

PMLD Network response to ‘The case for change – Why England needs a new care and support system’

Introduction

The PMLD Network is a group of organisations who are working together to fight for the rights of children and adults with profound and multiple learning disabilities (PMLD)¹. The Network believes that focusing on the needs of these individuals, who face double discrimination², should be a priority. The needs and rights of people with PMLD are frequently neglected. They remain some of the most disadvantaged people within our society. If this is going to change then it is vital that there is a much better understanding of the distinctive needs of these people who are so often excluded. There must also be a strong commitment to meeting these needs.

The PMLD Network believes that everyone has a right to be included in society. But this will not be achieved by a ‘one size fits all’ approach. Real progress will require an understanding that sometimes there will be a need to provide additional things to achieve the same outcome: an ordinary life. As *Valuing People* states, the ‘role of public services is to help people, no matter how complex their disability to live full and equal lives in their local communities’.

For the Government’s vision of independence, choice and control for all people with a learning disability³ to be realised, there must be a robust care and support system in place. This system must be able to meet the care and support needs of all people with a learning disability, including people with PMLD who have the most complex needs.

The PMLD Network’s response to *Valuing People Now* set out the main issues that need to be tackled so that people with profound and multiple learning disabilities can take up their rightful place in society. The reform of social care and support is a key part of this process and it is clearly crucial that when reforming the care and support system the Government needs to address the same issues.

In this response we outline the key issues for people with PMLD under the current care and support system, in order to inform Government’s plans for change. We will submit a more detailed response once the Government’s plans to change the care and support system have been outlined in a Green Paper.

Who are people with profound and multiple learning disabilities (PMLD)?

The PMLD Network has developed the following definition:

Children and adults with profound and multiple learning disabilities have more than

¹ Membership of the PMLD Network is listed in Appendix 1

² *Valuing people with profound and multiple learning disabilities’* Mencap 2001

³ *‘Valuing People: A New Strategy for the 21st Century’* DOH 2001

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.

Appendix 2 provides more information on what it means to have profound and multiple learning disabilities.

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Including Everyone

What we want

For the adult social care system to meet the needs of people with profound and multiple learning disabilities (PMLD):

- There needs to be a much better understanding of the numbers and needs of people with a learning disability, particularly people with PMLD, to ensure proper planning and monitoring of the support they receive.
- New initiatives which have the power to transform lives must work for people with the most complex needs, for example people with PMLD.
- There needs to be particular attention to the workforce issue: people with PMLD need staff who are trained to meet complex health, communication and behaviour needs.

The need to focus on those with the most complex needs

The PMLD Network welcomes the Government's focus on people with the most complex needs reflected in the Valuing People Now consultation document, in particular that:

- The Government recognises that people with the most complex support needs have been **missing out** on the changes brought in since *Valuing People*.
- It says that when planning and delivering services you should **start** by thinking about those with the most complex needs.
- It says that you should think about what **additional** services and supports are needed for people with the most complex needs rather than developing separate services. This is so that people with the most complex needs can be included with everyone else.

In the view of the PMLD Network, these are sound principles and they recognise that much needs to be done to ensure the inclusion of people with profound and multiple learning disabilities (PMLD).

In a recent study conducted by 'Inclusion Europe' (to be published), looking at the discrimination faced by people with severe and complex disabilities across 12 European countries, it concluded that the greater the progress towards mainstream services, the higher the risk of exclusion and segregation. This study is a stark warning of what will happen if we do not focus on the needs of this population.

If the Government is to meet the needs of a changing society, one in which there will be an increase in the number of people with complex needs - there are a number of important actions that must be taken to ensure that people with PMLD are included (see the next section 'Key actions needed to ensure people with PMLD are included'). We will mention a very important one here:

There needs to be an increased understanding of the numbers and needs of people with profound and multiple learning disabilities (PMLD)

Currently there is a serious lack of understanding of the numbers and needs of people with PMLD. This has resulted in poor planning and monitoring of the support they receive:

'If we don't know about the population of children with PMLD, how can we possibly plan for their future and get it right? We urgently need to address the needs of children and adults with PMLD' - Health professional (PMLD Network survey 2006)

Research has shown:

- A lack of recognition that people with PMLD are a group of people who might have specific needs requiring specialised support.⁴
- The lack of accurate information and consistency in definitions of need make longer term service planning and development difficult.⁵
- The numbers of children with PMLD are continuing to increase because more premature babies are surviving, medical science is prolonging lives that would have been lost in infancy and people with PMLD are living longer.⁶
- We have a **new** younger generation of people who are dependent on medical technology and have complex and continuing health care needs.⁷

There is very little data on the population of people with PMLD. However what there is, demonstrates a rise in the numbers of people with PMLD and the fact that their needs are becoming more complex. For example:

The Sheffield Care Trust (2006) – summary of findings from Adult Learning Disability Day Services PMLD sub group and additional Case Register information - found that:

The number of 10-14 year olds with PMLD has increased by 75% in the last 5 years, including an even higher number of children with PMLD who will need services as adults in 5 to 10 years time'

It is important that there is better data, planning and monitoring of people with PMLD from BME communities.

A key piece of research by Hester Adrian (Azmi et al 1996) projected that between 2001 and 2021 that 1 in 10 people with a learning disability might belong to a

⁴ Fyson, R and Ward, L (2004) 'Making Valuing People work: Strategies for change in services for people with learning disabilities'.

⁵ Mapping and service needs for those with ASD or PMLD, Research for Tomorrow, Today (2003)

⁶ Carpenter, B: 'Sustaining the family. Meeting the needs of families of children with disabilities' BJSE, September 2000

⁷ Kirk, S and C. Glendinning (2004) 'Developing services to support parents caring for a technology-dependent child at home' in. *Child: Care, Health & Development* **30** , 3, 209–218.

BME community. It also found that between the ages of 5 and 34 years of age, the prevalence of people with severe learning disabilities was approximately three times higher in the Asian communities.

More recently the report from the Sheffield Care Trust (2006)⁸ found that people with a learning disability from BME communities have a higher incidence of severe and complex needs: 37.5% of those with PMLD aged 14-19 are from BME communities.

Better data is crucial to inform planning to ensure that people with PMLD and families from BME communities are able to access appropriate support and services.

Key actions needed to ensure people with PMLD are included

A social care and support system which meets the needs of people with profound and multiple learning disabilities (PMLD) will need to have addressed the issues set out in the following sections: Personalisation, What People Do During the Day (And Evening And Weekends), Improving people's Housing situation, Partnership with Families, Local Citizens, Transition, Workforce.

1. Personalisation

What we want

- The Government needs to ensure that individual budgets include everyone. This means understanding the true cost of the support needs of people with profound and multiple learning disabilities (PMLD).
- Individual budgets must be properly funded with no capping at an arbitrary level and no maximum upper limit for people with more complex packages of care.
- The resource allocation process should recognise the true costs of support. The resource allocation should be transparent.
- It must be possible for people who are un-befriended or who do not have strong family support to have the same opportunity to have an individual budget.
- Individual budgets must be holistic. People with PMLD have complex health and social care needs. Support packages must take that into account and individual budgets should cover all parts of an individual's needs.
- The expense of supporting people with PMLD can have a great impact on local authority social care budgets. The Government needs to gather data about the highest level support packages for people with the most complex needs.

⁸ Sheffield Care Trust (2006) – summary of findings from Adult Learning Disability Day Services PMLD sub group and additional Case Register

- The Government should explore the idea of providing central government funding to enable realistic support packages for people needing high levels of support.
- People with PMLD should be given priority for person centred planning. Staff should be properly trained in engaging with people so that people with PMLD are involved meaningfully in their development.
- For people with PMLD support needs to be bespoke, competent and long term. The quality of relationships in people's lives is a critical factor.

2. What People Do During the Day (And Evening And Weekends)

What we want

- People with profound and multiple learning disabilities (PMLD) need meaningful activities. The focus shouldn't just be for local authorities to get people with a learning disability into work as this may not be appropriate for everybody.
- Day services should not close unless there are robust alternatives in place.
- Services must address the resource issues, staff skills and the practical challenges of meeting diverse needs in an imaginative way.
- Day services programme should be planned, monitored and evaluated with the needs of people with PMLD in mind.
- Day time activities should be stimulating and meaningful to the individual. There must be recognition that many people with PMLD experience the world largely on sensory level and activities need to be developed that take this into account.
- People with PMLD should be able to access the community by taking part in activities that the person finds genuinely enjoyable.
- People with PMLD's physical and health needs should be supported in a dignified manner. Community facilities should be designed to meet complex health and social care needs where possible. An example would be constructing more Changing Places toilets.
- There should also be some community resource bases equipped for meeting the specific complex physical and health needs of people with PMLD, for example with hydrotherapy pools. These should be designed in such a way that they can be share with other members of the community such as those with severe arthritis, where appropriate.
- There needs to be manual handling policy and practice that does not act as a barrier to taking part in community activities.
- There should be investment in a workforce that is both sufficient and skilled

to meet complex health needs and use non-formal communication techniques.

- There should be suitable and flexible transport provision that enables people to physically move around their community.

3. Improving People's Housing situation

What we want

- People with profound and multiple learning disabilities (PMLD) should have choice and control about where they live. There should be a range of choices from registered care to supported living.
- Support staff should be trained to meet complex needs so that lack of skilled support does not mean that people cannot choose where they want to live.
- More funding for high quality, safe and fully supported housing to be provided for all adults with PMLD.

4. Partnership with Families

What we want

- The importance of family carers needs to be recognised and their participation facilitated at the individual, local and national level.
- Families need to get the support they need, including a minimum entitlement to good quality short breaks. For those with the most complex support needs, this entitlement should be based on an expectation that it be not less than a minimum of 52 nights a year.

5. People as Local Citizens

What we want

- We want everyone to understand that people with profound and multiple learning disabilities (PMLD) have the same rights as every other citizen.
- We want all individuals with PMLD to be enabled 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.
- Recognition that co-payment between the state and the individual to meet the cost of social care is rarely an option for people with learning disabilities who have not had the chance to build up assets to help pay for their care. It is extremely unlikely that a person with PMLD has worked and their families are very unlikely to be able to contribute due to the serious financial disadvantage many are at due to giving up careers to be full-time carers.

6. Making the Transition to Adulthood A Positive Experience

What we want

- Good transition planning for young people with profound and multiple learning disabilities (PMLD).
- Adult social care needs to be planned from knowledge of the numbers and needs of young people with PMLD coming through the transition process. Too often there is lack of planning and adult services are taken by surprise.
- A holistic approach, covering all aspects of the support, including health and social care needs and not just education.

7. Improving the Workforce

What we want

- A skilled and sustainable workforce.
- Staff who are trained to meet people's complex health, communication and behaviour needs.
- Staff whose pay reflects the additional skills and training they need to provide good quality support.

Conclusion

The PMLD Network believes that the Government needs to tackle all the issues addressed in this submission when planning a new care and support system. If the new system is going to meet the needs of people with profound and multiple learning disabilities (PMLD) it is crucial that the needs of this part of the population are understood and planned for.

In summary, we believe it is crucial the Government understands that people with PMLD will require lifelong packages or support. These will be complex packages as they will need to meet the complex health and social care needs of people with PMLD. It is very important that the resource allocation process recognises the true costs of support. It also needs to be understood that co-payment between the state and an individual to meet the cost of social care is not an option for people with PMLD.

There is an urgent need for research to show how many people with PMLD there are, what their characteristics are, what good quality support would look like for them in a range of settings and what this will cost. The Learning Disability Coalition is lobbying the Government to undertake this research. We support the work of the Learning Disability Coalition and we fully endorse their submission to this consultation.

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For more information, please contact Beverley Dawkins, Chair of the PMLD Network on 020 7696 5558 or email beverley.dawkins@mencap.org.uk

Appendix 1

The PMLD Network consists of the following organisations:

BILD
Foundation for People with Learning Disabilities
Mencap
Rett Syndrome Association UK
SeeAbility
Sense
The Challenging Behaviour Foundation
The Children's Trust. Tadworth
The Ridgeway Partnership NHS Trust in Oxford
Parent representatives

Appendix 2

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.