



'Social Care'
**Report on the Lewisham People's
Parliament**
13 December 2019



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This report gives details of the second Lewisham People's Parliament meeting funded by the Big Lottery Community Fund. The Parliament meeting took place at the St Laurence Community Centre in Catford.

The aim of this Parliament meeting was to ask people with learning disabilities what they think about social care in Lewisham. This is based on:

- A number of issues raised by people with learning disabilities at our People's Parliament elections in September 2019
- The work of Lewisham self-advocates with Learning Disability England and Nesta UK on a social movement for health
- Our experiences of providing 1:1 advocacy to individuals with learning disabilities
- Current affairs around the future of social care in the UK

The Parliament meeting was well timed, as it happened on the morning after the general election. Everyone was waking up to a new government, so it was a good time to ask for opinions on social care.

The meeting was chaired by People's Parliament rep Peter with support from Marsh.



The Parliament meeting

Peter opened the meeting and told everyone what would happen.



The meeting started with talks from two guests. Emer O'Riordan is a psychology student from Kent. She is working on a research project looking at how people with learning disabilities use benefits.

She said that she wants to know what it is like for people with learning disabilities to use benefits. She would like to ask people questions about their experiences of using benefits. Emer asked if anyone wanted to volunteer to be interviewed about their benefits. Emer said she would be at the Parliament meeting all day and that anyone could speak to her about being interviewed. Some people said they would like to be interviewed.



Tom Bird from Lewisham Council spoke about how the council has to look at who runs learning disability services.

Every 4 years the council has to ask different providers to say how they would run a good service. The council has to make sure that they are getting good value for money. Tom talked about it being like a competition.

This is called 'retendering'. There are lots of complicated rules about how it all works. The council has to make sure all the providers who want to run the services are treated equally.

People with learning disabilities can be involved in interviews with the different providers. They can help to choose who gets to run the services, like supported living houses.

Tom said this will start in January 2020 with 12 supported living houses.

After the guest speakers had finished, the chairperson Peter told everyone about what we would be talking about. The subject for the day was social care.

Peter explained that this means the support that people get. Peter said that this was a chance for everyone to tell the new government what they think about social care.

Peter asked everyone to go to the workshop that they had chosen when they signed in for the Parliament meeting. There were 4 workshops:

- What makes good support?
- Not getting enough support
- Paying for your support
- The future of social care

The workshops and what people said

Each of the four workshop groups talked about their different subjects. Each group tried to come up with '4 things we say' and '4 things we want to change'.

After the workshops all the groups came back together and shared what they had said.

Green workshop 'What makes good support?'

This group talked about what good support means to them. The group facilitator also tried to have a discussion about what people thought about social care work being a registered profession. This was a difficult idea for the group to think about, so they didn't really have any views on this subject.

What we say about good support

- Good support is about help to meet people, make friendships and make the right kind of friends
- Good support is about helping you to find work
- Good support about is about people you trust and who let you make the decisions about your life
- Good support is about having help to go out and do the things you like

- Good support is about helping you with your money

What we want to change about support

- More funding to go on trips
- More planning about the things that are important to us
- More support with friendships and social life

Blue workshop 'Not getting enough support'

This group talked about the problems they face from not getting enough support. They talked about how this makes them feel. People in the group said they get less support now than they used to.

They said this stops them doing the things that they want to do. They do not have enough time to do things like ironing or cook proper meals. They find it more difficult to travel longer distances, for example outside of London. There is not enough support for people to go out on their own with support staff.

The group facilitator used objects of reference to help people think about the Care Act. The group looked at the reasons why people might get support under the Care Act. The group talked about whether this was enough support for them to live a good, full life.

There was a feeling that only the most basic needs are met and that things that have a big effect on wellbeing like friendships, relationships, holidays and being part of the community are ignored. People felt that sometimes they do not get the chance to learn new skills or make progress in their lives because they get very little support. Some people do not get any support at all.

What we say about not getting enough support

- There is not enough support to keep a clean and safe house
- There is not enough support to connect all people to their community. People felt that relationships and friendships were not seen as important
- There is not enough time and understanding from services and the council
- There is not enough support with accessibility and people do not always get treated with respect

What we want to change about not getting enough support

- We want 1 hour's support for 1 meal. People felt that there is not enough time for them to cook healthy meals or to learn how to cook for themselves. There are too many microwave ready meals eaten because there are too few hours' support
- Stop cuts to services and support hours. People felt that they are too often forced to rely on family support. This makes people with learning disabilities feel less independent than they would like
- We need holidays and want more choice about holidays
- We want to be supported to have long term goals with graduated support to achieve the goals

Red workshop 'paying for your support'

This group talked about paying towards the support they get, sometimes called care charges. Before the parliament meeting we collected some stories about people who have to pay some money for their support.

The group facilitator read out one of the stories about a man with autism who can't live the lifestyle that he had before. The person doesn't understand about care charges, but he blames the staff for not supporting him in the way they used to do before he had to pay.

The group felt that this kind of example was unfair. They felt that the government does not care about people with learning disabilities. They said they do not understand why the council is demanding people's money.

The group looked at some parts of the council's policy on charging. This says that information will be given to people in a way that is easy to understand. It says that the amount people pay will be looked at every year. It says that people will be sent a new bill every year.

People felt that they didn't get enough information about the charges they have to pay. They do not understand how things are worked out and they feel that charges are not explained properly to them. Several people said that they do not see bills or receipts for their charges.

What we say about 'paying for your support'

- The only time we see a receipt is on the bank statement
- We don't know how it is calculated
- The amount you pay goes up unfairly when benefits increase
- You should have more time to pay if you can't afford it

What we want to change about 'paying for your support'

- We want people to sit with us and talk about our bill
- We want letters and information in easy read format
- We want regular assessment every year
- We want more information about charges and how they are worked out

Black workshop 'the future of social care'

This group talked about what social care means. They talked about it being to support you to live a good life in your home.

The group talked about what might happen with social care in the future. The group spoke about the new government that had been elected the night before the parliament meeting.

The group agreed that this was good time to tell the new government what they thought about social care.

People in the workshop looked at some points made by a group called Social Care Futures. The group talked about some of the ideas that this group has put forward. Some of the ideas were quite hard to understand so not everybody could say what they thought.

What we say about 'the future of social care'

- At the moment vulnerable people are isolated
- Social care is about seeing people's qualities, not just their needs
- We know what good social care looks like and we should be listened to by government
- We want social care to be more creative and to find new ways of doing things

What we want to change about 'the future of social care'

- We want more money put back into social care not just the NHS

- We want people with learning disabilities who used to get support to have support again
- We want social care to be more tailored to people's individual needs
- We want to change the 'story' on social care and not just see people as 'users'. Good social care is good for everyone in society

What will happen next?

This report will be sent out to lots of people, including bosses and councillors in Lewisham. We will send the report to Learning Disability England so that it can be shared around the whole of the country.

The Lewisham People's Parliament reps will ask to talk about the report with:

- Councillors at Lewisham Council
- Bosses at the service providers
- The new Lewisham Disabled People's Commission
- The government Minister for Care Caroline Dinenage

The People's Parliament reps will ask these people what they can do about the things raised in this report.

On the next page you can find out more about who came to the People's parliament meeting and what they thought about it.

If you have any questions about this report please contact Marsh Stitchman, self-advocacy coordinator on 020 8692 1862 or at martin.stitchman@lsup.org.uk

You can find out more about the Lewisham People's Parliament at www.lsup.org.uk





Who came to the Lewisham People's Parliament?

48 people with learning disabilities came to the Parliament meeting.

Total number of people with learning disabilities	48
Gender	
Male	26
Female	22
Disability	
Learning disability	35
Autism	2
Mental Health condition	1
Unknown disability	10
Ethnicity	
Asian	2
Black	8
Mixed	1
White	18
Unknown Ethnicity	19
Age Range	
18 -24	2
25 - 44	14
45 - 64	14
65 -74	1
75+	0
Unknown Age	17
Sexual orientation	
Bisexual	1
Does not wish to disclose	3
Gay	0
Heterosexual	7
Unknown sexual orientation	37

What did people say about the parliament?

We asked people with learning disabilities to rate the parliament by using face stickers. 43 out of 48 people (90%) put up a sticker. This is what they thought about the parliament elections meeting:

Stickers	Number of stickers
Yellow smiley face (good)  =	43
Red sad face (bad)  =	0
Total of all stickers  +  =	43