

## **PMLD Network response to the Adult Social Care green paper**

### **Introduction**

The PMLD Network<sup>1</sup> 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)<sup>2</sup>. The Network believes that focusing on the needs of these individuals, who face double discrimination<sup>3</sup>, 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 disability 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.

### **PMLD Network consultation**

We have consulted with family carers, support staff and professionals to inform this response. What they are telling us is that people with PMLD are not getting the care and support they need to have an ordinary life. Their basic human rights are being denied because of this. They believe the key reason for this is because the social care system is inadequately funded.

### **Key issues**

For families of people with PMLD a lot of life is spent fighting to get the right care and support to meet the person's needs. Care and support should be a given, people should then be able to have a 'life'.

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<sup>1</sup> Membership of the PMLD Network is listed in Appendix 1

<sup>2</sup> Appendix 2 provides more information on what it means to have profound and multiple learning disabilities

<sup>3</sup> Valuing people with profound and multiple learning disabilities' Mencap 2001

We welcome reform of the social care system. We believe it is crucial for the Government to understand that many people with PMLD will need lifelong complex packages of support to meet their health and social care needs. It is extremely unlikely that a person with PMLD has worked and had a chance to build up assets and thus be able to contribute financially to their social care. It has to be recognised that this group of people will need their care paid for by the state throughout their life. We need to be upfront about this.

Our concern is that people with PMLD and their families are not getting the care and support they need now. Demographic changes: the rising number of elderly people, the increased number of people with a learning disability needing services (3-5% increase per year)<sup>4</sup>, the increasing numbers of people with PMLD (1.8% increase per year)<sup>5</sup> coupled with the economic climate is going to put even more pressure on the care and support system.

It is worrying that the green paper does not address the need for increasing funding for learning disability services nor does it propose reforms of how to fund the system to meet the rising demand on learning disability services.

- **Our main concern is that because of the funding crisis and the enormous pressure on social services the Government is going to avoid committing to expensive packages of support, which people with PMLD will often need, and only provide care in a crisis. This must not happen. Things need to get better for people with PMLD not worse.**

## **The vision in the green paper**

We welcome the creation of a National Care System and the green paper's vision for this.

### **National Assessment**

Families have said:

***'People are not getting good assessments. They don't understand needs.'***

***'It must be a needs-led assessment leading to a needs-led service. Not a service-led assessment.'***

***'Change the ethos of the way we are made to feel about applying for help and support, particularly financial. We still seem to be in charity mode, with values around who is deserving of support and who is not. There is no real***

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<sup>4</sup> Emerson, E and Hatton, C (2008) *Estimating Future Need for Adult Social Care Services for People With Learning Disabilities in England*. Lancaster: Centre for Disability Research

<sup>5</sup> Emerson, E (2009) *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England*. Lancaster: Centre for Disability Research

*sense of rights and entitlement. So the assessment process is never objective.'*

*'We can't even move out of the borough let alone to another area because we are terrified we won't get support. For most family carers you don't even contemplate moving.'*

We welcome the principle of National Assessment. Alongside this we would like the creation of a National Resource Allocation System, which is delivered locally. It is crucial that people with PMLD have good assessments and packages of support which meet their needs regardless of where they live.

At the moment there is little consistency and equity in the system. Packages of support which people with PMLD get differ depending on the area. People want greater transparency and fair funding.

Not surprisingly some parents who have fought and got a package for their son or daughter that is currently meeting their needs are concerned about assessment moving to the national level. This is no surprise. They have been let down too many times and have little trust left in the system.

- **National Assessment has got to be about bringing everyone up to the level of getting the care and support they need. No-one should have to experience it getting worse.**

### **Fair funding**

In order for the vision in the green paper to become a reality there clearly needs to be more money in the system. The Government does recognise this however much of the focus in the green paper is about how to get more money in the system to fund care for the elderly.

- **The Government urgently needs to address the need for increased funding for learning disability services and it needs to propose reforms of how to fund this.**

### **The other key principles**

We believe that **Personalisation** should be seen as the core principle of the National Care system. The other principles in the vision of **prevention services, a joined up service and information, advice and advocacy** are about how you ensure person-centred care.

To date these principles have not adequately underpinned the care and support that people with PMLD have got. They will be discussed further within the next section.

## **A care and support system which meets the needs of people with PMLD**

For a care and support system to truly meet the needs of people with PMLD the following are crucial:

### **Better information about numbers and needs**

There remains very little data about the numbers and needs of people with PMLD. However what there is, demonstrates a rise in the numbers of people with PMLD and the fact that there needs are becoming more complex.

An analysis of need conducted by the Sheffield Care Trust (2006) 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<sup>6</sup>.

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

We welcome that the Government has recognised the gap in knowledge about the numbers and needs of all people with a learning disability and are exploring ways to get better data.

The Government recently commissioned research into estimated future numbers of people with PMLD<sup>7</sup>, which showed that there is sustained and accelerating growth in the number of adults with PMLD in England. This research is a good start. It gives local areas an idea of the numbers of people with PMLD coming through the system. However, local areas have got to build on this and do a proper audit of numbers and needs. This is crucial for planning and commissioning appropriate services.

- **The Government must find ways to get better data about the numbers and needs of people with PMLD.**
- **Local areas need to monitor the numbers and needs of people with PMLD in the area on an annual basis.**
- **This data needs to be nationally collated to inform national funding decisions.**

<sup>6</sup> Sheffield Joint Learning Disabilities Service (2006) *Young people with profound and multiple learning disabilities: implications for adult services*. Sheffield: Sheffield Joint Learning Disabilities Service

<sup>7</sup> Emerson, E (2009) *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England*. Lancaster: Centre for Disability Research

## **Involvement of family carers and people with PMLD in decision making is crucial**

A key reason why people with PMLD remain such a marginalised group is that they are poorly represented on decision making bodies. This means that there is often no-one speaking up for their needs and ensuring that they are met.

Family carers are often the experts on their son or daughter's needs. If a social care system is to meet their son or daughter's needs then their involvement is crucial. One of the positive things that family carers said was that they are feeling more involved. For example, their involvement has been sought in inspecting services. This has made them feel more valued.

We are increasingly hearing that self-advocacy groups and partnership boards are appointing PMLD champions and seeking to meaningfully involve people with PMLD which is a positive step. Mencap and BILD's Involve Me project will showcase creative ways of how to creatively involve people with PMLD and put them at the heart of decision-making.

- **All groups involved in policy and decision making about issues affecting the lives of people with a learning disability should be meaningfully involving people with PMLD.**
- **People with PMLD should be creatively involved in decisions about their lives along with those who know them well such as family carers and independent advocates.**
- **They should be involved in all decisions which affect their lives from assessments and person centred plans through to planning and reviewing services.**
- **Involvement of family carers in service planning and review should be facilitated further.**
- **People with PMLD, family carers and advocates should be listened to and change should happen as a result.**

## **Personalisation agenda must be fully inclusive of people with PMLD**

The PMLD Network welcomes the Government's commitment to choice and control for all people with a learning disability and it welcomes that reform of the social care system is underpinned by this principle. Individualised support has the potential to transform the lives of people with PMLD. But there are many concerns about how this will be implemented for people with PMLD.

### **True cost of support**

Families and staff have said:

***‘All support is based on cost not personal need.’ – Finance manager***

***‘Individual budgets are being ‘marketed’ to SSD staff/ managers on the basis that individual budgets can actually ‘save costs’!’ – Advocate.***

***‘I don’t think they have got their head around how expensive this group of people are. How expensive it is to support people in the way Valuing People Now says people should be supported.’ – Manager of a day opportunity***

***‘My sister is currently funded for waking nights to keep her safe but there is talk of taking that away and putting assistive technology in. But we have tried it and it hasn’t worked. I am very concerned that the Government is always trying to find ways to reduce costs which in fact would put her at risk and that’s my biggest concern.’- Sister***

The Government must be committed to meeting the true costs of support packages for those with the most complex needs. The Network is aware that some families are in dispute over the Resource Allocation stage because of the cost of staff support. It is often the case that basic support staff are not skilled enough to meet people’s needs, especially when they have complex health or behaviour needs. No one should be seen as too disabled, too difficult and too expensive to have equal access to individual budgets.

We have heard from families who cannot recruit and retain staff who have the right skills to meet their son or daughter’s needs on the rate provided by the local authority. To make it work they are having to top up payments to staff.

Families are having to fight to get the true cost of support recognised. They are concerned that the Government is going to keep on trying to cut costs in the current climate without realising how serious the consequences could be for people with PMLD.

- **There must be no artificial top limit for individual budgets.**
- **The resource allocation process should recognise the true costs of support and be transparent and there must be commitment to provide the complex support packages which people with PMLD will often need.**
- **The Government needs to gather data about the highest level support packages for people with the most complex needs so that they can plan appropriately to meet people’s needs.**

### **Choice, flexibility and joined up working**

Families have said:

***‘Demand is making it hard to get good people – there are not enough good staff out there.’- Parent***

**Choice** is at the heart of personalisation and plans for individual budgets should be based on good person centred planning and the involvement of a circle of support.

However people need services to choose and we have heard from a number of people that the current reality is that there is little choice of services out there, from choice of staff to choice about housing and what to do in the day. Work needs to be done to ensure that choice is available.

**There seems to be a lack of creativity, joint working and commitment to meet needs.** We have heard from families who are not getting enough support from paid staff to help them care for their son or daughter in the family home. Reasons are given such as *'your home is not big enough to have night staff – they would need a room of their own'*. That option is then ruled out rather than trying to solve the problem by working with the housing department to get bigger accommodation or an extension.

People with PMLD are going to require complex lifelong packages of care. This requires input from different departments and agencies such as social care, health, housing, education. It is crucial the green paper's vision of joint working is realised in order for them to get the integrated care and support they need.

Unfortunately at the moment we know of many people with PMLD who are not getting the package of support they need. For example, some need more hours of support from paid staff in the family home. They are not getting it and consequently family carers are having to struggle on at or near breaking point. This is not in line with the green paper's vision of personalisation or prevention.

- **People with PMLD should be given priority for person centred planning and staff should be properly trained in engaging with people with PMLD.**
- **The Government and Care Quality Commission should monitor the levels and quality of choice.**
- **There needs to be joint planning at the local level with guidance from Government.**
- **All partners must understand their responsibilities and how they will work together to ensure there are no gaps in safeguarding the individual.**
- **There need to be regular reviews of people's packages to ensure they are continuing to meet their needs.**

### **Managing an individual budget**

Families and staff have said:

***'Direct payments and Individual Budgets are causing more stress for carers – we don't want them.'* - Parent**

***‘Individual budgets – what about the very large number of people who don’t have supportive, knowledgeable family carers.’- Day services manager***

***‘The one thing that’s not taken into account with an Individual Budget is that to administer it – to actually keep track of it ..do all the planning and organising - is time consuming. My husband estimated that it takes one day a week. There’s no money in the budget for that so a member of the family has to do that.’- Mother***

We are concerned that the work involved in managing and administering an individual budget for someone with PMLD is huge. It is crucial that this is explored so that issues can be resolved and this does not become a barrier to getting an individual budget.

We are also concerned that people with PMLD without families to manage the budget are not getting equal access to individual budgets which meet their needs. It must be possible for people who are un-befriended or who do not have a strong family to have the same opportunity to have an individual budget, but as with many things for people with PMLD it is difficult to imagine who is actually going to make this happen and drive things forward if there is no family involved. Pressure on social services resources is unlikely to help this.

- **There needs to be research into the work involved in managing and administering an individual budget for someone with PMLD and issues resolved.**
- **There must be support for people with PMLD who are un-befriended or who do not have strong family to have an individual budget.**

### **Personalisation for all**

Staff have said:

***‘People with PMLD get a different service depending on where they live. I think if you live in a forward-thinking borough they can be thinking ‘how are we going to make this work?’ and they really try. Lots of people don’t live in that kind of borough though.’- Manager of a day opportunity***

There are still a number of barriers to people with PMLD getting truly personalised care. These must be resolved so that people with PMLD are not left behind.

- **We support Mencap’s call on the Government to enshrine the personalisation agenda in all legislated future reforms of the care and support system, in order to ensure that the personalisation agenda is pushed forward and inclusive of all people with a learning disability.**

## **Family carers must get the support they need**

Families have said:

***‘He needs two people to go out and about. If one of his support workers can’t make it I will fill in. It is not fair for him to miss out on going out.’- Parent***

Many families want to care for their son or daughter with PMLD in the family home but they need support to do this. They fulfil a huge number of roles: family, carers and campaigners. Many are also taking on a new role of care ‘manager/co-ordinator’.

Often family carers don’t get the support they need until they reach crisis point.

Families who have paid support staff coming in to care for their son or daughter as part of their son or daughter’s package of care are often finding this isn’t enough support and they are still exhausted. They also often have to be involved and fill in when staff don’t turn up.

If a person with PMLD was able to get a package of care which really met their needs – either in the family home or elsewhere – this would enable many family carers to consider returning to work either full-time or part-time. This would benefit the Government too, as if family carers were working they would be paying tax.

### **Respite**

Families have said:

***‘There is very little choice. There are very few specialist services where staff have the right skills to meet communication and health needs. People have had bad experiences like their child has been given the wrong medication. But they have used it again because they were desperate - they just worried all the time.’- Parent***

Many families are not getting the right quantity or quality of respite.

Mencap’s second Breaking point report (2006) found that 7 out of 10 families have reached or come close to breaking point because of a lack of short break services. 5 out of 10 families who had had a carer’s assessment got no services as a result. 1 in 3 families had experienced a cut in their short break services in the last year.

Many families have found that things have got worse since Valuing People as day centres have closed and suitable college courses have often been cut, meaning they don't get the break during the day that they were used to.

- **It is crucial that families get 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 per year or its equivalent.**

### **Information and advice**

Families have said:

***'I don't know what I would do without Centre 404 – they are a lifeline.'***  
**Parent**

Information and advice is a key issue for families of people with PMLD. Not only are many family carers caring for all hours of the day they are also having to do their own research about everything from equipment, to funding to apply for, to benefit entitlement, to information around managing a staff team.

We really welcome the principle of better information and advice in the green paper's vision. This is a big gap for many. Where family carers are getting good advice and information it seems to make a big difference.

Carers' networks and centres, where they exist, are where people seem to be going to find information, for example where to get a new PA. Support from other carers often seems to be what enables many to cope.

People rarely seem to be finding that social services are a good source of information and advice. It may well be that information and advice is best given by other agencies for example in the voluntary sector. However at the moment, where carers' networks and centres exist, there is often a fear that they could close down at any moment because of lack of funding. This needs to be addressed.

In many areas, family carers are filling the gaps in information and advice. They shouldn't be expected to continue to do this for free.

- **Different models for giving information and advice need to be explored.**
- **There needs to be secure funding for 'lifelines' like carers networks and centres.**
- **Investment in family carers must be a priority.**

### **Fear about the future**

Families have said:

***‘The future is quite worrying although she is in residential care. Each time an issue has come up it has taken the family to step in and resolve it. If something happened to me who would be my sister’s voice? For people who don’t have family it does concern me. Their care is not as good as where family is involved.’- Sister***

***‘The future is one of our biggest fears.’ - Parent***

People with PMLD are vulnerable and parents are very concerned what will happen in the future. They are concerned about who will speak up for their needs and rights when they are not around.

- **There need to be people to speak up for the needs of people with PMLD when their families are no longer around.**

## **Access to non-instructed advocacy**

*Staff have said:*

***‘A way forward to improve the lives of people with complex support needs is to involve independent advocates in the PCP process or any major life decision making.’- Support worker***

Most people with PMLD will not use formal communication. They are most in need of someone to speak up for them and yet there are few advocacy schemes which can support them. There appears to have been little increase since the *Advocating for Equality* report (2004)<sup>8</sup> showed that only 11% of advocacy schemes could support someone with PMLD. Most advocates are still not trained in non-formal communication methods which are needed for non-instructed advocacy. The numbers of people with PMLD are increasing so robust advocacy provision is more essential than ever.

The Joint Committee on Human Rights Inquiry (2008)<sup>9</sup> backed up this view: ‘We are persuaded that for many people with learning disabilities, particularly those who are most vulnerable (including adults with complex and profound learning disabilities) would benefit greatly from the assistance of independent advocates in order to secure their human rights.’

We welcome the vision in the green paper of ‘people getting support from advocates where appropriate’. Non-instructed advocacy is vital to protecting the rights of people with PMLD. People with PMLD need advocates in all important decisions, including decisions around person centred plans and how to spend individual budgets.

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<sup>8</sup> Clipson, C and Lewington, W (2004) *Advocating for Equality*. London: Independent Advocacy Campaign, Scope

<sup>9</sup> Joint Committee on Human Rights (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities* (2008 HL Paper 40-1 HC 73-1). London: House of Commons and House of Lords

We support Mencap's call for the Government to place a statutory obligation on all local authorities to commission an independent advocacy service in their area, available for everyone who is eligible for services. This will involve ensuring there are advocates at the service trained in the use of non-formal communication methods. The use of professional, citizen and peer advocates should be explored.

- **'Access to advocacy' should be seen as a priority area in its own right in the green paper vision.**
- **People with PMLD must have widespread access to non-instructed advocacy.**
- **There should be a statutory obligation on all local authorities to commission an independent advocacy service in their area, available for everyone who is eligible for services. This will involve ensuring there are advocates at the service trained in the use of non-formal communication methods.**

## **The workforce is invested in to meet the needs of people with PMLD**

Families and staff have said:

***'The staff are key to everything. You could have the most wonderful living room, fantastic kitchen however if the staff aren't able to communicate and engage it is very distressing.'***- Family carer

***'You have great difficulty getting staff because of the rates of pay. You can get more working in a supermarket without the hassle.'***- Family carer

***'It's difficult to get the right people to stay long enough. It takes about 4-6 months to get to know her, her intricate ways, what she enjoys. They needed lots of training from us. But then they move on as we can't pay them enough.'***- Parent

***'Communication training is available but not resourced or prioritised to be as effective as it might.'***- Health professional

***'She actually lost 2 dress sizes when she moved into residential home because the carers thought she was refusing food because of her gestures but in actual fact that message to people who know her well is 'give me time, I want to look around and be nose before I start eating.'***- Sister

The PMLD Network is concerned that the lack of availability of a suitably skilled workforce and the fact that some local authorities refuse to pay for skilled staff support are major barriers to inclusion for many people with PMLD.

Families want highly skilled staff who can engage with and care for their son/daughter in the way that they would themselves. This is key for quality of life. Lack of the right skills can also have very serious consequences. There

are numerous examples of people with PMLD ending up in hospital and even worse because staff haven't understood their communication, health and behaviour needs.

Low pay means there is often high staff turnover which results in poor continuity of care and the process of learning to support someone well may start all over again.

- **Reform of the social care workforce must be a key priority of the National Care Service.**
- **Staff need to be trained to meet people's complex health, communication and behaviour needs.**
- **Staff should receive pay which reflects the additional skills and training they need to provide good quality support.**

## **Choice about where to live**

Family carers have said:

***'People with PMLD don't seem to be getting innovative housing as much. Staff are a problem – the skills needed to support someone with PMLD.'***

***'There is no choice about housing at the moment. A lot of people who have chosen not to live with family carers have had to move out of borough which obviously affects their relationship with the family carer.'***

***'There is some good work in the borough but those spaces are filled. Until someone moves on you can't access anything.'***

Currently most people with PMLD stay at home well into adulthood and many parents feel there are very limited alternatives that are able to meet the needs of their son/daughter. When parents become ill or die, there is a risk that local authorities make hasty and ad hoc decisions about where people with PMLD will be placed. Such placements are in very short supply and so some people will end up in inappropriate services, or far from the home community and will most likely be living in traditional forms of residential care.

The shift towards personalisation should mean that people with PMLD get packages of support which meet their needs, enabling them to have choice and control about where they live.

Too often choice about where someone can live is linked to the shortage of staff with the right skills. Families tell us what happens when these skills are not available, how the health and well being of a family member has been jeopardised by poor care.

Reform of the care and support system must acknowledge that the support needed to enable a person with PMLD to have a home of their own will often

be complex and costly. Lack of funding cannot continue to mean lack of choice for people with PMLD.

People with PMLD are nearly always placed with others with PMLD. However opportunities should be explored; for example there have been some instances of people with PMLD sharing with more able people with a learning disability that have been mutually beneficial. There are a few really good examples of the lives that people with PMLD could achieve when funding and skilled support is in place. However, the majority have been hard won and harder still to keep in place.

### **Victoria's story**



*Victoria (pictured above, left, with her mother Jean) lives in her own tenancy in the London borough of Islington. She has 24 hour support, a circle of friends and a person centred plan and very much lives the life of her choice. Her mother Jean has had to consistently fight to keep this in place. Islington have now, made the decision that they will never again fund individuals with complex needs to live independently because the costs are too high.*

- **People with PMLD should have a range of choices about where to live from registered care to supported living.**
- **They should also have choice about who to live with.**
- **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.**
- **There should be more funding for high quality, safe and fully supported housing to be provided for all adults with PMLD.**

### **Access to the community and activities**

Family carers and staff have said:  
***'A lot of progress has been made to make the community more accessible but still a lot of places are inaccessible for people with PMLD and this is discriminatory.'*- Parent**

***‘Little opportunities for fulfilling activities.’- Care home manager***

***‘He is not getting a good transport service to his day care service. At the moment it arrives so late he misses most of the morning session. This is happening because of transport budget cuts.’- Care home manager***

***‘That the emphasis should change from Day Services to people with PMLD getting PAID jobs is unbelievable.’- Parent***

The modernisation of day services programme has not always properly considered the needs of people with PMLD, such as the staff support needed for someone who requires 2:1 support for their moving and handling needs, how complex health needs e.g. PEG feeding can be met within a community setting, the special transport needs of someone who may not use a standard wheelchair, and the need for someone to have access to specialist facilities in the community such as Changing Places toilets – with a bench, hoist and plenty of space. This has resulted in people having less day time support than before.

There is an over emphasis on work which is not realistic for the majority of people with PMLD. We need to be realistic. The current situation, as evidenced in a scoping study commissioned by CSCI<sup>10</sup>, is that ‘none of the people within PMLD sample was in paid employment and that most- 59%- attended a day centre’.

When day services close and there are not appropriate alternatives in place, the result is that many people with PMLD are forgotten and remain at home with nothing to do.

Other opportunities for meaningful activities are college courses which have been held up as the alternative to day centres. But many of these have been cut. We have heard from a number of family carers about the problems of finding a suitable college for their son or daughter following school and the distress that is caused when the young adult suddenly finds themselves with nothing meaningful to do in the day.

The shift towards personalisation means that people should have more choice about how to spend their time. Reform of the social care system must ensure there are high quality options in terms of activity and support which people with PMLD can access.

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<sup>10</sup> Tempest K, and Fruin D. (2006) *Scoping study report: people with profound and multiple learning disabilities*. Leeds: Commission for Social Care Inspection

- There must be recognition that many people with PMLD experience the world largely on a sensory level and activities need to be developed that take this into account.
- Day time activities should be stimulating and meaningful to the individual. The skills of staff are often key in this. It is not just about 'buying' things to do.
- Community facilities should be designed to meet complex health and social care needs where possible for example, including Changing Places toilets.
- There should 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 inclusive to other community groups where possible.
- Manual handling policy and practice for staff must not act as a barrier to taking part in community activities.
- People with PMLD must also be able to access flexible and reliable transport.

## Good transition into adulthood and good planning for the future

Family carers and staff have said:

***'I really worry about people coming through with complex medical conditions who are technology dependent. Adult services have not got a clue. Training of staff to meet complex needs is an enormous issue.'*- Parent**

***'It's all very well identifying what needs to happen – but it needs to be followed through. They say we'll do this. 3 months later it's not happened. 6 months later it's not happened. 2 years' later it's still not happened.'*- Support worker**

Together with the lack of good data and proper planning for children and adults with PMLD, the lack of holistic planning raises serious concern. This concern is widely shared:

- The report from the London West Learning Skills Council (LWLSC) on mapping and service needs for those with ASD or PMLD<sup>11</sup> noted a lack of real understanding of the needs of these groups and poor sharing of information being the most critical.
- The PMLD Network survey 2006 results showed that less than a quarter of respondents thought that Local Authorities were planning for the needs of young people with PMLD leaving school.

It is not just transition from children to adult services which is a problem. Planning at all stages of a person with PMLD's life seems to be poor. Social

<sup>11</sup> Research for Tomorrow, Today (2003) *Mapping service and support needs for young people aged 16-25 with ASD or PMLD*. London: London West Learning Skills Council

services don't appear to strategically monitor who is living at home with family carers and plan for individual's future. It is a timebomb. It appears that often nobody has the job of 'planning services'. The focus of commissioning can be buying what is available rather than planning what people need.

Reform of the social care system has got to address this.

- **There is an urgent need for Government to monitor transition better.**
- **Good planning followed by timely service delivery needs to be a priority in the reform of the social care system.**
- **Good transition for young people with PMLD includes a holistic approach, covering all aspects of support, including health and social care needs and not just education. Joint working is crucial.**
- **Information must be carefully passed on from children's services to adult services and the person should have an up to date communication passport, health action plan and a person centred plan which the person has been creatively involved in.**
- **A young person with PMLD should have a transition social worker to help them and their family through the transition process.**

### **What high quality care and support for people with PMLD looks like**

The green paper emphasises the importance of high quality services. This is crucial. Bad support can be worse than no support.

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.

We welcome the work commissioned as part of the Valuing People Now delivery plan to find out more about the numbers of people with PMLD and what good support for this part of the population looks like:

- Research into Estimated future numbers of people with PMLD (Emerson, 2009)
- A scoping study into best practice support for people with the most complex needs and developing models for local application (Mansell, in progress)
- A good practice guide on communicating with people with the most complex needs (Goldbart, in progress)

- **It is crucial that research commissioned is used to inform design, commissioning and review of services for people with PMLD.**
- **The Government needs to issue best practice guidance around care and support for people with PMLD and carefully monitor the care and support services they receive. This needs to include monitoring the quality of care people are receiving from personal assistants through direct payments and individual budgets.**

## **Conclusion**

There is an urgent need for better care and support for people with PMLD. The reform of the social care system will only improve things for people with PMLD and their families if there is a specific focus on the needs of this group of people and a commitment to meeting these needs.

In the current economic climate the Government must not be tempted to ignore the needs of this group of people, only committing to complex packages and fully meeting needs in times of crisis.

This would be totally against the vision of the green paper.

The Government needs to ensure that there is enough funding in the system to truly meet people with PMLD's needs.

People with PMLD must not continue to be a marginalised group with their human rights largely ignored. There are many examples of the serious consequences that lack of the right support has had for this very vulnerable group of people. A new social care system must fully support the equal rights of this vulnerable part of society.

**For more information, please contact Beverley Dawkins, Chair of the PMLD Network on 020 7696 5558 or email [beverley.dawkins@mencap.org.uk](mailto: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  
See Ability  
Sense  
The Challenging Behaviour Foundation  
The Children's Trust  
The Ridgeway Partnership NHS Trust  
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.