

Consultation on 2020 Children and Young People's Workforce Strategy

Mencap's response

Mencap is the leading charity working with children and adults with a learning disability, their parents and carers. We are fighting for a world where everyone with a learning disability has an equal right to choice, opportunity and respect, with the support they need.

Mencap wants the entire children's workforce to understand the needs of all children and young people with a learning disability, including those with profound and multiple and learning disabilities (PMLD), and have the appropriate skills to effectively support them.

We want to draw particular attention to the needs of children and young people with profound and multiple learning disabilities in this response as they are a particularly marginalised group and one for whom specialist skills are required of the children's workforce.

Children and young people with PMLD:

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge us
- need high levels of support with most aspects of daily life

(See Appendix 1 for more information about what it means to have profound and multiple learning disabilities.)

Mencap welcomes the reference in the strategy to ensuring that people in the workforce have the skills and knowledge to support children who are particularly vulnerable. Children with PMLD need to be included within this vision.

This means that the children and young people's workforce need to have the skills and knowledge to meet the specific communication needs of children and young people with PMLD and the skills and knowledge needed to meet complex health needs, which many children and young people with PMLD will have. Complex health needs include conditions such as complex epilepsy or being 'technology dependent' – for example needing oxygen, tube feeding or suctioning equipment. See Appendix 1 for more information about complex health needs.

Communication needs to be prioritised

Meeting the communication needs of this group of children and young people is often something which gets ignored. Communication is not seen as a priority. But as the Bercow Review¹ identified communication is fundamental and needs to be

¹ The Bercow Report: a review of services for children and young people (0-19) with speech, language and communication needs 2008

prioritised. Without this, children and young people with PMLD will be unable to achieve the Every Child Matters outcomes and fulfil their potential.

Children with PMLD have very specific communication needs. Most do not use formal communication methods such as speech, symbols or signs. They may rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some children with PMLD may not have reached the stage of using intentional communication, and they may rely on others to interpret their reactions to events and people.

It is important that all those who support children with PMLD spend time getting to know their means of communication and finding effective ways to interact with them. There are different 'non-formal' techniques and approaches which can be used to help interpret the needs and choices of children and young people with PMLD. Staff should be supported to use non-formal techniques and approaches which can help them do this.

If children and young people with PMLD are to be fully included in society and to have access to the same activities and opportunities as all other children, then there needs to be increased focus on the children's workforce developing these essential communication skills.

Access to high quality Communication skills training

It is crucial that the children and young people's workforce have access to high quality training so that they can meet the communication needs of those with PMLD.

'Communication training is available but not resourced or prioritised to be as effective as it might'

Health professional, PMLD Network questionnaire 2006²

Each local authority should have a multi-agency training programme around communication. The Children's workforce including speech and language therapists, school and support staff and other professionals need to be trained in non-formal communication methods. Awareness-raising on what PMLD is and how people with PMLD communicate should be provided to a wider group of professionals who come into contact with children and young people with profound and multiple learning disabilities.

Need for joined up working around Communication

There are few examples of joined up approaches between professionals, school staff and parents to meet children's communication needs.

'My son has seen about 10 different people and each one begins from scratch'
Parent³

'We need more communication between the language therapist and home'
Parent⁴

² Mencap consultation to inform response to Bercow Review 2007

³ Mencap consultation to inform response to Bercow Review 2007

⁴ Mencap consultation to inform response to Bercow Review 2007

It seems to be down to luck whether the school has managed to have a joined up approach. It is crucial that a workforce strategy includes multi-agency guidelines to ensure that all agencies are co-operating to ensure that the child's communication needs are consistently and effectively met across all settings. Families need to be actively involved in this process. We welcome the emphasis in the strategy on the need to work together and the importance of having the skills and capacity to do so.

Children and young people with PMLD are particularly vulnerable at times of transition and it is very important that there is joined up working between the children's workforce and the adult workforce to ensure the communication needs of children with PMLD moving into adult services are consistently met. Communications skills training should also be a priority for the adult workforce.

'There are very few professionals with the expertise' A Parent⁵

Training to meet all the needs of children with PMLD

Whilst the focus in our response is Communication, it is essential for staff to also have appropriate training so that they can meet **all** the needs of children with PMLD. In addition to training in communication techniques, the workforce also need training so that they can support the other needs which children with PMLD may have, for example behaviour that challenges or complex health needs. Training to support complex health needs would include training to use suctioning equipment or tube feeding, which someone who is 'technology dependent' might need.

Pay and status to reflect skills

Staff pay should reflect the additional skills and training the children and young people's workforce need to provide good quality support to children and young people with PMLD. We welcome the focus on increasing professionalization of the children's workforce in the consultation document. There needs to be improved status for those working with disabled children, particularly those with PMLD.

Recommendations

Mencap welcomes the Government's commitment to ensuring that every child meets their full potential.

To make this a reality for children with PMLD, Mencap recommends:

- Communication needs to be prioritised
- Access to high quality communication skills training
- Need for joined up work to support children's communication needs
- Training to meet all needs of children with PMLD
- Pay and status to reflect skills

It is essential that when children's trusts identify skills gaps in their local areas that they give full consideration to the needs of all children with a learning disability, but particularly those with PMLD.

⁵ Mencap consultation to inform response to Bercow Review 2007

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Appendix 1**Understanding 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 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 are prescribed. 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. Conditions and syndromes that are more usually associated with profound and multiple learning disabilities include 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.