

# What do we call people?



The UK Equality Act 2010 defines a **disabled person** as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. The impairment has lasted or is likely to last for at least 12 months. Everyday things like eating, washing, walking and shopping) must be affected by one of the 'capacities' listed in the Act which include mobility, manual dexterity, speech, hearing, seeing and memory.

The term **patient** is popular<sup>1</sup>, although for some it emphasises a medical approach, and this sometimes continues through the use of the term **ex-patient** for those who have been discharged from hospital or from the entire health service. A **case** is an instance of disease or condition, not a person. The term **difficulty** suggests that the person experiences it as a **problem** rather than a **difference** and implies we should view the person as a problem too. We do not say that someone has a cancer problem! Similarly, the term **sufferer**, used by some drug companies (e.g. Wellcome, Priory) implies passive victims who have identical, unwanted experiences. **Survivors** triumph over their difficulties, the system or discrimination – although Ossie Newell goes further and defines himself as a **conqueror**. **Resilient** people may be unchanged, in contrast to those who grow and **flourish** through their experiences. The Paralympics have called participants **superhuman** but this '**inspiration porn**' sets people up as **heroes** who never give up or fail. People are **experts by experience** as they bring **lived experience** and **knowledge** of living with the condition, but some feel like novices and others say **privilege is experience** too, so this is just another devaluing label. Some ExEs are qualified professionals too and the label can sideline this. **Vulnerable** persons may be considered weak victims rather than **valuable**, while **people with care and support needs** are less able to protect themselves from harm.

The term **learning disability** refers to a serious intellectual and social impairment usually present from birth – a **congenital disability**. Stephen Dorrell launched the term in a speech to Mencap in June 1991. Serious intellectual impairment is an IQ more than two standard deviations below the general population mean, i.e. below 70. The science of IQ testing is disputed, as Binet never considered IQ to be fixed or promoted its use with all children, Burt used hoax data, and Sternberg showed how it has been used to support racist arguments. The social functioning component is often ignored. The plural form '**learning disabilities**' is used to emphasise that many people have **specific learning difficulties** and even those with a wide-ranging impairment are unique.

Further Education refers to people with **learning difficulties**. It may be hard to access and use education but learning rarely disables anyone. Where impairment is severe, the person may be eligible for health or social care, but the eligibility threshold is rising.

Some **People First** groups place the person before the label, and use **people with disabilities** which **increases** public tolerance. JobCentre Plus abbreviate this to **PWD**, but would you say 'people with oppression'? Acronyms, such as **PRM** distance the speaker from the humanity of the individual. Many **autistic people prefer** to celebrate diversity with identity-first language.

The Social Model of Disability separates the person's **impairment** from society's disabling processes. Social Model supporters (identified by use of the capital D) say that someone is made a **Disabled person** by society's response. Mole Chapman says, therefore, that the opposite of a

disabled person is not a **nondisabled** person but an **enabled person** and a **neuro-diverse** person<sup>2</sup> is not **neuro-typical**. The comedian Francesca Martinez avoids the medical term ‘cerebral palsy’, preferring **everyday words** – she calls herself a ‘wobbly person’. Some terms are derogatory, such as **wheelchair-bound**, as Tim Rusby-Smith notes that his wheelchair enlarges his freedom. Ordinary words acquire special meaning, as where the BMJ asserts that saying **affected by** is derogatory, while **lives with** dementia is not.

Professionals, such as lawyers, call the people who choose, engage and pay them their **clients**. Policy makers in a learning disability context commonly refer to **self-advocates**, although this can be confused with legal, independent or informal advocates. The economy defines a person as a **customer** when they prioritise choice over other values (such as fairness), while a **consumer** may be just getting the goods and services that they are given. Traditional economics assumes choices are rational and maximise self-interest, but newer theories disagree. A **claimant** asks for money.

The term **service user** refers to people receiving social care services although we all use many services, including transport and education, and some have been excluded by rising eligibility thresholds and others are forced to use them, such as people who are detained. The national learning disability self-advocacy movement has explicitly rejected use of the term **user** as they believe it (i) links them to people who ‘use’ illegal drugs and (ii) defines them in relation to the services they use rather than them as **citizens**. The idea of co-production suggests that people might be **participants** in selecting and achieving a shared goal. A **lay person** has no expertise.

**Carer** implies a one-way relationship in which substantial help is provided constantly, perhaps for money, while **relative** or friend implies mutuality. A **befriender** is not a **friend**. Relatives may, prefer **family carer** while staff want their professionalism recognised by the job title **care-worker**. An **informal carer** is unpaid and may live elsewhere.

The **public** may be everyone or a specific group, such as recipients of healthcare so **some** talk of multiple **publics** each with their own interests and **representatives** or **delegates** who speak for them. Researchers talk about **PCPIE** – patient, carer and public involvement and engagement, but these terms are used in **different ways**. Where people using services have a job in the service too, they are sometimes said to **live in both worlds**, but we all live in the same one.

Some terms have been generally rejected – **abnormal, birth defect, burnt-out, chronic, defective, handicapped, normal, schizo, special, special needs, subnormal**. **Negative terms** such as ‘noncompliant’ appear more often in casenotes of Black Americans.

Advice is available on disability from the **UK government** and **Disability Now**; mental health from **Shift** and the **British Journal of Psychiatry**; learning disability from **Mencap**, diabetes from **HEE**; dementia from **DEEP** and LGBTQ+ people from the **BBC** and **SMB**. Some agencies have their own definitions, such as the **NIHR**. WHO **guidance** advises on naming new diseases to avoid harm. The National Library of Scotland has a history of terms for Race, Gender and Sexuality, Disability, Religion, and Class; **BAME** is rejected as an unhelpful term. Neutral language can be spoilt over time and need replacing. Roy Lilley told us to ‘*dump jargon and speak like a human.*’

**NDTi** reports use the terms **person** and **people** for those receiving care, so others get the label. Readers are told this at the start of NDTi documents.

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<sup>1</sup> The survey by **Simmons et al** in 2010 and the systematic review by **Dickens and Picchioni** in 2012 found the term patient or client was preferred over service user by people receiving mental health services.

<sup>2</sup> In 2015, **Kenny et al** asked 3,400 people and found people and families liked the term ‘autistic’ but professionals weren’t keen.