Easy read

Lambeth PMLD project

What people with profound and multiple learning disabilities in Lambeth need

LAMBETH MENCAP

'I COUNT' Register Services

mencap The voice of learning disability

Who we are

We are a group of people in Lambeth. Lambeth is part of London.

We are

- family carers
- people from Lambeth council
- people from Mencap
- people from the NHS in Lambeth

- people who run the register of people with learning disabilities in Lambeth. The register is a list.

We wanted to find out about people with profound and multiple learning disabilities in Lambeth.

We wanted to find out

- what support they get
- what support the people that care for them get

- what needs to change to make their lives better.

What does profound and multiple learning disabilities mean?

People with profound and multiple learning disabilities

- need a lot of support all of the time
- have more than one disability
- find it very hard to communicate.

What we did

We worked to find out the number of people with profound and multiple learning disabilities in Lambeth.

We asked family carers and support staff some questions about what they thought life was like for people with profound and multiple learning disabilities.

We made a list of things we think should happen next.

What we found out from people

We found out lots of things. For example,

- there needs to be more training for staff working with people with profound and multiple learning disabilities

- some carers are not getting enough short breaks – short breaks are when carers have a rest from caring for someone

- there is not enough information about services for people with profound and multiple learning disabilities.

We also found out

- there are not enough choices for people with profound and multiple learning disabilities about where they live

- there are not enough things for people with profound and multiple learning disabilities to do

- there is not enough support for people with profound and multiple learning disabilities and their families if they live in the family home.

What we think should happen next

There should be more staff with the right skills to work with people with profound and multiple learning disabilities.

All carers should get enough short breaks. The short breaks should be right for them and the person they care for.

There should be one place for people to get all the information they need about support services.

There should be better support for older carers to help them decide what is best for them and the person they care for.

People with profound and multiple learning disabilities should have more choices about where to live.

Everyone with profound and multiple learning disabilities should

- get all the healthcare they need
- have a special health check every year
- have some plans that talk about what they need and want

- have a book they can carry with them to tell other people what they need.

There should be better things for people with profound and multiple learning disabilities to do in their local area.

More people with profound and multiple learning disabilities and their families should be able to choose their own support. They should also be able to decide how to spend the money they get for their support.

Young people with profound and multiple learning disabilities should still get the right support when they start to be an adult.

People with profound and multiple learning disabilities should have an advocate if they need one. An advocate helps people to speak up.

Support services should work better so that

- families do not have to wait a long time for support

- staff always have the right information about the people with profound and multiple learning disabilities getting support.

What happens next

Lambeth council and the NHS in Lambeth will look at the list of things we think need to change.

We will write something next year to say what changes have been made.

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