

About profound and multiple learning disabilities

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Why are we describing people with ‘profound and multiple learning disabilities’?



Children and adults with profound and multiple learning disabilities are, like everyone else, unique individuals. But sometimes it is helpful to talk about groups of people who have common concerns. This can help us as a society to make sure that people’s human rights are upheld. A good example of this is people who come from minority ethnic groups. Another example is people with profound and multiple learning disabilities. At the moment, the needs and rights of people with profound and multiple learning disabilities are frequently neglected.

It is vital that we understand the distinctive needs of people who are often excluded from society. That’s because, in doing so, we are respecting their right to be included. It is only by focusing on their needs and rights, and working to remove the barriers they face, that people with profound and multiple learning disabilities will achieve their rightful place in society. It also acknowledges that while many barriers can be challenged and even removed, ultimately we cannot change the nature of people’s disabilities. In doing so we are not being discriminatory, rather we are respecting people’s differences and valuing them for who they are. At the same time, we can continue to fight for equal rights.

Who has profound and multiple learning disabilities?



Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with autism and Down's syndrome may also have profound and multiple learning disabilities.

All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of daily life.

The needs of people with profound and multiple learning disabilities

Learning needs

Like all of us, people with profound learning disability will continue to learn throughout their lives if offered appropriate opportunities. Such opportunities must take account of the fact that most people are likely to be learning skills that generally appear at a very early stage of development. For example, cause and effect – such as pressing a switch to make something happen, or turn-taking – such as rolling a ball between two people. Learning is also likely to take place very slowly. For example, some people may have a very small short-term memory and so will need the opportunity to encounter events many times before they become familiar. Constant repetition and a great deal of support will be needed to generalise learning into new situations. Supporting the learning needs of a child or adult with profound and multiple learning disabilities also needs to take account of any additional needs, such as sensory needs (see sensory needs section), so that the best approach to learning can be established.

Communication needs

Many people with profound and multiple learning disabilities rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some people may use a small range of formal communication, such as speech, symbols or signs. However, some people with profound and multiple learning disabilities may not have reached the stage of using intentional communication, and they may rely on others to interpret their reactions to events and people. Most people are also likely to find it difficult to understand the verbal communication of others. Some people will rely heavily on the context in which the communication takes place, such as the clues given by a routine event. It is important that those who support people with profound and multiple learning disabilities spend time getting to know their means of communication and finding effective ways to interact with them.

Physical needs

Some people described as having profound and multiple learning disabilities are fully mobile. Many people may use a wheelchair. Others have difficulty with movement and are unable to control or vary their posture efficiently. These individuals will need specialised equipment to aid their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life. It is vital that people with physical needs have access to physiotherapy, occupational therapy and hydrotherapy, and that their carers receive training to enable them to manage their physical needs confidently on a day-to-day basis.

Complex health needs

There is a wide range of conditions that children and adults with profound and multiple learning disabilities may have, such as complex epilepsy. An increasing number of people are described as being 'technology dependent', which may mean they need oxygen, tube feeding or suctioning equipment. Some people have conditions that are described as 'life-limiting'. Others have fragile health and may be susceptible to conditions like chest infections and gastro-intestinal conditions. Skilled support may be needed for feeding and swallowing, as good nutrition is a vital part of achieving good health. Many people may experience a combination of medical needs and need access to specialised health support to ensure the holistic management of these conditions.

People with profound and multiple learning disabilities experience the same health conditions as the rest of the population. The challenge is about how these conditions are identified in people who may not be able to communicate their symptoms easily. For example, it is very important to develop effective ways to recognise and manage pain. It is crucial that a proactive approach is taken to ensure that each person is able to achieve the best possible health they can, for example, by arranging annual health checks and support to access general health care.

Sensory needs

Special attention needs to be given to the sensory needs of people with profound and multiple learning disabilities. Many people have some degree of visual and or hearing disability or a combination of both. Some people's sense of taste or smell may be affected by the drugs they may be taking. Other people may be hypersensitive to touch. It is essential to know as much as possible about a person's vision, hearing and other senses in order to develop the most effective way to approach their learning and communication needs.

Understanding behaviour

Some behaviour that is seen as challenging may arise because little attention has been given to other needs. It should never be assumed that certain behaviours are just part and parcel of having profound and multiple learning disabilities. For example, a behaviour that services may see as challenging, such as pushing people, may be an attempt to communicate a need. Other changes in behaviour may be due to undetected health needs, such as scratching the face because of a toothache. However, some behaviour will be because people are simply doing things that they enjoy, for example putting a hand under the tap to enjoy the feeling of running water. The important thing is to understand what the behaviour may mean and to respond accordingly, such as checking out any possible health causes or making changes in the environment.

Mental health needs

The mental health needs of individuals with profound and multiple learning disabilities are often not considered. For example, someone who becomes very quiet and passive may be seen as having improved their behaviour when in fact they are depressed. Research suggests that people with profound and multiple learning disabilities may be more susceptible to mental health conditions than the rest of the population. It is important that careful attention is given to these needs and that the right treatment and support is found to meet them.

Profound and multiple learning disabilities and other syndromes or conditions

There are many other conditions and syndromes used to describe people, some of whom could also be described as having profound and multiple learning disabilities. Some examples of conditions and syndromes that are more usually associated with profound and multiple learning disabilities are: Rett syndrome, Tuberous Sclerosis, Batten's Disease and some other rare disorders. However, some people who are described as having autism and Down's syndrome may also have the combination of profound learning disability and one or more of the needs we have discussed – therefore, they could equally be described as having profound and multiple learning disabilities.

Support needs

All children and adults with profound and multiple learning disabilities will need high levels of support from families, carers and paid supporters. This will include help with all aspects of personal care, such as washing, dressing and eating, as well as ensuring that each individual has access to high quality and meaningful activity throughout their lives. Those who offer this support will need access to good quality and appropriate training, especially around particular skills. For example, on particular feeding needs and communication approaches. Good support is person-centred, flexible and creative to enable the person with profound and multiple learning disabilities to learn and to achieve their full potential.

Why not use the term 'high support needs' or 'complex needs'?

It is true that people with profound and multiple learning disabilities have high support needs. It is most likely that they will need 24-hour-a-day support with all aspects of their lives. Their needs are also complex, for example, the range of medical conditions that they often experience. However, these terms alone do not help others to understand the specific issues that affect their lives. This is because many other people who do not have a profound learning disability could be described using these terms. For example, someone with a physical disability and communication impairment may be described as having complex needs or high support needs. The famous scientist and author Stephen Hawking is an example of this. The provision of a wheelchair, good personal support and an effective communication device enables him to demonstrate his high-level intellectual ability.

Attitudes

One of the greatest barriers that people who have profound and multiple learning disabilities face is the negative attitudes of others. Judgements are made about the meaning and quality of people's lives. This can stop people being offered some of the more innovative forms of support, such as individual funding, because some people do not think that they will benefit, or they think that the costs involved are too high. But these negative attitudes can also be life-threatening – for example, if they result in medical treatment being denied. These judgements are only ever subjective. Most people do not know what it is like to have a profound learning disability and perhaps experience the world by touch and smell. Such judgements also show a failure to understand the contribution that each individual will make to the lives of the people around them.

It is important that everyone understands that people with profound and multiple learning disabilities have the same rights as every other citizen. We must enable each individual to engage with their world and to achieve their potential so that their lives go beyond being 'cared for' to being valued for who they are as people.