



**Evaluation of the Lewisham People's Parliament on  
'Our Health'**

**July 6<sup>th</sup> 2018**



## **Evaluation of the July 2018 parliament on 'Our Health'**

### **Background**

This report gives feedback on the Lewisham People's Parliament on 'Our Health' on July 6<sup>th</sup> 2018. It gives information on who came, what was talked about in the workshops, what changes people would like to see and how people evaluated the parliament.

This parliament meeting was held to follow up on a similar health parliament that took place in June 2017. The subject of health is particularly relevant in light of the release of the LeDeR report in May 2018 which has highlighted serious health inequalities for people with learning disabilities.

We also wanted to follow up on some of the changes that people wanted to see at the parliament in 2017, especially 5 recommendations that had been made to Lewisham University Hospital in October 2017.



**People take their seats at the parliament.**

The parliament was opened by chair-person Kali, one of six elected People's Parliament Reps. Kali introduced the new Mayor of Lewisham, Damien Egan, who officially opened the parliament meeting. The mayor spoke about the importance of people with learning disability speaking up and being listened to. He said 'The Lewisham People's Parliament allows us to know what matters to you and it means the people in power are able to listen to what people with a learning disability have to say.'



#### **Mayor Damien Egan opens the People's Parliament**

There were also two other guest speakers. Carrie Tse from Leonard Chesire Disability spoke about the Can Do project. This is a volunteering programme for young people to develop new skills and meet people. The programme also helps to change attitudes to

disabled people. Carrie said they are looking for people with learning disability to join their steering group and help them plan what to do in the future.

Our other guest speaker was Edith Scott from Three Cs. Edith spoke about the Transforming Care Programme which is about people spending less time in special hospitals if they have poor mental health. Edith runs the South East London forum for Transforming Care. This is a meeting where people with learning disability and their families can have a say about services and what is and isn't working. Edith said that she was looking for people to join the group. She said that anyone who was interested would have to meet certain conditions and that people could ask her about it as she would be at the parliament all day.

### **How many people came to the parliament?**

Learning disabled people were asked to sign in and register for the parliament as they arrived. People were asked their age and gender when they signed in. People were also given a coloured name badge so they would know which workshop to go to.

### **Numbers of people at the parliament**





<b>Ages</b>	<b>Numbers at parliament</b>
Age 18 -24	1
Age 25 - 64	46
Age 65+	0
<b>Total</b>	<b>47</b>
<b>Gender</b>	<b>Numbers at parliament</b>
Female	22
Male	25
<b>Total</b>	<b>47</b>

## What did people think about the parliament?

At the end of the workshops, learning disabled people were asked to say what they thought of the parliament using smiley face stickers. People were asked to choose a sticker and place it on a flip chart.

35 stickers were put on the flip chart. This means that 74% of people with a learning disability put up a sticker.

31 people said the parliament was good (89%) and 4 people said the parliament was bad (11%).

Stickers	Number of stickers
Yellow smiley face (good)  =	<b>31</b>
Red sad face (bad)  =	<b>4</b>
Total of all stickers  +  =	<b>35</b>

## The workshops and what people said.

The main focus of the day was on workshops. There were 4 workshops on different subjects. They were:

- **Annual health checks** led by Jackie Downing, deputy head of nursing at Guy's and St. Thomas's NHS trust, Noor Butt, Primary care commissioning manager at Lewisham CCG and Marzena Zoladz from Lewisham Healthwatch.

- **Changes at Lewisham Hospital** led by Eunice Onaiyekan, Learning Disability Nurse at Lewisham Hospital
- **Good Mental Health** led by Dr Annabel Head, clinical psychologist at Lewisham mental health and learning disabilities service.
- **The LeDeR report**, led by Marsh Stitchman from Lewisham Speaking Up

The workshops took different formats, but the aim was to discover what people with learning disability thought needs to change in relation to that subject. This is what people said about the four areas.

### **Annual health checks**

This workshop started with a presentation about what annual health checks are and how they work. People then had a discussion about who has had an annual health check and what might make them easier. This is what people said they wanted:

- Explain why we need a health check
- The right support from staff
- A reminder phone call, text or letter
- Appointment letters in braille and easy read
- Appointments at a sensible time (that we choose)
- To see the same health professional each time
- To have health checks at home

### **Changes at Lewisham Hospital**

This workshop was a follow on from the health parliament in 2017. After that event, People's Parliament reps attended a meeting at Lewisham Hospital where they made 5 recommendations that would

make using the hospital easier for people with a learning disability. Eunice Onaiyekan is the Learning Disability Nurse at the hospital and she came and spoke about what things have been put in place so far. The hospital has partly met two of the five recommendations. The group then had a discussion led by a Lewisham Speaking Up facilitator. They spoke about what they wanted to happen at the hospital. This is what they said they wanted to happen:

- Having a quiet room in the A&E department is important
- People with learning disability should be involved in giving training to hospital staff
- There should be a universal hospital passport and it should be bigger than the one that is used now
- People with learning disability should be involved in audits at the hospital
- Hospital staff should talk to people with a learning disability
- The hospital should use Books Beyond Words to help communicate with people

## **Good Mental Health**

This workshop introduced the group to the 'wheel of wellbeing' which is a tool for helping to think about what you can do if you have low mood. The wheel is divided up into six different areas. The group talked about each area and how it can help you feel better. There was a discussion about what can help people when it comes to having good mental health. This is what people said they wanted:

- Less stress and more mindfulness. A chance to learn mindfulness and other ways to stay calm.
- More opportunity to talk to people
- More help to talk to people like psychologists

- More reassurance and support when going to health appointments. Someone to go with you to appointments
- Knowing where to go if you are hearing voices or feeling sad
- A special group about mental health for people with learning disabilities
- Books Beyond Words to help people prepare

## **The LeDeR report**

This workshop looked at the report published in May by the Learning Disability Mortality Review programme (LeDeR). The report caused some upset in the learning disability world as it found that there are some obvious health inequalities for people with a learning disability. It highlights that on average, people with learning disability have a lower life expectancy than the general population. The report makes several recommendations and at the time of the parliament, neither the government nor NHS England has made any comment.

Another figure getting a lot of publicity is that there are an estimated 3 people with learning disability dying avoidable deaths every day.

The workshop group had a discussion about the report and what should happen. This is what they said should happen:

- We want the programme looking into why people are dying early to carry on forever or until things get better
- We want proper funding for looking into deaths
- We want all self-advocacy groups to ask to meet with Jeremy Hunt and Theresa May
- We want to raise the issue with the media – BBC, Channel 4 and The Guardian
- We want self-advocacy to be given money. We want the National Forum for people with learning disabilities back



- We want to tell the London forum for people with learning disability our worries about people dying early

### **What will happen next?**

The Lewisham People's parliament reps will be asking to meet with people to tell them about what was said at the 'Our Health' parliament.

Parliament reps have already been invited to the Lewisham Safeguarding Adults Board so they will take the issues raised to that meeting. We will also be asking to meet with other health managers in Lewisham to ask them what they plan to do about the things raised in this report.

We want to let everyone know that people with learning disability have a right to be listened to and a right to a good life.

**If you would like to discuss this report or have any questions please contact us: [martin.stitchman@lsup.org.uk](mailto:martin.stitchman@lsup.org.uk) 020 8692 1862**



**Marsh (Martin) Stitchman, May 2018.**

**Lewisham Speaking Up self-advocacy coordinator.**