

PMLD Network response to ‘Support and aspiration: A new approach to special educational needs and disability’

Introduction

The PMLD Network¹ is a group of organisations working together to improve the lives of children and adults with profound and multiple learning disabilities.

We believe that it is crucial the government specifically focuses on the needs of children and young people with profound and multiple learning disabilities when looking at how it can improve SEN provision. If you can make it work for those with the most complex needs you can make it work for everyone.

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

PMLD Network definition
(short version)

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

The PMLD Network welcomes the overall tone of the Green paper, which promotes a co-ordinated approach to child services and to reduce the adversarial nature of the SEN system

The PMLD Network supports the emphasis that has been placed on early identification in an effort to ensure better support is put in place to enable children to have equal opportunities to education and families have better support to lead ordinary lives without discriminatory barriers.

The PMLD Network is encouraged by the focus on increasing schools’ cooperation with parents in the aim of improving the recognition of the children’s needs both in education and the wider community.

¹ There is a list of organisation which make up the PMLD Network at www.pmlDnetwork.org

The PMLD Network is however concerned that there has been a shift of responsibility signalled in the green paper; both from local authorities to schools and from schools on to parents, which if not handled correctly could deteriorate the universality of SEN provision.

The PMLD Network is concerned by the apparent disconnect between the green paper's emphasis on co-operation and the Education Bill removing the duty on schools to co-operate with local authorities. We will therefore seek clarification on the responsibilities of different agencies.

Main response

1. Identification and assessment

We welcome

- the commitment to increasing early years provision for children with SEN. It is encouraging that the government has focused on the importance of health visitors, who can provide parents with routine practical and emotional support to parents in vulnerable positions. Emphasis on the health visitor providing a co-ordination role to keep the family in touch with the necessary professions is very welcomed.
- the recognition in the green paper of the difficulties and complexities of finding appropriate early education provision for disabled 2 year olds.
- the principle of a 'single assessment', which aims to ensure joint working and make things as straightforward as possible rather than children having to have separate uncoordinated assessments.

We are concerned

- that health visitors won't have the training and skills needed to work with children with PMLD.
- the green paper does not detail how the focus on outcomes and the greater flexibility of provider will improve the accessibility of early years provision. Where there are fewer duties on providers to include children with higher support needs, it is naïve to assume that they will have the incentives to do so.
- the description given in the green paper did not detail how a single assessment would be undertaken to properly identify the child's support needs whilst also suiting the needs of the family life. It does not explain how joint-working will be ensured both in the assessment process and in the implementation of the resultant Education, Health and Care Plan and how clear lines of responsibility will be drawn up. If this is left to local areas, with no further guidance, it is difficult to see how lines of responsibility will be negotiated.

We want

- It is crucial that health visitors have a real understanding of children with PMLD and their complex health needs and communication needs. Complex health needs such as having complex epilepsy or being 'technology

dependent' – for example needing oxygen, tube feeding or suctioning equipment. Health visitors have a vital role in ensuring coordination of complex array of essential services.²

- Any sort of provision including Sure Start centres, must be backed up with increased resources and national standards to increase their ability to provide specialist support to disabled children and their families. It will be crucial that staff are trained to meet the very complex health needs which children with PMLD are likely to have.
- If the 'single assessment' is to work: it needs to be co-produced with the family and the agencies over a determined period of time from the initial request for it. There should be a clear lead agency which takes overall responsibility for the process, it should not fall on to the parents to manage and lead the process as they have enough on their plate. Planning for the assessment needs to be done in full consultation with parents and children. There needs to be full input into the assessment from all agencies (education, health and care) and clear lines of responsibility following it. Joined up working is crucial for children with PMLD – as they will have complex health needs, specific learning needs, and need full-time support.

2. Education, Health and Care Plans

We welcome

- We welcome the principle of a 0 – 25 plan in the hope that this will smooth the transition process across age boundaries and potentially across local authorities.

We are concerned

- There will not be the smooth joint working needed to ensure effective implementation of the plan.
- There will not be regular multi-agency reviews to ensure the plans continue to meet the needs of children and young people with PMLD throughout the 0-25 year period.
- by the proposals in the Education Bill (Clause 30) which would remove the duty on education to cooperate with local authorities and services as this clearly undermines and contradicts the philosophy of the Education, Health and Care Plan. The PMLD Network argues that without a duty to cooperate at a strategic level to agree a combined vision for meeting the needs of children with SEN collectively, each agency will have no inclination to collaborate in an effort to meet each child's individual needs where another agency can meet the costs independently.

The reason that statements of SEN have not met their potential is exactly because there is no shared duty upon education, health or care to meet the needs of children where those needs do not have a direct impact on educational attainment, and there is no shared budget to ensure each

² Appendix 1 for more information about the complex health needs and communication needs of children with PMLD

agency contributes financial resources. Without rectifying these issues within the Education, Health and Care Plan, and by taking away the duty to cooperate, it is plausible to suggest that the same bargaining between agencies will continue. Furthermore, where the Health and Wellbeing bill has indicated that there should be a cooperative approach taken between health, social care and local authorities, no such emphasis has been placed on including an education representative on Health and Wellbeing Boards.

We want

- the review process will be the key factor to ensuring that the Education, Health, and Care Plan reflect the changing needs of children, particularly at the transition stages. Furthermore, following a review, identified support changes must be put in place effectively and in a timely manner. All reviews of the Education, Health and Care Plan should be adequately reported and fed back to the family with an outline of when and how the identified changes will be implemented.
- a proper planning process to ensure that the individual's health and care needs will be met, and then the focus should be on supporting the child to maximise their learning and communication skills. The learning and communication needs of children and young people with PMLD can sometimes get ignored and the focus can be purely on health needs and care needs. This must not happen.
- It is crucial that as well as the Plan setting out how the person's health needs will be met, there are genuinely appropriate health services to access. There is increasing evidence to suggest there are insufficient services or gaps in health services to support children and young people with PMLD and their family carers, examples include: lack of dysphagia services, lack of pain and distress recognition, lack of postural care, lack of appropriate person centred health care support at home for individuals living with medical technology, inappropriate use of hospices, lack of community epilepsy services in primary care, inappropriate medication, poor oral health care.
- Co-operation to be viewed as a vital duty upon local authorities, which could equally be achieved through ensuring that Health and Well Being Boards have an education representative who can advocate for the holistic planning of local strategy to benefit all needs of disabled children.

3. Learning and attainment

We welcome

- the proposal to introduce new indicators into the performance tables relating to the progress of the lowest attaining pupils. It is important that the achievements of children attaining at their own level is given equal recognition so long as they are being assessed according to their agreed performance indicators.

We are concerned

- as to how the figure of 20 per cent has been derived and what pupils would fall into this category. We believe that performance tables should identify

achievements according to the relative ability of each pupil. The aim is to construct performance tabled in a way that can demonstrate whether children are progressing at a level in line with their potential ability.

We want

- Performance indicators to be designed in such a way where the learning of pupils with PMLD, which may be very slow and lateral, is valued. Any evaluation of progression needs to recognise and value the learning of pupils with PMLD; otherwise this will lead to unrealistic comparisons and goals which will not be helpful to the child or the teacher/ school.
- Indicators must take full account of children who will learn at a different rate to their peers and that their attainment will be measured according to their learning potential. We further seek assurance that the inclusion of such indicators do not negatively impact on the admission of disabled children and those with SEN who may be discriminated against according to the preconceptions of their learning potential.

4. Local Offer

We welcome

- the proposal of a 'Local Offer' as it is intended to provide parents with the tools to request the appropriate services for their children and ensure their right to education are being met within their area. The lack of available and accessible information currently on offer for parents often prevents them from accessing all the support that they are entitled to.
- We welcome the slimming down of information so that there is key information for parents, all in one place.

We are concerned

- the notion of slimming down the regulations on schools in relation to what information they must provide.
- The slimming down of information provided must not be an excuse to slim down the range of options locally available to young people.

We want

- that all local offers must meet a minimum offer that is applied nationally to prevent a post-code lottery. In order for this to meet the needs of all disabled children and those with SEN, the minimum standard must meet the needs of children with the highest level of need. If the local offer is left to local determination then it is crucial there is guidance to local authorities to think about those with the most complex needs first, when developing their minimum local offer.
- the local offer to include a range of options - to enable truly personalised support where families have genuine choice - and there must be good information about all the options.
- It is important that the local offer is developed in collaboration families and children and young people are involved in decisions about service provision, including children and young people with PMLD, who do not use formal communication, such as words or signs. There is more information

about how to creatively involve children and young people with PMLD in decision making and consultation in Appendix 2: information about 'Involve Me'.

5. National banding

We welcome

- We welcome that any banded funding framework will be national with local flexibility.
- We welcome the move to make funding decisions more transparent to families.

We are concerned

- We understand that the financial tariff associated with each band will be determined locally and this makes sense as costs will vary between areas. However, it is crucial that all local areas meet the true cost of support needed for children with PMLD to access the provision, and that they get the funding needed to access the provision as often as is necessary.

We want

- Local areas to meet the true cost of support needed for children with PMLD to access the provision they need which is not normally available in schools.
- The process for children with PMLD and their families to access this provision should start with identifying the needs of the child, how these can best be met and then there needs to be a commitment to meeting these needs.

6. Personal budgets

We welcome

- The expansion of the personalisation agenda is most often a welcomed move by disabled adults. Many parents of children and young people would want to see SEN budgets spent according to how they feel their child would best benefit from the support offered but would not want to take on the role of costing and commissioning their child's support.

We are concerned

- due to the possibilities that personal budgets could leave children vulnerable to the right to universal services being diminished and children's needs and opinions are decided by those handling the budget.
- that personal budgets for children with Special Educational Needs will make it more difficult for all schools to provide the right support for an inclusive environment. With financial autonomy comes responsibility, if this is taken away from schools, there will be less incentive for them to make the necessary provisions to support children's needs.

- Placing this responsibility on parents in terms of their child’s education will be an additional burden in their already complex lives. This could also potentially lead to parents having to prioritise aspects of their child’s developments raises legal questions around the responsibility of educating children with SEN.

We want

- It is crucial that safeguards will be put in place to ensure parents are fully empowered and receive the support and advice they may need to administer a Personal Budget effectively.
- It is important the children with PMLD can get the support they need, whatever setting they are in (special or mainstream) , with or without a personal budget.

7. Increasing parental choice

We want

- The PMLD Network believes that choice should be on the presumption that all schools can provide an equal educational experience. Therefore, all schools and services available must be of a good standard in order for there to be two or more legitimate options. For this to be the case, all schools and services on offer have to provide the same level of quality and opportunity for children of all abilities to maximise their potential.

PMLD Network believes that if a parent is forced to choose a special school because of the poor support provision in a mainstream setting, this is a negation of parental choice.

The reality is there is not a choice about whether parents of a child with PMLD can send their child to mainstream or special school. The bias is towards special school as mainstream schools often just say they couldn’t meet the needs adequately. Where parents have got their son or daughter into a mainstream school they have often had to fight a hard battle.

Jessie

Jessie is 13 years old and attends a mainstream school in September. It was quite a battle to get her there, but Jessie is having the time of her life. Jessie has profound and multiple learning disabilities, as well as some complex healthcare needs. She went to a mainstream primary school and naturally wanted to go to the same school as the rest of her friends.

The local authority was not supportive at first. They thought it would not be good for the other children and that it would cost too much to support Jessie. Jessie's mum firmly believes that all children should be educated together, both those with and without a disability. She challenged the local authority at a tribunal and was successful on every count.

The result is that Jessie loves all aspects of school. She is well supported by three trained carers, sensory specialist teachers and community nurses. The school tutors and staff have embraced Jessie and her own style of learning. The world is now Jessie's oyster!

8. Transition

We welcome

- PMLD Network welcomes the government's commitment to increasing the opportunities for young disabled people post school and we are pleased with the ambitions of the Green Paper that children and young people with a disability to reach their full potential in society.
- We welcome the increase of the Education, Health and Care Plan up to 25 as we believe support through transition needs to be a holistic, cross-agency, and raises the expectations and aspirations of people across the board.
- We welcome that the Department of Health will explore how to improve joint working across children's and adult health services for young people aged 16 to 25. And that as part of this, the Department of Health will explore the feasibility of GPs providing annual health checks for all disabled young people from the age of 16. Young people with PMLD are particularly vulnerable at transition, as they have multiple health needs and it is crucial that these continue to be well-supported once they move into adult services.

We are concerned

- That young people with PMLD are not getting the same opportunity to go to college as other young people because not enough appropriate courses are offered. This is often because the courses colleges decide to run are defined by what funding they can get. And funding bodies don't always recognise and value the learning of young people with PMLD.
- We are concerned that there are not enough meaningful day opportunities for young people with PMLD to access when they move into adulthood. Local authorities should ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities.³
- We are concerned that at the age of 25, young people with PMLD will still experience the same problems young people with PMLD are currently facing when entering adult services: a drop in support, even though their support needs have not changed and lack of meaningful activities for them to access.

We want

- All young people with PMLD to go to college, if that is what they want. There needs to be a redefinition of learning to include a wider range of non

³Mansell, Prof J (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities

academic services, outcomes and funding criteria so that people with PMLD can access appropriate FE opportunities

- To make transition work for those with the most complex needs there needs to be a holistic approach to transition planning; covering all aspects of the support, including health and social care needs as well as education. There must be mechanisms in place to ensure information is passed on and there is continuity of care. There needs to be good person centred planning. The person needs to have an up to date communication passport, which explains how the person communicates, to go with them into adult services. They also need an up to date health action plan which includes all aspects of people's complex health needs. There needs to be a designated transition worker who can support the young person and their family through the transition process. It is crucial there is also maintenance of therapeutic support; no sudden reductions in access to speech therapy and physiotherapy for example.
- Annual health checks for all disabled young people from the age of 16 is welcomed, although from the age of 14 would be preferred. It is important that these are thorough and personalised in terms of the person's complex health needs.
- There must be a wide-range of meaningful activities available for young people with PMLD to take part in once they leave school – including employment, education and leisure activities.

9. Teacher training

We welcome

- PMLD Network welcomes moves to improve the quality of training for teachers on issues regarding SEN and disability and appropriate ways to respond to those children who have behaviour which challenges. The current teacher training program provides inadequate provision in special educational needs. It is thought that on a typical teacher training course the voluntary module of SEN is only provided for less than 1 days training. The training of teaching staff with the specific abilities to provide adequate education to children with more complex disabilities, for example children with profound and multiple learning disabilities, is critically required.
- We welcome that the green paper highlights the importance of training teaching assistants. It is crucial that they too have the skills to support the learning of pupils with PMLD.

We are concerned

- That the Education Bill places responsibility for training teaching assistants on schools, as we are not re-assured that all schools understand how to support the learning of pupils with PMLD.

We want

- The PMLD Network wants teacher training to include the skills and knowledge needed to work with children and young people with PMLD. They need to understand how to communicate with children who don't use formal means of communication and rely on informal means, for example

gestures, vocalisations and body language. They also need to understand the learning needs of children with PMLD. Pupils with PMLD are likely to be learning skills that generally appear at a very early stage of development.

- Teaching assistants need to be able to access high-quality training in how to support the learning needs of pupils with PMLD.
- We want clarification as to how the Government intends to incentivise the wider and more effective use of training in schools. As part of the passage of the Education Bill we are also lobbying the Government to ensure that initial teacher incorporates more effectively a wider understanding of SEN issues and the development of skills in this area.

10. Local authority freedoms

We welcome

- We welcome the emphasis placed on joint planning to meet local needs. The most important factor in service provision for families is effective co-ordination. It is therefore hoped that the services co-ordinate at the strategic level, this will improve the delivery of such services on a day to day basis. While we support the principle of joint commissioning, in a time when all local authorities have reduced budgets, it is a concern that the notion of sharing their budget for the benefit of another local authority will not be actively practiced.

We are concerned

- We are concerned that neither the NHS white paper nor the Education Bill suggested that an education representative will be present on the Health and Well-being Board. There has also been no consideration of how the Health and Well-being Boards will gather the views of disabled children and their families, including those with the most complex needs. and their families. Without instruction it is not unreasonable to suggest that the views of disabled children and their families will not be heard and therefore will not be represented.

We want

- We want those commissioning services to fully understand the health and communication needs of children and young people with PMLD. Many are currently not getting adequate access to therapies which they need for example, physiotherapy, speech and language therapy and hydrotherapy. It is also crucial that there is a postural care pathway in all local areas for young people with complex health needs to access. Part of this will be early identification of postural care needs by professionals.

For more information, please contact Beverley Dawkins OBE, National officer for profound and multiple learning disabilities at Mencap and Chair of the PMLD Network, on 020 7696 5558 or email beverley.dawkins@mencap.org.uk

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.

Appendix 2

Involve Me

Involve Me is a three-year project about how to creatively involve people with profound and multiple learning disabilities (PMLD) in decision making.

The project is supported by the Renton Foundation and is being run by Mencap in partnership with the British Institute of Learning Disabilities (BILD).

Staff and people with PMLD at four sites are taking part in the project. Each site is using a different creative approach to involve people with PMLD.

An interactive DVD and training guide will be produced at the end of the project and will show how the creative approaches have been used at each site. It will also show how everyone, including staff, families and policy makers, can start involving people with PMLD in decision making.

The project resources will be available from the end of September 2011.

Why is the project needed?

People with PMLD are some of the most excluded people in society. Most people with PMLD don't use formal communication like words and symbols. This makes communication very difficult and can mean people with PMLD are not involved in important decisions, such as where to live.

But people with PMLD should be involved in all decisions which affect their lives. They have important preferences and experiences to share. We just need to give them the opportunity to do this.

The Mental Capacity Act says that when people are not able to make their own decisions they should be **involved** as much as possible. Involve me will help those supporting people with PMLD to work in line with this law and ensure that their legal and human rights are respected.

For more information visit www.mencap.org.uk/invoveme