

Submission to UN Universal Periodic Review UK's examination (13th Session - 2012)

About Mencap

Mencap supports the 1.5 million people with a learning disability in the UK and their families and carers. Mencap fights to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want.

We are also one of the largest providers of services, information and advice for people with a learning disability across England, Northern Ireland and Wales. See www.mencap.org.uk for more information.

About learning disability

A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always life-long and affects someone's intellectual and social development. It used to be called mental handicap but this term is outdated and offensive. Learning disability is NOT a mental illness. The term learning difficulty is often incorrectly used interchangeably with learning disability.

Introduction

Mencap has supported the submissions made on behalf of Disability Rights Watch UK and the British Institute of Human Rights and fully endorses the positions taken by those submissions. However, there are some areas of concern specific to the rights of people with learning disabilities that warranted an additional submission.

In particular the needs of people with profound and multiple learning disabilities have not always been met sufficiently and there is a concern that this may prevent their enjoyment of their rights. In particular limited access to advocacy, day time activities and adequate healthcare services is likely to restrict their right to community and family life and access to healthcare and justice obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

People with profound and multiple learning disabilities (PMLD) are unique individuals but sometimes it is helpful to talk about groups of people who have common concerns, have distinctive needs, face barriers to being included and who need help to fight for their equal rights.

1. People with profound and multiple learning disabilities:

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

Recent research estimates that there are just over 16,000 adults with PMLD in England.¹ This is a relatively small and easily identifiable group, yet their support needs are particularly high. Indeed, research by Mencap showed that 60% of parents of children and adults with PMLD spent more than ten hours a day on essential physical care and a third of these said that they were caring for their son or daughter 24 hours a day.²

In March 2010, Professor Jim Mansell published his report *Raising our sights*, which was commissioned by the Department of Health which highlighted the challenges facing many adults with PMLD and their parents and carers. It offered 33 recommendations on how to improve the lives of these individuals and the Government said that it would respond to each of the recommendations.

This response was published on 10th February 2011. Mencap is disappointed with the content of the Government's response as there is no commitment to implement any of the recommendations and, therefore, to ensure that the lives of people with PMLD and their families and carers are improved. Mencap is concerned that, as a result of a lack of action regarding this issue, people with PMLD will remain marginalised, without the support they need to achieve an acceptable standard of life, and families caring for adults with PMLD at home will continue to be pushed towards breaking point as they struggle on without appropriate support.

2. Advocacy and access to justice

The Government has determined that determined that advocacy services should be commissioned by local commissioners and advocacy service provision should be advanced by councils. Furthermore the cuts in Legal Aid for advocacy services mean that people may struggle to get proper representation. This is because under proposals of the Legal Aid, sentencing and punishment of Offenders Bill, Legal aid will be cut for people representing others in a number of cases. If people are denied access to justice as a result it would be a serious breach of their human rights and Mencap would like to see the government take steps to protect legal aid for advocacy and to over reassurances that it

¹ Emerson, E. (2009) *Estimating future numbers of adults with profound and multiple learning disabilities in England*. Lancaster: Centre for Disability Research

²
<http://www.mencap.org.uk/document.asp?id=1671&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=pageType&pageType=112&pageno=&searchPhrase=>
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intends to ensure people with PMLD and those who support them have access to due legal representation

Recommendations:

- Mencap seeks clarification on how the specific support and advocacy needs of people with PMLD will be identified and provided in local areas.
- The government should take steps to ensure that advocacy services for people with PMLD are adequately funded, and that there is sufficient monitoring of these services make sure that the needs of people with PMLD are being met.

3. Access to the community and living independently

The ability to access community is an essential part of the rights of people with PMLD. The UNCRPD states that disabled people should be able to live independently and be included in the community. Mencap is concerned that progress in this area is limited, particularly with regard to people with PMLD.

Changing places facilities

The government is currently reviewing Building Regulations with consideration of including Changing Places Facilities within Part M (Access to and use of buildings) of the Building Regulations. These facilities include additional features such as a hoist, adult changing bench and extra space for carers to support someone to access toilet facilities. Without these facilities, a person with PMLD may be severely limited in their access to community facilities and may be faced with the choice of being subject to degrading treatment of being changed in unsuitable, unhygienic conditions or not going out at all.

Assistive technology

Communication aid and assistive technology help people with PMLD to access the community live independently and enjoy their private and family life effectively.

The government has said that it is committed to implementing Article 25 of the UN Convention which specifically addresses rights in health and social care. In addition it is running a large randomised control of telehealth and telecare (Whole System Demonstrator programme) which will provide the best evidence base possible for local commissioners to make decisions about how best to use this type of technology to support locally assessed needs.

It has however said that it the decision about funding the provision and repair of communication aids for adults with PMLD is the responsibility of the NHS or the Local Authority. Mencap is concerned that there is no leadership from the Government as to how information about assistive technologies and communication aids will be achieved, as per

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the Raising our sights recommendations. We also seek assurances that the large trial on telehealth and telecare will address the specific needs of adults with PMLD as this is often not the case. It is unclear therefore about how much guidance the government will give to local authorities or how it will ensure local authorities are meeting their obligations to provide this support. An effective guidance and monitoring system would enable a consistency of access in all authorities whilst also helping to drive up standards.

Employment and day activity

Mencap welcomes the government's determination that all people with learning disabilities – including people with PMLD – should be supported to have fulfilling lives including opportunities to work, study and enjoy social and leisure activities.

However despite this commitment to help ensure that people with PMLD are part of all plans and opportunities and that reasonable adjustments should be made, we would call for greater leadership from government by offering further guidance on this and disseminating best practice. This is particularly the case around encouraging Local Authorities to continue to provide somewhere which can be used as a base from which adults with PMLD can go to different activities during the day.

Access to education

The government had previously committed to local FE provision for all young people aged 16-19 with learning disabilities as part of the SEN Green Paper. It has also highlighted the fact that Skills Funding Agency regularly publishes data on the number of learning aims achieved by learners with a self-declared learning difficulty or disability.

Despite Raising our sights making it clear that a specific focus on improving access to FE for young adults with PMLD is needed, the Government does not seem to have any plans to focus on the specific needs of this group. The Skills Funding Agency data is not broken down to give information about students with PMLD and, at present, there is no data about the volume and quality of FE provision for people with PMLD (with no indication that there are plans to start collecting this information).

We have now seen the Green paper on SEN and Disabilities and there does not appear to be a specific focus on the needs of this group in relation to accessing appropriate FE.

Short breaks

The government has announced that there is extra funding for carers breaks over the next 4 years through a £400 million investment (as set out in Recognised, valued and supported: next steps for the Carers' Strategy November 2010) along with additional funding in PCT baselines to support the provision of breaks for carers made available in the Spending Review.

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Mencap calls for greater Government leadership to encourage local areas to ensure that short break services are commissioned which specifically meet the needs of people with PMLD. This is crucial as so often short break provision does not have the staff skills and expertise needed.

Recommendations:

- **The Government should extend Building Regulations to ensure that all new buildings must include Changing Places facilities to enable people.**
- **There is useful existing research and practice on the use of communication aids and assistive technology for adults with PMLD. Mencap calls on the Government to commission the review and dissemination of this.**
- **Mencap calls on the Government to check that local areas have worked out whether the funding for the provision and repair of communication aids for adults with PMLD is the responsibility of the NHS or Local Authorities, so that lack of clarity on this does not continue to make access to communication aids difficult for people with PMLD.**
- **Mencap asks the Government to seek commitment from Local Authorities to develop plans and opportunities for meaningful activities for people with PMLD.**
- **Mencap would like to see a policy commitment to improving access to Further Education for people with PMLD in order to help funding bodies develop appropriate objectives and plans. We would like all work being done to improve access to FE for people with learning disabilities to include a specific workstream focusing on young people with PMLD. Mencap would like the Government to ensure that the funding provided for short breaks, referred to in their response, reaches people with PMLD who have the highest level of need.**

4. Access to Health care

Article 25 of the UNCRPD declares that governments should provide access to healthcare for disabled people. There are concerns that recommendations from the Raising our sights report have not yet been implemented to ensure people with PMLD have adequate healthcare services

Healthcare for people with PMLD

The government claims that the needs of people with a learning disability are covered by the NHS Operating Framework 2011/12 and the Confidential Inquiry into premature and

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avoidable deaths of people with learning disabilities and the Public Health Observatory for people with learning disabilities. It has stated that that NHS bodies should already be ensuring that services meet the needs of all patients – including those with PMLD – and are required to comply with the Equality Act 2010 and from April 2011 its Equality Duty.³

Mencap is disappointed that the Government has not taken on board the *Raising our sights* recommendation that the Board of each NHS Trust should consider a report specifically focused on the adequacy of health services for adults with PMLD and approve an action plan to ensure adequate treatment. We are concerned that this will see a continuation of a lack of focus on this group when it comes to healthcare.

Clinical procedures

The Government's recently claimed that high quality person-centred transition plans are currently being developed in children's services that focus on outcomes and cover health, housing, employment and community participation and that the New Health and Wellbeing Boards will help meet needs in a joined up way.

However we believe that there is a lack of detail in this response and that it does not adequately address the Raising our sights recommendations about clinical procedures. We would like to see it call on Local Authorities to develop local policies about clinical procedures in all relevant care settings or offer assistance with this.

Recommendations:

- **Mencap would like to see progress made around the health of people with PMLD including better monitoring of the uptake of health checks, provision of health services and improved planning to ensure adequate treatment.**
- **Mencap would like to see central guidance from the Department of Health on how local areas should adapt policies and procedures used in children's services for use in services for adults.**

Conclusions

Mencap feels it necessary that in addition to the achievements, issues and challenges outlined in submissions coordinated by Disability Rights Watch UK and the British Institute of Human Rights, the unique challenges faced by people with PMLD in enjoying their rights merits an additional response focussed on those challenges alone.

The government has made a wide number of promises and assurances on access to services which would allow people with PMLD to enjoy their community and family life and

³ New organisations established as part of the health and social care reform programme, for example GP commissioning consortia, will be covered by this Duty

to access high quality healthcare. However these promises are not always translating into visible improvements in the way people with PMLD can secure their rights.

We have made a number of recommendations which we urge the government to consider as part of the Universal periodic Review Process, with a particular emphasis on accessing the community and independent living including education, healthcare and adequate legal representation.

For further information please contact:

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