

Hidden in plain sight

Disability

'a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities'

Invisible Disability

'an invisible disability is a physical, mental or neurological condition that *is not visible from the outside*, yet can limit or challenge a person's movements, senses, or activities'

https://invisibledisabilities.org/what-is-an-invisible-disability/

Examples of Invisible Disabilities

Chronic Fatigue

An umbrella term for several conditions involving severe exhaustion, insomnia, and cognitive impairment.

Chronic fatigue is often brought on by a viral infection – long covid is a now well-known example.

Hypermobility

A connective tissue disorder primarily affecting the joints, skin, and blood vessels.

Symptoms include joint pain, frequent dislocations, unusually severe scarring, dizziness, and atypical reactions to drugs.

Multiple Sclerosis

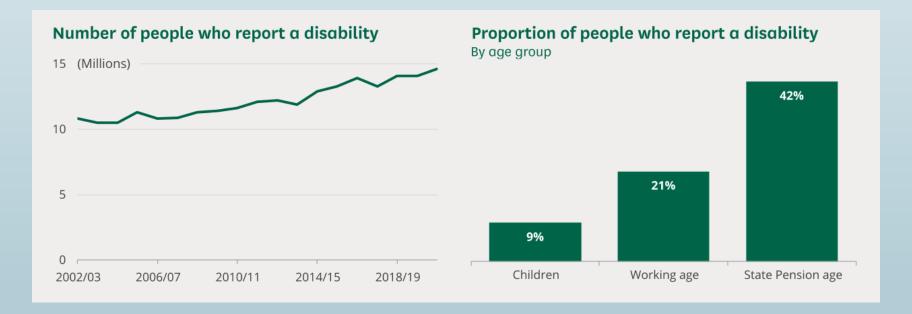
An autoimmune disorder which involves damage to protective sheaths around nerves in the brain and spine.

Symptoms include muscle weakness, disruption of coordination and balance, and visual impairment.

https://www.disabled-world.com/disability/types/invisible/

Prevalence of Disability

- In a 2021 survey, 14.6 million people in the UK reported a disability.
- This represents 22% of the population.



UK disability statistics: Prevalence and life experiences (2022)

Can't vs Cost

With many invisible disabilities, whether or not a person is able to do something isn't a simple yes or no answer.

Spoon Theory is a widely used analogy which uses spoons as a metaphor for energy as a currency which is spent on day-to-day activities, and with which an energy debt can be incurred.



The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.



Christine Miserandino, "The Spoon Theory", 2008. https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/

Disclosure

Who do we tell, and why?

Why Not Disclose?

- Fear of discrimination
- Lack of official diagnosis
- Not wanting to have to "prove" it
- Not fully understanding the extent of the condition
- Not wanting to accept that they are disabled

Barnes, 'Suffering in Silence: The Epidemic of Invisible Disabilities in the Workplace', 2020

Discrimination

The type of discrimination people with invisible disabilities face is different than that faced by people with visible disabilities.

"It's all in your head."

"Have you tried yoga?"

"You just want attention."

"What if someone who really needs that seat comes along?"

"It's not that difficult, just try harder."

Kattari, Olzman, Hanna; "You Look Fine!": Ableist Experiences by People With Invisible Disabilities', 2018

Diagnosis

- Many invisible disabilities are difficult to diagnose clinically.
- A formal diagnosis can be hard to get.
 - A study of patients with a diagnosis of Fibromyalgia found that the mean time to get the diagnosis was 6.5 years, and the majority of patients had seen at least three different doctors.
- Discriminatory attitudes exist in the medical community as well.
- There are many reasons someone might not seek a formal diagnosis.

Choy E, Perrot S, Leon T, et al. A patient survey of the impact of fibromyalgia and the journey to diagnosis.

Accepting Disability

We live in an ableist society – discriminatory attitudes are common. A person does not immediately unlearn these attitudes just because they become disabled themselves. This is called **internalised ableism**.

We only have our own experiences to judge by. It may take someone a long time to understand that what they are experiencing isn't normal.

Someone with an invisible disability may struggle with believing they have the "right" to call themselves disabled.

Why Disclose?

- Finding community
- Promoting visibility
- Seeking informal support
- Seeking accommodations
- Seeking other legal entitlements

Kattari, Olzman, Hanna; "You Look Fine!": Ableist Experiences by People With Invisible Disabilities', 2018

Accessibility & Accommodations

Who gets to live in a world that's designed for them?

Accommodations

'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights'₁

"Reasonable Accommodations"

'any change to a job or a work environment that is needed to enable a person with a disability to apply, perform and advance in job functions, or undertake training.' 2

1. UN Convention on the Rights of Persons with Disabilities

2. https://europa.eu/youreurope/business/human-resources/equal-treatment-qualifications/reasonable-accommodation/

Examples of Accommodations



OpenDyslexic-Regular.otf OpenDyslexic-Italic.otf OpenDyslexic-Bold.otf OpenDyslexic-Bold.otf OpenDyslexic-Bold.otf OpenDyslexic-Bold.otf OpenDyslexic-Bold.otf OpenDyslexic-Bold.otf OpenDyslexic-Bold.otf









Disability exists in the context of the environment

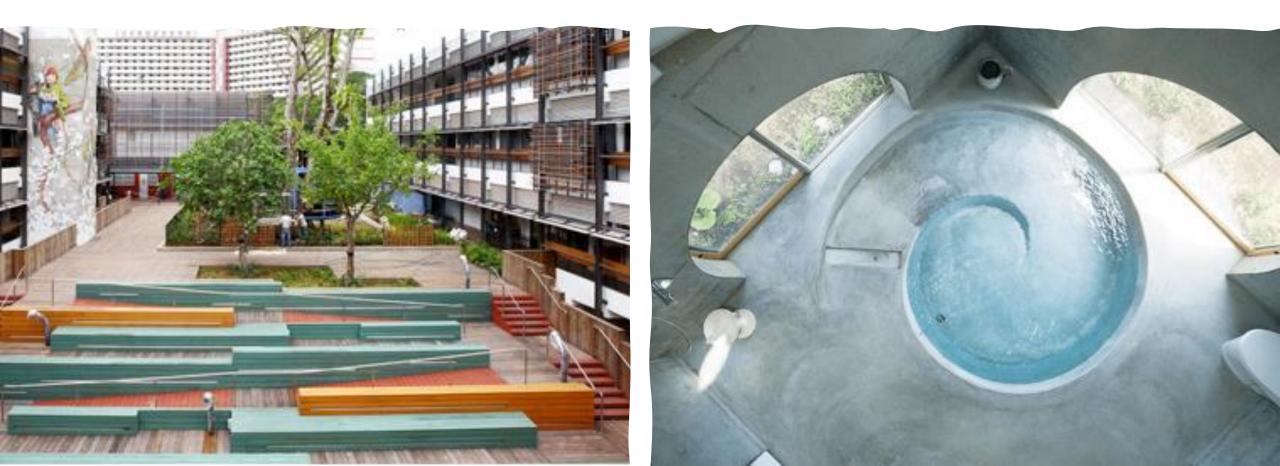
Accessibility by Default

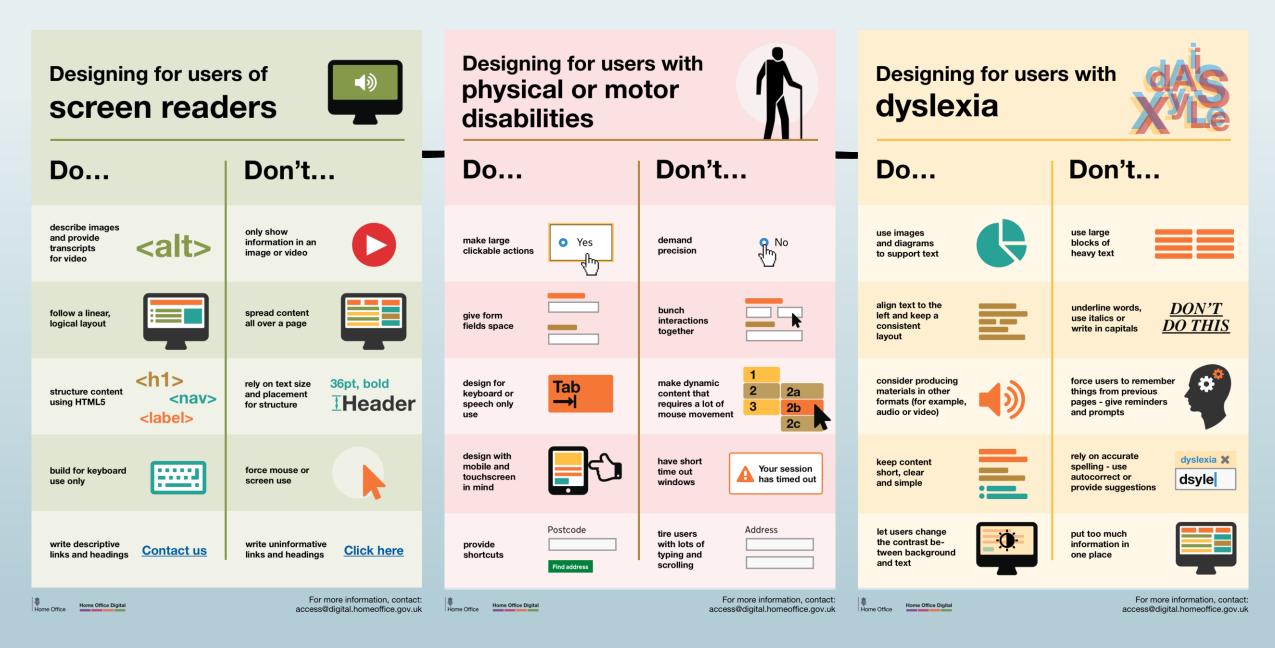


Our Anticipatory Duty (relating to students)

The University must plan ahead for reasonable adjustments and not wait for a student to approach us before considering how to meet the duty. We must anticipate the type of barriers that students with various impairments may face. We must also anticipate the adjustments we can make to remove these barriers.

Accessibility by Default





https://accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility/

The Benefits of Universal Design

- When accommodations must be requested rather than being provided by default, it requires extra effort from someone who is already struggling.
- Universal design allows people with disabilities to interact with the world without forcing them to disclose their disability to receive accommodations.
- Universal design makes life easier for everyone.

Accommodations at the University

What help is available to staff and students?

for Staff

for Students

- Staff can register a disability on their CoreHR profile.
- Local accommodations should be discussed with:
 - Line management
 - Occupational Health
- Disability Services can assist with any costs associated with making reasonable adjustments.

- Students can register with the Disability Service.
- For temporary issues or flare-ups, the School and their Adviser of Studies should be informed.
- Coursework extensions can be granted locally, but additional exam time must be approved by the Clerk of Senate.
- Additional support is organised through Disability Services.

Any questions?