



Lambeth PMLD project

Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth



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Foreword



Beverley Dawkins OBE, national officer for profound and multiple learning disabilities, Mencap

“We are delighted to be part of this ‘good practice’ project – a local area finding out about its PMLD population. We hope it will encourage other local areas to do the same. It will also help us increase our understanding of the issues we are campaigning on nationally.”



Dreenagh Lyle, carer representative on Lambeth Learning Disability Partnership Board

“My concerns about the lack of awareness of the specific needs of people with PMLD have grown since the publication of *Valuing People Now and Improving The Life Chances of Disabled People*. I hope this report will raise awareness and contribute to public knowledge about this overlooked minority of non-self-advocating individuals.”



Alex McTeare, commissioner, Lambeth Council

“This has been an interesting project. We have lots of plans for people with a learning disability and this project has helped us see how we can deliver them to better include people with PMLD.”



Mary Wells, carer representative on Lambeth Learning Disability Partnership Board and chair of Lambeth Mencap

“Two years ago family carers proposed to Lambeth Learning Disability Partnership that a study of the lives of residents with PMLD and their families should be undertaken. The commissioners were enthusiastic, Mencap’s PMLD experts generously offered to do the work and register services gave invaluable support. This report is the result of our collaboration. I hope that it will be the catalyst for making concrete improvements.”



Liz Clegg, commissioner, NHS Lambeth

“PCTs across London have been required to report on how they will improve the experience for people with a learning disability when using health services. This project will help to inform us of the needs of people with PMLD and other PCTs may benefit from carrying out a similar exercise.”



Anne Bowman, head of service, register services, part of the public health department of NHS Sutton and Merton

“We were delighted to work with Mencap and Lambeth Council (one of our stakeholders), to identify people with profound and multiple learning disabilities and produce data from the Lambeth *I Count Register*. We’re happy to assist in this very worthwhile project, concerning this particularly marginalised group of people. It was a good use of the register data and shows how beneficial good learning disability registers can be.”





Introduction

About this project

The aims of this project were to:

- identify people with profound and multiple learning disabilities (PMLD) in Lambeth
- find out about their needs
- learn about the support and services they are currently receiving
- discover what needs to change to improve support and services for them
- develop recommendations for Lambeth Council and NHS Lambeth to take forward
- establish it as a 'good practice' project and encourage other local areas to find out about the numbers and needs of people with PMLD in order to address gaps and plan appropriate services.

Why did we decide to do this project?

Family carers in Lambeth said that people with PMLD were not getting the support and services they needed to have a good life. They took this concern to Lambeth learning disability partnership board. The board agreed that a piece of collaborative work, focusing on the needs of people with PMLD in the area, would be a valuable step in improving the lives of people with PMLD and their families in Lambeth.

The project group

- Family carers of people with PMLD in Lambeth
- Lambeth Council and NHS Lambeth
- Register Services (Lambeth *I Count Register* for people with a learning disability)
- Lambeth Mencap
- Mencap PMLD team

Background to the project

Valuing People (Department of Health, 2001) stated that 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.” However, the subsequent programme of action and the initiatives that followed have, largely, failed to impact positively on the lives of people with PMLD. So, while things have improved for some people with a learning disability, things have not improved for the majority of people with PMLD.

A key reason for this is that there is generally poor information about the numbers and needs of people with profound and multiple learning disabilities. As a result their needs have not been properly understood and services have not been designed appropriately.

Valuing People Now, the government’s updated learning disability strategy, was published in 2009. It recognises that people with PMLD have been missing out. There are some specific actions in its delivery plan to ensure that people with PMLD are included. Two of these actions have now been completed – research into estimated future numbers of people with PMLD¹ and a review of services for people with PMLD.²

The former has given a sense of the national picture of the numbers of people with PMLD who will be coming through into adult services from children’s services. It will also help local areas estimate these numbers. The latter has identified what the elements of good services for people with PMLD are and made recommendations about how services can be improved. These are both welcome reports and should help local areas make improvements for people with PMLD.

However, it remains crucial that local areas identify who has PMLD, their individual needs and the support and services they require. This information should be used to address gaps in the current support and services for people with PMLD.

Local areas should be planning for people with PMLD. A key starting point, of course, is understanding what profound and multiple learning disabilities means – only then can this part of the community be properly identified and appropriate services planned.

What the project group did

- Using the PMLD Network definition of profound and multiple learning disabilities, we worked with Register Services to develop criteria to identify who on the Lambeth *I Count Register* was likely to have profound and multiple learning disabilities.
- We developed surveys that were sent, by register services, to family carers and paid staff of people identified as likely to have PMLD. Our aim was to find out more about what life was like for people with PMLD.
- Family carers of people with PMLD were interviewed to better understand what life was like for people with PMLD and their families.
- We looked at the findings and developed a number of recommendations to help improve life for people with PMLD in Lambeth. We know it is unlikely that all of them will be implemented straight away, especially in the current economic climate, with cuts in public spending putting pressure on health and social care services. Nevertheless they map a clear way forward so are all included here.

1 Emerson, E (2009) *Estimating Future Numbers of Adults with Profound and Multiple Learning Disabilities*, Lancaster: Centre for Disability Research

2 Mansell, J (2010) *Raising Our Sights: Review of Services for Adults with Profound Intellectual and Multiple Disabilities*



Definition of PMLD

What does profound and multiple learning disabilities (PMLD) mean?

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, complex health needs or mental health difficulties
- may have behaviours that challenge us.

This is the short version of the PMLD Network definition of profound and multiple learning disabilities. The full version can be read in the appendix.





Information from the Lambeth *I Count Register*

The Lambeth *I Count Register for People with a Learning Disability*

Register Services³ has set up and maintains a voluntary register of people with a learning disability in Lambeth. It has information about people's health and social care needs, as well as information such as how people spend their time and where they live. The register information is used by Lambeth Council to help plan for people with a learning disability in the area. At the moment information from the register is helping GP surgeries identify patients with a learning disability for health checks.⁴

In his recent report, *Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities* (2010), Professor Jim Mansell highlighted the importance of local areas having good information about people with a learning disability so that they can plan properly. In the report he says:

“Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected future to enable effective planning of services.”

³ Register services' website, www.registerservices.nhs.uk and www.i-count.org

⁴ More information about health checks can be found in the appendix

Identifying people with PMLD on the register

Lambeth *I Count Register* does not have a specific category indicating which people on the register have PMLD.

The project group explored how the PMLD Network⁵ definition of profound and multiple learning disabilities⁶ could be used to identify people with PMLD. Register services developed criteria which, when applied to the register database information, would identify people with the health and social care needs and skills associated with people with PMLD. The specific criteria developed can be found in the appendix.

The criteria identified people who were likely to have PMLD. They were people who:

- had a severe learning disability (there is no 'profound' category so we had to look at the wider 'severe' category)
- needed full-time support
- used speech and signing 'sometimes' or 'never' (most people with PMLD will use little or no formal communication)
- were not able to read or write at all
- were not able to cook alone
- needed support when using the toilet.

Once people with PMLD on the register had been identified, using the criteria, their numbers and needs were analysed to give some key information about the population of people with PMLD in Lambeth (see appendix for more detailed information).

Information on the register about people with PMLD

1. Numbers

968

Total number of adults with a learning disability on register.

81

Total number of adults identified as having PMLD.

The number of people with PMLD identified on the register corresponds with Emerson's report⁷. He estimated that in 2009, in an average area in England, with a population of 250,000, there would have been 78 adults with PMLD receiving health and social care services. In Lambeth, the total adult population is approximately 220,800⁸, so using this model, we would expect the number of people with PMLD to be close to 78, which it is. This suggests that the criteria developed have been successful in identifying people with PMLD on the register.

⁵ The PMLD Network is chaired by Mencap www.pmldnetwork.org

⁶ The full PMLD Network definition of profound and multiple learning disabilities can be read in the appendix.

⁷ Emerson, E (2009) *Estimating Future Numbers of Adults with Profound and Multiple Learning Disabilities*, Lancaster: Centre for Disability Research

⁸ Office of National Statistics population estimates for 2008, Crown Copyright

2. Where they live

34

in the family home.

47

not living in the family home (43 in residential accommodation⁹, 4 in their own home¹⁰).

All those living in the family home are within the borough of Lambeth.

Of the 47 people with PMLD not living in the family home, 15 live in the borough of Lambeth, 32 live outside the borough.

3. Health needs

They have an array of physical disabilities, complex health needs and sensory disabilities (see appendix for full list).

The most common health needs of people identified as having PMLD on the register were as follows:

55

have a physical disability.

48

present challenging behaviour.

46

have epilepsy.

43

have a sight problem.

72

have a continence problem.

4. Gender

452 out of 964 adults with a learning disability on the register are female and 516 are male.

44 out of 81 adults with PMLD on the register are female and 37 are male.

5. Age

Of the 81 adults with PMLD on the register, the age range breaks down as follows:

2

are 18-19.

20

are 20-29.

18

are 30-39.

28

are 40-49.

8

are 50-59.

3

are 60-69.

2

are 70-79.

Note:

People are living to an older age:

- 13 are 50 or older
- 5 are 60 or older
- 2 are 70-79.

6. Black and minority ethnic (BME)

The ethnicity of adults with PMLD reflects the ethnicity of the general population of Lambeth. 47 out of 81 on the register are white, 34 out of 81 are from a range of ethnic minorities.

7. Elderly carers

34 registered Lambeth adults with PMLD live in the family home. 6 of them are living with family carers who are 70 or older.

There is 1 adult with PMLD living with a family carer who is 80 years old or older.

⁹ In this report 'residential accommodation' includes all residential care, such as a registered care home or adult placement (please note in Lambeth 'adult placement' is now defined as 'own home' however we have not incorporated this change in our report.)

¹⁰ 'Own home' refers to people living in a home they own or rent, alone or sharing, with support.



Surveys and interviews

The project aimed to find out more about the lives of people with PMLD in Lambeth. This included which services were (or were not) working well and what family carers and paid staff thought needed to change.

We developed a survey¹¹ to be completed by family carers and paid support staff of people with PMLD. For the 34 adults living in the family home, a survey was sent to their family carer. For the 47 adults not living in the family home, a survey was sent to paid support staff where they live and also to their family carer who they didn't live with.

For some people with PMLD not living in the family home two surveys were returned. One was from their paid support staff where they live and one was from their family carer who they were not living with.

After we had analysed the survey responses, we carried out eight interviews to gather more detailed information about some of the issues raised.

¹¹ There were three versions of the survey. They all asked similar questions but they were tailored to the recipient (family carer of a person living in the family home, paid support staff, family carer of someone not living in the family home) to ensure people were only asked relevant questions.

Who answered the survey?

11 family carers of people with PMLD living in the family home.

12 family carers of people with PMLD not living in the family home (3 people with PMLD living in the borough, 9 people with PMLD living outside the borough).

16 paid support staff (7 people with PMLD in the borough, 9 people with PMLD outside the borough).

These were paid staff who were either supporting the person in residential accommodation or supporting the person to live in their own home.

The survey did not include paid staff who support people living in the family home.

We received 39 responses to the survey. However, we received two surveys per person for three people with PMLD, not living in the family home.

In total, we gathered survey information about 36 people* with PMLD. 20 were living in the borough and 16 were living outside the borough.

*See appendix for more detailed info about 36 people for example their ages and where they live

Who did we interview?

The focus of this project was on how to improve life for people with PMLD in Lambeth, so support staff of people living outside the borough were not interviewed.

We interviewed:

- six family carers of people living in the family home
- one family carer of someone not living in the family home
- one paid member of support staff for a person with PMLD living in a residential care home in Lambeth.

Interviews focused on:

- transition
- young adults who have recently entered adult services
- elderly carers
- people receiving direct payments
- people with individual budgets.

Note: The project group received information for 36 of the 81 people identified as having PMLD on the register (44% of the total number of people with PMLD identified on the register).

It is important to remember when reading this report that in addition to information from the register, findings are based on a relatively small sample of survey responses, and limited qualitative data from interviews.

At the end of the report we have asked family carers and paid support staff, who have not taken part in this project, to tell us whether they think this report is a true reflection of life for the person with PMLD they support.

We are also interested to hear why some family carers have not wanted to take part in this project. It may be simply a question of not having enough time to complete the survey, but it may also reflect that they are disillusioned with their experience of authorities or organisations. Alternatively they may have already responded to a number of other surveys, leaving them unwilling to participate in another.

Family carers who did take part have told us that there are a number of hard-to-reach families with important experiences to share and we will explore ways to get their views.

We will look at this feedback and we can include further recommendations, if needed, in the short follow-up report, to be written in a year's time.





Summary of main findings

- Staff working with people with PMLD need more specific training.
- Some family carers are happy with the respite they receive but others feel there is not enough choice, they are not getting enough respite or there is not enough suitable respite provision in Lambeth.
- There is not enough information about the services available to people with PMLD in Lambeth and how to access them.
- There is a significant number of carers aged 60 or over caring for someone with PMLD in the family home.
- There is little choice in Lambeth about where someone with PMLD can live.
- People living away from the family home appear to be getting better access to health services than those who are living with their family.
- There are not enough meaningful activities for people with PMLD in Lambeth.
- There is some confusion over what direct payments and individual budgets are. When they are accessed, not all family carers are getting the support they need to manage them.
- Some young people in Lambeth experience a reduction in services and activities when they move into adult services.
- There needs to be better access to independent advocacy for people with PMLD in Lambeth.
- Half of the people with PMLD on the register have a person-centred plan. People with PMLD are more likely to have a person-centred plan if they are not living in the family home.

- People with PMLD are more likely to have a communication passport if they are not living in the family home.
- Family carers said they have to make repeated enquiries to have services delivered and get other things done.

Many of the findings indicate that family carers feel that they are not getting enough support and information.

The findings also reflect what people had fed back through the consultation process for the current five year adult learning disability strategy for Lambeth, *Your Care, Your Way*.





Main findings

Support for family carers

This section includes:

- a.** Support from paid staff and their skills
- b.** Respite
- c.** Information
- d.** Support for elderly carers

a. Support from paid staff and their skills

The national picture

People with PMLD need support with all aspects of life. Many parents want to care for their son or daughter with PMLD in the family home, but they need support to do this. Often family carers don't get the support they need until they reach crisis point.

Families need support they can rely on. They want highly skilled staff who can engage with and care for their child as they would themselves. Staff need to have the right skills so that they can meet the person's communication and often complex health needs. Lack of the right skills can have serious consequences in terms of the person's health and quality of life. There is often a high turnover of support staff, so just as someone gets to know the person well they leave and the whole process starts again.

The picture in Lambeth

How much support are family carers getting from paid staff to care for their family member with PMLD in the family home?

Although family members with PMLD require a great deal of support, over half of those who took part in the survey said they don't have paid staff who help them care for the person at home.

- 9 of the 11 family carers who took part in the survey said that sometimes the person with PMLD they cared for in the family home needed more than just one person to support them.
- Those family carers who responded to the survey are providing between 5 and 24 hours of care per day. Of these family carers, some are spending up to 10 hours per day on physical care.
- 5 out of the 11 family carers who took part in the survey said they have paid staff who help.

Skills of staff

What family carers think of the skills of staff

From the survey and interviews, it seems that family carers are not confident that staff have all the skills needed to support people with PMLD, particularly staff from agencies. There were some examples of staff working well when they were employed directly by the families.

Family carers say staff need better skills

Only 2 out of 11 said they think paid staff understand the person's communication needs and how to communicate with them. Two others said, "Yes and no." in response to this question.

Only 5 out of 11 said they think paid staff understand how to support the person's complex health needs.

Respondents' comments about using staff

"Even if they are trained there is still a tendency to overlook the individual's wishes."
Family carer

"I think they do understand how to support her complex health needs. If they didn't, we would not leave our daughter with them."
Family carer

"The paid staff we use understand her communication needs and complex health needs because we recruit them with great care from her school. Unless somebody knows her well, the family spend days helping a new supporter get to know her and understand her needs. For any support worker to care for her at home they need to spend time with her, and us, in the home environment." Family carer.

"The support staff who come in the morning and evening every day are agency staff. They are not working well for her. Sometimes staff won't try to communicate with her and some have no idea about how to support her complex health needs. It takes time to get to know her and these staff change all the time. Those that stay are often the ones who don't listen properly about how to support Samantha. I often have a lot to clear up after agency staff have been in." Family carer.

"It is mostly the same staff from the agencies that come in and support him unless they are sick. I think they do try and communicate with him but not all staff are patient and they can be a bit rushed. There is one woman who comes and supports him though who is particularly patient." Family carer.

“I have found it difficult to find and keep the right staff. I’m thinking about making the shifts shorter as I think that could be what’s going wrong. It is hard to get staff who are passionate about supporting someone and have the skills. It’s important staff use active support with her, so they can help her fulfil her potential. Sometimes you will have staff shadowing you for six weeks but they still won’t support her in the right way. I top up the rate for staff pay, which is costed into the individual budget, otherwise I couldn’t get staff with the right skills.” Family carer

Some families who were employing staff directly said it was working well

“The support worker we employ with the money from ILF [independent living fund] is fantastic. She is a friend of a friend and has all the skills needed to work with her. She is full of energy and passionate.” Family carer

“The direct payment is working well. The support worker we have employed understands her needs and is able to support her well.” Family carer

What training have staff received?

This survey did not ask paid staff supporting people with PMLD in the family home about their training. It did however ask about training for paid staff of those in residential accommodation and paid staff who support people to live in their own home.

We would expect paid staff supporting people in the family home employed through an agency to paint a similar picture or even be less skilled than permanent staff.

The findings show that just under half of the paid staff who took part in the survey had trained in communicating with people with PMLD. Half had trained in supporting complex needs. More had trained in managing behaviour that challenges than in communicating with people with PMLD.

7 out of 16 said they had received training in communicating with people with PMLD.

8 out of 16 said they had received training in complex health.

11 out of 16 said they had received training in managing behaviour that challenges.

“Not all staff [here] have had the training.” Paid staff member at a residential care home

Staff said it would be helpful to have more training in:

- communication - **7 out of 16**
- complex health needs - **8 out of 16**
- managing behaviour that challenges - **3 out of 16.**

“She is 64. I feel I need ongoing training as her health needs are changing as she gets older.” Support worker

Main finding

Staff working with people with PMLD need more specific training.

Recommendations

What we want to see:

1. An increased number of support staff who have the skills to work with people with PMLD.

How do we get there?

- Commissioners need to review the training of staff in commissioned services who work with people with PMLD. This can be done through contract management processes.
- The council should develop a strategy to improve the skills of all staff working with people with PMLD, ensuring they are able to meet their complex health and communication needs.
- There should be a review of staff pay. This should reflect the range of skills staff need and the intense work they do, particularly around meeting communication needs. Individual budgets and direct payments should take into account the cost of skilled support and the training needs of staff.
- Commissioners must ensure that there are criteria for services to meet the communication needs of people with PMLD.
- Service providers should involve family carers in building workforce development strategies and explore involving them in the delivery of training, for example having support staff shadowing them.
- Staff should be trained in how to undertake 'active support' so that they work in a way that helps individuals develop their skills.
- The council needs to explore the reasons behind dissatisfaction with agency staff that some people report, for example that they are rushed.
- Agencies need to review their policies and procedures, and address any barriers stopping people with PMLD receiving good personalised support.

Work already underway

- The council already has plans to involve parents in the delivery of staff training. They will ensure that family carers of people with PMLD are involved in this.
- There is a re-procurement process underway for the provision of domiciliary care or community support services in Lambeth. The issues that people have highlighted, in terms of the skills of staff, have been noted and will feed into the development of the service specifications.
- Lambeth is implementing electronic monitoring of all domiciliary care or community support services. This will help to make sure that care workers spend the time that has been commissioned with the people they are caring for.

b. Respite

The national picture

Many families are not getting the right amount 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. They found that half of the families who had a carer's assessment received no services as a result and 1 in 3 families had experienced a cut in their short break services in the last year.

There is concern about whether staff at a particular short breaks (respite) service have the skills to meet the needs of a person with PMLD, can stop families accepting a place there. In the absence of alternatives this can result in them getting no respite.

The PMLD Network says 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 a minimum expectation of 52 nights per year or the equivalent.

The picture in Lambeth

The majority of family carers of people with PMLD living in Lambeth are receiving short breaks, however there are a number who are not.

From the survey and interviews, we can see that although some people say they are happy with the respite they are currently receiving in Lambeth, others are less satisfied.

Reasons for being unsatisfied included a lack of choice of respite, not getting enough respite or a lack of suitable respite provision within the borough of Lambeth.

From the register:

21 of the 34 people with PMLD living in the family home are receiving short breaks.

From the survey:

6 of the 11 people with PMLD are receiving short breaks.

7 of the 11 family carers of someone living in the family home have had a carer's assessment.

Those who were getting short breaks were asked how many days per year they were getting.

Responses were: 42 days, 45 days, 4 to 6 weeks, every weekend, 1 day. Two respondents left this question blank.

They were also asked the following questions:

Is there a choice of short breaks?

2 out of 6 said yes

Are you happy with short breaks?

4 out of 6 said yes

Do you get enough short breaks?

2 out of 6 said yes

Those not getting any short breaks were asked why not?

Responses were:

"Not much information sent."

"Don't know."

"We are waiting to hear whether there is room for our daughter there."

Other participants left this question blank.

Lack of suitable respite in Lambeth

“She was getting some short breaks, but she is no longer eligible for these places because she is over 18. She has had referrals to two other respite providers since, but we’ve not yet heard whether there is space for her. Both are far away so the short breaks will need to be for a minimum of three nights to be worthwhile.” Family carer

“There is no suitable respite in Lambeth for her to go to. Hopefully there will be something soon to meet the needs of people with PMLD locally. There was a place that was good but Lambeth Council shut it down. There is some money set aside for a new place, but I don’t know whether this will happen. They are looking at buildings but I don’t think they have thought about staff yet.” Family carer

“Families’ resources are limited and when we ask for assistance we need it.” Family carer

Choice of types of respite

“At the moment we don’t get any respite. I’ve had a carer’s assessment but I’m not sure what respite care she is entitled to. I don’t want her to go into a residential respite home as I would worry that they would not know how to take care of her properly. But it would be good to know if there are other options. For example, her going away with her support worker who knows her well.” Family carer

Good respite provision

“The respite she has is working very well. She goes to one short breaks service in Norfolk and another place in North Yorkshire. The staff are great. They really understand her needs and are very respectful. She finds it difficult sitting up for food. She needs to start thinking about food and preparing for mealtimes about half an hour before. They do this with her.” Family carer

Kelly and her mum

Kelly is 23 and lives at home with her mother and brothers.

About Kelly

Kelly loves music and she likes going out, particularly to parties with loud music. She taps her feet to music she likes. She enjoys having people around her all the time.

Kelly has profound and multiple learning disabilities and this includes cerebral palsy and some complex health needs. She has chronic epilepsy that has improved in the last year. She is on four types of medication for it and it seems to be working. Before she was having up to five seizures a day. She also has a PEG (tube nutrition). Kelly is a wheelchair user, she does not walk at all.

Currently the support Kelly and her family receive includes:

- Two support workers come in for one hour in the morning and one and a half hours in the evening, seven days per week.

- Another support worker provides 19 hours of support per week. This is funded by the ILF. The support worker works with Kelly's mum because Kelly needs two people to support her. This is flexible but usually the support worker comes on Tuesday afternoon and on Saturday and Sunday.
- Kelly attends the day centre four days per week.
- One morning per week she goes to college.

Kelly's mother has been told they are entitled to 40-46 nights of respite per year. However they have had no respite care for almost two years because no suitable provision has been found.

The support Kelly's mother provides

Kelly's mother provides much of the 24-hour care Kelly needs. She shares a room with Kelly so that she is there if she has a seizure in the night. She turns Kelly up to three times in the night to stop her getting bed sores. As a result Kelly has none. Kelly's mum often needs to change her in the night. She has not asked for any night support from paid workers for Kelly, but in the future this may be something she will need. At the moment Kelly's mother is tired most of the time.

Respite

Currently the main problem for Kelly and her family is that they are not getting any respite. Kelly's mother has been told there is no suitable provision. Two years ago Kelly had a very bad experience at a place that provided respite. She was there for two weeks, came back with lots of bed sores and almost lost her little toe. They hadn't looked after her at all and Kelly's mother said she would never go back there.

No other respite provision has been found for her since. Kelly's mother recently emailed Kelly's care manager to find out whether they had found any suitable provision yet and was asked if she wanted to look for a suitable unit on the internet herself. Her GP has suggested a unit, the details of which she has forwarded to the care manager, and is waiting to hear back. She said it is often difficult to get hold of the care manager. The ILF are now asking what is happening about respite as they should not be funding support for those weeks in the year when respite is meant to be provided.

Kelly's mum said that because Kelly is non-verbal, respite staff have got to explore why she is crying. She needs staff who understand her needs.

They did have a good respite service in Lambeth with really skilled staff but it closed down. Kelly's mum said they got it right and then closed it down!

Lack of respite is a real concern. They need to know there is a place Kelly can go to if she needs to. Somewhere reliable where she will be safe and well looked after. Lack of regular respite also means Kelly's mum is permanently exhausted. Getting respite would make a huge difference.

Kelly's mum has had a carer's assessment but she said there is no emergency plan in place yet. This is something she wants to address with the care manager for peace of mind.

Main finding

Some family carers are happy with the respite they receive. Others feel that there is not enough choice, they are not getting enough respite or there is not enough suitable respite provision in Lambeth.

Recommendations

What we want to see:

2. All families of people with PMLD with regular access to high-quality short breaks. For those with the most complex support needs, this entitlement should be based on a minimum expectation of 52 nights per year or the equivalent.
3. Appropriate local respite care. This must meet the needs of people with PMLD, and tailor care specifically to the requirements of individuals.
4. A choice of respite provision, for example not just residential respite, but options for someone to go away with paid staff or for paid staff to provide respite in the family home.
5. Clear information about how much respite individuals are entitled to, following a carer's assessment.
6. Information about respite provision that is easy to understand and available locally and further away.

How do we get there?

- The council and PCT need to map and regularly update information about the respite currently available in Lambeth and close by. In the absence of suitable local services they should list places elsewhere in the UK.
- The council and PCT should develop a group to design appropriate respite provision for people with PMLD in Lambeth, including family carers.
- There needs to be a workforce strategy, to ensure respite staff are able to meet the health, communication and behaviour needs of people with PMLD.

- Care managers need to ensure that respite is identified in the care plan of the person with PMLD. They should also tell family carers of people with PMLD living in the family home that they are entitled to a carer's assessment, and explain that it will identify how much respite the family needs.
- It is vital that, following a carer's assessment, the plan developed includes an emergency plan – so that it is clear what happens in an emergency.

Work already underway

- The council has plans in place to develop a residential respite facility in Lambeth and will ensure the facility meets the needs of people with PMLD.
- The council is setting up a respite project group to look at respite provision for people with PMLD, including family carers, and to oversee the work around respite.
- The carers' breaks service was re-tendered over 2009/2010, and the contract was awarded to Certitude (formerly Southside Partnership).

c. Information and advice

The national picture

Many family carers of people with PMLD struggle to get information. In particular, details about local services, benefit entitlements and how to manage direct payments, all of which they need to support them in their caring role.

They often find that social services are not a good source of information and advice. Where people are getting good information and advice, it is often from carers' networks and centres. Support from other carers often seems to be what enables many to cope.

The picture in Lambeth

From the survey and interviews it would appear that family carers want better information about services and support for people with PMLD in Lambeth. Even if there is a general lack of services to find out about, family carers still want good information so that gaps can be easily identified and addressed. Otherwise people don't know if local services exist or not.

This needs to include information and advice for family carers about direct payments and individual budgets¹².

Is there is enough information about what services there are for people with PMLD in Lambeth and how to access them?

Only 3 out of 11 family carers said yes.

"It is often difficult to get hold of the care manager." Family carer

"The support provided by Lambeth Mencap is a real lifeline – my 'umbrella'. You can call on them any time." Family carer

"There is not enough information about what services there are for people with PMLD in Lambeth and how to access them. Or if we do know about all the services available, then there are none suitable! We have to make huge efforts if we want to find anything, or alternatively set it up ourselves." Family carer

"We would like more information about respite options, including clear information about how much respite care she is entitled to. I would also like for her and I to go on holiday together but I haven't managed to get information about how this could work – for example how they could make sure her needs were met abroad." Family carer

Main finding

There is not enough information about what services there are for people with PMLD in Lambeth and how to access them.

Recommendations

What we want to see:

7. A centralised local information service to signpost the services and support available to people with PMLD and their families, and where they are located.
8. A forum where families and support workers of people with PMLD can share information.

How do we get there?

- The council should map and raise awareness about where information and advice is currently available for those supporting people with PMLD.
- The council should review its strategy on information and advice in order to address gaps identified. As part of this they would explore the following:
 - Where a centralised local information service could be based and who would run it (for example the council or the voluntary sector).
 - What features it would have (for example advisers, a library of resources).
 - Funding to support the development and maintenance of the service.

¹² See section on direct payments and individual budgets.

- Having an identified PMLD lead, based in care management (this could be a social worker or other professional), who can advise on all aspects of meeting the needs of people with PMLD.
- Voluntary sector organisations in Lambeth need to develop a project group to explore how a local forum for sharing information about PMLD could work, including whether it would build on existing family carer forums.

Work already underway

- Lambeth Council has just consulted on its information, advice and advocacy strategy that will be finalised and published in Autumn 2010.
- Lambeth Council is developing an information portal that will provide access to a wide range of information. It will also include the option for people to rate the services that Lambeth commissions – giving people good information about the services provided in Lambeth.

d. Support for elderly carers

The national picture

Adults with PMLD are living longer due to medical advances. Because many live in the family home, this is resulting in an increasing number of adults with PMLD being cared for by elderly parents.

Elderly carers are likely to need more support because of the physical challenges they will face caring for someone with PMLD. It is crucial that they receive the support they need as early as possible. This will ensure their health, and that of the person they care for, does not suffer.

There is often poor planning for people with PMLD. Local areas rarely identify where people's circumstances are likely to change and plan ahead appropriately. This is particularly important for people with PMLD who are very vulnerable due to their complex needs – so any transition needs careful planning.

It is unlikely that many local areas are planning properly to meet the specific needs of people with PMLD living with elderly carers. It is also probable that they are not planning properly for the future when the elderly carer is no longer around.

The picture in Lambeth

In Lambeth, according to the register, 6 people with PMLD are living with elderly family carers (family carers who are 70 years old or over).

There are, according to the register, 10 people with PMLD living with family carers aged between 60 and 70 years old.

From an interview with one elderly family carer, it appeared that increased support was being given in the family home, to allow him to continue to care for his grandson there. It appeared that further support would be useful. It did not appear that planning for the future had taken place yet but that this was likely to happen soon.

Register information

16 of the 34 people with PMLD living in the family home in Lambeth are cared for by family carers who are 60 or older.

6 of the 34 people with PMLD living in the family home in Lambeth are cared for by elderly family carers (70 years old or over).

1 of these people with PMLD is living with a family carer who is 80 or older.

Simon and his grandfather

Simon is a 44-year-old man who lives at home with his grandfather, Paul, who is 81 and has cared for Simon since he was very little.

Simon needs to be supported at all times. He receives support from two different agencies. One provides night support and the other provides support in the day.

The support Simon receives:

- Seven nights of sleep-in cover, 10pm–7am. The member of staff sleeps but they are there if Simon wakes up and needs support.
- Two hours of support in the morning, five days a week. The support worker helps Simon get up, wash and have breakfast before transport takes him to the day centre.
- Half an hour of support in the evening, seven days a week. This is to change him before he goes to bed.
- Five days a week at the day centre, 9.15am–4.15pm (this includes time spent travelling to and from the day centre).
- Four hours of support on Saturday morning.
- Four hours of support on Sunday morning.
- Six weeks of respite per year.

Simon's grandfather provides support the rest of time:

- Every evening, 4.15–10pm (apart from half an hour).
- Saturdays and Sundays, 1pm–10pm (apart from half an hour).

Night support

Paul has recently managed to get sleep-in cover for seven nights per week. Before that he was getting fewer nights per week.

Paul is pleased that they now have staff coming in each night. Previously he had been sleeping in Simon's room so he could hear him if he got up and fell. But that wasn't comfortable for Paul, he was in pain and slept badly.

Weekends

At the weekends Simon doesn't attend the day centre and support workers come in for four hours in the morning. Saturday and Sunday afternoons, and evenings during the week, it is just Simon and Paul for most of the time. They are not able to go out because Paul does not have the strength to push Simon's wheelchair.

Paul said it might be good to have more hours of support in the afternoon on Saturdays and Sundays, so that Simon could go out. When Simon has a GP, dentist or hospital appointment they can call the agency whose staff will come and support them to attend by pushing his wheelchair.

Extra support

A careline system has recently been introduced into Simon and Paul's home. This is added support. If Simon falls over Paul can press a switch and someone will come or call an ambulance if necessary. Simon falling over is a concern as Paul is not physically able to lift him. In the past when this has happened he has had to go outside and ask a stranger to help lift Simon up.

The careline system can also be used if Paul falls over or needs support himself.

What Paul thinks of the support Simon receives

Paul is generally happy with the support he is getting. He said it is good to have the support in the home, sleep-in cover and regular respite breaks.

Challenges

One of the main challenges for Paul is the length of time he sometimes has to wait for something to be done and the amount of time and energy he spends chasing things up. This can be exhausting.

Paul said there are often things that need to be addressed, so this is an ongoing problem. Often they are practical things. For example the equipment used to lower Simon into the bath broke and Paul had to spend a long time pursuing the right people to get it fixed. In the meantime Simon hadn't been able to have a bath, as Paul doesn't have the strength to help him in and out without the proper equipment.

Planning for the future

Paul says he has not done any planning for the future yet but he has thought about it. His grandson has just got a new care manager and he thinks it will be good to have a conversation with them about the future. He would be glad to hear about different options for Simon. His dream is for Simon to be able to stay in the home he has been in all his life, with the support he needs, once his grandfather has passed away.

Main finding

There is a significant number of carers aged 60 or over caring for someone with PMLD in the family home.

Recommendations

What we want to see:

9. Family carers getting the support they need to continue caring for the person at home if they want to - including enough respite.

10. A choice of options for the person with PMLD, if the elderly carer no longer feels able to care for them in the family home.
11. Planning must take place earlier so that the person will be able to get support and accommodation that meets their needs in the future.
12. There must be a timely response and follow-through of actions so that elderly family carers don't have to chase for results.

How do we get there?

- All carers aged over 60 need to be identified.
- Plans should be put in place for the future for people with PMLD living with elderly carers.
- Elderly carers should have an up-to-date carer's assessment, including an emergency plan.
- There should be close monitoring of the support received by elderly carers.
- There should be other housing options available for people with PMLD – see housing recommendations.

Work already underway

- The council is in the process of refreshing its carers strategy.
- A carers coordinator has been employed by the council.
- The carers' hub has been developed at Woodlawns in Streatham.
- A review of services for carers is underway.

Housing

The national picture

People with profound and multiple learning disabilities are more likely to be living in registered care homes, with at least four other occupants, who usually also have PMLD.

They are more likely to be living outside the area, usually due to difficulties in meeting their care needs locally.

The majority of people with PMLD are likely to still be living in the family home.

A small proportion of people with PMLD have started to access more individualised or self-directed support.

A small proportion of families will use direct payments or individual budgets to purchase personal support, to share the caring role in the family home.

The picture in Lambeth

Where are people with PMLD living?

Of the 81 people with PMLD on the Lambeth *I Count Register*, the majority were living in the borough of Lambeth. However those not living in the family home were more likely to be living outside the borough.

Almost all people with PMLD not living in the family care home are living in residential accommodation.

Of the 81 people with PMLD on the Lambeth register:

49 live in the borough of Lambeth.

32 live outside the borough .

34 live in the family home .

43 live in residential accommodation (30 outside the borough).

4 live in their own home with support (2 outside the borough).

Note: We did not receive survey responses for all 81 people with PMLD on the register. The table below shows where the people with PMLD we received survey information about were living.

Of the 36 people with PMLD who we received survey responses for:

20 live in the borough of Lambeth.

16 live outside the borough.

11 live in the family home.

21 live in a registered care home (14 outside the borough).

1 lives in an adult placement home outside the borough.

3 live in their own home with support (1 outside the borough).

How does this compare to where other people with a learning disability in Lambeth are living?

Of the 968 adults on the Lambeth *I Count register* (this includes the 81 people identified as having PMLD):

693 live in the borough of Lambeth.

275 live outside the borough.

Of these:

348 live in the family home.

416 live in residential accommodation (248 outside the borough).

204 live in their own home (27 outside the borough).

There is a considerable difference between the living situations of people with PMLD and other people with a learning disability living in Lambeth.

- 204 out of 968 people with a learning disability are living in their own home.
- 4 out of the 81 people on the register with PMLD are living in their own home.

People with PMLD not living in the family home are more likely to be living outside the borough (32 out of the 47 people with PMLD not living in the family home are living outside the borough).

The majority of people with a learning disability not living in the family home are living in the borough (345 out of the 620 not living in the family home are living in the borough).

Is there enough choice about where someone with PMLD can live?

The findings suggest that there is little choice in Lambeth about where someone with PMLD can live.

Only 7 out of 23 family carers who answered the survey said there was enough choice about where someone with PMLD could live.

The findings suggest that a main reason why people are living outside the borough is because there were few suitable housing options for them in Lambeth.

This appears to be a current issue (not just historical) as three of the people with PMLD living in registered care homes outside the borough, who we received survey information for, are under 30.¹³

¹³ Information about the ages of people with PMLD, for whom we received survey information, about their accommodation, and whether or not they are living in Lambeth, can be found in the appendix.

General responses

“The number of people with PMLD is relatively small, their needs do not seem to be well understood and so a suitable range of services has not been commissioned.”

“No – we are in the process of moving my brother and the choice of homes for his complex needs is very limited.”

Regarding someone in a registered care home in the borough:

“To my knowledge it is the only one in the borough to cater for her needs.”

“This is a no-brainer! There simply isn’t enough provision for people with PMLD anywhere – let alone Lambeth.”

“I can see myself caring for her at home until I am unable to do so. No one has suggested other housing options for her. It would be good to know what they are.

“She would need 24-hour care from two people, who are committed to her and who understand fully that her life depends on them. I am not hopeful that there would be any good housing options. If they can’t even get respite right, how on earth can they get housing right!?”

“I don’t think there is enough choice in Lambeth about where someone with PMLD can live. I would like her to have the option of moving from the family home to a high-quality alternative in the future. I would like to see her spending up to perhaps 50% of her time in a suitable comfortable, safe environment with 24-hour high-quality trained, loving, professional support, familiar to our daughter, outside the family home – so that her care is not fully dependent on the family. It is crucial that this is local. I would be very happy to work with Lambeth Council on the establishment of a suitable local facility for a small number of young adults with PMLD, to live with 24-hour, high-quality healthcare and social support.”

“People with PMLD do not have many options about housing. Residential provision is not as good as it looks in the shiny brochure. In reality there are often untrained, uncommitted staff. It is often management’s fault for not developing staff. Management should be making it an environment where staff are providing active support. It is something about the culture, how to get staff to keep giving active support. It is about leadership. Directors and managers should be doing one day per month and leading by example.”

Why are people with PMLD living outside the borough?

Family carers' responses:

"It seemed the right time to plan for her future but there was no appropriate service available in Lambeth."

"In 1974 when he needed accommodation Lambeth had no placement available so he was moved to Surrey."

"No suitable homes found in Lambeth."

"This was the best home for her needs."

"Lambeth felt it best suited her needs."

"Lambeth could not provide care in Lambeth borough."

"The care home is in the borough of Croydon because Lambeth felt it best suited his needs but Lambeth pays."

"The residential service she requires is not available in her borough."

"Lambeth placed him here because of the suitability of the placement and the specialist sensory knowledge of the charity."

"Due to availability of appropriate services for people with severe physical disability."

Family carers of people with PMLD not living at home were asked if they were happy with the housing and support the person was receiving.

Family carers' responses:

"Yes she is happy and her needs are met."

"Yes it is a very small home with only six residents and the staff are excellent. Almost like a 'home away from home'."

"I am now but would still like more activities for her."

"Extremely happy – her social worker from Lambeth Council is also extremely happy with her placement."

"Yes for reasons given in previous question: that he would be supported by skilled staff, that there would be enough things for him to do, that you would be able to be as involved as you want. Also he needed a more 'normal' environment. Currently in a house with far more able clients, which is quieter and works well for him."

"Yes very happy and so is she. As indicated elsewhere there are improvements we would like to see but we think she is very fortunate to have found such a happy house. There is an exceptionally thoughtful and experienced house manager and she has been keen to develop the service."

"His current home is closing but has been excellent. The help from Lambeth to relocate him has been unsatisfactory."

Survey responses from family carers of people with PMLD not living in the family home showed that the majority are happy with the housing and support the person is currently receiving.

Family carers of someone who had left the family home and paid staff were asked why the person had moved into their current type of accommodation.

Responses:

“No appropriate service in Lambeth. Person-centred planning led us to the conclusion that a small residential home run by a reliable specialist organisation was the best option for her.”

“Family wanted long-term care placement.”

“Person needed full-time 24-hour support and [their] needs could not be met at home (Mum terminally ill and single parent).”

“Too difficult to continue caring at home as post-19 provision is non-existent to enable shared care ie residential school and home.”

“The accommodation is purpose-built for [people with] PMLD and clients with physical health needs.”

“Left college and needed a long-term supportive placement because of his needs.”

“Because my mother developed cancer and could no longer care for her.”

“Because his mother had increasing osteoarthritis and was unable to continue home care.”

“We were unable to cope at home.”

“The residential home they were in was being closed.”

“Father of that person is getting older and started to experience difficulties with providing care for his daughter. She was in the family home for 38 years.”

Family carers of people with PMLD no longer living in the family home were asked what (from a list) mattered most when deciding where the person would live.

Almost all said:

“That they would be supported by skilled staff.” (10 out of 12)

“That you would be able to be as involved as you want.” (10 out of 12)

Some said other things that took into account the individual’s needs:

“He needed a smaller more ‘normal’ environment. He is currently in a house with more able clients, which is quieter, and works well for him.”

“Person-centred planning led us to the conclusion that a small residential home run by a reliable specialist organisation was the best option for her.”

Caroline

Caroline, 42, lives in a residential care home outside Lambeth. She is one of six residents. The home is owned and managed by an organisation that specialises in supporting people with visual disabilities.

She is very happy in the place she is now living. The family feels fortunate that they were able to find such a happy home for her with such a thoughtful manager and skilled staff.

Caroline had lived at home with her family all her life (for 36 years). When all her brothers and sisters had left home and her father had retired, the family decided it was a good time to plan for the future. They were also finding that provision in Lambeth was becoming increasingly unsatisfactory. For example, people were starting to be offered fewer days at the day centre, without any suggestions for alternative things to do for the rest of the week. Also, they had received regular, flexible respite services, but those in the area that were suitable for people with PMLD seemed to be closing.

Person-centred planning led the family to the conclusion that a small residential care home, run by a reliable specialist organisation, was the best option for her. They found there was no appropriate service available in Lambeth so they had to look elsewhere.

It was important to the family that the home could meet all of Caroline's needs. It also needed to be within convenient travelling time from the family home so they could be as involved as they wished. They soon realised how few available satisfactory options there were anywhere. When a place became available that met the criteria they were looking for, Caroline took it up.

The family do not think there is enough choice in Lambeth about where someone with PMLD can live. They don't feel the needs of people with PMLD are understood enough and consequently a suitable range of services has not been commissioned.

Main finding

There is little choice of accommodation for people with PMLD in Lambeth.

Recommendations

What we want to see:

13. Increased choice of housing options available to people with PMLD in Lambeth.

How do we get there?

- There needs to be detailed mapping of current housing options for people with PMLD in Lambeth with a view to identifying particular gaps.
- An equality impact assessment must be undertaken to ensure people with PMLD in the borough have the same housing options as others.
- The housing strategy in Lambeth must specifically address the accommodation needs of people with PMLD.
- A project group should be established, including family carers, to focus on developing housing options for people with PMLD in Lambeth.
- Innovative housing options should be available. These might include allowing someone to live in their own home (on their own or sharing with someone else) with support.
- Community care assessments must include housing needs.
- Planning needs to start early as it can take a long time to find the right housing for people with PMLD.
- Choices about housing for people with PMLD need to be based on good person-centred planning. This will ensure the accommodation suits their individual (and support) needs.
- A skilled workforce should be developed. This will give families reassurance that staff have the skills to support people in a range of housing options, including those who live in their own homes, using an individual budget

- Information on housing options for family carers and support workers of people with PMLD must be accessible and easy to find.
- Identify the funding streams needed to make a choice of housing options a reality for people with PMLD in Lambeth.

Work already underway

- The council is leading the development of more supported housing options, such as 'Extra Care' and supported living schemes.
- An assistive technology strategy is in development. This will outline the approach to ensure that the use of assistive technology and Telehealth is used effectively to support people to live independently.
- The Health and Well Being Partnership is currently undertaking a housing needs analysis and review of pathways into housing for vulnerable people. The partnership will be reporting back in the Autumn 2010. This will inform the development of housing for vulnerable people in Lambeth going forward.

Health

The national picture

It is widely understood that all people with a learning disability, but particularly those with PMLD, have difficulty accessing good-quality healthcare.

People with PMLD have a number of complex health needs. They may have issues such as complex epilepsy or they may be technology-dependent, needing oxygen or tube feeding for example. As a result it is especially important that they have access to both mainstream and specialist healthcare. These are needs that will grow as a greater number of children, with more complex health requirements, move into adult services and because life expectancy is increasing.

The picture in Lambeth

Does the person get all the services they need to support their health requirements?

4 out of 11 family carers of someone with PMLD living in the family home said yes.

11 out of 12 family carers of someone with PMLD not living in the family home said yes.

14 out of 16 paid staff said yes.¹⁴

Responses:

"Yes they can access the health services they need, because as parents and full-time carers we ensure this happens. It takes a huge amount of parental time and energy."

¹⁴ This includes paid staff of 6 (out of 7) people with PMLD living in Lambeth (who took part in the survey).

“We are getting older and weaker. I am nearly 60, my husband is nearly 65. Our daughter is 40 years old and has many needs. We desperately need help with her panic attacks, ie a special doctor. We haven’t seen anybody for 14 years. Has technology moved on? We would like some help.” Family carer

In answer to “What else is needed?”

“Access to relevant health services is generally good but [the person we care for] would benefit from hydrotherapy.” Family carer

“It is hard work getting to see anybody who understands our daughter.” Family carer

“Physiotherapy and hydrotherapy.” Family carer

“Physiotherapy and hydrotherapy every other day not just once a week or fortnightly” Family carer

“Speech and language therapy.” Family carer

“More support from health services, on a more regular basis, preventative care, a communication programme.” Family carer

“Access to local hydrotherapy pool.” Family carer

“Whilst most direct or emergency treatment is excellent, support from more specialist fields is in very short supply. This includes physiotherapy, psychology and speech and language therapists.” Paid staff

How easy is it to access mainstream and specialist learning disability health services?

Family carers and paid staff were asked about access to mainstream health services

(such as the GP, hospital, physiotherapist and dentist) and specialist learning disability health services (for example dentist and physiotherapist).

Reasons given why health services are difficult to access:

General

“Long waits for appointments.”

“It is far away, so difficult to travel by bus (no parking).”

“My grandson uses a wheelchair. Without the help of paid support it would be difficult for me to assist him to the GP, hospital or dentist.”

“Hospital services are accessed through two parents providing transport and accompanying their daughter to appointments, with manual handling. Requires time away from work for parents.”

“It’s very difficult with any appointment. When you have to wait with many other people who don’t understand PMLD you feel very alone. Special appointments should be made such as at the end of surgery for GPs or special times. Hospitals should be aware of PMLD patients and their difficult needs.”

“Sometimes getting her health needs met can require real effort, flexibility and joined-up working by all involved, and this can be a challenge. For example it took 18 months to coordinate her having the hearing tests and dental checks she needed at the same time, so she only had to be under general anaesthetic once.”

Physiotherapy

“Just a lack of physiotherapists in the borough to work with people with PMLD.”

“Mainstream physio – almost impossible to get the appointment at all. Very long waiting

time. No regular input. Specialist physio – not easy to get home visits on a regular basis.”

“She was referred to the physiotherapist two years ago to help posture. I think this is still needed as it did start to help and progress was made but the referral ended and was not renewed.”

“She desperately needs physiotherapy because of the stiffness in her limbs from her cerebral palsy. When she was at full-time college she had physiotherapy everyday, but since she left two years ago she only gets it through the day centre, where there is one part-time physiotherapist. This means she is hardly getting any physiotherapy at all. There is a lack of physiotherapists in the borough to work with people with PMLD.”

“She has a tightness on her back and she needs physiotherapy input. But she gets very little physiotherapy. She has been on the list since 1993, but because others’ needs are greater she rarely gets seen.”

Speech and language therapy

“Long waiting list and because of age (no longer a child) limited support or sessions, there are often excuses that due to age they cannot learn or they have limited resources. It’s always an endless circle of phoning until there might be an assessment.”

“We are not happy with the lack of speech and language therapy for her. This is a service which she could benefit from as she has shown clear progress since her last referral. Regular speech and language therapy would have a huge beneficial effect on the quality of her life.”

Hydrotherapy

“Hydrotherapy is her number one enjoyment. Warm water and inflatable armbands equals independence! She would like to spend more time in the hydrotherapy pool but it is not possible for her to do this because of lack of facilities, lack of appropriate support staff and lack of family financial resources.”

“She is not getting hydrotherapy at the moment because of a lack of staff to support her. It is something she has really missed getting regularly since school. She greatly benefits from hydrotherapy. You know when she has had it as she will have a good night sleep.”

Health action plans and health checks

Health action plans

The findings show that a person with PMLD was more likely to have a health action plan (HAP) if they were living in residential services than in the family home. In fact some family carers of people living at home seem unsure as to what a HAP was.

Does the person have a health action plan?

Family carers of person living at home

0 said yes

6 said don't know

5 said no

Family carers of person not living in the family home

10 said yes

2 said don't know

Paid staff

16 out of 16 said yes

If so, has it helped?

Family carers of those not living in family home:

5 out of 10 said it helped, others said they didn't know or left the question blank.

"It has helped because [we have] seen a GP when needed."

"It has helped, keeping a food diary, IBS [irritable bowel syndrome] symptoms minimised, instruction on how to brush his delicate teeth."

"It has helped because the plan of care is strictly adhered to by staff at home – most excellent care."

"It has helped as they now know how to understand her and have been told to be careful because of her fragile bones."

Paid staff

10 out of 16 said it had helped, 2 said it had not helped. Others said they didn't know if it had helped.

"It has helped because you know more information about the service user."

"It enables staff to keep records of health appointments/intervention."

"It has maintained and stabilised a health condition."

"Staff know what food he can eat and what to avoid."

"It maintains good daily therapy and routine."

"We can monitor their health needs."

"Agreed action plans are followed through. HAP book completed on medical appointments."

"Staff supporting her read it and know how to support her."

"You can access the information of appointments attended and the outcome."

"All support workers can refer to it for information on how to support the service user."

"It has not helped because all actions were already in place."

Health checks

34 out of 52 Lambeth GP practices have signed up to access Register Services' secure website. This allows them to find data on their patients with a learning disability, who are on the Lambeth *I Count Register* database, as a pre-requisite to giving health checks.

Generally it seems that the person with PMLD was more likely to get a health check if they were not living in the family home. This may reflect a lack of the right support and information.

Families of people living at home

3 out of 11 said the person has had a full health check in the last year.

Family carers of those not living at home

6 out of 12 said the person has had a full health check in the last year.

Paid staff

11 out of 16 said the person has had a full health check in the last year.

Anna and her mum

About Anna

Anna is 25 and lives at home with her mother, brother and sister. She will show you she is enjoying something by smiling. She will also bang on objects and hug people when she is happy. Anna enjoys swimming, music and having lots of people around. She is able to walk and she enjoys walking around the house.

Anna has profound and multiple learning disabilities. Her health needs include epilepsy and she also has a PEG through which she receives nutrition overnight. She also receives medicine through the PEG. Anna visits a specialist dentist a lot as she grinds her teeth.

The support Anna and her family receive:

- Anna has a support worker for 40 hours per week. This is funded through direct payments and divided over:
 - Monday, Wednesday and Friday – four hours per day (two hours support in the morning, two hours support in the evening)
 - Tuesday, Thursday and Saturday – eight hours per day
 - Sunday – four hours.
- Anna attends the day centre three days per week, leaving home at 10am and coming back at 4.30pm.
- At the moment Anna is not getting any respite care.

Accessing support for health needs

Anna accesses therapies through the day centre, for example physiotherapy, speech and language therapy and sessions with a dietician.

It would be good if she could have more physiotherapy and hydrotherapy. And also more activities where she has the opportunity and support to move her body, for example, more walking.

Anna used to have hydrotherapy but has not for about nine years. It is something that has been looked into but it has not actually happened.

Her family have meetings with the day centre and with a social worker where they discuss

Anna's needs and what she wants to do. This is where they have talked about hydrotherapy.

The social worker was looking into how Anna could access hydrotherapy. They were also investigating access to more physiotherapy and speech and language therapy on a regular basis. However this social worker then left.

Social workers change frequently and this is a big problem. Often a social worker starts looking into something like hydrotherapy and then leaves. Anna has had lots of temporary social workers. With each new social worker the family have to start all over again explaining Anna's needs and asking, once more, for hydrotherapy.

Getting more hydrotherapy, physiotherapy and speech and language therapy is a priority for Anna's health and wellbeing.

Main finding

People not living in the family home were reported to be getting better access to health services than those living elsewhere.

Recommendations

What we want to see:

14. All people with PMLD able to access the mainstream and specialist health services they need. This would include physiotherapy, speech and language therapy, occupational therapy and hydrotherapy – where a need has been identified.
15. Good health support available to all people with PMLD regardless of where they live.
16. All people with PMLD having annual health checks, including onward referral to health specialists, when they need it.

17. All people with PMLD having a health action plan.

18. All people with PMLD having a hospital passport that has key information about their health and communication needs.

How do we get there?

- The range of health services being used by people with PMLD in Lambeth needs to be mapped to enable a better understanding of the barriers.
- Therapy services available to people with PMLD should be reviewed, with the aim of addressing the apparent shortage. This should include the PCT reviewing the system of 'finished episodes', for therapies, as many people with PMLD will have lifelong and continuous need for therapeutic input.
- It is important to identify the number and location of hydrotherapy pools in Lambeth and develop a plan to increase access for adults with PMLD.
- The reasons why it may be harder for people with PMLD, living in the family home, to get the health support they need to be explored.
- The PCT should inform family carers and support staff how the person with PMLD can get a health check.
- The PCT should monitor the quantity and quality of health checks for people with PMLD, including tracking of referrals to specialists, to ensure that they are seeing them where appropriate.
- Families must get the support they need, to ensure that they understand the benefits of health action plans and hospital passports, and have support to ensure that their family member has one.

- The PCT needs to start monitoring and planning for the increasingly complex health needs of both an ageing population of people with PMLD and people with a learning disability who acquire additional disabilities and conditions as they get older, for example dementia, which may mean their needs become similar to the needs of people with PMLD.

Work already underway

- The PCT is pushing for the implementation of Adult Learning Disabilities Direct Enhanced Service (DES) to achieve 100% registration. The figure currently stands at 65%.
- The Adult Learning Disability Partnership Board is setting up a health sub-group to steer the health service elements of the *Valuing People Now* action plan.
- Lambeth will be part of the pan-Lambeth, Southwark and Lewisham health strategy forum to focus on the needs of service users with a learning disability, including people with PMLD. The forum will lead on the development of a standard hospital passport across the three boroughs.
- The commissioning arrangements for the health and social care team are under review. This will ensure a more integrated approach to the provision of community services for adults with a learning disability, including PMLD, and an appropriate skill mix within the team.

Meaningful activities

The national picture

Many people with PMLD do not have enough meaningful activities each day.

The shift towards personalisation means that people are getting more choice about how to spend their time. However there are not always high-quality options in terms of activity and support.

What are ‘meaningful activities’?

- They are stimulating and meaningful to the individual.
- People’s physical and health needs are supported in a dignified manner.
- The person can access the community by taking part in activities that they find genuinely enjoyable.
- They recognise that many people with PMLD experience the world largely on sensory level and take this into account.
- People are included in community activities in ways that are meaningful to each person.
- Manual handling policy and practice don’t act as a barrier to the person taking part in community activities.
- They recognise the importance of one-to-one interaction, with a workforce who are skilled in meeting complex health needs, and trained in non-formal communication techniques.
- Suitable and flexible transport is provided that enables people to physically move around their community.

The picture in Lambeth

Information from the register shows that a large proportion of people with PMLD have a day activity. This is described on the register as attending a day service, college or being in employment. However there is no clear information about the number of days per week the person spends on this activity.

Survey responses showed that some people with PMLD were attending a day service five days per week. The majority of people who were attending a day service or college, were only doing so for part of the week. No one appeared to be in employment.

Where people were doing a number of activities during the week, this required a lot of effort from the family carer or paid staff. They had to find activities meaningful to the person, plan the person's time and support them.

Family carers and paid staff think there are a number of barriers preventing people with PMLD accessing more activities in the community.



Simon

Simon, who is 44, lives at home with his grandfather who supports him most of the time. He gets support from paid staff for two hours in the mornings, half an hour in the evenings and sleep-in cover overnight. He gets four hours of support from support workers on a Saturday and Sunday.

- He spends five days per week at the day centre in Lambeth. He does different activities when he is there - some are out in the community and others are indoors.
- On Saturdays and Sundays Simon doesn't attend the day centre and support workers come in the morning. They may go out in the community or stay in.
- On Saturday and Sunday afternoons and evenings Simon is alone with his grandfather Paul for most of the time. Their activities in the home include watching television, listening to the radio and having visitors. They are not able to go out because Paul can't push Simon's wheelchair.

Simon did attend the Gateway club every Monday but this has stopped for the moment while a new venue is found. A while ago he used to attend a music session with Lambeth Mencap that he really enjoyed, but unfortunately this stopped. He does get invited to evening activities (like the pub with Lambeth Mencap) but he would need support to go and Paul isn't able to take him because of his own health needs.

How are people with PMLD spending their time?

From the register:

30 out of 34 people with PMLD living in the family home have a day activity.

39 out of 43 of those living in residential accommodation have a day activity.

3 out of 4 people living in their own home have a day activity.

Of the 81 people with PMLD on the register:

69 attend a day service.

21 are in education (6 in a mainstream college, 1 at a residential college and 14 in a special course for adults with a learning disability).

Family carers said that ensuring someone with PMLD has meaningful things to do requires a lot of effort, energy and creativity.

“We work extremely hard for weeks trying to organise activities and time out of the house for Michelle in the holidays.”

“Sometimes we wrack our brains thinking what Sharon might like to do.”

Activities outside the home

How many hours per week does the person spend out of the home?

The majority of those who took part in the survey were spending between 20 and 35 hours per week out of the home. This equates to an average of between 3 and 5 hours outside the home per day.

What activities do they do out of the house that you think are high-quality and meaningful for them?

Answers included:

Physiotherapy, hydrotherapy, going to the park, the day centre, swimming, music sessions, walks, shopping, going out for meals, short breaks service, going to the countryside for breaks, activities that enhance learning, college, visiting family.

What is it about these activities that the person enjoys most?

Common themes:

Different sounds, textures and smells. Sensory experiences, for example music, sensory lighting, being in water. Fun aspect of the activity. Physical movement. One-to-one interaction. Social interaction. Change of scenery. Freedom without a wheelchair. Attention. Being out in the community. Being with familiar people. Being able to express oneself in a non-verbal way.

“She really enjoys spending time with one particular support worker who is a joy for her to be with – she gives 110% attention to her entertainment!”

“As a person with a profound hearing impairment, sound is very important to her. Physical sensation is also very important to her. We want to give her more opportunities to learn and explore – we want to expand her world as much as possible.”

Are there more things the person would like to be doing out of the home?

Family carers of people in the family home:

Only 1 out of 11 said: 'No, there isn't anything I think they would like to spend more time doing out of the place they live'.

Others said yes, don't know or left the question blank.

Paid staff:

Only 5 out of 16 said: "No, there isn't anything I think they would like to spend more time doing out of the place they live."

Others said yes, don't know or left the question blank.

Responses suggested that there are more things people with PMLD would like to be doing out of the home.

What out-of-home activities would they like to be doing more?

Responses included:

"Swimming."

"Swimming and hydrotherapy."

"Physiotherapy and hydrotherapy."

"A centre that has sensory stimulation equipment."

"They would like to be doing more of all the things they are doing, especially using the hydro-pool and having more fun people around."

"Visiting theatres for music, museums and other places."

"Access to appropriate local/central London buildings/environments."

"Access to activities with people who welcome those who are different, and celebrate their noisiness/enthusiasm/joy de vivre!"

"More activities on offer after school (in the evening) that continue to be available when a young person has officially left, because there is nothing to replace them."

"More time at college."

"There are some fantastic one-off things, for example, paper-making. But we want regular, high-quality activities that the person enjoys, for example music, art and pottery activities."

"We have been looking for local voluntary jobs I can support her to do, for example giving out leaflets and information for the church."

What is stopping them doing it?

"Resources unavailable."

"Shortage of staff."

"Lack of facilities, lack of appropriate staff, lack of financial resources."

"Lack of suitable changing facilities. She is double incontinent. It is usually very difficult to find a place where she can be supported with personal care. She would have to use a specialised minibus."

"Two support workers are needed for sessions. So far the funds haven't been applied for."

"Funding cuts. She used to go to college two days per week but this was cut to half a day, which is a short amount of time to actually do anything."

“She did go to a music session at a local college but it became popular and then it was too noisy for her. She also started going to a pottery class but was told it wasn’t suitable for her as she was too noisy.”

“Swimming is something that we have never got on top of. There was a session at a nearby pool specifically for people with a learning disability, but mums and babies would come to it too. Sharon doesn’t like noisy children so we tended not to go. Sharon needs a place that is right for her. We can’t have a session in a school pool when it is not in use because of health and safety – there would have to be a lifeguard there.”

Creative solutions

“When we renegotiate the budget I am going to discuss how we can meet her need to swim. She needs a calm environment. It may be that to meet her need to swim we need to cost-in hiring a pool for an hour plus a lifeguard. I also want us to explore how she could use her individual budget to buy some input from a music therapist. They could design a music programme for her and train support staff.” Family carer

Activities in the home

How many hours is the person spending at home?

Assuming people with PMLD spend around nine hours sleeping, and the majority are spending between 3 and 5 hours outside the home per day, this leaves between 12 and 15 hours per day that they are spending on activities in the family home.

How does the person spend their time at home during the week?

The number of hours individuals spent doing different activities in the place they lived varied from person to person.

How time was spent on different activities:

1 person was spending 48 hours per week “chilling” (around 7 hours per day).

1 person was watching 35 hours of television per week (5 hours per day).

1 person was spending up to 28 hours per week listening to the radio (4 hours per day).

1 person was spending 6 hours per week doing therapeutic activities (around 1 hour per day).

1 person was spending 12 hours per week helping to prepare food (around 2 hours per day).

1 person was spending up to 8 hours helping with gardening (around 1 hour per day).

Family carers and paid staff said that personal care and eating were activities that took up a number of hours per week.

What activities do they participate in at home that you think are high-quality and meaningful for them?

Answers included:

Aromatherapy, watching TV and listening to the radio, one-to-one physical contact, chilling with family and friends, helping to prepare food, participating in domestic chores such as cleaning, playing with his keyboard, being on the swing-seat in the garden, banging objects, sensory bath, music.

What is it about these activities that the person enjoys most?

Responses showed that the key things people seemed to enjoy in activities in the home were the same as the things they enjoyed in activities elsewhere: sensory experiences like light and sounds, one-to-one interaction and attention.

Are there more things the person would like to be doing at home?

Most family carers and paid staff seemed unsure whether there were more things the person would like to be doing at home.

Family carers of someone living in the family home

9 out of 11 left it blank or said they didn't know if there are more things the person would like to be doing at home. 2 said yes.

Paid staff

10 out of 16 said they didn't know or left it blank.

2 said yes. 4 said no.

A few mentioned other activities:

"More trampolining with others and playing games." Family carer

"More hoovering and washing up plates, with support." Paid staff

But it was currently not possible to spend more time doing this.

It is not possible to spend more time doing this at the moment.

Family carers of someone not living in the family home were asked if they think the person has enough meaningful things to do in the day.

The majority said yes. But some said they would like to see the person doing an increased number of meaningful things.

Family carers of someone not living in the family home

8 out of 12 said yes, they thought the person had enough meaningful things to do.

Additional comments

“No, due to lack of funds she does not have access to day centres and other facilities regularly for stimulation.” Family carer

“I don’t know. I know what she is meant to do as planned activities and I know that sometimes they don’t happen because of her health or staff logistics. The planned activities cover a relatively small number of hours and I suspect she spends a fair bit of time not doing much.” Family carer

“There seems to be no specialist further education course available for people with PMLD in the area she lives in (out of Lambeth). She would benefit from that – accessing appropriate continuing education is important for developing the skills of very slow learners.” Family carer

“Yes, but could be increased: more outings, use of public transport (eg more trains as well as buses). Staff need to be confident in their own abilities to support him when out.” Family carer

“No, she would love to go to the hydrotherapy pool more often. There are not enough activity centres for her to attend. Her complex needs mean she cannot do the more normal things very often, like going to the cinema, as she can be very loud, as it is her only way of communicating.” Family carer

“No, my son would like to be active every day but the funding only pays for two days at ‘in house’ activity or day centre. The remaining five days are spent at the residential care home, with staff members trying to occupy and entertain – but with other residents also needing support, this means they cannot give my son enough to keep him fully occupied.”

Main finding

There are not enough meaningful activities for people with PMLD in Lambeth.

Recommendations

What we want to see:

19. An increased range of meaningful activities for people with PMLD in Lambeth, including hydrotherapy and sensory activities.
20. Creative joint-working with other council departments, to develop activities that are meaningful to people with PMLD and other community groups, for example a sensory path in one of the parks.
21. People with PMLD participating in meaningful activities everyday whether outside or inside the home.
22. Decisions about what activities someone does based on good person-centred planning that has involved the person with PMLD.

How do we get there?

- The quality of day activities for people with PMLD in Lambeth should be audited by the council. This should include day centres and further education. Barriers to good practice should be identified.

- The council and voluntary organisations in Lambeth should:
 - map the activities that are available to people with PMLD in Lambeth and identify barriers to accessing mainstream activities, venues and clubs
 - provide information about activities available for people with PMLD in Lambeth
 - explore how ideas for meaningful activities can be shared via a local forum, particularly activities in the home.
- Changing Places toilets should be installed by the council in large public venues in Lambeth.
- Lambeth Council should ensure staff receive training in how to communicate with, and meaningfully involve, people with PMLD in person-centred planning. They should ensure family carers can access the support and training that they need.
- The council should explore a place in Lambeth that could be used as a base, by people with PMLD and their supporters, from which they can access the community. It should also consider what activities could take place at the base and how other community groups could be included.
- A strategy group should be set up by the council to focus on how to increase meaningful activities for people with PMLD in Lambeth. This would involve family carers as well as different council departments such as health, education, leisure and parks. They should work together to see how the community can be more inclusive for people with PMLD and other groups. They should refer to the 'What are meaningful activities?' section of this report when doing this work.
- The council should explore having an identified PMLD lead based in care management (this could be a social worker/ professional) who can advise on all aspects of meeting the needs of people with PMLD (see the information and advice section).

Work already underway

- The council is at the early stages of reviewing current day care provision in order to transform day opportunities for all adults with a learning disability, including people with PMLD in Lambeth.
- The council will be working closely with service providers to ensure that they understand what people with PMLD have told them about the activities that they want to do, so that they can develop these services.
- Adult social care commissioners are working closely with colleagues in cultural services, as they develop the cultural services strategy, to ensure that Lambeth Council's cultural services reflect the needs of all vulnerable people, including those with PMLD.
- The information portal will include information about services and activities available to people in Lambeth.

Individual budgets and direct payments

The national picture

Direct payments and individual budgets give people choice and control about their support. Individualised support has the potential to transform the lives of people with profound and multiple learning disabilities.

However, there are many concerns about how this is being implemented for people with PMLD. A key issue is that the true cost of support for people with PMLD is not being recognised. People with PMLD need staff who are skilled in meeting their communication and complex health needs, but families often can't get staff with these skills for the pay rate that is factored into the budget. This causes some families to be stuck at the resource allocation stage.

Many families are also finding that managing an individual budget is stressful and takes a great deal of time and energy. They are not getting the information and support they need.

The picture in Lambeth

There appears to be confusion about what individual budgets and direct payments are. Some respondents gave the unlikely replies that people were receiving direct payments for clothes and food, and that people living in residential care homes had individual budgets.

Consequently, it is difficult to gather from the survey how many people with PMLD are accessing direct payments and individual budgets.

Does the person receive direct payments?

From the survey:

Family carers of someone living at home
3 out of 11 said yes

Family carers of someone not living in family home
5 out of 12 said yes

Paid staff
4 out of 16 said yes

What are they spending it on?

"Paying for carers."

"Clothes."

"Food."

"Six hours per week of paid care."

"Mobility aids."

"Not sure."

"Outdoor activities."

"Escort to and from day centre and swimming."

Does the person have an individual budget?

There is currently no information on the register about who has an individual budget.

From the survey:

Family carers of someone living at home
3 out of 11 said yes

Family carers of someone not living in family home
8 out of 12 said yes

Paid carers
10 out of 16 said yes

From the interviews, it appears that individual budgets and direct payments are working well, in terms of the individualised support they give people with PMLD. However, family carers are finding that it is more work for them.

One family had a positive experience where they got all the information and support they needed to manage a direct payment. However another family carer had a less positive experience, putting her off considering an individual budget for her daughter.

Some other issues arose concerning individual budgets. For example, lack of transparency of the system and a lack of availability of support staff with the right skills, for the cost allocated in the budget.

What families said

Challenges

“Family carers need more support to manage direct payments for someone with PMLD. I have not looked into her getting an individual budget because I don’t want further responsibilities. I have enough on my plate.”

“The budget and staff management is more work for the carer.”

“The responsibilities that come with employing your own staff should be clear from the start. People need to be aware that they will have to find their own staff. It has been difficult to get the answers to questions that come up, for example whether to pay staff sick pay. The care manager hasn’t been able to answer my questions. Lambeth Mencap have been a great support though.”

“Because she needs a lot of support there are always PA’s (personal assistants) around. There is a problem with boundaries and privacy and ownership of the environment from the rest of the family.”

What is working well

“The individual budget allows her more freedom but it’s more work for the carer.”

“The support worker we have employed is fantastic.”

“The direct payment is working well for her and us. The support worker we have employed understands her needs and is able to support her well. We get help from an agency to manage the direct payment. The agency will calculate hours and sort out tax and the contract for staff. The council gave us a list of agencies that we could go to for help with managing the direct payment. The agency is paid out of the direct payment. We can also call DASL (Disability Advice Service Lambeth) for advice about direct payments.”

Sharon

Sharon is young woman of 32 and lives at home with her mother, Vicky. She has an individual budget. Sharon loves music, particularly 80s. Sharon has a bright personality and thrives on company. She enjoys it when people come to the house.

Before she got her individual budget Sharon was in a shared care arrangement that Vicky set up with the local authority. This meant Sharon was home for half the week and spent the rest of the week in a local residential care home. Unfortunately her needs were not met and Vicky felt she had to withdraw her daughter after too many ‘lack of care’ incidents.

Sharon has had an individual budget for just over three years. Staff are employed to support her at home. Vicky is also very involved in her care.

Sharon's support:

- She had a team of five support staff providing care Monday to Saturday, 10am–10pm but some staff have left so there isn't a full team at the moment. Vicky is in the process of recruiting more staff.
- Staff sleep over twice a week.
- Vicky supports Sharon five nights per week if and when required.
- Vicky supports Sharon on Sundays. At the moment she is also supporting her three evenings per week 5pm–10pm because there isn't a full staff team.

Vicky contributes to increase the rate for staff pay, which is costed into the individual budget, otherwise she says she couldn't get staff with the right skills. She pays £10 per hour in the week and £12 per hour at the weekends. To enable her to pay for this from the budget she has to have staff for fewer hours and provide more support herself.

Sharon also has six weeks of respite care per year. This comes out of the budget too. She takes this from April to September – one week per month.

How Sharon spends her time

Mondays, Tuesdays and Thursdays

Sharon spends the day outside, including lunch. For example, she will do some exercise and perhaps go for a walk to the shops or a longer walk through the park. If it is nice weather and the worker is confident, they might take the bus or tube to go further. There is also a Portuguese café that she might go to if the weather is good. She also likes going to museums and art galleries.

In the evening she enjoys helping with housework like Hoovering and hanging clothes. She also likes listening to music or interesting voices on talking books and tapes.

Wednesday

She will go to college (Orchard Hill at the Redfern centre).

Friday

Sharon has a manicure and pedicure at home. In the afternoon or early evening she will go to the Southbank for a free jazz session. Sharon has been going regularly for a couple of years.

Saturday

She will go to the local farmers market. When the weather is warmer they will sometimes take a longer trip to somewhere like the seaside.

Sunday

Sharon spends a "chill out" day at home when people will often visit.

The individual budget is working well for Sharon. It enables her to have the individualised support she needs.

But Vicky finds that the system is not as transparent and open as it should be. She has often filled in forms only to find out that if she had written something different she would have been given more support.

Vicky says it is challenging because of the responsibilities that come with managing the budget: “You become the care manager!” Vicky thinks that when families are providing hours of care as part of someone’s package of support, they should be paid too. But this only seems to happen in ‘exceptional circumstances’, and no one can explain what this means.

Vicky is keen for the whole arrangement not to be dependent on her as it is at the moment. She wants to see it all working without her – with just Sharon and the support staff. Otherwise she worries: “What if I drop dead?”

They will be re-negotiating the individual budget soon. Vicky has only recently found out you can do this. She will explain that she wants the support to work without her. She will explain she can’t do Sundays anymore. Until recently she had also been taking Sharon to respite that was quite a long way away. Again she wants support staff to be able to take her. She had a carer’s assessment done recently and this will feed into the re-negotiation – not surprisingly caring for someone has taken its toll on Vicky’s health. Vicky is also going to check that her carer’s assessment incorporates an emergency plan. At the moment if she was suddenly taken ill it isn’t clear what would happen. She wants this to be written down and clear.

Sharon’s individual budget means she can get support to do the activities that suit her individual needs. However, there are some barriers to accessing meaningful activities, for example there have been problems finding a music session that is suitable for Sharon. Vicky is going to explore how the individual budget can help Sharon access activities she hasn’t been able to for various reasons.¹⁵

Main finding

There is some confusion over what direct payments and individual budgets are. Not all family carers are getting the support they need to manage them.

Recommendations

We want to see

23. Increased numbers of people with PMLD accessing direct payments and individual budgets.

How do we get there?

- Lambeth Council and register services need to work together to identify how many people with PMLD have a direct payment and how many have an individual budget. Currently self-reporting through the register or this survey is unreliable due to lack of understanding about the terms.
- The council should set targets for the number of people with PMLD accessing direct payments and individual budgets, in line with targets for the wider learning disability population, to ensure people with PMLD are getting equal access to individualised support.

¹⁵ There is more information about some of the barriers to participating in meaningful activities that Sharon faces, and how these might be addressed in the ‘Meaningful activities’ section.

- The council should ensure the resource allocation system is transparent and that the cost of packages for people with PMLD reflects the support they need. This will involve monitoring and reviewing how individual budgets for people with PMLD in Lambeth are currently working.
- Lambeth Council needs to ensure family carers and support workers have information about direct payments and individual budgets, covering what they are, the benefits they can bring and what support is available to manage them.
- Lambeth Council must make sure that their strategy around information and advice for family carers and support staff of people with PMLD includes information and advice about direct payments and individual budgets. This should include:
 - awareness about what direct payments and individual budgets are
 - making sure people understand the benefits they can bring
 - ensuring family carers can get assistance to manage, and are aware of, the support available to them
 - exploring which agencies are best to deliver information and advice on direct payments and individual budgets - this may be, for example, the council itself or the voluntary sector
 - understanding how the knowledge of family carers can be utilised, without expecting them to offer advice for free.

Work already underway

- Lambeth began piloting self-directed support for adults with a learning disability with the In Control project in 2007. They have now expanded this to other service areas.
- From October 2010, self-directed support will be offered to all service users, who will then be able to choose how they wish to receive their services in the future.
- As part of the learning phase, Lambeth Council has tendered various provider organisations to act as support brokers. In return Lambeth Adults' and Community Service (ACS) has offered support and training to develop knowledge and learning in this role. Through this arrangement, people with a learning disability, and people with PMLD and their families, will receive training on how to recruit personal assistants, manage money and be an employer.

Transition

The national picture

There is a lack of holistic planning for young people with PMLD leaving children's services and entering adult services. There also does not appear to be the same commitment to meeting needs. As a result, once they enter adult services, many young people with PMLD are not getting the support they need to meet their health, social care and education needs.

The picture in Lambeth

Interviews were conducted with family carers of people with PMLD who have recently entered adult services and those with PMLD in the process of entering adult services. It was clear that some young people with PMLD in Lambeth are experiencing a reduction in services and activities when they move into adult services. It is difficult to know whether this is the case across the board in Lambeth.

"Since she left school she has really missed getting regular hydrotherapy. My advice to other parents would be when your child moves into adult services don't expect them to get what they got as a child. Services go down. People hear your voice but they don't listen. If you ring children's services they do act. Once your child is an adult it all goes, but the person continues to have the same needs." Family carer of a young person with PMLD who has recently entered adult services.

Michelle

Michelle is a young woman of 19 who lives at home with her family. She is in the process of entering adult services.

Using her whole body to communicate, Michelle makes use of gestures, eye-pointing, tone of voice, facial expression, whole-body movement and direct action. When she is enjoying herself she makes thrilled sounds and happy faces and sometimes giggles.

Michelle remains the responsibility of children's services until she leaves full time secondary education. However her mother says that in reality, she and her peers have fallen into the gap in funding between children's and adult services. Since her 18th birthday, eligibility has been questioned and they have seen some services withdrawn. Lucy's mum feels this should be challenged.

The family are concerned that once Michelle leaves school she will not have as much access to therapies that support her health needs. They also think it will be more difficult for the family to get advice and expertise on her specific health issues.

Although Michelle is still in paediatric services by special arrangement, her parents are told that this will have to change in the future. As a result the hospital appointments she needs will be shorter, less frequent and not with the same consultant each time – indeed, perhaps not with a consultant at all. The family has been advised that their GP, who has never seen Michelle because all her monitoring has been hospital-based to date, will be the gateway to adult health services. They are worried by this change.

The family worry about what Michelle is going to do during the day when she has left school and college. Michelle's mum said: "We fear for our daughter – we see very little that is suitable on offer for her. We shall take advantage of every opportunity we can find or create for her and are willing to travel far afield – but how do we fill 110 hours weekly?"

In terms of planning for Michelle's future, the family has found that person-centred planning meetings involved some creative thinking. However the only practical outcome was access for two years to direct payments for the six hours of support she gets per week from a support worker. More recent engagement in the creation of a *Self-Directed Support Plan* for Lucy has been exciting for those involved but has shown how much there is to be done to develop suitable activities.

College

Michelle's family are hoping that she will be admitted to a further education college in a neighbouring borough that has part-time and full-time residential facilities. Unfortunately there is no place for her in 2010. The college have suggested she take a 'gap' year with a view to her starting the year after. But the family are unsure how Michelle might spend her time during the year.

Another college has offered her a place but it is non-residential and they are only offering her 20 hours per week. Two residential facilities were suggested but they are so far from home (Midlands and North) that Michelle's parents have not even considered them. It is important that Michelle is close to home so that her family can remain involved in monitoring her wellbeing.

The family feels that spending time at a good college where the focus would be on Michelle learning and developing her cognitive skills would be a meaningful use of her time for the next few years. However the family are aware that after college the question of how she spends her time will arise again. While she is at college the long holidays will continue to present the same challenges for the family as they have done during her time at school.

Activities

Michelle's family works extremely hard for weeks trying to organise activities and time out of the house for Michelle in the holidays.

To date, children's services have given funding for her to spend three weeks per year on a play scheme. This still leaves ten weeks for the family to do their best to be ingenious with activities. This is increasingly difficult as Michelle grows older and can no longer access activities targeted at young children. Sometimes a 'trip out' during school holidays is a simple walk around the local area in her wheelchair, which is not fun for her at all! Her enjoyment depends totally upon the commitment, imagination and energy of her companions.

Michelle's mum thinks more after-school (evening) activities should continue to be available when the young person has left school, as there is nothing else to replace them.

Michelle's mother believes there must be many young people with PMLD who want to access local leisure activities in suitable buildings. She would be happy to engage with commissioners and others involved with developing such provision.

The future

The family wants to continue to play a pivotal part in their daughter's life however they also want to plan for the future for when they are no longer able to do this. They said this is very scary. What is lacking and what they need are informed, experienced, energetic and engaged partners with whom to plan.

Michelle's family also want the professionals and social care staff involved in her life to accept responsibility for following through promises – without being chased.

What is working well for Michelle?

Until now school has been a good experience for Michelle. The family has spent years working with children's services to ensure she has access to the services she needs. This worked well provided the family kept engaged, however since Michelle turned 18, things have not been working so well.

Main finding

Some young people in Lambeth are experiencing a reduction in services and activities when they move into adult services.

Recommendations

What we want to see:

- 24. Good transition planning for young people with PMLD in Lambeth.
- 25. Young people with PMLD continuing to receive the support and services they need when they enter adult services.

How do we get there?

- All young people with PMLD about to enter adult services within the next four years must be identified.
- Those young people with PMLD coming into adult services should have a PCP (person-centred plan), that they have been meaningfully involved in, as well as a communication passport and a health action plan.
- Young people with PMLD and their families should have a transition social worker to help them move through to adult services.

- A project group including family carers should be established. The group would explore access to meaningful activities for young people with PMLD who have just entered adult services. This should be supported by the recommendations about increasing meaningful activities for all adults with PMLD in this report.

Work already underway

- Lambeth has set up a multi-agency transition steering group. It has already agreed a strategic transition protocol for children with disabilities that has sign-up from all agencies, reflects good practice and meets statutory requirements.
- There is also a transition panel to ensure the effective transfer of learning disability cases from Children and Young People Service to Adult and Community Services.
- The development of a transitions service for young people aged 14 to 25 is under way with the appointment of a transitions manager and a clear focus on developing personalised support services.
- Lambeth currently commissions two services to support adults with a learning disability into work placements, volunteering and paid employment: the Mencap Pathways project, and the Camden Society Pro Work Project. There are close links with these two projects and Lambeth College.

Advocacy

The national picture

Most people with PMLD will not use formal communication like words, signs or symbols. Despite being the people most in need of someone to speak up for them, there are few advocacy schemes that can support them. Most advocates are still not trained in the non-instructed advocacy techniques needed for advocacy with people with PMLD.

Picture of Lambeth

The findings do not give a clear picture of how easy it is for people with PMLD living in Lambeth to get an advocate. However it appears that access to advocacy could be improved.

Paid staff of people with PMLD, not living in the family home, but still living in Lambeth were asked:

Does the person have an advocate?

2 out of 7 said yes

5 out of 7 said no

How easy is it for the person to get an advocate?

2 out of 7 said it was easy

1 out of 7 said it was quite easy

2 out of 7 said it was difficult

2 out of 7 said they didn't know

Comments from paid staff:

"They used to have an advocate but due to funding cuts the service has been withdrawn."

"We are still waiting for a reply from the agency we applied to for an advocate four months ago."

"When we got through to the advocacy service it was suggested that she does not need one."

"She does not have any close family members still alive. I think she would benefit from an advocate, independent from any of her services, but I am not aware of any services."

Main finding

There needs to be better access to independent advocacy for people with PMLD in Lambeth.

Recommendations

What we want to see:

26. All people with PMLD in Lambeth in need of advocacy able to get an independent advocate who has the right skills to work with them.

How do we get there?

- Mapping of advocacy services in Lambeth that are able to meet the needs of people with PMLD.
- The council should commission advocacy services in Lambeth that are able to meet the needs of people with PMLD. This will require advocates trained in the non-instructed advocacy techniques needed to work with people with PMLD.

Work already underway

- These recommendations are being taken forward as part of the information advice and advocacy strategy.

Person-centred plans

The national picture

Person-centred support has the potential to transform the lives of people with profound and multiple learning disabilities.

However, many people with PMLD do not have an up to date PCP. Even when someone with PMLD does have a PCP they have not always been meaningfully involved in developing it. This can mean the plans are not always effective.

Developing the plan with a circle of people who know the person well (a circle of support) can help ensure that it reflects the things that are important to the person with PMLD. They can also help make sure it is kept up to date and implemented.

The picture in Lambeth

Only half the people with PMLD on the register have a person-centred plan. The findings show that people with PMLD were more likely to have a PCP if they were not living in the family home.

Does the person with PMLD have a PCP?

From the register:

6 out of the 34 people living in the family home have a PCP.

34 out of 47 people not living in the family home have a PCP.

In total

40 out of 81 people with PMLD have a PCP.

From the survey:

2 out of 11 of those living in the family home have a PCP.

19 out of 25 of those not living in the family home have a PCP.

In total

21 out of the 36 people we received survey responses for had a PCP.

The survey shows that people were more likely to have a circle of support if they were not living in the family home.

For three people with PMLD we received responses from both family carer (not living with the person) and paid staff. Interestingly, in each case, the family carer and the paid staff member gave conflicting answers as to whether the person had a circle of support. This suggests some confusion as to what a circle of support is.

Does the person have a circle of support?

Family carer of someone in family home

2 out of 11 said yes

Family carer of someone not in family home

10 out of 12 said yes

Paid staff

8 out of 16 said yes

Comments

“He doesn’t have a person-centred plan but I have given information about his likes and dislikes to the day centre, which they use when planning activities.” Family carer

“She has a PCP and a circle of support. This is only attended by paid staff. She does not have any close family members still alive.” Support worker

“Person-centred planning meetings have involved some delightful blue sky thinking. However the only practical outcome was access for two years to direct payments for six hours support per week from a support worker.” Family carer

“She doesn’t have a proper person-centred plan. We would like support to develop one. It would be good to have information about her dreams and wishes, including that it is a priority for her to have hydrotherapy. We could write down what she might do in the future if she has hydrotherapy, does more walking and builds up her strength. Everyone, including new social workers, would know what we are aiming for.” Family carer.

“Person-centred planning led the family to the conclusion that a small residential care home run by a reliable specialist organisation was the best (housing) option for her.” – Family carer

Main finding

Half of the people with PMLD on the register have a person-centred plan. People with PMLD were more likely to have a person-centred plan if they were not living in the family home.

Recommendations

What we want to see:

27. All people with PMLD in Lambeth with an up-to-date person-centred plan that they have been meaningfully involved in developing.

How do we get there?

- People in Lambeth with PMLD should be given priority for person-centred planning. It is crucial to explore what their dreams and wishes are as they will not be able to speak up about these in the same way that others.
- There needs to be an improvement in the support given to people with PMLD living in the family home and their family carers to develop a person-centred plan. This should include defining who initiates and manages the process.

- Person-centred plans need to be part of inspection criteria for services. Random checks would ensure plans are being implemented and updated. Checks would also assess the meaningful involvement of people with PMLD, ensuring plans are used to inform decisions about the person's life.
- It is important to raise awareness about the benefits of a person-centred plan.
- Staff should be properly trained to engage with people with PMLD so they are meaningfully involved in the development of their person-centred plans.
- Explore and review the help given to developing circles of support, to ensure that more people with PMLD can benefit from them.

Work already underway

- In April 2010 the Department of Health issued new person-centred planning guidance, aimed specifically at people with a learning disability. This will provide the framework for a joint review of current practice in respect of person-centred planning in the adults with learning disability team and other services.

Communication passports

The national picture

A communication passport explains how someone communicates, for example how they show they are happy, they don't like something or they are in pain. It can help ensure that a person with PMLD is properly supported by giving new staff or other people who come into the person's life important information.

Awareness about the benefits of communication passports has increased in the last few years and a number of people with PMLD now appear to have them.

The picture in Lambeth

The findings show that someone with PMLD is more likely to have a communication passport if they are not living in the family home. Over half of family carers of someone with PMLD, living in the family home, said they didn't know if the person had a communication passport. Some also left the question blank, suggesting they may not be sure what a communication passport is.

People with PMLD living in the family home

3 out of 11 had a communication passport.

2 out of 11 didn't have a communication passport.

6 out of 11 family carers said don't know or left blank.

People with PMLD not living in the family home

16 out of 25 had a communication passport

7 out of 25 didn't have a communication passport

2 out 25 family carers and paid staff said they didn't know

How do we get there?

- It is important to raise awareness amongst family carers and paid staff about the benefits of communication passports and hospital passports.
- Ensure family carers get the support they need to develop a communication passport for the person with PMLD they support.

Work already underway

- Lambeth is looking at developing communication passports as part of the work to develop hospital passports.

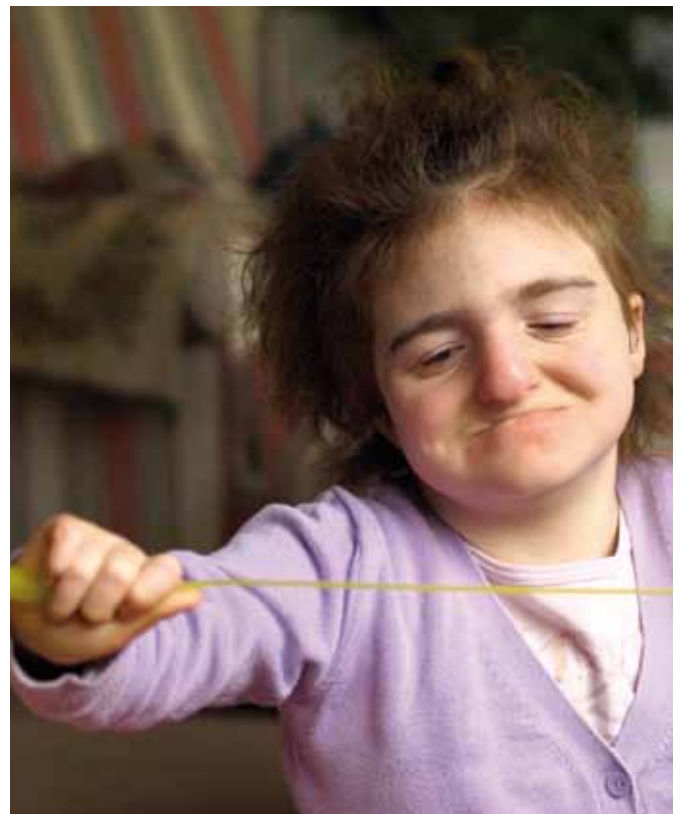
Main finding

People with PMLD were more likely to have a communication passport if they were not living in the family home.

Recommendation

What we want to see:

28. All people with PMLD in Lambeth with an up-to-date communication passport with information that can be used to develop a hospital passport, with key information about the person's health and communication needs (see health section).



Follow-through and delivery of services

The national picture

Many families say that they have to spend a lot of time fighting to get the services they need and chasing up on promises on top of their usual caring responsibilities.

The picture in Lambeth

Family carers who were interviewed felt that a key issue was that on top of their caring role, they have to chase to get things done (and services delivered). They said that one reason for this is high staff turnover, both of social workers and of senior staff at the council. They said that information and priorities are not passed on to new staff. This means that family carers often have to start all over again, explaining the person's needs to new staff, and fighting for services.

"I often need to ring again and again to get things done. The equipment used to lower him into the bath broke and I have had to really chase to get it fixed. An occupational therapist has also been looking at his bed to see how it could be made safer with rails. But it is taking a long time and I am having to chase it up." Family carer

"A real problem has been that senior staff at Lambeth Council have kept leaving. This has meant that things have had to start all over again with fighting for better services. Things just haven't happened, for example the poor local respite situation hasn't been sorted out." Family carer

"We want the professionals and social care staff involved in her life to accept responsibility for following-through with promises, without being chased again and again." Family carer

Main finding

Family carers said they have to chase to get things done and have services delivered.

Recommendations

What we want to see:

29. Better follow-through and delivery of services – without family carers having to chase repeatedly.
30. An improved process for passing on information to replacements when staff leave.
31. A commitment to following through on agreed actions and priorities when senior staff leave.

How do we get there?

- There must be recognition that many family carers are spending all hours of the day caring for a person with PMLD so they don't have time to make repeated calls requesting the support or services they need. It should be a priority to ensure that there is timely delivery of services for carers of people with PMLD, particularly elderly carers.
- There should be a review of procedures at the council to ensure information about individuals is passed on to replacements when staff leave.

- People with PMLD must have an up-to-date communication passport, PCP and health action plan. This will help ensure consistency in meeting individual's needs when staff change.
- Ensure that when senior staff at the council leave, there is a commitment to follow through on actions, and stick to agreed priorities.

Work already underway

- Lambeth has recruited a number of permanent social workers in the last 18 months.
- In 2009 Lambeth appointed permanent assistant directors for adult social care and adult commissioning, and a permanent service manager for adults with a learning disability.





Summary of recommendations

Support for family carers

1. An increased number of support staff who have the skills to work with people with PMLD.

Respite

2. All families of people with PMLD should have regular access to high-quality short breaks. For those with the most complex support needs, this entitlement should be based on a minimum expectation of 52 nights per year or the equivalent.
3. There must be local appropriate respite care. This must meet the needs of people with PMLD and tailor care specifically to the needs of individuals.
4. People should have a choice of respite provision. For example not just residential respite, but options for someone to go away with paid staff or for paid staff to provide respite in the family home.
5. There should be clear information about how much respite individuals are entitled to, following a carer's assessment.
6. There should be information about respite provision that is easy to understand available locally and further afield.

Information and advice

7. There must be a centralised local information service to signpost the services and support available to people with PMLD and their families and where they are located.
8. A forum where families and support workers of people with PMLD can share information should be established.

Support for elderly carers

9. Family carers must get the support they need to continue caring for the person at home if they want to – including enough respite.
10. There must be a choice of options for the person with PMLD if the elderly carer no longer feels able to care for them in the family home.
11. Planning must take place earlier so that the person will be able to get the support and accommodation that meets their needs in the future.
12. There must be a timely response, and follow-through, of actions so that elderly family carers don't have to chase for results.

Housing

13. Increased choice of housing options should be available to people with PMLD in Lambeth.

Health

14. All people with PMLD must be able to access the mainstream and specialist health services they need. This should include physiotherapy, speech and language therapy, occupational therapy and hydrotherapy, where they have an identified need.
15. Good health support should be available to all people with PMLD, regardless of where they live.
16. All people with PMLD should have annual health checks, including onward referral to health specialists when they need it.
17. All people with PMLD should have a health action plan.
18. All people with PMLD should have a hospital passport that has key information about their health and communication needs.

Meaningful activities

19. There must be an increased range of meaningful activities for people with PMLD in Lambeth, including hydrotherapy and sensory activities.
20. Creative joint-working must take place with other council departments, to develop activities that are meaningful to people with PMLD and other community groups, for example a sensory path in one of the parks.
21. People with PMLD should be participating in meaningful activities everyday whether outside or inside the home.
22. Decisions about what activities someone does must be based on good, person-centred planning that has involved the person with PMLD.

Individual budgets and direct payments

23. Increased numbers of people with PMLD should have access to direct payments and individual budgets.

Transition

24. There must be good transition planning for young people with PMLD in Lambeth.
25. Young people with PMLD should continue to get the support and services they need when they enter adult services.

Advocacy

26. All people with PMLD in Lambeth in need of advocacy should be able to get an independent advocate who has the right skills to work with them.

Person-centred plans

27. All people with PMLD in Lambeth should have an up-to-date person-centred plan that they have been meaningfully involved in developing.

Communication passports

28. All people with PMLD in Lambeth should have an up-to-date communication passport that includes information that could also be used to develop a hospital passport, with key information about the person's health and communication needs (see health section).

Follow-through and delivery of services

29. There must be better follow-through and delivery of services – without family carers having to chase repeatedly.
30. It is crucial that there is an improved process for passing on information to replacements when staff leave.
31. A commitment to following-through on agreed actions and priorities when senior staff leave is essential.





Conclusion

This piece of work was embarked upon because family carers in Lambeth, Lambeth Council and NHS Lambeth recognised that people with PMLD had been missing out. They understood that this is a group of people who have specific needs and who require a specific focus to ensure their needs are met.

The project has confirmed that the picture in Lambeth is similar to the the national picture with regards to the barriers people with PMLD and their families face.

The project has identified key recommendations about how to improve the lives of people with PMLD and their families in Lambeth. Many of these reflect the recommendations in the *Raising our sights* report by Professor Jim Mansell.

The Council and NHS Lambeth already have work underway which begins to address some of the barriers people with PMLD face in Lambeth. They will now be looking at other steps they can take to carry out the recommendations.

As a result of the project, Register Services now has a set of criteria to enable it to identify people with PMLD on the register. It will be able to look at the specific needs of this group at appropriate intervals. This should mean Lambeth council and NHS Lambeth are able to better plan for their needs.

This project has firmly put people with PMLD on the radar in Lambeth and is a first step to improving the lives of this group of people and their families.

Next steps

Lambeth Council and NHS Lambeth will look at how they can take the recommendations forward.

There are 31 recommendations in the report so the council, the health service and their partners will need to decide which to prioritise and implement.

A priority area appears to be ensuring that family carers get the support and information they need. This includes access to good-quality respite, support from paid staff with the right skills, support to manage direct payments and individual budgets and support to ensure access to meaningful activities.

We will hold a consultation event for family carers to discuss the recommendations and find out which they think should be prioritised.

Lambeth Council and NHS Lambeth will write down the short- and long-term actions they are taking in their plans. Family carers will be able to see these plans.

We will undertake a short follow-up report in one year to see what progress has been made in implementing the recommendations.

Question for family carers and support staff of people with PMLD

Not all family carers and paid staff of people with PMLD in Lambeth took part in the surveys and interviews that informed this report.

If you didn't take part, please let us know if this report reflects what life is like for you and the person with PMLD you support.

We would also be interested to hear why you chose not to take part in the project, if you would be happy to tell us. It may be just because you didn't have enough time or it may be because you are disillusioned, have answered too many surveys already or for another reason entirely.

Please contact us if you would like more information about this project.

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You can get more copies of this report online at www.mencap.org.uk/lambethpmld



Appendix

About profound and multiple learning disabilities

To print this factsheet click on **file** and then click **print**



Why are we describing people with ‘profound and multiple learning disabilities’?



Children and adults with profound and multiple learning disabilities are, like everyone else, unique individuals. But sometimes it is helpful to talk about groups of people who have common concerns. This can help us as a society to make sure that people’s human rights are upheld. A good example of this is people who come from minority ethnic groups. Another example is people with profound and multiple learning disabilities. At the moment, the needs and rights of people with profound and multiple learning disabilities are frequently neglected.

It is vital that we understand the distinctive needs of people who are often excluded from society. That’s because, in doing so, we are respecting their right to be included. It is only by focusing on their needs and rights, and working to remove the barriers they face, that people with profound and multiple learning disabilities will achieve their rightful place in society. It also acknowledges that while many barriers can be challenged and even removed, ultimately we cannot change the nature of people’s disabilities. In doing so we are not being discriminatory, rather we are respecting people’s differences and valuing them for who they are. At the same time, we can continue to fight for equal rights.

Who has profound and multiple learning disabilities?



Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with autism and Down's syndrome may also have profound and multiple learning disabilities.

All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of daily life.

The needs of people with 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 people 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 may be taking. 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. Some examples of conditions and syndromes that are more usually associated with profound and multiple learning disabilities are: 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.

Why not use the term 'high support needs' or 'complex needs'?

It is true that people with profound and multiple learning disabilities have high support needs. It is most likely that they will need 24-hour-a-day support with all aspects of their lives. Their needs are also complex, for example, the range of medical conditions that they often experience. However, these terms alone do not help others to understand the specific issues that affect their lives. This is because many other people who do not have a profound learning disability could be described using these terms. For example, someone with a physical disability and communication impairment may be described as having complex needs or high support needs. The famous scientist and author Stephen Hawking is an example of this. The provision of a wheelchair, good personal support and an effective communication device enables him to demonstrate his high-level intellectual ability.

Attitudes

One of the greatest barriers that people who have profound and multiple learning disabilities face is the negative attitudes of others. Judgements are made about the meaning and quality of people's lives. This can stop people being offered some of the more innovative forms of support, such as individual funding, because some people do not think that they will benefit, or they think that the costs involved are too high. But these negative attitudes can also be life-threatening – for example, if they result in medical treatment being denied. These judgements are only ever subjective. Most people do not know what it is like to have a profound learning disability and perhaps experience the world by touch and smell. Such judgements also show a failure to understand the contribution that each individual will make to the lives of the people around them.

It is important that everyone understands that people with profound and multiple learning disabilities have the same rights as every other citizen. We must enable each individual to engage with their world and to achieve their potential so that their lives go beyond being 'cared for' to being valued for who they are as people.

Criteria for PMLD (profound and multiple learning disabilities)

This criteria has been developed by Register Services and Royal Mencap to identify those adults with PMLD registered on the Learning Disability Registers run by Register Services (**using available data**).

Since all those registered will have a learning disability, those recorded with the following responses will be deemed to have PMLD:

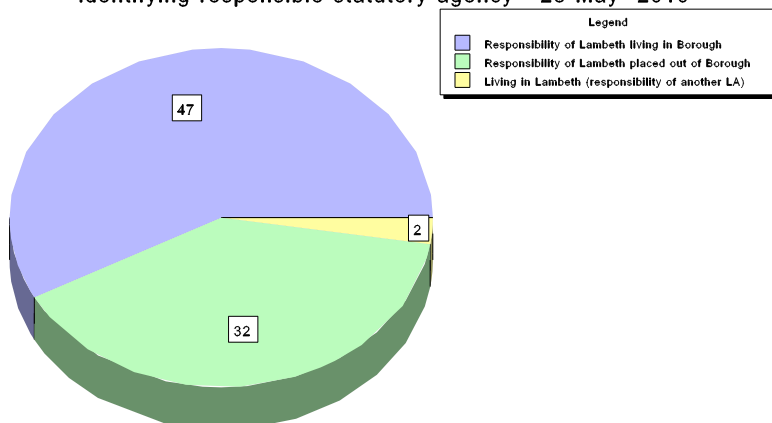
- Level of learning disability 'severe', 'unspecified' or 'not known'
- Level of support required 'full time' or 'not known'
- Level of communication:
 - speech: 'sometimes', 'never' or 'not known'
 - signing: 'sometimes', 'never' or 'not known'
 - understood by others: 'sometimes', 'never' or 'not known'
- Level of literacy:
 - Read: 'not at all'
 - Write: 'not at all'
 - Count: 'not at all'
- Self help skills
 - Cook: not like 'yes'
 - Self toilet: not like 'unaided'

Lambeth PMLD (profound and multiple learning disabilities) as at 28 May 2010

Using the above criteria, the following applies for Lambeth people with learning disabilities:

Total number of adults (>18 years) with learning disabilities registered: **968**
Number of adults identified with PMLD: **81**

Figure 1
Adults (>18 years) with PMLD recorded on Lambeth 'I Count' Register
identifying responsible statutory agency - 28 May 2010



	Responsibility of Lambeth living in Borough	Responsibility of Lambeth living out of Borough	Living in Lambeth (responsibility of other LA)
Residential accommodation	11	30	2
Family home	34		
Own home	2	(1 In Control) 2	

Source: Lambeth 'I Count' Register for People with Learning Disabilities - May 2010

Table 1: TOTAL registered people with PMLD unable to perform personal tasks/wheelchair users

WALKS	SELF FEED	SELF WASH	SELF DRESS	USE WHEELCHAIR	TOTAL
No	No	No	No	Yes	38
No	No	No	No	No	5
	No	No	No	Yes	6
	No	No	No	No	4
No		No	No	Yes	8
No		No	No	No	3
		No	No	Yes	3
		No	No	No	12
		No		No	1
No	No		No	Yes	1

NB Responses of 'Not at all' or 'Only with help' for Walks, Self feed, Self wash, Self dress included.

Source: Lambeth Register for People with Learning Disabilities, April 2009

Fifty six (56) of the total of 81 people identified with PMLD (69%) say they use a wheelchair - 51 (91%) of whom say they cannot manage it alone.

Table 2: TOTAL registered people with PMLD with one or more of the specified disabilities:

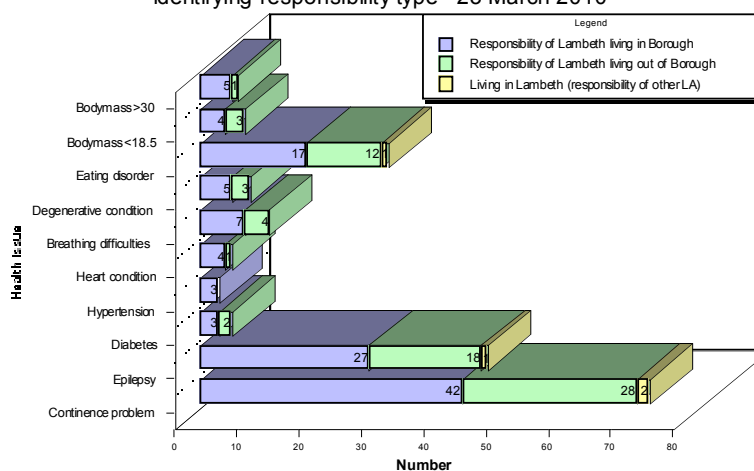
PHYSICAL DISABILITY	SIGHT PROBLEM*	HEARING PROBLEM**	CHALLENGING BEHAVIOUR	AUTISM	TOTAL
Yes					10
Yes			Yes		12
Yes			Yes	Yes	1
Yes		Yes	Yes		1
Yes	Yes		Yes	Yes	1
Yes				Yes	1
Yes		Yes			1
Yes	Yes				9
Yes	Yes		Yes		10
Yes	Yes	Yes			4
Yes	Yes	Yes	Yes		5
			Yes		5
	Yes				3
	Yes	Yes			1
	Yes	Yes	Yes		4
					3
			Yes	Yes	4
	Yes			Yes	1
	Yes		Yes		3
	Yes		Yes	Yes	1
	Yes	Yes	Yes	Yes	1

NB A registered person with PMLD may be included in more than one of the above categories. *Sight problem = yes to 'blind', 'partially sighted' or 'sight: difficult to know'. **Hearing problem = yes to 'deaf', 'hard of hearing' or 'hearing: difficult to know'.

Source: Lambeth Register for People with Learning Disabilities, March 2010

Figure 2

Prevalence of health issues in registered adults with PMLD (n=81)
identifying responsibility type - 23 March 2010

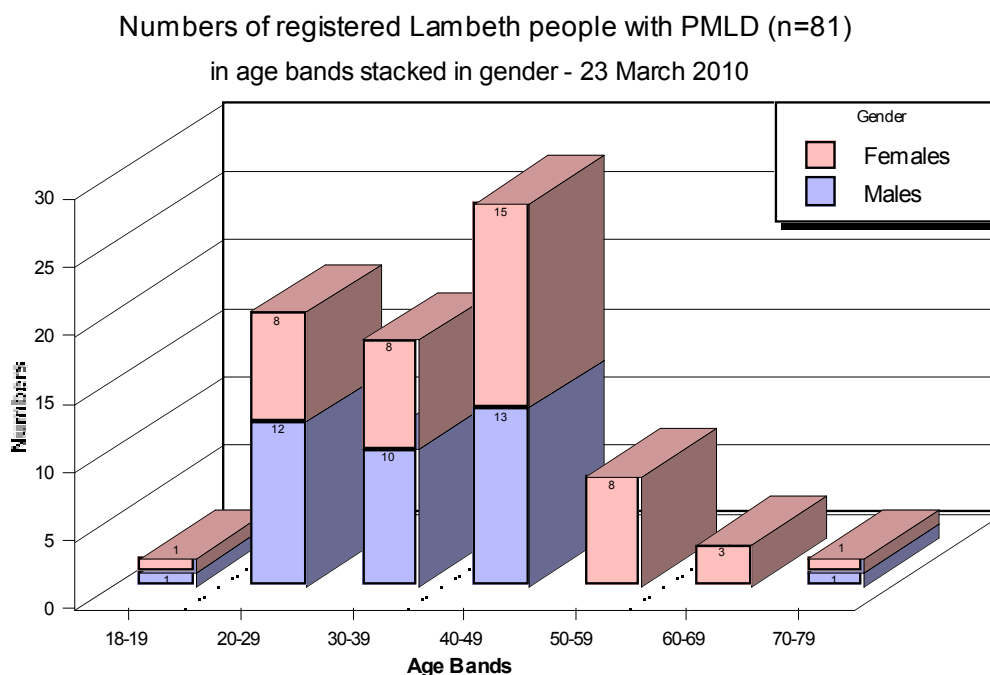


NB A registered person may have more than one health issue

Source: Lambeth Register for People with Learning Disabilities, March 2010

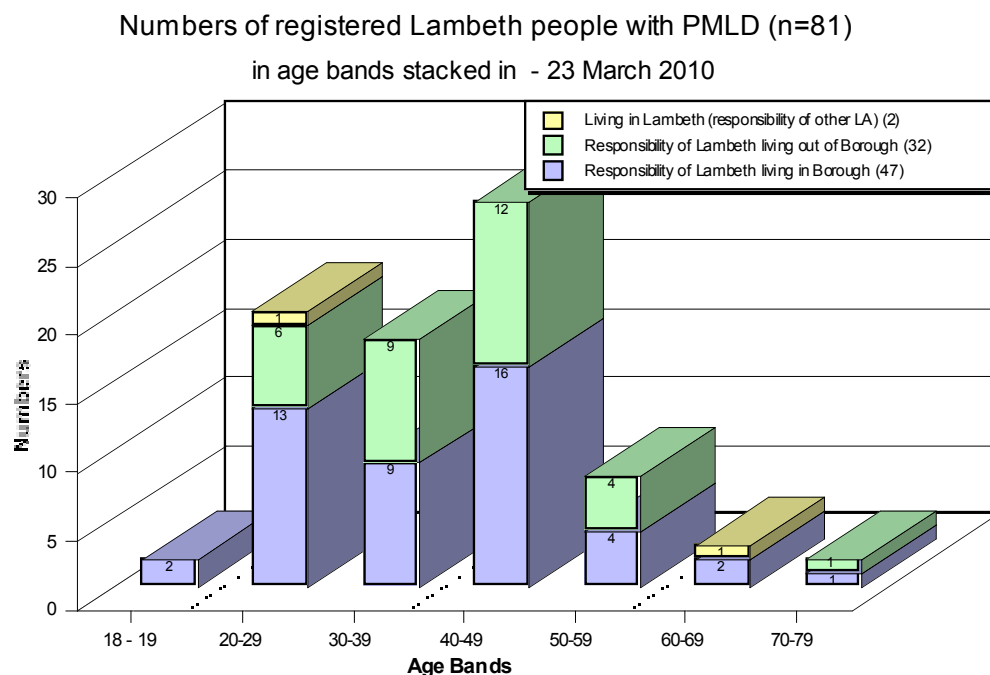
The gender ratio for adults on the Lambeth Register for People with Learning Disabilities generally is 47.7% female (452) and 53.3% male (516). Conversely for adults with PMLD it is 54% female (44) and 46% male (37).

Figure 3



Source: Lambeth Register for People with Learning Disabilities, March 2010

Figure 4

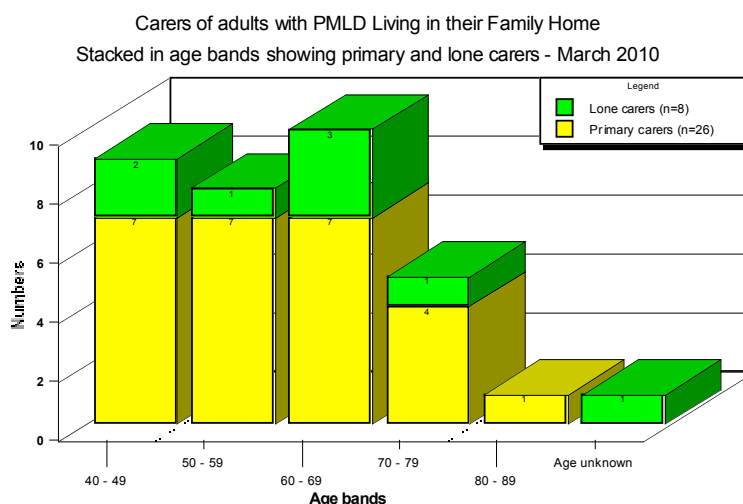


Source: Lambeth Register for People with Learning Disabilities, March 2010

The ethnicity of registered adults with learning disabilities on the Lambeth Register for People with Learning Disabilities generally reflects the ethnicity of the general population of Lambeth as does the registered PMLD population - 58% white and 42% from ethnic minorities.

34 registered Lambeth adults with PMLD say they live in their family home. *Figure 5* identifies the number of carers of these individuals (in age bands) stacked in whether or not there is a 'backup' carer.

Figure 5

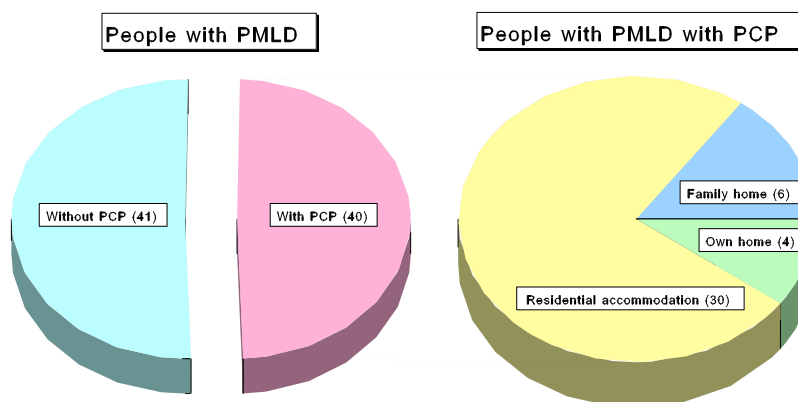


Source: Lambeth Register for People with Learning Disabilities, March 2010

15 Lambeth carers of PMLD living in their family home (44%) say that they receive short breaks (respite care). 27 registered PMLD living in their family home (79%) and 39 of those living in residential care (91%) say that they have a day activity.

40 people with PMLD have a Person Centred Plan. *Figure 6* identifies their residence type.

Figure 6
Number of Lambeth PMLD who have a PCP identifying
their residence type - 28 May 2010



Source: Lambeth Register for People with Learning Disabilities, May 2010

Anne Bowman
Head of Service

Key information about the 36 people with PMLD who we received survey information for

Age	Placed out of borough	Residence type
19	No	Family home
22	Yes	Registered care home
23	No	Family home
23	Yes	Adult placement home
25	No	Family home
28	Yes	Registered care home
29	Yes	Registered care home
29	No	Family home
33	Yes	Registered care home
34	Yes	Registered care home
37	Yes	Registered care home
39	Yes	Registered care home
39	Yes	Registered care home
39	No	Family home
41	Yes	Registered care home
41	No	Family home
42	No	Family home
42	No	Family home
43	Yes	Registered care home
43	Yes	Registered care home
44	No	Family home
44	Yes	Registered care home
46	No	In their own home with support
46	No	Registered care home
46	No	Registered care home
47	Yes	Registered care home
47	No	Family home
48	No	Registered care home
52	No	In their own home with support
52	No	Family home
53	Yes	In their own home with support
59	No	Registered care home
62	No	Registered care home
64	No	Registered care home
76	No	Registered care home
78	Yes	Registered care home

Resources

Mencap

www.mencap.org.uk

Lambeth Mencap

www.lambethmencap.org.uk

PMLD Network

www.pmldnetwork.org

Raising our sights report and DVD

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Estimating Future Numbers of Adults with Profound and Multiple Learning Disabilities

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103201

Breaking Point

www.mencap.org.uk/breakingpoint

Valuing People Now

www.valuingpeoplenow.dh.gov.uk

Information about health checks for people with learning disabilities

http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_094352

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The project group would also like to thank their colleagues at Register Services, Mencap, Lambeth Council and NHS Lambeth for their assistance with the project.

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

Department of Health (2009) *Valuing People Now: A new three-year strategy for people with learning disabilities*. London: HMSO

Mencap (2006) *Breaking Point – families still need a break*. London: Mencap