue you know? I just own up and say I have this problem that's why I'm showing a bit or anything else, but its ownership. I think it's one way to accept yourself as well be proud, like you said, wear it as pride.
So that was a tangent and a half! We will have another episode coming up at a point where we talk about who can be disabled. So today we're kind of just introducing ourselves and we thought talking about our diagnosis and how we came about it is quite interesting I think you've probably got quite an interesting story yourself, because you didn't have your diagnosis close together, did you?

Tasha: Well actually, they won't they won't that separate they were within the same two years

Niamh: So mine was in like 6 months, so that's why I was comparing

Tasha: In current scheme of things, they were quite close but definitely separate, like they didn't come from the same kind of investigation or anything like that. Like the way that it worked for me is that when I was really young like before I even turned 4 they had started thinking I might be autistic and then my dad passed away, and so like they kind of put all of my like developmental delays and things down to bereavement at that point. They were like she's just grieving like this at the other and then as I got older these issues never changed, they still continued to put it down to bereavement, I had years and years bereavement counselling

Niamh: What kind of issues are you talking about?

Tasha: I guess things like I didn't really make friends, like I really like kept myself to myself. I remember that in year one for example I spent a lot of my year just cutting up a giant Cardboard people and I would make friends with giant Cardboard people instead of actual people.

Niamh: Ooh that sounds pretty cool!

Tasha: Yeah it was fun! Yeah she let me do that, I don't really know why! Miss Cooper if you're listening thanks! Like those kind of things like developmental delays and stuff like that that just never really went well for me and I didn't really have friends or stable friendships. Then it ended up with I went through a lot of issues like with mental health during secondary school and I was in the hospital a lot and then that from then through that being referred to camhs and then through then I got a diagnosis but it took a lot of time and not fighting. They first thought I was probably autistic when I was like a child like three years old and then I wasn't diagnosed until I was 16 so that's 13 years that that took

Niamh: What was it like for your mentality then to feel like, did you feel like something was wrong? I say wrong is in like being a bit different or something new

Tasha: I think I knew I was autistic like before I had my diagnosis I still would have referred to myself as being autistic. Like I just, that's just how I knew that I was, it's not really a way to describe it very easily because that's not those conversations you have often. It's just that I knew I was really yeah

Niamh: And then how did you what was the actual diagnosis process that you said you were referred to CAMHS right?

Tasha: yeah CAMHS, they're child and adolescent mental health services, and I think for me like the basic diagnosis process as I had to see a lot of different people like I guess they were like counsellors and stuff like that. And then I saw this one woman, I think she must have she probably had some fancy title like some kind of psychologist, and they went through a lot of like my details, they had like a massive like wad of paper like stacks up of like my entire life! Everything, like all my school reports like they had to make a timeline and they made me sit there and make this timeline of my life from when I was a child up until like at that age point I was at that moment and I think I was 15 when I had that done. So it was quite a long process and they asked me a lot of questions, asked my parents a lot of questions, they asked my school a lot of questions and it was through that that they figured out. But like it's not like a test, they don't give you a blood test

Niamh: Oh no! I meant – going on to me now. So my main struggle is my dyslexia and the reason I was saying types of test was, I mean for me what I had was this

five hour long types of tests. Some people might be longer, some people might be shorter, I was diagnosed with severe dyslexia but because my intelligence is higher than the average population it makes me seem average and so it's like undetected but in reality I'm severely dyslexic.
So with my test it was like ‘oh okay so arrange these wooden block into this shape and this shape in this shape’ and then it's like spelling tests. They also did ‘I'm going to say a word you gotta say word related to it. So if I say round you say car or something’ and all of these are – it's a mixture of intelligence tests with dyslexia sort of things. So for example to show (I know it sounds really bad because of the intelligence is in many forms) but for this test intelligence is shown through finding patterns. So moving blocks into place to look like a triangle or seeing links between this picture in this picture, that's how they showed intelligence. Then with the spelling, I had to read whole paragraph they had to write and he time me and those ones are more for the dyslexia actual diagnoses. So it was really really thorough

Tasha: So I didn’t have anything like that

Niamh: Oh so was it mainly questions?

Tasha: Yeah pretty much just questions about my life but there was one test I had to do which was kind of like people’s faces and like you had to guess their emotions.

Niamh: Oh yeah I’ve seen that test before!

Tasha: But other than that, I didn’t have to do anything like intelligence related or anything no

Niamh: I got a bit stressed out, how long did your diagnosis take?

Tasha: Well I suppose it kinda just depends you mean like the actual test or like the time?

Niamh: Yeah the test, both really

Tasha: I think it was probably a couple hours but it would have been longer because we were there at the place all day because they had to speak to everybody in my life, for example my mum they had to speak to her separately then had to speak to me separately then me and my mum together then they had to speak to like different people.

Niamh: Really, a massive process

Tasha: Yeah a lot of time but it didn't take that long on me and I can’t really remember it, I think I found quite a lot of the process quite like daunting and I kinda just blocked it away because it was quite like a difficult point in my life and anything to do with mental health I kinda shunned I was like no thanks goodbye.

Niamh: Yeah, when I was doing mine I specifically remember crying because I didn't know how to spell word magpie and I thought a 7 year old is gonna be like “oh my god, I know how to spell magpie” and I'm like I have no freaking clue I was like is it “π PIPIEPYI” I don't know! Like it sounds so silly but those are the type of things

Tasha: It isn't silly

Niamh: You know like today the word disclosure I can say it I know how to spell it in my head but when I came to type I can't spell it I I just couldn't I get to disc and then I wouldn't know what to write

Tasha: I can imagine it is quite frustrating like one of those moments where like your brain and your like body can't make that connection. I get the problem physically with my nerve problem, like my brain could run in my legs can’t

It’s just kinda like that kind of thing but more like learning disability style that's how kind of how I feel like that would feel

Niamh: Well for me I mean technically my learning difficulty is development of my brain so technically I've been disabled all my life however I didn't know until I actually joined University. My whole life younger you know my family are very stereotypical in like we need to get the good grades and do this you know, stay away from boys strict enough but not too strict. Just sort of guiding you where you should be going and so there was a lot of competition with between my older sister and younger sister and so I used to think I was very clever you know. I normally get quite grades, top of my class, and I got I think A’s and A stars I got 1B I think in my GCSE. But like that's going really well and then came my A levels and that was where I started to think what's going on here you know, my whole life I always thought you know everybody likes little things so for example spelling has always been a thing with me. But I never knew that it was because I couldn't spell so I would fake being ill on spelling test days and I'd seen in the average category and so

Tasha: I can relate to all of these things just in a physical capacity like for example, you obviously you're worried about standing out as different and like kind of being yourself in spelling tests and I was the same with PE.

I pretended I was ill every single key lesson because I just physically couldn't do it, my body physically couldn't do those things and so yeah I totally understand those emotions and those feelings. So was it kinda like a relief to have that diagnosis and to know that you weren’t making it up in your head?

Niamh: Yeah, to be honest my family are quite strict and they want you to be really well so there a bit sceptical that are you ill are you really ill? You know if you want to take a day off school or something, so saying that I think there's something wrong with me you know I used to call myself stupid all the time. And be like what is wrong with me you know? Like I for example in my history a level test we would have three big chunky tests to read through and it would be like a diary entry of newspaper clipping at transcription speech you know all these sort of things and I would read a whole paragraph and not remember a single thing of it! Or I would read a sentence and not understand it five times in a row reading it you know?

And I remember in my history a level exam I cried because I was like I'm running out of time. That's another thing, all my levels were handwritten because I wasn't diagnosed

Tasha: Exactly, so like not having that diagnosis puts in more barriers that that just means that you can't access the support that you need. Like yeah for my GCSE I had something similar, like in my GCSE I had just been diagnosed with HMPP and so I got given a scribe and I've never used a scribe before like I never I had to do that. If anyone that doesn't know a scribe is essentially when you say what you want to say and somebody else writes it down for you and so you have to say like all the punctuation in the sentence and like stuff like that. It's very unnatural way yes very unnatural way of writing an essay or anything if you've never done it before and I had about two weeks to learn how to use a scribe before my GCSEs. It was really hard but by my a levels I was Luckily allowed to use a computer and so I was able to type it for myself and that was a lot more natural for me.
Without that diagnosis I would have 100% failed my GCSEs, no way I could have written that much, my hand would have paralysed like I would have been in severe pain it would never have worked like it would never have happened. So like diagnosis really is a privilege like it's one of those things that if you don't have it can make or break you but at the same time self diagnosis is valid and should be a lot more valid.
Like I find that a lot of the time for example before I was diagnosed and I could I would say to someone I'm autistic I just don't have an official diagnosis yet and it would be like "oh well you're not being autistic then"
Not until you have that piece of paper but that piece of paper doesn't matter! Like I was autistic before I had that piece of paper, I could say I was before that piece of paper, it doesn't mean anything. Like not in terms of accessing that support for example our University you can only access support most of the time if you have that formal piece of paper that says you can but that's definitely a barrier that I really tried to breakdown last year and I hope that you continue to try and breakdown this year.

Niamh: Well one thing that I wanted to focus on so actually getting diagnosed. In University I started to find that writing in lectures while I was you know I was listening to them that lecturing one in half writing it down then I tried to use a tablet and that got better but it still wasn't fully there about me learning it. I wasn't learning it I was either listening and learning or writing and not learning and obviously if you don't write anything it does seem a bit of a waste because at some point you gotta write it down and learn from it later.
So I would just choose you know what would you like it down learn it later and obviously that doubles the amount of work, you know if you have 15 contact hours, IE, you go to lectures 15 hours or seminars or whatever…I would then have

30 hours of learning additional to revision and coursework and exams! And also so I said get behind a bit on work and I originally “oh okay so I'll get a diagnoses for dyslexia”, I'll go and I took the lead GP it's a medical thing.
So I went and spoke to him and he was like “yeah we don't deal with that it's not it's not dealt with under the NHS” then I was “what do you mean this is not dealt with under the NHS?” And so I had to privately book an appointment with a specific college who had a specialist in dyslexia and it cost me £325 - that's a big boy number. Just to get a diagnosis just to get like you said a bit of paper to say that I am disabled

Tasha: Exactly, and you wouldn't access that support without it and that's just one of those barriers that so many people will never be able to afford to just fork out that money

Niamh: I literally at that time I had £100 to my name because I was paying 2 rents, the rent that I was currently in and then the new house that I was moving into

Tasha: They think students will be able to fall back like

Niamh: I don't get it! Like literally every diagnoses, you breaking an arm – you go to the hospital. They say “yeah you have a broken arm” they don't say “yeah now cough up 200quid for your X Ray diagnosis”. Or if you go you know hard of hearing they don't go ohh okay yeah yeah pay us 150 to just look at you

Tasha: I do think somethings, I haven't looked into this all that much but with hearing you do have to pay for a hearing aid. Wheel chairs, they don't come free people think they come free they don't, they are expensive. And even with that diagnosis even with that that thing there still these massive barriers like even though I have HMPP and I sometimes need a wheelchair to get around it's not common like it's not all the time it's just when I have really bad palsy then I will need it.

Oh by the way it palsy is a flare up, it's like when I can't feel my legs and stuff. So I had to pay staff myself and that was expensive it meant that the wheel chair that I have isn't actually suitable for my needs it's too heavy I can't push it myself my partner has to push me around if I need it. And so I have no independence some days when I have flare ups because I just cannot have it like impossible. And there's all these additional costs of being disabled but I'm sure we will cover in the future but like people just don't consider it people don't know that's a thing and yeah.

Niamh: You know obviously the NHS does need some areas where you need to pay for things for example prescriptions you need to pay for them unless I think you're a child or you've applied like if you're on benefits or something you can get medical aid where they paid your prescriptions or you know anything like that. Even if your student you can apply through the NHS to get your repeat prescriptions discounted or paid for

Tasha: It is difficult though because for example I have to pay £9 per prescription and you can like pay in bulk and I think it's like 100 and something pounds but that's like 100 pounds just about to have my pain relief so that I can function. It's just again that's another additional costs on top of everything else that I have to pay for being disabled

Niamh: Yeah I think in all of our conversations so, Tasha and I we have lots of meetings together and all the projects we do and a lot of the time we complain! Lots of things to pay for! We are in a capitalist society and you think of America for example you know they have to pay for almost everything in medical care or they get it under the insurance.

Tasha: I feel like most insurance companies would be like “heck no” to me!

Niamh: So it's kind of like I'm glad we have the privilege that most of our medal compare is taken care of. Obviously it would be much better than disabled –

Tasha: I just wish we were in a society where disabled people were genuinely supported and austerity didn’t kill us. That our lives our valued; I find that a lot of the time if I tell someone I'm disabled they look at me like I'm a fraud.

Niamh: Yes or they’re in shock! I'm overweight lazy and I can call myself fat and it's like as soon as you say that there like no I'm not you're fine it's like it's the same reaction I get if I say I'm disabled. ‘I don’t see anything’

Tasha: I get that all the time

Niamh: Ohh yeah course I spent £325 for a test that said that I was disabled because you think that you can't see it I don't!

Tasha: I just wish we could live in a society where I could just say to somebody that I was disabled and they just accept it and be great moving. Because I either do get that “ohh no you're not there is no real disabilities it's all ability”

Niamh: “I would never have guessed”

Tasha: It's just you’re differently abled, that random stuff that I hate or you get the opposite which is like I'm so sorry that so I'm so sad for you like his a bucket of sympathy would you would you like me to like stroke your head you like a child?

Niamh: But I think one good example is the solicitor, so obviously I'm doing an internship at the moment, and a solicitor that I'm shadowing you know I'll apologise for spelling something wrong or taking extra time to read something. And he’ll be like “nah you don’t need to apologise, it's cool it's fine”, you know no one cares like no one cares in the nice way you know no one's bother. I think that's the exactly it just needs to be like nonchalant it's like okay. “Oh I need to get here early in the morning because I need to get my wheelchair up to the third floor expect longer " – okay that's fine!

Tasha: You just want somebody to just be like okay great we will make these reasonable adjustments for you brilliant make it so it is accessible for you and now will move on and then everything will be fine. I don't want people make a big deal about my disability because it just is always then becomes about their comfort in the situation it's never about how comfortable I am it's always about all "I'm so sorry I'm like I'm gonna turn you into my inspiration because that makes me feel better about myself as an able bodied person".

It's just I find that that happens so frequently and I hate it.

Niamh: Here is a random question what kind of board game, how has it affected you in any sort of board games that you can't play or that you feel vulnerable playing because of your disability?
This is just cause I yeah I've got answers to this I just wanted to know if you have before I start talking about it

Tasha: Twister I'd love to but I could never play twister

Niamh: I never thought about that, yeah that be scary I'd be like I'd be worried if you even attempt to do that like coz you told me that you paralyse your arms for a year was it?

Tasha: Oh wasn't a year! Like I have paralysed the last two fingers on both my hands, I paralysed for a couple of days, it's not been like a long time. But I suppose for anyone else that's a long time!
Niamh: Yeah if you say to an able bodied person: Oh yeah you'll be intermittently paralysed with

Tasha: I might not feel my arms and but yeah they last two fingers on both my hands I've had I've had that might not be able to use them for like probably a year maybe more. Like the last two fingers of my hands are probably the most problematic symptom I have. Yeah, Twister certainly out the question unfortunately. But I can't really think of many other board games I do love board games

Niamh: What's your favourite then?

Tasha: My favourite? Oh you probably won't know it but one night werewolf

Niamh: I think I've heard of it actually, is it a card game?

Tasha: Yes it is, basically someone's a werewolf and you have to figure out who it is. I'm really bad at lying so I don't know what why I love it so much I think I actually do you know why maybe it's an autistic thing that I like to try and figure

it out like I'm really like I like to kind of put things in structure and like be like get your you definitely that person you know this person.
That kind of like structural kind of game

Niamh: Like you you're talking to me that lying is really quite hard for me because not only have you got to cover for your lying but I have a slow process of someone's talking to me I've got to think of an answer I then also gotta think of to say it and so if I'm lying that's an extra third step. So like I have no idea unless I think sometimes if I

Tasha: Can we just said you do not abdicate lying

Niamh: So, my boyfriend says oh where's the last bit of the cheese, and I'm like "I don't know", this is something someone put me on the spot like that but I'm just like ????

Tasha: What is your board game that you cannot play?

Niamh: Scrabble

Tasha: Yeah I thought you're gonna say that Scrabble

Niamh: My mother loves it and so does my sisters, and the whole time I feel like, first of all, my vocabulary is not very large because in case you guys don't know another thing dyslexia is memory. So short term memory not that great long term memory is okay for certain things but a certain things but when it comes to like spelling and stuff it falters quite a bit. So, Scrabble first of all thinking of the words, second, spelling the words, but yeah I just cry. I think I played it with my partner one time and my friends and I cried afterwards I was like no one cared, we were all bad because we aren't professional Scrabble players

Tasha: I don't like Scrabble - I think it's kind of a boring game like sorry to all those Scrabble fans out there, I just much prefer something a bit more. And Scrabble and monopoly are probably like the lowest in my in my lineup. I like Monopoly but it just it takes too long and I just I cannot sit down like cannot do it. I played it with my partner quite a bit and every single time we end up writing down in our notes how much money we all had four or like properties we own how many hotels and then we never come back to it.

Niamh: My favourite board game, well technically there are two and don't have a board, but they're card games. One is called jungle speed, and one is the famous Uno. And the reason for this: so Uno first of all colours great that doesn't that's not for me at least my dyslexia doesn't isn't affected by colours so I can recognise colours and be like okay yes that that and that really quickly. Numbers as well I am you, with the other thing as well as so you can actually be I can't remember the word but there's a form of dyslexia but just for numbers
I don't have that so numbers are okay with me

Tasha: It’s calculus

Niamh: There you go

Tasha: I don’t see it as a disability though but I have this calculus because I have an issue with my eyes because I imagine it's something to with HNPP

Niamh: You don’t see it as a disability for you

Tasha: Not for me personally. It's kind of annoying thing I definitely don’t have severe calculus it's just that I really struggle to tell the difference between certain numbers. So like when I was doing my optician's thing they thought I was just really really bad at seeing, it was just because I couldn't tell the difference between five and eight, six and nine and like or the other numbers like they kinda just merged and I would really struggle to get to like differentiate.
And so like that that's a big issue that happened

Niamh: I just had some epiphany moment I just realised that is so technically I wear glasses. I mean I don't think technically but I could identify disabled because I wear glasses as well. I literally only just thought about that now I've been wearing glasses since I was eleven.

Tasha: This will definitely be in the who can be disabled things in our future podcast this thing we have is that people wear glasses all the time it's like it's a it's a disability in a sense that like everyone sees all the time. But like you see something is on constant view but like we don't identify it like that is being disabled because society is ablest. Society as a whole doesn't like the idea of disability

Niamh: I also think with glasses one in three people are affected with their eyesight in some form or other, and I think out of most thing wearing glasses is probably one of the most accepted. We do, it's kind of a fashion statement as well now, I remember when I was younger people would either poke the lenses out or just with fake glasses that were just literally glass there's nothing

Tasha: Yeah and like for example Snapchat filters. Snapchat filters, they give you glasses like and that is a very accepted form of disability and that people have. But society views other forms of disabilities completely differently like for example when I went to Comic Con I went dressed as the pizza planet truck because I turned my wheelchair into it and I got comments from people being like “oh that's offensive to disabled people” because I choose my wheelchair in doing that and they didn't know that I was physically disabled because I'm often invisible disabled.
Yeah they thought I was able bodied and using a wheelchair to my advantage in my costume but I wasn’t

Niamh: That is so random! If I see someone in a wheel chair I don’t think that’s able bodied person

Tasha: Yeah exactly and I put a lot of negative comments about like using wheelchairs and stuff when you don't need it but I didn't need it

Niamh: If it's me I just go well I'm disabled mate

Tasha: So that's the thing like a big issue invisible, this is definitely gonna come up again, but big issue with having an invisible disability as the people do not believe you. All my diagnosis personally, I've really struggled getting a diagnosis of HNPP because my doctor told me I was lying.
I'd gone in, my mum is disabled and so I grown up around disability and I think that he thought that I was using that like the fact that my mum is disabled it was like kind of in his mind attention seeking off of that. And so I've got in and said "hey look I cannot feel my hands and he was like okay whatever like not my problem" and so I went back and he was like okay it's fine and then he realised I was just gonna keep coming back and back and back.

And so he referred me for a nerve conduction test and I had to go to like a town that was like an hour drive from my house and we went to this test centre and we were the first people in the day and I was booked in for a 10 minute slot because my doctor didn't believe me. My notes literally said that my doctor thought I was lying and they had only put me in for a really small slot just to settle my mind. For anyone that couldn't see that cause this is a podcast I did just put that in quotations!

Basically like within the first 30 seconds that the woman who was doing the test her face dropped she was like my mum was saying "what's wrong? What's wrong?" and then the nurse was like "ohh your daughter has the nerves of an 80 year old woman". Oh great cheers and then we had to just chill in that town that we didn't really want to go to for the rest of the day and come back at the end of clinic because they had the doctor didn't think I was telling the truth so hadn't even put me in for long enough slot to do the whole procedure.

So I had to go back to have it done properly and that was what eventually led to my diagnosis but if my doctor had just believe me in the first place we wouldn't have had to mess around. Opening up now had anxiety over telling doctors things I now feel like no doctor will ever believe me and I now have a lot of like built up issues surrounding things like telling somebody my issues and my struggles. Because I feel like they are not believable and it caused me a lot of internal problems and my internal anxiety and my internalised ableism as well.

Just because this one doctor decided that he thought I was lying that wasn't fun

Niamh: No I mean that leads me to dyslexia diagnosis specialist with lovely he was very nice he you know if I apologise for getting things wrong or crying but no it's fine, take your time the point is you just being you and me assessing it.

However with my foot condition that was kind of the opposite. So I kind of when I first got it so normally they don't really know what causes it it's a swelling in the feet when obviously your feet don't need to be in so it causes pressure it hard to walk one and it almost feels like a pole is being shoved up your heel into your knee. So like you can feel it sometimes through the shin sometimes in the knee but mainly in the ankle in the arch of the foot.

And so I let it get worse like everyday it would get worse pain worse pain worse but I thought you know I want you know I pulled a muscle or something and it got so bad I was at work and I literally was like to my partner “we have to go to A&E. I can't and I can't even walk it's so bad. Straight away you know, when I got seen to she said, the doctors said “yeah you’ve definitely got ***”. But she was really prodding my foot and she could see I was in severe pain crying when she was doing that so literally okay fair enough then one prod to see could be faking it I guess. One prod or a couple of prods fine, but not like five all over my foot when I'm literally like really back in pain like taking my foot away because it hurts so bad

Tasha: I just wish that they’d just straight believed you like I said it's very unlike people, yeah it can happen but it's a lot more uncommon than people think that people lie about this kind of thing. And it's always to the detriment of people that are telling the truth that the doctors and the medical professionals tend to side on the fact that it's kind of like the opposite of the innocent until proven guilty thing.

Like a diagnoses should be taken on okay we believe you until we can prove that it's not true

Niamh: And this is obviously for medical diagnoses

Tasha: Yeah for me medically it's always been the other way round – so it’s always been well we’re not going to believe you until we can prove 100% that you are definitely telling us the truth. I wish it was the other way around; fair enough it does happen people lie like whatever but the amount of additional pressure and stress and everything that that puts on us As people who are just trying to find help and get better have a better quality of life… it's just an unreal and unnecessary

Niamh: Yeah and to add to when I, after she prodded my foot she said I had *** and I'm going to have to take weight off of my feet for the next week or so otherwise it could become permanent and I would need steroid injections into my ankles and that freaked me out!
Because I was in full time work to pay my rent and so I said “So what do I say to work” and she just laughed at me and said “I don't know you gotta choose”. And I was just like are you actually kidding right first of all laughing at me and acting like it's your problem what happened to the Hippocratic Oath?

Tasha: Yeah it quite often happens to be that like people kind of act like that's just your problem just get over it like and it shouldn't be like that. Like I feel like everyone should just be, I feel as a society we should have a lot more responsibility to disabled people because I find that often I get people comment things like, because I'm quite open with my disabilities and stuff, it does draw in a lot of hate comments but like that's the way it is.

When I get a little people comment things like "we look after we give you our taxes and what not" and it's like you just assume that I live on benefits and even if I did, you pay taxes for the good of society but well done

Niamh: Yeah so are you gonna choose OK so you've got a learning difficulty but you've broken your arm going to pay for the person who broken their arm. You do realise they could be in the same category if they if they wanted to choose identifying disabled

Tasha: Yeah exactly so like you could become like you could be disabled right now and not know.

Niamh: Like I didn't know I was dyslexic until I was 18 years old

Tasha: Yet I've always been autistic since birth I've always had HMPP since birth I just didn't know until I was like 15 and 16 like. I just didn't know and that could be the same for literally everybody who's listening to this podcast right now like you might have a disability or be disabled and not know about it or it might happen in your future. And so why shun those people out like I pretend like we are problem or like being in society are not worth anything or that everything is our problem to deal with yeah when really that should be society's problem to deal with.

Niamh: Yeah and obviously when we're talking about you know doctors and things we're not saying every doctor it's just from our personal experience you know. I've had you know I've had norovirus before where I've been constantly throwing up and doctors have been so lovely you know in the past it's just with my experience getting diagnosed with my foot condition I was basically outted for saying that I'm fat and it's my own problem because I'm fat and I've caused this.

Even though I used to run to work everyday and she didn't even think as a sport injury is one of those potential causes she didn't even think to say that it was oh you started running for work that's the problem… no she was like you're fat I don't care let me prod your foot so you're in more pain even though I can clearly see that you've been crying this whole time

Tasha: Weight often brought up as a reason and like for example when I was diagnosed with HMPP I was underweight like really really underweight. And I was going through a lot of issues with like eating disorders and stuff and so like the doctors thought that the issue that I was having was that my nerves were just

too exposed because I was under weight and so they were like oh you just need to eat more you just need to do this more like put on more weight and then you'll be fine.
Obviously that made no difference like it's gonna make no difference this is just something I was born with

Niamh: I mean, it's not illogical to say you know weight could be a factor

Tasha: Yeah it could they just threw all their eggs in one basket - yeah 100% would fix this it won't happen again after.

Niamh: Yeah I've been fat all my life. If it was because I was fat why did it not happen two years ago why would it happen now you know?

Tasha: Yeah it's frustrating how doctors sometimes do have that kind of mentality of like Oh well once you fix this one problem all your other problems will just magically be fixed. They kind of treat all kinds of issues in that way and I don't need to say problem in a sense that of these things that we're talking about are negative because they're not. Like that's kind of the best way to describe it

Niamh: Yeah so actually we should probably go through what ableism is - do you want to describe that?

Tasha: Well basically ableism is like discrimination or like a social prejudice against disabled people and more in favour of able bodied people really. That's more like what ableism is and there's also disablism… disablism I don't really have best to pronounce that and that's basically I think the same thing I find that the terms are kind of used interchangeably but I personally refuse ableism I think it's horrible American thing to use but it's just what I see most in my research and my kind of reading is that that is used most commonly.

Niamh: So like with ableism it is not just you are able bodied, you are discriminating against people who are not it is not just simply that. It is yeah it can it can easily be for example internalised ableism for myself you know I have a learning difficulty, it's not visable but sometimes I do think I'm not disabled enough to go in the disabled loos for whatever reason over someone in a wheelchair. You know that that's kind of the internalised I'm not good enough you know

Tasha: There also different forms of like institutional ableism we see a lot with our University I'm sure we'll go into that more in detail in another podcast, and then you have like I've also experienced of internalised ableism when I first I remember when I was first diagnosed I went and cried in the toilets in next to the thing. Not necessarily because I was upset for my own life but more because of to be honest eugenics, we will bring it up again in the future but like I shouldn't have children because of genetics and passing that on and I was upset because I wanted to have children and I didn't want my children to be disabled

but that's a lot of internalised ableism. And a lot of ableism against having disabled people on the planet and we shouldn't feel that way it's just as a young girl before I've looked into all of these things and before I realised that I could take pride in this, I didn't know that I should take pride in this and I still have a lot of internalised ableism and I think everybody kind of has that that they need to combat.
But it's just it's something to work on you know it to be aware of as long as you're consciously aware of it and consistently reading up on it and kind of like checking that and then continuing to make progress

Niamh: So as we're drawing to an end I had a little question to hopefully put it on a more positive note. What misconceptions would you like to change about your access ability needs?

Tasha: I mean for HNPP there are basically not really that many because obviously not many people know that HNPP is. I usually just get like a is that kind of thing instead of any kind of other comments. I'd say the biggest thing is that it's and it can be an invisible and visible illness so sometimes I get things like just the standard like you don't look disabled stuff or people thinking that I can't walk if I'm using a wheelchair and so like if I stand up out my chair people literally think that like some miracle has just happened.

So one big thing is please do not think that wheelchair users can't walk because quite often we can. Then for being autistic there are lots of misconceptions about autism like it's not caused by vaccines, let's just debunk that, it's not caused by vaccines, wasn't because of that. I can communicate like not not every autistic person can communicate but autism doesn't mean that I cannot communicate. It does not necessarily just mean yeah and these things can be different everyone like I'm not saying this is for everyone but for me personally but like being autistic doesn't cause this for me.

People often think that or ask me like what's your special gift or like are you like Einstein Mozart all these kind of things I'm not gifted in that sense like I don't I'm not someone I don't have some kind of like magical powers people seem to think that I must have or I do, no. People also think that I have no empathy, I am very hyper empathetic I have a lot of empathy. I find that I have too much empathy sometimes or that they think that I won't get to understand things or other people's emotions - not true.

I can understand people's emotions just not all the time and people also often think that being autistic will just go away when I get older, no.

Niamh: You'd learn to deal with it better but it doesn't disappear

Tasha: Or you can only be autistic if you're a man that happens a lot. No women can be autistic, anyone any gender can be autistic doesn't matter if you're a man or not like can happen and it does happen.

And probably the biggest ones are people quite often say to me like oh we don't look autistic you don't sound autistic you're not this that the other. That happens a lot in uni especially like people compliment me on how not autistic I seem and an autistic person who is proud of being autistic that really bugs me

Niamh: Yeah because they are also taking it away from you

Tasha: Yeah you're just removing my identity and then also like kind of linking to that, often people say “oh we're all a little bit autistic” which is not true we're not all of little bit autistic your either autistic or alistic which is like kind of acting opposite of what autistic – neurotypical- probably more people know what neurotypical means. You can't be a little bit autistic in that sense, you are either autistic or you're not. Like the spectrum does not include every human on the human race just so everyone knows. What about you?

Niamh: Well I think a very common one is that I am stupid you know I don't have brain cells you know I'm very outed for “look at that stupid person they have to use a computer” for the exams, you know they can't read quickly or I've literally said the same sentence too five times, why didn't understand it?
And going on from that some people think that I could I am racist you know or xenophobic because one thing with dyslexia is if you hear something speech to then you speaking back and also be a delay so if someone has a thick accent you know my partners lithuanian and sometimes I have to ask him to repeat things lots of times.

It is not too antagonise you I promise I have a learning difficulty you know. With my foot condition I'm just outed for being fat and I'm discounted for being fat in that I am fat and my life doesn't matter it's worth less, so anything that I've done is coming to me because of my own actions. And it's like well I have this condition when the issue was caused by exercise so it doesn't make sense that oh you're fat and so that's why life is a cruel mistress because the way to help my foot condition is to exercise. I exercise I get hurt, but I have to exercise to get rid of it so yeah those are mine

I think we should end this on a positive note maybe we'll make this thing for the rest of the podcast; what has happened to you in the past week that has made you happy or proud? Doesn't have to be disability or access related it could be anything

Tasha: I think we will make it disability Accessibility related, I'm not sure how much of this I should speak about but the sensory garden project is going well! It makes me happy we've took it to the big board like one of the biggest boards in the University and pretty much everyone was on board according to people went to board. I couldn't actually go because it's not a board that I could attend but I did my proposal and it went well I'm satisfied with it and so fingers crossed things are looking positive and promising actually building the sensory garden. Stay tuned!

Niamh: I am happy with this podcast, you know we created it from scratch and I'm so happy that you decide to come on board with it and do it with me I think we gel really well. I also bought a kitten. I know I was surprised, genuine reaction right now! He okay for his mum was a ragdoll cat which is a big fluffy white cat and his dad was a ginger tabby cat so he's ginger sort of in his head and white everywhere else and we called him hummus
Tasha: Hummas, awh, my heart, tears in my eyes people can't see the home but like I'm so excited

Niamh: keep on social media so I'll post something! So I'm Niamh and I'm with Tasha and this is us signing out from the all access podcast I hope you have a lovely day and will see you soon

Tasha: Bye!