



'Mental Health'

**Report of the Lewisham People's
Parliament December 2023**

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 in various ways, including from the South East London Integrated Care System.

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.

Learning disability is often confused with a mental health condition, when in fact they are two very different things.

People with learning disabilities are just as likely to have mental health issues as non-disabled people. Some studies have shown that people with learning disabilities are even more likely to have mental health issues.

We have known for a long time that people with learning disabilities often have worse health than other people. This is especially true for people with learning disabilities from ethnic minority backgrounds. We believe this is also true for mental health.

We have worked with the SLAM (South London and Maudsley) Mental Health in Learning Disabilities team for several years.

This was our third People's Parliament event on mental health and we were really pleased to work with SLAM psychologists and trainee students again. We would like to thank them for helping to put on a great event.

The Parliament 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 14th December and **33** people with learning disabilities came in person.

The meeting was chaired by People's Parliament rep Mary Hamilton.

Mary chairing the meeting

Mary welcomed everyone to the meeting and went through some ground rules. She then made a speech to open the Parliament.

Mary said that we would be talking about:

- Worrying and being stressed
- Feeling low
- How best to look after ourselves

Mary said that lots of people worry and have stress and want to know what they can do to cope with stress.

Mary also said that people want to know how to deal with feeling low and what they can do to feel better.

Mary introduced our guest speaker for the day, Grace McGill from SeeAbility.

Grace said that she was the London Eye Care Champion for SeeAbility. They are an organisation that helps people with learning disabilities to get better eye care.

They have a new programme in South East London that helps people with learning disabilities get better support from opticians.

This is called the Easy Eye Care service. You can ask your GP or optician about this if you want to know more.

Grace also told everyone about a condition called Charles Bonnet Syndrome.

This can cause people with sight loss to see things that are not really there.

Grace said she saw spiders and when she told people they thought she was having mental health issues. She was actually seeing things because of Charles Bonnet Syndrome.

Some of the psychologists from SLAM had not heard of this before. They said they would go away and learn more about Charles Bonnet Syndrome.



Grace from SeeAbility doing her presentation

Mary then invited everyone to join one of two workshops:

- A workshop on 'Feeling Low'
- A workshop on 'Anxiety'
- A workshop on 'Wellbeing'

You can read what people said in the workshops on the next pages.

Workshop 1 – Feeling Low

This workshop was led by the Mental Health in Learning Disability Team from SLAM.

The group in this workshop talked about feeling low and what that means. These are some of the things the group said they think of when they hear the words 'low mood':

- Depression
- Nervous breakdown
- Shutting yourself off
- Mood swings
- Aggression
- Self-harm
- Not eating
- Eating too much
- Suicidal feelings
- Feeling sick
- Being snappy
- Up and down emotions
- Feeling unhappy
- Crying
- Feeling destructive

What we say about feeling low

These are some of the things people in the group said about feeling low:

- Anxiety and depression is the worst thing. It's good to talk
- When I talk about feeling low, I feel like I'm not listened to
- IAPT haven't helped me at all
- Sometimes I feel like I can't go out because I don't know how I will be accepted in society
- Sometimes when I'm feeling down, I tense up and don't talk
- When I'm stressed I go to the toilet more
- I get very tired when I'm feeling down
- Sometimes I feel like I am a bad person
- Losing someone in your life can make you feel down
- Money worries can make you depressed

What we want to happen about feeling low

The group spoke about what helps when you are feeling low. Most people said that talking about things helps. They said you can talk to friends, staff, advocates, doctors and psychologists.

People said there were other things that could help.

This is what people said they wanted more of:

- More time with your GP
- More reasonable adjustments with health appointments
- Having a routine of healthy eating and exercise
- More groups that you can join to help your mental health
- Having more choice and control in your life
- More standing up for your rights
- More support for people with special needs



One of the workshops at the People's Parliament

Workshop 2 – Wellbeing

This workshop was led by the Mental Health in Learning Disability Team from SLAM.

This group talked about how to look after your mental health in general.

They talked about an idea called the wheel of wellbeing. This is a way of thinking about everyday things in your life that can make you feel better. There are six parts to the wheel of wellbeing.

They are:

- Your body, which is about being active and doing things like exercise
- Your mind, which is about using your brain to keep learning new things, like going to classes or doing hobbies
- Your spirit, which is about giving back, by doing things for other people or for the community
- People, which is about connecting with other people like friends and family or making new connections
- Places, which is about taking notice of where you are, getting out and enjoying places you like to go
- Planet, which is about doing things to care for the world, like being environmentally friendly or more 'green'

This group talked about things that they do already like:

- Going to the gym (body)
- Doing puzzles (mind)
- Listening to music (mind)
- Exercise (body)
- Connect with people (people)
- Being with family (people)
- Staying active (body)
- Distracting themselves by going out (places)
- Learning new skills at work (mind)
- Learning about new people (people)

They also talked about things that they would like to do more of:

- Learning new exercises
- Learning more about ourselves, our bodies and our minds
- Learning to adapt things for myself
- Learning to find time for ourselves
- Learning to be compassionate to ourselves

Workshop 3 – Anxiety

This workshop was led by the Mental Health in Learning Disability Team from SLAM.

The group in this workshop talked about anxiety and what that means. These are some of the things that the group said about anxiety:

- You feel sweaty and hot, aggressive. People invading your space and you want freedom
- Sweaty hands, a lot of tension. Violent thoughts and verbally aggressive, swear words
- Panic attacks, difficulty in breathing, headache. You want to run away
- Breathing too fast, you get worried and feel breathless
- It's scary, sometimes chest pains or palpitations
- Feel like self-harm or hurting others
- Our blood pressure can get high
- Pins and needles in your hands
- Lack of appetite
- Lack of sleep
- Don't want to do anything
- Lack of concentration

The group spoke about things that cause anxiety like:

- Covid Lockdown
- Bullying
- Institutional racism
- Cost of living crisis

The psychologists from SLAM explained that anxiety is a normal thing for people to experience. They said that when your body reacts to stress it sends a message to your brain to either get ready to fight or run away. This is known as 'fight or flight'.

This means that a lot of blood rushes around your body and brain and makes you feel anxious.

People in the group said it was good to talk about anxiety to your friends and family and health professionals like your doctor or mental health staff.

People said that there were things that helped them to deal with anxiety. They were:

- To go for a walk
- Listen to music
- Go swimming
- Eat chocolate
- Avoid crowded places
- Cry it out
- Writing down your feelings
- Have a chat with your friends
- Avoid watching the news on TV
- Doing a colouring book
- Try and focus on something else



Feeding back what was said in the workshops

Summary

People with learning disabilities do not find it difficult to talk about mental health. This is always a popular subject in our groups and people always seem happy to discuss mental health issues and what can help when you are unwell.





People with learning disabilities would like to have more chances to talk about mental health. We will try to create as many opportunities as we can for this to be discussed.

We think that mainstream mental health services should have more training about learning disability and how they can support people to use their services.

What did people say about the Parliament?

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

We asked people with learning disabilities to rate the Parliament by choosing a face sticker. 27 out of 33 people (82%) put up a sticker. This is what they thought about the Parliament meeting:

Stickers	Number of stickers
Yellow smiley face (good)  =	27
Red sad face (bad)  =	0
Total of all stickers  +  =	27

What Next?

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

- Send this report to the Mental Health in Learning Disability Team at SLAM
- Send this report to Local Members of Parliament, Lewisham Council, NHS bosses, service providers in Lewisham and other people who may be interested
- We will continue to work with the Lewisham Learning Disability health stakeholder group. We will support people with learning disabilities to be a part of the forum. We will help them to understand what is going on in Lewisham
- We will join with other self-advocacy groups that are already campaigning about health inequalities for people with learning disabilities

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

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