



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

**June 2017**



## Evaluation of the June 2017 parliament on Health

### Background

This paper gives detailed feedback and results about the Lewisham People's Parliament on health on June 23<sup>rd</sup> 2017.

It gives information on what people expected from the parliament, what was talked about in the workshops, what changes people would like to see and how people evaluated the parliament.

The parliament was held at Catford Civic Suite with the main business taking place in the council chambers. .

The focus of the parliament was on 'day to day' healthcare, mainly using GP and hospital services. In February 2017 the parliament reps agreed that we would work with National Mencap on their campaign for better health treatment for people with learning disability. The parliament was the first part of that joint work, to be followed up in July and August by another 2 workshops.



The parliament starts in the council chamber.

There were five workshops planned for the parliament covering:

- Visiting your GP and getting an annual health check
- Going into hospital
- Accessible information and healthcare
- Your rights to good hospital treatment
- A story based workshop about healthcare for people with high support/communication needs

As people arrived and signed in they were also asked to choose which workshop they would like to go to. A system of colour coded name badges was used so people would find it easy to know which workshop they should join.

The parliament was opened by chair person Kali, one of six elected People's Parliament reps. Kali introduced three guest speakers. The first was Josie and Eve from Royal Mencap Society. Josie has a learning disability and she spoke with Eve about what Mencap is planning as part of their health campaign.

The second guest speaker was Jane Abraham who has been supporting learning disabled people to check health services in Lambeth. Jane told the parliament about working with Healthwatch Lambeth to do 'Enter and view' visits. Unfortunately, the people with learning disability that should have presented with Jane could not make it on the day, so she did the presentation by herself.

Our final speaker was Colin, another of our parliament reps, who had spent several weeks in hospital last year. Colin did a live onstage interview with our advocacy service manager, Will. Colin answered questions about what had gone well with his hospital treatment and what could have been better. The main thing that helped Colin was getting good support from a learning disability liaison nurse.

## Part 1 How many people came to the parliament?

Learning disabled people were asked to sign in and register for the parliament as they arrived. People's age group and gender were collected at this point.

<b>Ages</b>	<b>Numbers at parliament</b>
Age 18 -24	7
Age 25 - 64	48
Age 65+	0
<b>Total</b>	<b>55</b>
<b>Gender</b>	<b>Numbers at parliament</b>
Female	27
Male	28
<b>Total</b>	<b>55</b>

Numbers were slightly down on the last parliament which had 60 people with learning disability; however they exactly match the attendance of the parliament before that. Overall numbers are below our ideal target and we will need to continue thinking of ways to increase attendance at future parliaments.

## Part 2 What did people expect from the parliament?

Learning disabled people coming to the parliament were asked to fill in a questionnaire about what they expected from the parliament. Some people had help to fill in the form. 21 learning disabled people (38%) filled in a form.

Here are the questions and the answers people gave.

### 1. Why have you come to the parliament today?

- To meet people
- Come to listen and find out information
- To talk about speaking up for health
- Because for the health and safety

- We came to listen to the speakers
- I wanted to get out of the house
- To talk about health
- Cause I enjoy it
- I want to know more about voting
- Election
- To listen to what people are going to say today
- Because I like it. It's interesting. I like to speak up.
- To talk about health
- The people's parliament is big
- I like Lewisham Speaking Up
- Listen and talk
- To learn about the healthcare
- To talk about health
- To listen to the speakers
- Because I have a pain in my tummy and neck

## **2. Have you been to a parliament before?**

Yes = 20

No = 1

Don't know = 0

## **3. What do you think will happen at this parliament?**

- I am not sure. I am a bit nervous
- Talking about everything
- Talking to people about health
- I wanted to get a T shirt
- Don't know
- Learn new information
- We have a chair person
- Speaking up about health
- Talk about health

- Health
- I will help people
- Talk about health
- Meet in hall. Greet people. Guest speakers. Workshops.
- Talk about speaking up about health
- I don't know
- I want to feel better about my health. My tummy hurts.
- I can't think of anything
- Discuss things
- Talk about jobs?
- I will learn more about health
- Meeting doctors and nurses

**4. What things do you think parliament meetings should be about?**

- Jobs, housing, more shops
- How to get a job
- Job centres
- Don't know
- Transport, day centres
- Parliament, speaking up
- Relationships
- Hate crime
- Transport
- Hate crime and police
- Relationships
- Painting, drawing
- Jobs
- Hate crime, jobs
- Don't know
- Relationships (girlfriend and boyfriend)
- Appointments

### **Part 3 The video interviews**

At this parliament we tried again at doing some video interviews with people with learning disabilities. 6 people gave a video interview (11%) and below are some of their comments, first about using health services and then about the Lewisham people's parliament itself.

#### **Comments on video about health services**

- I told him (GP) I was sick and they gave me tablets for it, to stop me being sick.
- I had an operation on my legs, it's all good. Sorted my legs out. I'm there.
- Sometimes with the doctors, it takes a bit of time before you have your appointment. Sometimes reception, the people behind the desk in hospitals are not particularly that friendly. I went to hospital once and I didn't know that I didn't have an appointment cos that's why behind the desk didn't help me at all, not until my mum came in and realised that's what happened. So we complained about it.
- (on going into hospital) Well I've been treated quite well. I haven't had any problems at all. I mean all the doctors are friendly, that I know, and they're helping me with all my things and everything.
- (on what needs to change) Well some receptionists, people behind the desk need to have more understanding of people, because some of them the way they run it is more military and they're not particularly helpful to people like me who have like disabilities. Sometimes it's hard to know if you have got an appointment or not. If I'd have gone on my own, I might not realise that I haven't got in at all or be seen.
- I went for some more help, to get more tablets for my migraine and they need to give me some more migraine tablets. It's

quite good, I like it. (About the front desk) the woman is ok you know, they're friendly, it's ok. (About the GP) The doctor is ok to me, sometimes he's friendly but sometimes he's not friendly but he's alright. (About going into hospital) Hospital is ok you know, well you have to wait and wait and wait and wait.

- (On how they were treated) Really good, nice doctor, if I got any problems, I say can I come back and see you and he says yes that's ok. I'm going back in July, because I'm taking tablets for my thorax and the night ones I'm taking as well. The thorax one is putting more weight on and I've got swollen legs, a big fat tummy, a big fat bottom. I'm trying to lose weight and it's so difficult to lose weight.
- (On reception staff) Alright, sometimes, because if I ask something and they say I'll call you back or you have to wait a bit longer. When you phone people up and it takes time, you get a bit of music on the phone and I think that's a bit wrong because they should be there answering the phone for the customers, it wouldn't be too bad then. So yeah, just be there for the customers. Sometimes when you go in there, they're still on the phone. Sometimes I see that as well, when in go in there, to my doctors, they're on the phone and we have to wait behind the counter for them to answer the phone all the time. I think that's not really right.
- Everything needs to be changed about health, people have to care about it and they have to help people to find jobs and not cut services. I'm very upset that disabled people, they don't have enough support and they're cutting the services, cutting everything. It's very difficult for people, I mean I'm saying you need people who help, they need to really help and they need to be looked after. They're cutting everything down, really down. The health service is not really good, it's not enough good.

- (on what would make things better) Give more support, give me good services, not cutting benefits, no cuts to health services. Get more things like more support, more services.
- (on how they are treated by GP) Good, I'm treated very well, because I have depression and stress and have thought about suicide myself. The doctor helps me to speak to him and try to step my life forward, but I think everything has fallen down for me and I'm scared I'm gonna be on the streets soon.

### **Comments on video about the Lewisham people's parliament**

- Well, I enjoy it, one reason is cos I can help out.
- I think it's good and I enjoy coming every time it's on. I think it's a good thing for people with disabilities to come because we have great people to speak about what's going on.
- The people's parliament is ok you know, they're friendly, they're good and all my friends is there. It's for us, it's for disabilities.
- People need to speak up, the groups people work in need to speak up with government. Sit down and talk about what can we do better, what they need to be good services.

### **Part 4 The workshops and what people said.**

Workshops made up the main part of the day. There were four workshops in the morning run by external guests.

- Visiting your GP and getting an annual health check. Led by Ian Ross, associate director of primary care transformation, Lewisham CCG and some of his colleagues.
- Going into hospital. Led by Eunice Onaiyekan, learning disability nurse at Lewisham hospital and Amina Sesay, Community nurse for people with learning disability.
- Accessible information and health care. Led by Marzena Zoladz from Lewisham Healthwatch.

- Your rights to good hospital care. Led by Eve Jackson and Josie Scantlebury from National Mencap campaigns team.
- Interactive story based workshop on health for people with high support needs. Led by Jo Hart from Lewisham Speaking Up.

Each workshop was asked to produce '4 things we say' and '4 things we want' from the discussions that people with learning disability had.



**Feeding back from some of the workshops**

After lunch all of the workshop groups came back together and shared what they talked about. These are the main points from each group.

## Workshop: Visiting your GP and annual health checks



### What we say

- Appointments should be longer
- We get nervous when going to see the GP. Sometimes GPs can be short with us.
- We would like better access to GPs. We would like to get a second appointment straightaway if we need one.
- We do not always know what a health check is for.

### What we want

- For GPs to be more patient with us.
- To have longer appointments
- To be offered afternoon appointments if we need them
- To have home visits if people are anxious about going to the GP surgery

## Workshop: Going into hospital



### What we say

- We don't like injections. We like a cream or spray before an injection.
- Hospital staff help and they care about you
- Hospital passports are good because they tell people about you
- Nurses are good and are very helpful

### What we want

- Waiting times at hospital need to be better
- We want more beds at Lewisham hospital
- We would like the food to be better and a bit healthier
- Communication needs to be easier to understand. Doctors can be very difficult to understand.

## Workshop: Accessible information and health



### What we say

- Doctors don't give you enough time when you see them
- Getting appointments is sometimes difficult
- We don't like to see different doctors
- Not all surgeries or hospitals follow the accessible information standard

### What we want

- We want doctors and staff to be nice and kind
- We want more large print and big writing
- We want to be heard
- We want to be able to have support from parents, carers and key workers.
- We want to be more independent

## Workshop: Your rights to good hospital treatment



### What we say

- We should be treated equally and with respect in hospital
- Staff should communicate better with patients in a way that they understand.
- We have the right to make decisions for ourselves in hospital
- There is not enough staff
- Our experience of hospital is both good and bad

### What we want

- Better trained staff that are kind
- Hospital passports with shared information
- Staff to make reasonable adjustments for us
- We need to be given priority and be seen first

## Workshop: Health care and people with high support needs



### What we say

- The reception staff are good
- Hospital passports are good
- We can get our medication delivered by the chemist

### What we want

- Doctors talk to our parents or support staff. They should talk to us.
- People who live at home with their family may not have a health plan. They and their families should be told about and offered a health plan.
- The waiting can be very long sometimes. We would like shorter waiting times.

## Part 5 What did people think about the parliament?

At the end of the parliament meeting, 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.

24 stickers were put on the flip chart. This means that 44 % of people with a learning disability put up a sticker.

22 people said the parliament was good. (92%)

2 people said the parliament was bad. (8%)

Stickers	Number of stickers
Yellow smiley face (good)  =	<b>22</b>
Red sad face (bad)  =	<b>2</b>
Total of all stickers  +  =	<b>24</b>

## Part 6 What did people say about the parliament?

At the end of the parliament meeting learning disabled people were asked “is there anything you want to say about today?” People were asked to put what they wanted to say on a post it note. They

then stuck the note onto a flip chart. 20 people (36%) said something. This is what they said:

- It was very good
- It was really good. Friendly and great fun
- It was good. I liked the workshop
- Today I liked talking about the NHS employing more people with learning disability
- ☺ Happy
- I liked all of it
- I really liked it today
- The guests explained what they do really well
- The speaking was good, so was the workshops
- It was good
- I feel that hospital staff didn't give me enough information
- It's good. Ian was good and funny
- It was very good and I liked the parliament
- It was really interesting
- It was good workshop
- I'd like more doctors
- I think it's good
- It was good all the things we talked about in the workshop
- Today was good, all of it
- Speaking and the food was healthy

## **Part 7 What have we learnt?**

### **Evaluation**

This was our fourth Comic relief funded parliament. The parliament was successful. 55 people with learning disability came with slightly more men than women. We had 7 people in the youth age range and no-one over 65.

The total number was a little down on last time but we still need to think about ways to increase attendance at the next parliament.

Over the course of four parliaments attendance has always been between 55 and 66 people with a learning disability, so is fairly consistent. We have since delivered some workshops in local schools and colleges to encourage a higher attendance amongst young people. We have reached 29 people in the 16-25 age range with these workshops. More workshops are planned for after the summer holidays.

Most people rated the parliament good with very few bad ratings. However the evaluation feedback was still lower than we would like.

The smiley face evaluation exercise was once again the most successful, with 44% of people giving their opinion. The post it note and questionnaire evaluations were valuable but with slightly fewer people taking part at 36% and 38% each.

In the previous parliament evaluation we said we would have a verbal staff and volunteer briefing on the morning of the parliament (in addition to the written briefing that is circulated beforehand). At this briefing we stressed the importance of staff and volunteers supporting as many learning disabled people as possible to give their feedback. We did get more questionnaires completed before the parliament started but we still didn't get as much feedback towards the end of the parliament as we hoped for. This is largely down to people leaving early for various reasons.

Our suggestion is that at the next parliament event we will have someone to encourage those who do have to leave early to give some feedback as they go. We will place a staff member or volunteer outside of the main parliament event so that they may catch people as they leave and ask for their feedback. We also plan to collect feedback at the end of each workshop which will

give us another layer of people's opinion on the parliament activities.

At this parliament we tried a new type of inclusive workshop aimed at people with what is referred to as 'severe' learning disability. This means people with higher support needs and often limited communication skills. Traditionally, this group is often left out of self advocacy activities because they are seen as unable to speak for themselves and they have to rely on family, friends and support staff that know them well. We wanted to try something that would help this group feel part of the people's parliament.

The workshop was run by Jo, our Speak Up and Stop Hate Crime project lead and took the form of a story about a person needing some health treatment. Jo used a variety of props and communication aids, including sounds, pictures, sign language and medical equipment. At various points in the story, Jo stopped and asked the opinions of the group on a certain issue e.g. waiting times. The group were supported to respond, either for themselves or through a support worker who could speak about their experiences supporting that person in a similar situation. The workshop received many positive comments from those taking part and we have been approached by NHS England to give them some advice about how the workshop was put together. We intend to try a similar workshop at the next parliament meeting.

We also ran a brief 'Ask the bosses' session after the workshop feedback had been given. This was fairly successful and three senior managers gave their response to the workshop feedback and answered some questions. We will need to run this type of session again to evaluate whether it is an effective use of time at the parliament.

## Workshop outcomes

The inequalities in health treatment for people with learning disability are well documented and have been getting increasing media press coverage in recent months. The closure of assessment and treatment units remains a serious issue that still needs addressing. The fact that many deaths of people with a learning disability are considered 'avoidable' and are happening early is and should be, truly shocking. However, our workshops looking at people's day to day experiences of using health care services such as GPs and hospitals show that some simple steps can make a big difference.

The experience of people with learning disability using health services is mixed, with some people reporting a good experience. Often, people's experience is mixed and largely depends on three areas. These are good communication, good staff attitudes and the right reasonable adjustments. Looking at what people said in the workshops we would recommend;

- Much wider use of hospital passports, health action plans and annual health checks. This includes promoting these things with people with learning disability living on their own or with family, not just among professionals.
- Inaccessible language and jargon can be a real barrier. More training for staff in how to communicate well with people with learning disability and treat them equally.
- More reasonable adjustments for people with learning disability, which often means adjusting attitudes or the ways of communicating. A reasonable adjustment should not be seen as a 'burden' by health staff but seen as a necessity to enable equal treatment to be given.
- Shorter waiting times and longer appointments would make using GP and hospital services much easier for people with learning disability and autism.

- A better understanding from health professionals that people with learning disability have the right to make their own decisions about health care. People with learning disability want health professionals to talk directly to them in a way they understand, but they also want to be able to have the support of family, friends or support staff when they choose to do so.

As a result of the Lewisham people's parliament on health, the parliament reps will be asking to meet with health and social care managers and decision makers. They will ask what can be done differently as a result of what people with a learning disability have said they want to happen.

Marsh Stitchman, July 2017.

Lewisham People's Parliament Project Lead.