

# WHAT IS DISABILITY?



# Welcome

My name is Elizabeth Wright. I am Australian, but live in the UK. I'm a speaker, writer and consultant working in the disability and inclusion sector. My proudest moment was competing at the Paralympics in Sydney 2000 and winning my silver medal in the S6 400m Freestyle race.

I was born with my disability. The medical name for my disability is "congenital limb deficiency," but I prefer to call it "limb difference." My limb difference includes my right arm, which finishes at the elbow, and my left hand which has a finger missing and my thumb and index finger are joined together. I am also missing half my right leg. I wear a prosthetic leg to give me mobility. Most of my life I have never thought of myself as being different. I went to a mainstream primary school and high school. I was the only child with a physical disability at my schools.

I do have some accessibility issues, I can use stairs, but if there is an option for a lift I will take it instead. I figure out ways around other accessibility issues— disabled people are great problem solvers! I often get stared at in public. Being patronised is also frustrating. And having to explain constantly and answer intrusive questions can be tiring. I really wish that non-disabled people would take the time to learn about disability and limb difference.

Which is why I created this pack- to help you learn and understand about disability.

Please take this pack and share it, learn from it, use it in your work and community. This is a chance for you to become more empowered in your disability allyship.

Feel free to contact me if you would like to book me to speak or consult for your organisation/business/event

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**"Disabled people are great problem solvers!"**

# Introduction

“Think of disability as a country. Inside this country there are people that have lived there their whole life. There are also some people that have entered the country and never left. Sometimes people visit this country, they may stay for a few days, weeks, or even years. There are some people that have family and friends that live in this country, though they themselves don't. And anyone can end up moving to this country at any time.”

- by anon

I read this beautiful interpretation of what disability is during my disability studies at university. I cannot remember the person who originally wrote it, but it really spoke to me as an analogy for disability that was neither negative or positive.

Disability is nothing to be frightened of or confused about.

Disability is nothing to fear or reject.

For many disabled people their disability isn't a point of pity or tragedy or anger. It is their lived experience, not to be judged as something other than how they view and see themselves.

Your understanding of disability may be based off just one or two people's experiences. Some people might know someone in their family who's a paraplegic, another person might have a neighbour who's got a prosthetic leg, or perhaps your child's friend has Down's Syndrome.

Disability is so much broader than this, so much more complex, and the lived experience of disabled people can vary widely.

Lack of understanding can create fear that you, as a non-disabled person, might offend a disabled person.

You might not feel comfortable engaging with a disabled person, you might even make judgements about someone who's disabled.

If we want a world where disabled people are accepted, included, and given opportunities in life to live fully and flourish, we need to tackle the misunderstandings that are out there.

We need to change the way that we view disability. We need to humanise disability and eliminate the unease that non-disabled feel towards it.

A disabled life isn't a life to grieve, ignore, or hide. It is a life that is already at a disadvantage due to social and accessibility issues. It is a life that you, today, could work towards making more equal, more fair.

This pack "What is disability?" is an introductory ebook to help you see the bigger picture. It can't be comprehensive as it is impossible to cover every single condition and impairment that is experienced.

What it is though is an exploration of lived experience and, hopefully, a breaker of stereotypes.

In this ebook you will meet individuals who have lived experience of disability. You will read about their lives and how disability impacts them. You will discover their ideas of what makes life more accessible and inclusive.

An ever evolving document, this ebook will grow, shift and change over the coming years, so do please check back for updated versions as they come out.

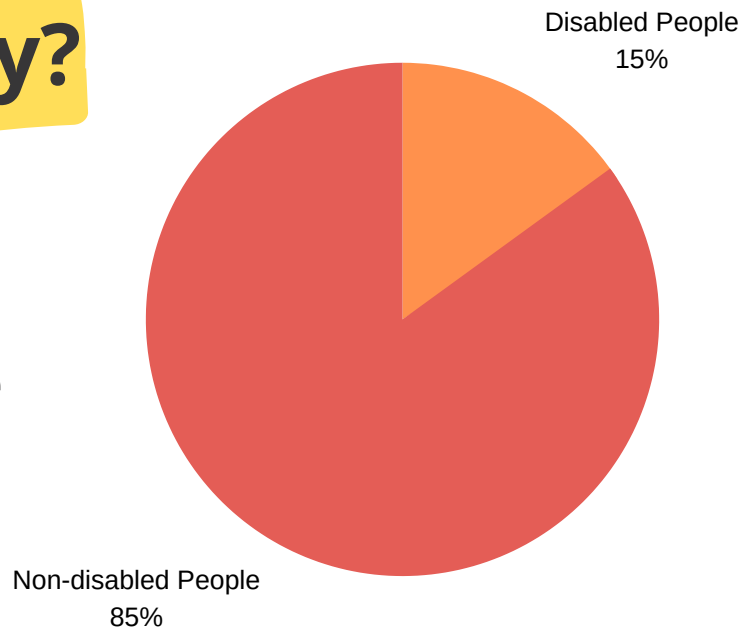


**Welcome to the big picture of disability.**

# What is disability?

**Approximately 15%, or 1 billion people worldwide are disabled.**

One-fifth of this estimated total experience significant disabilities. This global estimation is on the rise due to an ageing population, the rapid spread of chronic illness, and improved methodologies for measuring disability.



and...

**1 in 5**

**children has a disability of some kind, old age doesn't determine who is or isn't disabled.**

Globally, disabled people are stigmatised, discriminated against and live in abject poverty. A majority face barriers that prevent them from accessing education, work, transport, health care, safe environments, etc.

Disability is complex and made of various phenomena that interacts at a very individual level. Disability can be looked at in so many different ways. Within disability no two people will have the exact same experience, even of the same impairment.

# How to use this pack.

This pack is for teachers, inclusions leads, Human Resource leads, employees, etc. It can be useful for individuals and teams, through to wider organisations that want to understand disability better.

If a student or peer comes to your school or organisation with a declared disability it is your job to learn and understand as much as you can about that disability so that you can provide the best support for that person.

If it is an individual with an undeclared disability and they confide in you about their disability, it is your job to learn and understand as much as you can about that disability so that you can provide the best support for that individual.

Use this pack as a resource, a tool with which you can gain some further insight and understanding into the experience of disability. The stories in this pack have been provided by individuals who want you to understand their lived experience so that you can engage and connect with, and promote disabled individuals you work with- whether that be peers, employees or students.

Some information in these stories may have been changed and some names may be pseudonyms for anonymity.

The pack is divided into 5 categories of disability. Read through all of them initially if you like, but you can refer back to each category as you need to.

- Physical Disability
- Invisible Disability
- Cognitive Disability
- Neurodivergent
- Chronic Illness

Included in each category are a number of lived experience stories. These are the focus of the pack and come first. Then a brief description of the category is given with a number of examples and some links for support.

Also, at the very end of the pack are some resource lists for websites, books, and videos.

# Physical Disability

## Meet... Gem

Hi! I'm Gem. I'm 27 years old and I'm a disabled blogger, speaker and consultant from West Yorkshire. I'm massively passionate about people being able to be their true selves in life. As someone who is physically disabled, I've experienced a number of barriers in life - and I want that to change for others. When I'm not talking about disability and inclusivity - you'll probably find me drinking a can of coke, doodling on my iPad and stroking my two chocolate labradors. I LOVE technology, not only because it helps me everyday, but also because I love to get stuff done and learn how to do things even easier in life.

My disability is called Osteogenesis Imperfecta but to everyone, it's easier to say Brittle Bones. I've broken over 300 bones in my lifetime. When I tell people this, they're obviously shocked, but to me it's my normal. I'm 3 foot 1 and use a wheelchair pretty much 24/7. The barriers for me are not my condition and the symptoms - but people's attitudes.

The constant patronising, underestimating what I can do and achieve have been something that I go through daily. If I'm not careful it can chip away at me. On my good days, I brush them off but sometimes it can be a lot. I can get anxiety about leaving my house - knowing that I'm going to be stared at or patted on the head (yep people still do that). I have a Yorkshire humour and use that to shake it off - but sometimes it's either that or not going out.

People think that the pain must be really hard - but honestly there's painkillers for that - but the cure for ableism is something that we all need to be part of.

I wish people would understand the importance of the little things they do and say and the consequences they have. For example when I'm out and about and a parent stares, I know the child will then learn that it's ok for them to stare too.

**"...the cure for ableism is something that we all need to be part of."**

# Physical Disability

Imagine if they taught their child before they even went out about different people? I would love for people to take on the responsibility of teaching their children (and themselves to be honest) about disability and diversity.

Another aspect is having low expectations of disabled people. I would say that because of this, I'm actually a very high goal reacher. With disability, a lot of people well, as long as they can do the bare minimum that's all that matters. However, my parents have always been my biggest cheerleaders. If I reached a goal, they would say "that's brilliant, well done! What's next?". I think that's the most important mindset to learn in order to really encourage disabled people around you and also teach yourself that disabled people can also bring skills and talents too.

I think for me disability awareness in general is imperative led by disabled people. Not specifically learning about particular disabilities, but just learning to communicate with disabled people.

Not feeling nervous or shy or worst of all avoiding disabled people. I think this would really help normalise disability and enable people to be included in society, therefore leading to increased employment/leadership roles ran by disabled people.

I would love for more people to look around them and start thinking about why disabled people aren't in the room. Is it because they can't get in? Or they can't apply for the jobs because it's not accessible? It would be really good to take the energy away from disabled people managing these things and put the responsibility on everyone.

**"I would love for more people to look around them and start thinking about why disabled people aren't in the room."**



# Physical Disability

## Meet... Bev

I'm Bev and I live in a village near Sleaford, Lincolnshire, but I was born and grew up in Wolverhampton, West Midlands. I was born way back in 1972 so I'm pretty old, but in my head I'm 20.

It's funny how your interests change over time! My main hobby is Roller Derby, a brutal and bonkers full contact sport that is the fastest growing sport in Europe. I used to skate everywhere as a child and was lucky enough to have a school roller disco, but of course in my late teens it became uncool so it didn't do it again until I was 40! I then played for the Lincolnshire Bombers team, and became involved coaching their juniors, The Bombinos. Suddenly I felt at home and I realised that I absolutely loved coaching. As a teenager I used to play concert xylophone (I'm not kidding) and taught others to play.

I'm one of the founding members of the Team Great Britain Junior Roller Derby team and one of my greatest achievements is getting 23 under-18-year-olds to the junior world cup in Philadelphia in 2018. I also love painting Watercolours and discovering historic landscapes.

I got my Heritage Studies degree 11 years ago and since then I've been a Project Manager for the Woodland Trust, the Wildlife Trusts, Heritage Lincolnshire and now the Heritage Trust Network.

I was born missing my left arm just below the elbow. It's described as 'missing' but I actually have teeny tiny fingers that grow nails and I've never really been given a good explanation as to why I was born this way, other than 'your Mom must have eaten potatoes that were sprouting'... I had an amazingly supportive family that didn't wrap me in cotton wool and made me wear my prosthetic arm, tie my laces, do up my buttons etc and instilled a great sense of what independence in me.

**"I had an amazingly supportive family that didn't wrap me in cotton wool..."**

# Physical Disability

They never told me that I wouldn't be able to do anything. I swam in swimming galas, I rode horses and I learned to drive a manual car. If someone tells me they don't think I'll be able to do something it's like a red rag to a bull. The problem is I take it to extremes - someone once said I'd never be able to tie a balloon. I then went on to run a successful balloon decoration business, building live sized dragons, knights, clowns, all sorts out of balloons.

But there are downsides, and some of them are mental, not physical. I struggle to ask for help and I hate people offering me help. Until I break. Then ask for help but usually it's too late. I suffer from imposter syndrome and think that people aren't really offering me an opportunity or praise because of my actual experience, abilities or strengths. I automatically think they're just buttering up the one armed woman. Physically, it's the things you might expect such as there being no handrail on the right hand side, or the toilet roll holder being on the wrong side, or seat belts... I'm also in almost constant pain from my shoulder and neck from overuse and imbalance, and my hand aches and swells up through overuse. This is my major worry.

I would like people to notice my arm but not suddenly start talking to me in a different way, to realise that I'm exactly like them and my arm is nothing to be regretful of. My lack of part of my arm has made me who I am. I have a son and daughter and while it was awkward when they were wriggly babies I found my way around all the obstacles. I want them to understand that I'd rather try to do things for myself first, but they shouldn't try to force or coerce me into doing something I know I can't do and that will make me feel low when I fail at it.

I think disability awareness training for retail workers would be a good start, and some thought going into the design of everyday items such as handrails, toilet roll holders, seat belts, umbrellas, the levers that flush toilets, locks and handles on doors.

**"I would like people to notice my arm, but not suddenly start talking to me in a different way..."**

# Physical Disability

## Meet... Geoff

My name is Geoff. I'm 36. I am from Saratoga Springs New York. I am currently in between roles at the moment but I have been social media and public relations management for fashion, technology, Automotive, professional and collegiate sports.

I love sports, European and Ancient history. I'm a huge fan of kings and queens. I am also studying German, I hope to live and work there someday. Additionally, I'm a fan of coffee and cakes etc.

I have Cerebral Palsy, left side weakness. I am a wheelchair user. I am held together by surgical grade Titanium. My disability is static, but the way it impacts how I engage with the world is in a constant state of flux. To be honest, this is where I struggle. The bigger my life gets, the more recalibrating I must do. How do I achieve my evolving goals and objectives with my disability?!

I grew up with the "normal " kids. My siblings and I take no prisoners. My friends are the same way. I love them all for it. My right hand is strong. It is my lifeline. On the other hand (my left hand) is "broken"...bent. I hold it close to my body due to my high muscle tone and spasticity. My legs fit into this group as well. They do their own thing on most days.

The older I get, the more I wonder how the world perceives me. Whether I like it or not my wheelchair is not subtle. My left hand and body are a little off. Not to mention the challenges I face as a result of just being human. How much do these things and others affect how I am viewed in the workplace, dating, etc? Would I have greater success if I stood at 6 feet?

**"The older I get, the more I wonder how the world perceives me."**

# Physical Disability

I have also moved across the country in my mid-20s. I wish people understood the sheer number and volume of microdecisions I am making a day just to do the things that I need or want to do. I am an uber planner. How do I feel physically today? What to wear? Gotta be easy to put on/ take off. Will that 'fit, help or hurt my ability to transfer safely? Gotta look good though! Now, I'm on the go... I hope it's my regular driver. He/She won't pass me up. I am constantly making mental maps of public transportation routes, stops and sidewalks to the smallest details. Even the buses themselves, different models can change how I board the bus and where I sit. Can I make that small space work? It's all about angles- think The Matrix X Chris Farley "fat man in a little coat". All of these decisions happen fast. My brain is just wired that way.

Managing my disability would be easier if I wasn't such a social person. Spontaneity doesn't really exist. If I'm going out with friends, which wheelchair am I taking? Will my fold-up chair fit in the car? Where are we going? Can I physically get into this place? I always assume the bathroom layout is less than ideal. My team and I will make a plan for that. Oh yeah, don't forget to turn your brain off and have fun!

Awareness training for Public transportation drivers would be amazing. I would also like to see committees set up to have a more open dialogue with people with disabilities. Often times I think that things are built to the letter of the law and not necessarily for my consumption independently and safely. I run into this a lot with apartments for example—angles, room to turn, cabinet height. etc.

**"I wish people understood the sheer number and volume of microdecisions I am making a day..."**

# Physical Disability

## What is Physical Disability?

Physical disability is a condition or impairment that affects a person's mobility, dexterity, physical capability, and stamina. The causes of physical disability are wide and varied, but can generally fall into two categories: born with or acquired.

Physical disability can be caused by inherited and genetic disorders, serious illnesses, and injury.

Physical disability can be permanent or temporary.

A permanent physical disability means that there will be no or limited changes to the person's condition. A temporary physical disability means that the person's condition will improve, for example a broken leg or arm.

## Examples of types of physical disability:

**Spina Bifida**— for information you can check out Shine.

**Dwarfism**— for more information you can check out Little People UK.

**Muscular Dystrophy**—for more information you can check out Muscular Dystrophy UK.

# Invisible Disability

**Meet...** Fern

My name is Fern. I am 30 years old and I come from Hastings on the South East coast of England. I am a motivational speaker and radio broadcaster. I love to share my stories, listen to others and see what lessons we can all take away from our experiences. I am very interested in communication and relationships, particularly romantic relationships. I love getting stuck into the psychology of why people act and behave the way they do. For this reason, I also find true crime stories very interesting from a psychological standpoint - even though a fascination with murder may not be a great thing to introduce yourself with! On the other hand, I do love a good romcom or Disney film, a day out clothes shopping or coffee with a friend. Yes, I am quite a girly girl overall, it has to be said.

I was born with a condition called aniridia, which means I have no irises, (the coloured part of the eye which controls how much light is being let in). I was also born with an associated condition which is more common amongst visually impaired people called nystagmus. This means that my eyes shake involuntarily and this can make it hard to focus. Over the years, I have developed other associated conditions including cataracts, glaucoma and cornea problems. People often ask me what condition I have and by the time I've rattled off the long list, I think they generally regret ever asking in the first place!! All of this, (along with a few operations) has left me registered blind.

My vision is now very minimal, although I can make out shapes, colours, objects and even at times text - as long as the font is very big and my face is very close! I have a guide dog called Nancy who helps me to navigate my way around independently. I have a good sense of humour, which is required in my situation, as other ways my conditions affect me include answering questions which weren't meant for me, speaking to strangers and thinking they were my friends, (or worse, boyfriend!) and stroking furry jackets due to being under the impression they were beloved family pets. I am definitely not entirely immune from embarrassment, but being able to laugh certainly makes matters more bearable.

**"... being able to laugh certainly makes matters more bearable."**

# Invisible Disability

I think it's easy to assume that if you can't see, you would have no interest in what other people look like or indeed what you look like yourself. However, in my experience this could not be further from the truth. Heck, I'd like a heart-throb boy-band member hanging off my arm just as much as the next fangirl. I cared so much about my looks that when I was a teenager, I would go for days on end without eating simply in the pursuit of that beautiful beach body that all my sighted friends wanted too.

In fact, I may care even more about my looks than the average person, because I am unable to give myself that cheeky once over in the mirror. I mean, I could try - but it would be anything other than subtle and I'd likely leave a misty nose print in the centre of your mirror. The fact is, most of us don't put on a full face of make-up when we're snacking on the sofa on a Sunday night - we don't doll ourselves up for our own benefit, we do it for everyone else who certainly can see us!

Most importantly, I want people to understand that without sight, you are emotionally exactly the same. You still have hopes and dreams and aspirations for your life and everything you want to be. You still wish to have friendships, relationships, a love life. You still want a job, to earn money, to feel valued and to have purpose. Rejection is still painful and laughter is still special. You still make mistakes and you still get things wrong. Essentially, regardless of your sight, you are first a foremost simply another human being.

In a world where everyone has their face in their phone, I quite literally have my face ON my phone. As I still have some remaining useful vision, I like to use my phone by enlarging text and icons to make it easier for me to see. I think there is definitely more that could be done around app accessibility, as quite often apps do not sync up with the device's core enlargement features, which make them either very difficult or impossible for me to use. Where they do sync up, the screen is often morphed so that many options no longer fit on it and I have no way of reaching them. Now, everyone knows how quickly we want to just go ahead and accept the darn cookies already to get on with looking at "5 Top Dating Secrets of the Stars", (or y'know, whatever it is you read) and imagine my frustration when the Agree button isn't even there to select! Dating apps are also a prime suspect for this and at times, my boyfriend has been left wondering whether I just didn't have the option to swipe no!

**"...my boyfriend has been left wondering whether I just didn't have the option to swipe no!"**

# Invisible Disability

## Meet... Laurence

My name is Laurence, I'm 29 years old from Cardiff, UK and I am a teaching assistant/1:1 learning support assistant who alongside professional interests in getting the best I can out of those with Additional Learning Needs academically and personally in terms of their own development.

In my spare time I am very sport-orientated and watch as much as I can (football and rugby mainly; but I love Olympic/Paralympic years!). I don't manage to get involved with sport as much as I used to now that I'm older - I used to swim for a local disability swim club, but that fell to the wayside after 8 years or so. I briefly flirted with participation in wheelchair basketball but that too fell by the wayside and now the only thing that I do remotely close to being defined by sport are my physiotherapist prescribed strength and mobility exercises. Outside of sport, I also read a lot, dabble in creative writing and enjoy home cookery and baking.

As a means of a bit of context, I was born 10 weeks prematurely and incubated in a Special Care Baby Unit and diagnosed with spastic diplegia cerebral palsy (right-sided) and congenital hydrocephalus - abnormal build-up of fluid in the brain.

The hydrocephalus, to me, is the 'worst' of the two conditions day to day, because the migraines it causes through a bleed on my brain can be prolonged and self-limiting to the point where I either have to struggle through a day at work dosed up to the brim on medication or just write the day off completely and spend the day sleeping in a cool, darkened room. People do not seem to appreciate the severity of these, or trivialise my own experiences of migraines by saying 'I suffer headaches too!' — our experiences are polar opposites, I assure you.

**"People do not seem to appreciate the severity of these, or trivialise my own experiences of migraines by saying 'I suffer headaches too!'"**



# Invisible Disability

As for the cerebral palsy, with this being more 'visible' than the hydrocephalus - I have been subjected to infantilisation in the past and sometimes even in the present; which is hugely demeaning for someone who struggles with their own self-image and confidence on occasion at the same time as being stubborn.

But on the other side of my experience however while this infantilisation can prove to be frustrating, something that is even more so is the refusal to help when it is asked for and lead to being confronted with things like: 'I'm sure you can do that for yourself', "I'm not doing that for you, don't be silly" or "that's pretty easy". I can only stress: IF I'VE ASKED FOR HELP, I NEED IT - don't give me your platitudes of 'I'm helping to develop your own independence' when you're actually leaving me to stutter, flounder or sink. Simply be kind, assist however, I'll thank you (sincerely) for that help and we can move on with our days once again - don't make a bigger deal out of it than it actually is!

Personally, I feel quite empowered to live independently in current society and any existing accessibility considerations already in place. I do have quite strong opinions on things such a 'blue badges' and things like RADAR keys, but I don't think that's what you're asking me about — I just think there needs to be more of everything: handrails, ramps, and dropped kerbs, for just an example. One thing that would perhaps make my life a lot more pleasant and comfortable (as opposed to easier) is a reduction in loud, thumping music in high streets shop and bright lighting that upsets me due to an increased sensitivity to sound and light on my less-than-good days.

\*Laurence would fall under both invisible and physical disability- this can be common for disabled people as their impairments and conditions can impact them in a multitude of ways.

**"...don't make a bigger deal out of it than it actually is!"**

# Invisible Disability

## Meet... Jennifer

I was born in the eye of the collective storms of the 1969 Atlantic hurricane season, that summer twelve storms reached hurricane status. It wasn't until I was six or so, that they noticed I didn't turn my head when they called me and was sitting closer to the television to hear. At the time, my mother thought maybe I needed my ears cleaned or had an ear infection. Both issues were ruled out. I was sent for a hearing evaluation which revealed quite a moderate loss. Since I communicated so well, they were shocked that not only would I need hearing aids, but that my loss could progressively worsen over time.

Looking back, it makes sense why I've always been drawn to the written word. Raised in a house of voracious readers, I started reading at three and half, wanting to discover what was so captivating within the pages of the newspapers, magazines and library books that covered all the surfaces of our home. I understand now, it's because it was a way of making sense of the world. In school I did not have any friends as no one wanted to be associated with the girl with a hearing aid. I always looked forward to lunchtime, recess and going home—the time I could spend with my friends: The Hardy Boys, Nancy Drew, Trixie Belden... I've lived through books, educated myself through books, and earned an undergraduate degree in English and Literature.

I am a daughter, a mother, a wife, a sister, a dog lover, a book lover and I'm hard-of-hearing (deaf)—I am a soul, with beautifully dark inner scars, on a human journey prey to all the collateral damages that entails.

The earliest audiogram record, in 1981, shows I was able to discern some noises from a threshold level of 60 decibels in both ears. My most recent audiogram record shows that the right ear starts to recognize sound at 90 decibels and then tapers all the way down and off the register; the left (the ear I wear an aid in), starts at about 88 decibels and then tapers all the way down across frequency threshold to the lowest point and down. This classifies me as having a profound hearing loss and considered legally deaf.

**"I am a daughter, a mother, a wife, a sister, a dog lover, a book lover and I'm hard-of-hearing (deaf)..."**

# Invisible Disability

Quiet environments are the easiest for me to navigate. I've had to adapt and learn to maneuver situations I've led teams in noisy rooms where the acoustics were horrible and the noisy air conditioning system drowned out people's voices, or sat in lecture halls of two hundred students and had to find the right spot in the front row and hope the professor didn't pace around too much as it caused eye strain and brain fatigue.

I work HARD at hearing, at EXISTING in a world I feel excluded from. Fortunately, I've become more empowered and confident and determined to fight for mutual respect, yet, its not always so simple. Language and communication connects us just as easily as it divides us.

True allyship calls for one to check his/her unconscious biases, to educate themselves, to listen to what someone elucidates instead of framing their experiences within one's own schematic and heuristic knowledge. I can only speak from my experiences, but even well-intentioned people use ableist language or demonstrate behaviors persistent with ableist attitudes.

When speaking with someone who is hard-of-hearing or deaf, look directly at the person when speaking. Make sure not to cover your mouth so your lips are visible and if you have sunglasses on, take them off, as facial expressions are a big part of decoding communication for those who can't hear. Avoid over exaggerating mouth movements when speaking and please, above all, don't yell or talk excessively louder—it will only serve to aggravate those nearby and embarrass me, as natural voices do not amplify in specialized pitches and tend to lose clarity the louder one gets.

It's hard to believe, but even in this day and age, I still confront people who conflate deaf with dumb and treat me like a toddler or broken bird when dealing with me. Not all people who are deaf or hard-of-hearing can read lips, thus, be prepared to write things down if necessary or offer to text the information...always ask "what works for you?".

Lastly, don't label me or box me in to some preconceived stereotype based on some movie character or show you've seen—everyone's disability and impairment and the challenges they face are uniquely personalized and even two people with the same type of hearing loss may have vastly different methods of coping and adapting.

**"I work HARD at hearing, at EXISTING in a world I feel excluded from."**

# Invisible Disability

## What is Invisible Disability?

Invisible disability is an umbrella term for a wide spectrum of hidden disabilities and chronic illnesses.

Invisible disabilities can include visual or auditory conditions that do not require a person to wear hearing aids or glasses. It can include people with joint problems or chronic pain where mobility aids are not used or are only used some days. It can include neurological conditions. It can include chronic illness as well.

It is important to note that people with invisible illness may not identify as someone with a disability.

Invisible disability can be temporary or permanent. It can be congenital (from birth) or acquired.

Unfortunately invisibly disabled people are often have their lived experience questioned. Just because a person has no visible/external signs that they are disabled doesn't mean that they are not disabled.

## Examples of types of invisible disability:

**Crohn's Disease**— For more information you can check out Guts Charity.

**Ehlers-Danlos Syndrome**— For more information you can check out Ehlers-Danlos Organisation.

**Rheumatoid Arthritis**— For more information you can check out NRAS.

# Learning Disability

## What is Learning Disability?

If someone has a learning disability it means that they find it harder to learn certain life skills. The condition varies from person to person and may include aspects like difficulty with learning new things, communication, managing finances, reading writing and/or personal care. Because of this variability in the condition some people with learning disabilities are able to live independently with minimal support, whilst others require 24 hours support and care.

Learning disabilities can be congenital (born with) or acquired due to accident or illness.

An example of a learning disability is someone living with Down's Syndrome. With learning disability there can be crossover with physical or invisible disabilities. For example some people with Cerebral Palsy might also have a learning disability. Please note the word some, unless there is a clear diagnosis of learning disability be mindful not to assume a learning disability.

It is estimated that there is one and a half million people living with a learning disability in the UK. However, it is suspected that there are many more with some level of learning disability that have not been diagnosed. In the UK approximately 200 children a week are born with a learning disability, with males slightly more likely to be diagnosed.

There are many misconceptions around learning disability and what that can mean for an individuals chances in and quality of life. As we come to understand more about these conditions we can see that many individuals with learning disabilities can and do successfully complete education, gain employment, have healthy relationships, get married, have children, etc.

## Examples of types of learning disability:

**Down's syndrome**— For more information you can check out **Down's Syndrome Organisation**.

**Williams Syndrome**— For more information you can check out **Williams Syndrome Foundation**.

**Fragile X Syndrome**— For more information you can check out **Fragile X Organisation**.

# Neurodivergent

## Meet... Youlande

I am Youlande and I am 31 years young. I was born and raised in South East London. Currently, I am an Assistant Headteacher at an inner-city secondary school. I truly love being an educator and I have the ambition to become a headteacher. Outside of work, I am a self-taught seamstress (thanks to YouTube) and strangely, I have developed a keen love for gardening. Growing up in central London, there was not much green space, but now I have my own garden and thoroughly enjoy pottering around in my garden.

Throughout my education, from primary through to sixth form, my mother provided very hands on support. She taught me many learning techniques and was my greatest cheerleader. I decided I would go to university outside of London and continue my educationally journey on my own. My first year of university was exceptionally hard. I started to realise how difficult I found reading and interpreting text. I failed many essay assignments and the course leader met with me and said, "Perhaps you should consider dropping out. University is not for everyone!".

This statement motivated me to prove her wrong! I knew I had to figure out what was causing me to fail my essays. I visited the additional learning support center with my essays. After one glance, I was referred to meet with the educational psychologist. After several activities, he announces, "You're severely dyslexic. How was this not picked up earlier?" I was shocked. I called my mother, an experienced special needs teacher, to tell her the news. To my disbelief she said, "I know! I didn't tell you because I didn't want you to use that label as an excuse."

**"This statement motivated me to prove her wrong!"**

# Neurodivergent

Learning I am dyslexic helped me understand many issues and challenges I faced growing up. I see my dyslexia as a unique difference as my mind works differently than most peoples. As a teacher, I am perceived as someone who knows all the answers. However, my dyslexia allows me to be seen as human in the eyes of my students. I do make mistakes and encourage my students to point them out. It means my classrooms have a safe and encouraging culture which the students partake in.

I find proofreading and live spelling challenging. Some think this means I am unable to teach spelling. A teaching assistant questioned how someone who is dyslexic is allowed to become a teacher - in front of my class. However, I openly share that I am dyslexic with my students so they know that I can and may make mistakes and I encourage them to highlight them. This goes a long way to create a trusting culture where mistakes are allowed. As I teach A level Psychology, I can remember how to spell challenging words such as schizophrenia and parahippocampal gyrus. More importantly, I successfully teach students how to spell them as I remember how word looks rather than the individual letters with in it. Students often find this method helpful. Despite my challenges during university, I am in my final year of my masters. Dyslexics can study at a postgraduate level.

I hope society realises the visual stress dyslexics face on a day to day basis as the majority of what we read – digitally and hardcopy- are on white backgrounds. It would be easier for dyslexics to have a choice to change the background of what they are reading without having to use glasses similar to those worn by Bono and Elton John.

**"I openly share that I am dyslexic with my students so they know that I can and may make mistakes..."**

# Neurodivergent

Meet... Kate

My name is Kate, I turned 40 at Christmas time. I am originally from Lancashire but I live in Leeds, West Yorkshire. I am a Disability & Inclusion Consultant. I have spent 10 years working in Universities managing student-facing disability support teams and have decided to start my own business to support individuals to work to their strengths and to help employers remove barriers to high performance by embracing meaningful inclusion.

I love to get out and enjoy the countryside, I love to spend time with my friends and family. I am a big music fan, with old funk and soul being my favourites and I enjoy watching rugby and films, particularly gangster films. I am also desperate to get a Bernese Mountain Dog!

I have dyspraxia with ADD sprinkles! This was only identified very recently. My plan for my 40th year was to start a business (check!), get a dog (working on it!) and finally find out if, as I had long suspected, that I was dyspraxic!

I now understand why my intuitive response to first holding a pen meant all of my early childhood drawings and a round of Christmas cards one year were all penned by ytak (Katy backwards) as I wrote right to left. It explains why I have to wear orthotics in my shoes, as I was born with dislocated ankles, but now I understand that weak or loose joints are commonly associated with dyspraxia.

I'm a great problem solver and multi-tasker. I'm deeply compassionate and empathetic towards people. I can communicate well and create and sustain meaningful relationships.

**"I have dyspraxia with ADD sprinkles!"**



# Neurodivergent

Dyspraxia is certainly one of the lesser known neurodiverse conditions; it is far more than 'clumsy child syndrome' although I do my fair share of dropping, spilling and breaking!

For me it is interesting that this wasn't picked up whilst I was in education, I was always in the top sets whilst at school in the 90s and there probably wasn't anything obvious that stood out to my teachers. I was able to find my own ways to work and take in information. However it does make me wonder how, my pretty decent grades, might have been bettered if assessment methods were more inclusive.

Why can knowledge only be demonstrated by regurgitating reams of written text in a timed and often pressured environment of an exam hall? Why can't it be demonstrated by talking through ideas, creation of art work or demonstration of physical ability - why are these seen as on the periphery of knowledge and educational attainment? Why does success depend on what you can hold in your memory and what information you can process in a short, pressured amount of time? Isn't knowledge best demonstrated when it's applied?

For me, time and space to concentrate and process is important, whilst having a backup for my working memory. I also find that time management can be a tricky one, I'm sure time speeds up in the morning and I am often late and end up leaving the house really stressed.

The most important thing is for lived experiences to be listened to and heard. Barriers can be invisible to those who don't experience them and so involving and including into discussions, the widest range of voices and experiences, can only increase inclusion. However this only becomes meaningful if those barriers are then removed.

**"Barriers can be invisible to those who don't experience them..."**

# Neurodivergent

## What is Neurodivergence?

Neurodiversity refers to the diversity of human brains and the infinite ways of neurocognitive functioning in humans. Just as disabled people in general are trying to change the understanding of disability from a medical perspective to a social model, so the neurodivergence movement is aiming to remove the meaning of neurodivergence from medical/psychiatric to one of social and cultural prejudice.

Neurodiversity means that people with autism, ADHD, dyslexia, bipolarity, etc are no longer pathologised, in other words psychotherapists and other specialists who integrate with the neurodivergent meaning are no longer trying to “fix” an individual. Instead they work with their patients to find a way of living that enables the individual to thrive.

When we talk about Neurodiversity we are saying that a person condition is simply a part of who that person is. The condition is not something to be cured, but something to be celebrated. In fact some advocates believe that common therapies used to treat behavioural and language differences could be misguided and even unethical.

There is a Neurodiversity Movement that is tackling the human and civil rights of neurodivergent people. Similar to the disability civil rights movement, this movement wants to ensure that neurodiverse people are fairly included in society and given the same rights, access and opportunities to a full, happy life as any other individual.

## Examples of types of neurodivergence:

**Epilepsy**— For more information you can check out **Epilepsy Action**.

**Tourette Syndrome**— For more information you can check out **Tourettes Action**.

**Autism**— For more information you can check out **Autism Organisation**.

# Chronic Illness

Meet... \*Rebecca

I'm a 35 year old woman originally from Australia, I have lived in the UK most of my adult life. I work fulltime for the NHS. I have a first class honours degree and 2 postgraduate degrees. I love learning, being creative, travelling and going to see live music.

I have an autoimmune condition similar to the more familiar Rheumatoid Arthritis, called Psoriatic Arthritis. I have lived with this since the age of 6. It affects mostly my larger joints and in the past my eyes. Uveitis which has left me blind in one eye. When I get really stressed I can end up with little blotches of psoriasis all over my skin. It is variably controlled by a medication I need to inject weekly called a biologic. This also makes me more susceptible to infections and illness.

I can sometimes have 'flare' ups of my disease, this can leave me with swollen joints and in extreme amounts of pain and unable to walk or pick up/lift/carry anything, pretty much not get out of bed. On good days I have limited pain and stiffness. On any normal day I get general pain and stiffness that eventually loosens up.

Every day I am always in pain, and I am always fighting fatigue. I see this as a kind of manageable pain I suppose... because if I just let myself cave into the pain and tiredness I don't think I'd ever leave my bed.

It has really impacted my mental health over the years. It was hard to deal with arthritis when you were a 17 year old at high school being stuck around other teenagers that think arthritis is an old persons disease. I ended up developing quite a significant anxiety disorder and depression that impacted my final year of high school. I ended up withdrawing from a lot of my social circle and cutting myself off from a lot of my friends, and stopped myself from doing a lot of the things I used to enjoy.

**"...I rather hate that arthritis has such a simplified meaning to it."**

# Chronic Illness

While I consider myself mostly free of the anxiety and depression that crippled me in my late teenage years and early twenties they still remain because I intrinsically link them to how I feel about myself and my health. So, when my arthritis flares I tend to feel myself want to withdraw from the world.

I wish people were more understanding of others and their individual experiences. There are many forms of arthritis. The nature of inflammatory/autoimmune diseases is that they are often systemic – and I rather hate that arthritis has such a simplified meaning to it. It's not confined to just the bones. For me it also affects my energy levels, skin and eyes, for other people it can affect their lungs and heart. It is a disease of any age group, babies can have it. It is certainly not just an old persons disease.

I manage to work full-time. It's been hard to get work to understand how my condition affects me. Because when it comes down to it – they look at me and think I'm perfectly healthy. It's hard for them to grasp something they can't see. I do struggle working 5 days a week at the office, and I do think it has an affect on my condition. Small or large flares can be triggered by stress, overworking, even certain weather conditions. Work flexibility is everything, the ability to work from home a few days a week makes a big difference to my overall pain and fatigue levels, it definitely gives me positive health benefits.

I've never let it control me. I love travelling, I drag my sore ankles and feet around different cities – I might not be able to walk the next day, but it'd be worth it to me!

In my case, because I manage to make myself do things, it doesn't mean I'm well or am fine. I think society puts a lot of emphasis on disabled people and their inability to do things. But in my own disabled experience I focus on what I can do, or think I can manage to do, because ultimately I have to live my life. I can't let the pain be a barrier for me to do the things I want to do. I just get out there and do them and live with the physical consequences of that decision.

**"... because I manage to make myself do things, it doesn't mean I'm well or am fine.**

**\*Rebecca is a pseudonym.**

# Chronic Illness

## Meet... Ruth

I'm Ruth and I am 52 years old and working on being an ultra-visible over 50! I am an incredibly happy person (despite the odd rant about inequity). I've lived with my partner Martin for 25 years (we became Civil Partners in February now they are available to heterosexual people too). We have a son, Bram.

I like writing. The freedom of expression that I feel through singing and art is like no other. I read lots across all genres, and there is nothing more relaxing than settling down to watch the TV. I watch everything from Breaking Bad to Question Time. I have practiced Transcendental Meditation for over 30yrs and I am a Reiki Master.

I work full time as a Head of School in the South West. I am a Governor at my son's school. I am one of the Network Leads for #WomenEdEngland. I am also involved in #DisabilityEdUK, running the Twitter account, developing the website and working the Development Group to raise its profile nationally. DisabilityEdUK is for all educators who experience the disabling impact of living in an ableist society. I believe that love is the most important value in life.

The condition I live with is primary lymphoedema. This condition means that my limbs are swollen, misshapen and heavy. I'm at risk of cellulitis which is inflammation in the tissues. I have to take antibiotics everyday to prevent this. To manage my condition and work I have to wear compression garments (a triple layer on my feet, double on my legs and one on my arm). I need reasonable adjustments so that I can work fulltime. When I get home, I require caring from my partner. If I have a late night at work, that always has a detrimental impact on me, and I always experience illness the following day. I am constantly fatigued and my life is a careful juggling act of self-care.

Every day I have to wash my skin and then apply cream to the limbs to protect the skin. Standing for any length of time is virtually impossible and I always need access to seating which is not always available.

**"I need reasonable adjustments so that I can work fulltime."**

# Chronic Illness

Lymph is a clear fluid in the body, and is part of the lymph system. I get small blisters on my skin and the lymph seeps out, wetting all of my garments/clothes when this is happening. It can gross people out who don't have the condition, but for me it's normal.

The condition is progressive which means it gets worse as I get older and I need additional bandaging every year to stop it worsening, protect my skin and prevent tissue changes. This condition has affected my self-esteem and mental health over the years, my teenage years in particular were very difficult, as I never felt good enough compared to other people. Over time I have learnt my value and self worth.

I may have lymphoedema but as a young person I still captained the school rounders and tennis teams and won an accolade for my role as Dorothy in the Wizard of Oz. As an adult I have always worked full time and have achieved promotions. I have been a senior leader for over over ten years. I may have limbs that don't look like yours but that doesn't make me less loveable and I am loved and appreciated by many people. I know you mean well, when you say that 'you are so brave', or 'I couldn't cope like you', or 'I don't think of you as disabled', but none of these are compliments, they are ableist and they are saying that you can't see beyond your non-disabled identity.

If you want to be a better ally for someone with lymphoedema, find out about the condition. There is lots of information out there- [www.lymphoedema.org](http://www.lymphoedema.org) is a good place to start. Be aware of reasonable adjustments for all disabled people. Learn the specifics of that person's condition, we don't all feel everything in the same way. Make sure your seating is not too high seating as a swollen leg/s can mean that we slide off these kind of seats. Have seating available enables the person to rest and not stand in queues. Notice when people are getting tired and lighten their duties as short term help. Look at any changes in your organisation from a disabled perspective...what will the impact of this change be on my disabled colleague and ask what can I do to prevent any negative impacts?

See beyond a persons condition.

Disabled person...just like you but with extra skills!

**"I may have limbs that don't look like yours but that doesn't make me less loveable..."**

# Chronic Illness

## What is Chronic Illness?

Chronic illness or chronic diseases are conditions that are lifelong and have no cure. Conditions such as diabetes, arthritis, hypertension, chronic fatigue, asthma, Cystic fibrosis, Multiple sclerosis, depression, stroke, etc. Chronic illnesses are managed with medication and other supports. It is possible to develop a chronic condition at any age, however, it is more likely to develop in those over the age of 65.

Many chronic illnesses to fall under the umbrella of disability, due to the long term effect that a person's condition could have on that person's life. Not everyone with a chronic illness, however, identifies as disabled. You may notice that there is some crossover in this pack between categories and conditions, i.e., chronic fatigue is considered both an invisible disability and a chronic illness. Take the lead from an individual with a chronic illness on how they want to identify.

People with chronic illnesses may need some support to manage their health. For example, a child with a chronic illness may need a parent or teacher to manage their medication and remind the child when to have it. Some people may also need to be encouraged to practice self care. Reasonable adjustments might also have to be considered in a school or workplace to allow an individual with chronic illness to continue learning/working in a safe way.

## Examples of types of chronic illness:

**Cystic Fibrosis**— For more information you can check out **Cystic Fibrosis Trust**.

**Asthma**— For more information you can check out **Asthma UK**.

**Diabetes**— For more information you can check out **Diabetes UK**

# Resources

## Books:

- Disability, the basics - Tom Shakespeare
- Disability Visibility - Alice Wong
- The Pretty One: on life, pop culture and other reasons to fall in love with me - Keah Brown
- Disabling Barriers, Enabling Environments - John Swain, Sally French, Colin Barnes, Carol Thomas
- Crippled: Austerity and the Demonisation of Disabled People - Frances Ryan

## Media:

- 'Crip Camp' - Netflix
- 'Judith Heumann's Fight for Disability Rights' - Comedy Central "Drunk History" (YouTube)
- 'People Living with Disabilities Review Characters with Disabilities' - BuzzFeedVideo (Youtube)
- 'Inspiration Porn and the Objectification of Disability' - Stella Young, TEDx (Youtube)
- 'The Truth About Growing Up Disabled' - Dylan Alcott, TEDx (Youtube)

## Websites:

- [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)
- [www.un.org](http://www.un.org) (Convention on the Rights of Persons with Disabilities)
- [www.equalityhumanrights.com](http://www.equalityhumanrights.com) (Disability Advice and Guidance)
- [www.scope.org.uk](http://www.scope.org.uk)
- [www.mencap.org.uk](http://www.mencap.org.uk)

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