



# **'Mental Health Report of the Lewisham People's Parliament June 2025**

**This report is written in plain English**

## **The Lewisham People's Parliament**

The People's Parliament is here to represent the views of people with learning disabilities who live in Lewisham. It is a project run by Lewisham Speaking Up and it is currently funded by the City Bridge Foundation.

There are six Lewisham People's Parliament reps who are elected by other people with learning disabilities. They are paid above the London Living Wage for their work with Lewisham Speaking Up.



## **Background to this report on Mental Health**

This Lewisham People's Parliament was held to find out what people with learning disabilities think about mental health services.

This topic is always requested by our members, so we try to come back to it when we can. Our last People's Parliament on mental health was in December 2023. In that People's Parliament, people said they wanted more opportunities to talk about mental health. People also said that mainstream mental health services need to have more training for working with people with learning disabilities. People with learning disabilities are more likely to have a mental health issue than people without learning disabilities. At any time, 36% of people with learning disabilities have a mental health problem. For the rest of the population, this is only 17%.

Earlier this year, we had two Big Groups about managing anxiety and managing low mood. People said it is getting harder to manage their mental health because the news is really difficult to listen to. They also said that the cost of living means it is harder to do things for mental health, like activities with friends, or therapy.

Our men's and women's group talk about mental health regularly, and they often share strategies for managing mental health.

We have been working with My Life My Choice on their We Can't Wait campaign. It is about prioritising people with learning disabilities on NHS waiting lists to stop them from dying before their time. We have been focusing on physical health, but our reps said that we need to campaign about waiting lists for mental health services too, because it can be dangerous to wait on a waiting list without any support.

## The Parliament meeting



**Dinesh chairing the meeting**

The meeting was held in the Lewisham Council Chamber. We would like to thank Lewisham Council for letting us have the rooms for our meeting.

We invited people to join us on the 6<sup>th</sup> June and 48 people with learning disabilities came in person.

This included guests from Generate Voices, Advocacy In Greenwich and Bromley Together. We would like to thank them for joining us.

The meeting was chaired by People's Parliament Dinesh Sattee.

Dinesh welcomed everyone to the meeting and went through some ground rules. Then he made a speech to open the Parliament.

Dinesh said that we would be talking about:

- What mental health support is there for people with learning disabilities and autistic people?
- What can we do to get people with learning disabilities out of long stay hospitals?
- How can people with learning disabilities be more involved in decisions about their treatment?

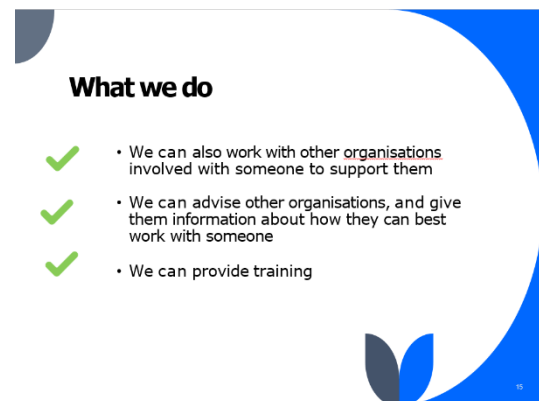
Dinesh shared his experience of struggling with his mental health after the death of George Floyd in 2020. He said it is very challenging to get specialist mental health support now, because services aren't funded enough and so many people need support.

Dinesh said it was really important that we all took care of each other while talking about this, and told people to speak up and ask for help if they are struggling.

**Dinesh then introduced our first guest speakers: Julie, Lauren and Louise from South London and Maudsley mental health and learning disability team.**

They told us about their mental health services, that work with people with learning disabilities who can't access mainstream services.

They help people who are feeling sad, angry, worried or scared, or who are worried about their behaviour. They also work with people who might have dementia.



**A slide from the SLAM presentation**

They give people support and advice, and give support and advice to their family. They put together a care plan with people, so that they can work towards recovering.

They also talk to people about medication and help people decide if it is right for them.

People can phone the team if they would like support, or ask their GP, a family member, friend, carer or social worker to refer them.

The team then answered some of our questions. People asked the following questions:

- What counselling services do you have?
- Do you have to have been in hospital for mental health support?
- Is the referral from written in Easy Read?
- Do you work with Oxleas hospital trust – they don't have a mental health and learning disability team anymore
- Are there drop in places in the community where people can go to talk about mental health?
- People are tired of getting tossed around the system, why can't we have specialist services from the beginning?
- Are there services for autistic people?

### **Then Dinesh introduced a video from Ady and James from My Life My Choice**

Ady and James were going to join us in person, but they had an emergency. Instead they sent a great video of their presentation!

They told us about their Don't Lock Us Away campaign. The campaign is trying to get people with learning disabilities out of long-stay hospitals.

They asked us to tell the person next to us what we have done since February 2020. Then they said that the average time somebody with a learning disability spends in a long-stay hospital is 5 years and 3 months.

They told us about their colleague, who was in a long-stay hospital. She now lives on her own and is much happier.

Ady and James went to a protest on the 29<sup>th</sup> April. They handed in a letter to the department of health about why people with learning disabilities should live in the community, not in long-stay hospitals!

Ady also supports people who are in hospital, sending them letters and talking to them so they know their rights.

They asked us if we would support their campaign. Everyone gave them a massive clap and said yes!



They asked if we had any ideas for how to get people out of long stay hospitals. We said:

- There should be a financial punishment for keeping people in hospital too long without having a plan for them to move back home. The CQC should be involved in this.
- The media should share what it is like in hospital, like the Winterbourne documentary
- There should be a self advocacy group set up in hospitals



**Ady presenting his campaign**

**Dinesh then invited everyone to join one of three workshops:**

- A workshop on 'accessing mental health services'
- A workshop on 'medication for mental health'
- A workshop on 'suicidal thoughts'

Thank you to South London and Maudsley mental health and learning disability team for leading our workshops.

## **Workshop 1 – Accessing mental health services**

Why aren't mental health services always accessible for people with learning disabilities?

- Face to face appointments aren't always offered
- Some services don't give you a chance because you have used the system too many times
- It's hard to get easy read information
- Not everyone can get the information online
- Lots of services only have online self referral forms
- Getting an appointment with a GP is hard, and getting a referral from the GP is even harder

What challenges do people have with accessing mental health services?

- There are not enough services out there
- Some people can't go out and need a home visit from the mental health team
- The waiting times for appointments are too long
- People not listening to your needs
- It feels like no one helps unless you say you are having suicidal thoughts
- Mental health training is too expensive
- People's voice gets lost, there is more focus on facts than feelings
- It's not easy to talk about your mental health and it takes time

What do people with learning disabilities need to access mainstream mental health services?

- More money
- More services
- Support to speak up
- To feel like people will listen
- Less waiting
- More training for staff on learning disabilities and mental health



## **Workshop 2 – medication for mental health**

What do people think about medication for mental health?

- I take medication for anxiety and it helps me
- Medication can help, but so can mixing with people and doing things. There's more to it than just medication
- I went into hospital because I was down and depressed and self harming. I didn't need any medication
- It's important to go to your medication reviews. I used to find them stressful but now it's helpful
- I live with someone with mental health issues and when they shout it can affect me. Their medication helps me and helps our relationship
- It's important to let your staff know that you take medication

How can people with learning disabilities be more involved in the decision to take medication for their mental health?

- People need to know the risks and benefits. They need lots of time to go through this with a doctor
- People need to know the other options
- The other things they want to do shouldn't be forgotten, like if they want to do therapy or more activities. We shouldn't say the problem is fixed just because someone is taking medication
- People should have a plan to come off medication if they want to
- Everyone should have a medication care plan for themselves and their staff. It's useful for people who are non-verbal. It should be in Easy Read too, which South London and Maudsley can do for you.
- People need to know about the STOMP campaign to stop over-medication for people with learning disabilities with mental health issues.



**Workshop 2 feeding back from their discussion**

### **Workshop 3 – suicidal thoughts**

This was a difficult topic to talk about but people said they were glad they got the chance to. We want to say thank you to everyone that took part in this group and looked out for each other.

What do we want to share about suicidal thoughts?

- Painful experiences can trigger off feelings
- Death is a topic that we all need to face, but it is difficult
- Time is a healer – it does get better

Why is it difficult to ask people about suicidal thoughts?

- They are intense and painful
- They can be caused by professionals like staff or advisers – words are important so be careful what you say to people
- They can be hard to admit
- It can be hard to hear that someone you care about is struggling in this way

What support can we get if we have suicidal thoughts?

- Talk to your family
- Go to A&E. This can be hard, and professionals need to be trained in autism and learning disability awareness
- Lewisham Gateway – this is the safeguarding team
- Ring 111 because they can arrange an appointment for you at A&E
- The police can do a welfare check
- Ring Samaritans on **116 123**
- The crisis number for Lewisham is **0800 731 2864**

How can we support each other?

- Advocacy groups should link up and talk together about death, because we need to support each other
- More people should have mental health first aid training
- Remember that mental health builds up over time. The sooner someone gets support, the better
- Be compassionate with people. Try not to get frustrated if it feels like they're not listening to you
- Small details are important
- Check in with people regularly if you are worried about them
- Take care of yourself, because it can be difficult to support people with. Don't do it on your own – tell someone.

**For the first time, we had an art exhibition in the Foyer. We displayed art and poetry by people with learning disabilities about mental health.**



**Ifeoma Orjiekwe** is an artist with Heart n Soul, Touretteshero and is a Lewisham Speaking Up rep. She shared some of her art from our big groups.

**Hannah James** is an artist, dancer and is the Associate Director at Entelechy Arts. This artwork was done with the support of her mentors, Jo and Ames.



**Maria Bialowas** displayed art work and poetry that she has done with The Albany. She says that poetry and art helps her express things that she can't always put into words, and it helps her feel calmer. The poem is written here:

### Roses

I am sleeping  
With my head  
In the ditch  
But  
I am Smelling  
The Roses

We also displayed **Lloyd Page's** poem, about his journey as a self advocate and what it means to him:

I was born in 1959.

I started in Downham where I spent my time.

I went to a school called Pendragon.

I told jokes to the students, it was a phenomenon.

They made me go to a day centre with a mate.

This made me angry and so full of hate.

I had a voice, and I wanted to be heard.

So, I would feel free like a bird.

I became a self advocate for Lewisham speaking up.

I also became a campaigner for Mencap.

They were so good to me.

I would give all of them an OBE.

Then I met my good friend Jim Blair.

I like him so much; he treats me fair.

I now speak at conferences all over the place.

I spread the good word with great grace.

I help write books for Peter and Friends.

Spreading the word so it transcends.

I have a good friend called Steve with whom I teach.

But we promise that we won't preach.

People with learning disabilities all have rights.

We have talents, we will shine in the light.

## Summary

Mental health is frustrating to talk about, because people with learning disabilities don't feel there is enough support when they need it. But, people said that we should be talking about it more, and we should support each other because we all have experiences with mental health problems.

Mental health services are not meeting the needs of people with learning disabilities. People are finding it hard to get a referral because GP appointments are difficult to get, and sometimes staff and services they are working with don't listen to their concerns. When people are referred, their waiting times are too long, and a lot of people shared their concerns that the wait time makes mental health issues worse and more complicated. People said that they are not getting any help until their situation is an emergency.

When people do finally get mental health support, many people said that they haven't felt listened to, and they have been turned away because they've used services too much. People with learning disabilities don't feel that they are given enough time to get better from services, and they don't feel that mainstream services understand learning disabilities or autism enough.

People with learning disabilities need to be more involved in their treatment plans. Lots of people said that their voice gets lost, because there is more focus on preventing an emergency. People with learning disabilities need time and compassion to share what they are experiencing in whatever way they can. People with learning disabilities also need to understand their treatment so they can be involved in the decisions about it. This means that they need Easy Read information about things like medication, and they need time to go through this with professionals. People should be given a proper chance to understand the risks of different medications, and shouldn't be given something that hasn't been properly explained to them!









Nobody at our People's Parliament shared that they had been to a long-stay hospital. Some people shared that they went to a mental health hospital for a short time. But we were not happy to hear that people with learning disabilities are staying in hospital for an average of 5 years and 4 months. People said that it is important that this stops. Mental health treatment is supposed to be about helping people live the life that they want to live. This means supporting people to live in the community, and making sure their voice is put at the centre of their care.

### What did people say about the Parliament?

To evaluate the success of the People's Parliament on Money and Benefits, we used an accessible method with facial expression stickers.

We asked people with learning disabilities to rate the Parliament by choosing a face sticker. 39 out of 48 people (81%) put up a sticker. This is what they thought about the Parliament meeting:

Stickers	Number of stickers
Yellow smiley face (good)  =	<b>36</b>
Orange unsure face (in the middle)  =	<b>2</b>
Red sad face (bad)  =	<b>1</b>
Total of all stickers  +  +  =	<b>39</b>

## What Next?

These are the things that the People's Parliament will do next:

- Send this report to Local Members of Parliament, Lewisham Council, service providers in Lewisham and other people who may be interested
- Share this report with the South London and Maudsley team, both the learning disabilities team and other teams
- Present this report to the Lewisham Learning Disability Partnership board and the "Health and Wellbeing" subgroup
- Send this report to Learning Disability England and other self-advocacy groups around the country
- Join the Don't Lock Us Away campaign to help get people out of long-stay hospitals

For more information or to discuss anything to do with this report, contact Lewisham Speaking Up.

Email [info@lsup.org.uk](mailto:info@lsup.org.uk)

Web [lsup.org.uk](http://lsup.org.uk)

August 2025 © Lewisham Speaking Up