

Glossary

This glossary contains definitions and descriptions of some of the key terms used throughout the What Matters to Me project.

Advocacy: Means getting support and representation from another person, often a family member, to express your experiences, preferences and views.

Best Interest: When somebody is deemed to lack capacity themselves, the Mental Capacity Act (2005) states that a decision must be made in their best interest. To make this decision, an assessment will take place, which should involve and include the person, their support circle as well as the professionals involved in their care.

Capacity: Refers to the ability of a person to make their own decisions. It involves an individual understanding information relevant to a decision, retaining that information, using or weighing that information as part of the process of making the decision, and communicating their decision (whether by talking, using sign language, or any other means).

Challenging Behaviour: The term “challenging behaviour” has been used to refer to behaviours which may be shown by children or adults with a learning disability and which pose a challenge to those supporting them or pose a risk of injury to the individual. Characteristically, challenging behaviour puts the safety of the person or others at risk or has a significant impact on the person’s or other people’s quality of life. Challenging behaviours can be many and varied, but aggression towards others, self-injury, and environmentally destructive behaviours tend to be the most reported. It is important to note that challenging behaviour represents a person’s best (or only) way of communicating an unmet need and getting that need met.

Children and Families Act 2014: The Children and Families Act 2014 is a UK law designed to improve support and protection for children, young people, and their families. It brings together several areas of legislation, with a strong focus on: adoption, family justice, special educational needs and disabilities and childcare and parental leave.

Commissioner: A commissioner is a person with specific responsibility to deliver a particular public service.

Continuing Healthcare: Refers to a free package of health and social care for adults with complex health and care needs funded and delivered by the NHS.

Education Health and Care Plan (EHCP): An education, health and care plan identifies the additional educational, health and social care support needs of children and young people aged up to 25.

Hospital Passports: Otherwise known as ‘health and care passports’, hospital passports contain information relating to the health, care and communication needs of a person with a learning disability to ensure that staff can provide the right support when they are in hospital settings.

Independent Advocate: An independent advocate supports and represents an individual to have their views heard but does not have any personal or organisational investment in the outcome.

Integrated Care Board (ICB): ICBs are statutory NHS organisations that are responsible for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area.

Intensive Interaction: Intensive Interaction is a communication approach designed to develop shared understanding and meaningful interactions between individuals, particularly those with severe or profound learning disabilities.

Learning Disability Nurses: Learning disability (LD) nurses are specialised healthcare professionals who support individuals with learning disabilities to improve their physical and mental health, while also promoting independence and social inclusion. They work in various settings, including hospitals, communities, and schools, to provide tailored care and advocacy for their patients.

Makaton Signs: Makaton is an augmentative communication method, which combines signs, symbols and speech to support individuals to communicate.

Mental Capacity Act 2005: The Mental Capacity Act 2005 establishes a legal framework for supporting individuals who may lack the capacity to make decisions for themselves.

Non-Instructed Advocacy: Refers to taking affirmative action on behalf of an individual who lacks the capacity to advocate for themselves.

Non-Verbal: Refers to people who do not communicate using speech and may use alternative forms of communication, for example, sign language or gestures.

Observable Indicators: Observable signs (body language, facial expressions, interactions, speech or vocalisations, behaviours etc.) a person displays that express their feelings.

Personal Assistant: A personal assistant (PA) is a member of paid staff that provides tailored support for people with a disability.

Pica: Refers to the eating of objects that are not suitable to be eaten.

Profound and Multiple Learning Disability: Someone with profound or multiple learning disabilities (PMLD) will have more than one disability and will have difficulty communicating verbally. Many people with PMLD may have additional sensory, physical or health needs or mental health difficulties. (Mencap and PMLD Network)

Reasonable Adjustments: Reasonable adjustments refer to modifications or accommodations made to ensure individuals, particularly those with disabilities, can access, participate, and thrive in various environments without facing undue barriers or disadvantages.

SEND: Special Educational Needs and Disabilities

Severe Learning Disability: Someone with a severe learning disability will likely use little to no speech and will need lifelong support with daily activities like dressing, washing, eating and keeping safe. A severe learning disability will be identified at birth or during someone's early childhood.

Support Circles: A support circle is a group of people who meet regularly to discuss how to help an individual with learning disabilities to accomplish their goals, dreams and aspirations. People in circles are usually friends and family but professionals can be invited to join as and when needed.

The Equality Act 2010: The Equality Act 2010 is a UK law designed to protect individuals from discrimination based on characteristics such as disability, race, gender, age, and religion. It promotes equal treatment and ensures reasonable adjustments are made to accommodate diverse needs.

Total Communication: Total Communication is an approach that combines multiple methods of communication, such as speech, sign language, gestures, and writing, to ensure effective understanding and expression.

Transition: There are many important transitions in a person's life. For the purpose of the What Matters to Me project, 'Transition' refers to the period in a young person's life during which they move from children's to adults' services, which officially occurs when they turn 18. People with a learning disability and their families often describe this transitional period as a 'cliff edge' and they struggle to get the right support in place. Please see the Transition film and resources for more information or to read the 8 Transition Findings that we identified through this project.

Voice Output Communication Aids (VOCA): Voice Output Communication Aids (VOCA) are devices that assist individuals in communicating by producing spoken messages or sounds.

Young Person: The young people who took part in the What Matters to Me project were all aged between 16 and 25, therefore, for the purposes of the project, 'young person' refers to the eleven project participants.