

# 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 his or her ability to carry out normal day-to-day activities. Long term means that the effect of the impairment has lasted or is likely to last for at least 12 months (there are extra rules covering recurring or fluctuating conditions). A normal day-to-day activity (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 mental health **difficulty** suggests that the person experiences it as a **problem** 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. In contrast, some people call themselves **survivors** – either through triumphing over their difficulties, or enduring an oppressive system – although Ossie Newell has gone beyond mere survival to define himself as a **conqueror**. The Paralympics have called participants **superhuman** but this '**inspiration porn**' sets people up to be either helpless or exceptional with no middle ground. People with long term conditions are **experts by experience** in recognition of the knowledge they have of themselves and their responses to living with the condition, but some feel like novices. It may be hard to see the resilience of a person labelled **vulnerable**, especially if they have a **congenital disability**.

The term **learning disability** means a serious intellectual and social impairment usually present from birth. Stephen Dorrell, Minister of Health, first used 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 two groups of learners – those with **learning difficulties or disabilities**. Dyslexia, visual impairments etc. make it difficult to access and use education, and for some, their learning 'disability' is severe enough to gain eligibility for health or social care. But learning rarely disables anyone, and the eligibility threshold is rising.

Some **People First** groups and **Connect in the North** have voted to place the person before the diagnosis, and use **people with disabilities**, and this terminology has been **shown** to increase public tolerance. JobCentre Plus abbreviate to **PWD**, but would you say 'people with oppression'?

The Social Model of Disability separates the person's **impairment** from society's disabling processes. Social Model supporters assert that an impaired person is only made into 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**. The comedian Francesca Martinez avoids the medical term 'cerebral palsy', preferring **everyday words** –she calls herself a 'wobbly

person'. Some ordinary words acquire special meaning, as where the BMJ asserts that saying **affected by** is derogatory, while **lives with** dementia is not. Tim Rushby-Smith says his wheelchair expands his freedom, so he is not **wheelchair-bound**.

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 and statutory advocates. The economy defines a person as a **customer** when they choose to buy particular goods or services, 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 recent theories note other drivers. A **claimant** asks for money.

The term **service user** tends to refer to people receiving mental health or learning disability services (rather than everyone who experiences these difficulties), although we all use many services, including transport and education, and some people have lost entitlement as eligibility thresholds have risen while others have not had a choice, 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 a mutual exercise of negotiation to bring about a shared purpose.

**Carer** suggests a one-way relationship in which substantial help is provided on a regular basis, perhaps for money, while **relative** or **friend** implies kinship and mutuality. Some people dislike the term carer which underplays their family tie, preferring **family carer**, rather than 'carers' as they believe the latter denies their family tie. An **informal carer** may not live with the person.

The **public** may be everyone or a specific group, such as recipients of healthcare or campaigners. **Barnet and Mahoney** talk of multiple **publics**, each with their own interests and priorities. Some researchers talked about **PCPIE** – patient, carer and public involvement and engagement, but a **survey** found that 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**.

Advice is available: on disability from the **UK government**, Disability Now (**Hacked off**, 2005), on mental health from Shift (**What's the story?** 2008) and the **British Journal of Psychiatry**, and for learning disability from Mencap (**Reporting without Prejudice**, 2008). Specific agencies have their own definitions, such as the National Institute of Health Research (**Lay Reviewers Jargon Buster**). The World Health Organisation has published **guidance** on how to name new diseases to avoid unintended harm. Neutral language can become tainted over time with pejorative attitudes and so will need replacing<sup>2</sup>. Roy Lilley advised us to: *'dump jargon and speak like a human.'*

**NDTi** reports use the terms **person** and **people** for those receiving care and everyone else is given a descriptive title, such as worker or relative. This means that the professional relationship exists between the person and the worker. Readers are told this at the start of NDTi documents.

---

<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> Rapid changes may occur in acceptable language as in the terms used to speak of transgender people. Guidance is **here**.