

Hello! And welcome to Disability Decoded. I'm Nadine, your host. I'm a New York based performer/writer and now podcaster! I'm so happy you've decided to join me today. I would love it that if you enjoy my podcast to share it with your friends who may be interested. My mission is to spread the word and help make the world just a smidge kinder.

While a lot of what I say will be political in nature, because what isn't political, I will not have this become a jeering House like Prime Minister's Questions are. My stance is left but that does not mean I disregard the views of the right. If you want to learn and be civil then I welcome your conversation but I will not stand for nonsense. My view on the world is valid and I will not be demeaned by anyone no matter where in the chamber they sit and no matter their ability. You have been warned.

With so many podcasts out there already why should I decide mine is worth listening to? Well I feel we don't talk enough about disabled performers and how many theatres and performance spaces are still woefully non compliant with acts that prohibit discrimination against the disabled community. I want to show other people that the life of a disabled and or chronically ill performer/writer/dancer/choreographer/stunt performer/stage manager and more can be very challenging in an ableist world. The performing art world is riddled with all sorts of prejudice and discrimination and ableism isn't left out at all. Another reason for choosing to focus on disability and chronic illness is because of all the marginalised communities disability is the one who doesn't discriminate on who it chooses. While yes some disorders have a predilection for certain groups of people, such as your race or the sex you were born as, anyone can join the disabled community at any time. God forbid you could end up in a horrible car crash that leaves you paralysed or start to lose your sight where you become legally blind you require a Guide Dog. That is why accessibility is so important. You can't just join the Black Community or LGBTQ+ Community for example but anyone can become disabled or chronically ill. Remember that.

So for today's topic I thought we'd focus on a few things. Today is a very special birthday and is why I wanted to launch today. The Americans with Disabilities Act turns 32 today! Happy Birthday ADA! This month is also special because it is Disability Pride Month as well. Like with LGBTQ Pride Disability Pride coincides with a special date toward the end of the month. On this day, 26th July, 32 years ago the ADA was passed to prohibit the discrimination of disabled persons, in alignment to what protections were

granted during the Civil Rights Act of 1964, and this month is to recognise and celebrate that disability is a natural part of human diversity. Like other Pride and history months Disability Pride also comes flying a flag.

The Disability Pride Flag was created by Ann Magill, a disabled woman, and each of its elements symbolizes a different part of the disabled community.

1. The Black Field: this field represents the disabled people who have lost their lives due not only to their illness, but also to negligence, suicide and eugenics.
2. The Colours of the flag run diagonally across the black field. Each colour on this flag represents a different aspect of disability or impairment.
  - Red: physical disabilities
  - Yellow: cognitive and intellectual disabilities
  - White: invisible and undiagnosed disabilities
  - Blue: mental illness
  - Green: sensory perception disabilities

There are also localised parades across the United States in cities like New York, LA, Chicago, San Francisco, San Antonio and others. And it's been celebrated in other countries like the U.K. Norway, Germany and South Korea. It has also received media attention in South Africa.

I actually didn't know such a thing existed and I'm thankful for the disabled and chronically ill content creators on Instagram and Tik Tok who had me learn about this!

I feel that the word Pride evokes an odd feeling for me. Other movements such as Pride within the LGBTQ+ community for example don't evoke the same feelings as a chronic condition that causes me pain...I wouldn't quite use that word. I have trouble feeling proud of my illness that causes disability. Am I ashamed of it? No definitely not but there are feelings and such like that I wouldn't call myself "proud" ...it's a part of me and my life. It's helped me become an advocate and wanted to create this podcast but I'd hesitate to use the word proud. If you want to use to the word proud and are so then rock on and we are still within the same chapter of the same book but Pride gives me different feelings...especially given how inaccessible many LGBTQ+ Pride events are I think calling it that gives an impression that we are all united...and whilst I think so many of us in marginalised communities want to be and say we are...we just aren't.

You can comment on my Instagram what you think about what I just said. I love friendly debates. So while I feel a little disconnected to the word "Pride" I would still say we need it and we need the month to raise awareness about inaccessibility as well as discrimination in other areas too such as how many disabled people lose their benefits if they move in with their partner...how in the world do governments that have passed acts like the ADA and think that one income can easily support more than two people like it did in the 1950s?

In each episode I want to speak about certain illnesses and disabilities that causes particular difficulties on the stage or within the performance area.

Today I thought I'd talk about me and my condition. Hypermobility Spectrum Disorder. This, if you don't already know, is a group of musculoskeletal connective tissues disorders characterised by symptomatic joint hypermobility that cannot be explained by other conditions.

Symptoms of this condition not only include varying degrees of hypermobility but symptoms like chronic pain (I am always in some form of pain and this can range from mild to severe), disturbed proprioception, which is the sense of the relative position of parts of the body and how much effort is needed for movement and this can be reduced.

Not understanding where my joints are and how much muscle strength is needed can lead to a cycle that will increasingly limits my ability to manage everyday life. Macrotrauma includes joint dislocations (even in areas you may not associate with that sort of trauma like the floating rib and metatarsal) subluxations (partially dislocated) and connective soft tissue damage and no matter how many times my shoulder dislocates and no matter how many times I reduce it myself it always hurts...Microtraumas are often too small to be noticed as they happen but overtime they may make someone susceptible to recurrent and persistent pain.

And possible early onset osteoarthritis. HSD is often diagnosed when other conditions have been ruled out. Like hEDS or Ehlers Danlos Syndrome which comes in many various different types of which I believe the hypermobile type is the most common but the only one in which a specific gene or fault known to cause the condition has yet to be found.

In some people joint hypermobility can be without all of these unpleasant symptoms with the exception of the unusual mobility and these are often

the kids in your class you called “double-jointed”, the ones who did “tricks” and were often good with musical instruments like the violin and maybe good at gymnastics.

So...how does this affect performance? Well for me it can make the rehearsal period difficult for example as they are often involving long days and repeating similar movements over and over again gets more troublesome with an aggregated knee or can start on with hip pain for example.

I often get fatigued quickly which can create the impression I am either lazy or unfit for the role and/or career.

This was especially so in the conservatory I attended in New York. The school itself was only accessible via several flights of stairs, my grandmother had issues when I went for my audition, and many of the faculty although experienced and passionate seemed to only believe in “suffering for your art” and had purist ideas of the theatre in general. Many of them had me believe I was unfit for a career and tried to remove me from the school...they underestimated my determination.

Whilst I was already working in some capacity prior to attending the conservatory I did think that professionally I just wouldn't be able to keep up but that hasn't been completely case.

If I'm filming call sheets are sent out before the day of the shoot. This means that I know what I'm filming, what scene I need to know and who will be there. So knowing that a scene includes a lot of running beforehand is always helpful so I can bring anything I may need like ankle braces I can hide under my socks or certain medicines or when I should probably go to bed the night before.

Unfortunately these sheets are often only sent out a few days if not the day before the shoot so if I'm in the midst of a bad flare that doesn't help...if it was sent out the week before I'd have time to try not to exert myself but I understand the nature of filming and how this is a bit of an unrealistic ask...one can dream however.

If I'm in the theatre I will be open about my condition and thus far I've been met with kindness and patience. Contrary to popular belief at school with faculty members and some of my peers I am not lazy and thankfully the people I've worked with so far have seen that. Of course I also graduated during a little something recently we may all remember called a Pandemic

so we are only just getting back into it and I'm sure I'll meet some of the nastiness soon, I can't wait. Theatres too can be inaccessible.

There is a belief that certain buildings fall under a "grandfather" loophole in which because of their age they cannot be upgraded because it will destroy their character. This is actually not the case and the ADA does not have any such such provision. However a "safe harbour" provision exists in the 2010 ADA regulations. City and state governments erroneously believe that because it is expected to make a building accessible within reasonable expectation that they don't have to upgrade the building because of the so called "destruction of character" non existent clause. Title II of the ADA is flexible. You aren't being asked to destroy the building you are being asked to make it accessible. A ramp does not destroy character, I have been to castles where they put in railing next to dilapidated stairs...it didn't do anything to take away the medieval feeling of the rotting castle. No one asked for an elevator to be put there. Within reasonable means are you being asked to upgrade and that does include having to remove some architectural aspects to achieve this. You can also receive financial help for this from the building owner who is unlikely to want to be seen as ableist, especially a big company. Why hark for a time when discrimination was rife? The building may be pretty but I prefer accessibility over aesthetics really. So while patrons may be able to access the theatre more easily backstage is a different story. Performer Ali Stroker has spoken about this and I know the backstage of Oklahoma was transformed for her to quickly navigate in her wheelchair...I do know that this was removed as soon as the show left and was probably only accommodated because she was bringing in dollar for the theatre. This is different story for me as I don't have the name Ali does and is an issue for many other disabled and chronically ill performers and because we aren't as well known we may not bring in the cash bigger names so our needs are often overlooked.

If any of you are in NYC and can go to Free Shakespeare in the Park to watch their production of Richard III it features not only Ali Stroker as Lady Anne but also has the Duchess of York sign and other performers who are disabled. It's great for inclusivity. Also if you're in the UK you can see the RSC's Richard III that includes the first disabled actor as Richard. Historically the monarch had scoliosis and for some this can be disabling so it's great to see it!

For this time my pilot episode is coming to an end. I hope to make these episodes longer, with guests and other sections, and I thank you for being

patient with me as I learn to make this great to listen to as well as making this accessible to those who are deaf and hard of hearing. I welcome any and all constructive criticisms and advice. For today though have a lovely one.