



## People's Parliament

Friday March 27<sup>th</sup> at  
Catford Town HALL

## Our Shout!



MP's report of Lewisham's  
People's Parliament about Health.



We chose Lucy Reeve to be  
our Chairperson .

Lucy welcomed us and our guest  
health bosses to the Parliament.



Then we heard from our MP's for  
health Lisa Lye and Mark Snead.



They told about their Healthy  
Living Speaking Up group and the  
work they do.



Then we joined 3 workshops about health. We were asked **what we say** and **what we want** from health and health services.



Workshop 1 was about **My Health**, workshop 2 was about **My Local Health Services** and workshop 3 was about **My Local Hospital**.



The health workshops.

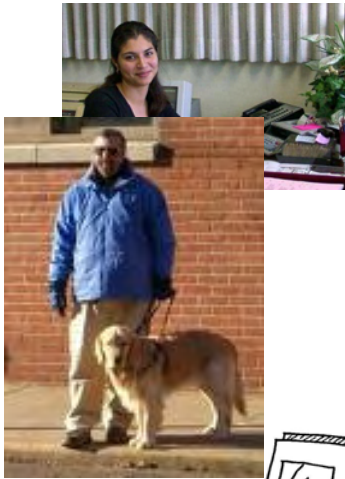


After lunch we met with the Health Bosses to tell them what people in the workshops said.



**People in workshop 1 said,**

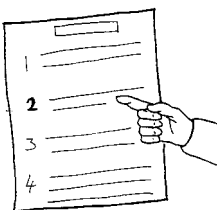
- ⇒ We want health services to talk to us
- ⇒ We, our supporters and families all need good information. We want easy to read leaflets and guides to where services are
- ⇒ We want to know about First Aid.



- People in workshop 2 said,**
- ⇒ Our local services were friendly.
  - ⇒ We like to be able to walk to our GP.
  - ⇒ Staff needed training to listen to us - not just our supporters, and to not use jargon and big words.



- People in workshop 2 said,**
- ⇒ People said there are good things about Lewisham hospital and some things that could be better.
  - ⇒ We suggested information needs to be easy to understand - letters from the hospital could have a photo of the hospital on so we knew who had sent it.



Lots more about what we said in the workshops are in the notes at the end of this report.

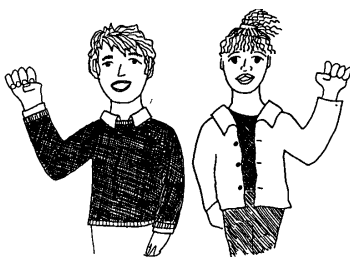


Afterwards Lucy our Chairperson asked the Bosses what they would do.

They had listened carefully and thanked everybody for what they had said. They promised to take action!



Before our meeting finished one of our guest Bosses presented certificates to the MP's and our supporters for all our work and training.



A BIG Parliament thank you to all our guests and everybody who came and help us on the day!

## Notes and feedback from the 2009 Health Parliament workshops

**Attending;** 21 people with learning disabilities including 13 MP's, plus 5 guest 'health bosses', 5 LSU supporters and 5 service supporters.

### ***My Health workshop – 1***

#### **Workshop facilitator notes.**

The group was comprised of approx 12 participants with a 3 serving MP's and was facilitated in 3 parts. Session was supported / facilitated by Luke Williams from Speaking Up and was joined by Barley Oliver and Alison Keens from the health MDT.

Firstly group members looked at what things, as well as health services that helped people with learning disabilities in Lewisham stay healthy. Group members took turns to speak and give examples so as to ensure everyone had an opportunity to input.

The group then looked at what things either were bad for people's health or were barriers to people being more health. Again the group were able to come up with a range of examples. Barley and Alison assisted the group by helping us all to look at some examples with of what can happen when people do not have good information.

The group then looked at the 'What we want' section of the workshop. Luke spoke about Health Action Plans as a way for everyone to set up their own list/plan of what THEY want to stay healthy. Group members knew very little about Health Action Plans, and agreed for Alison to explain more about what they were, how/who can help you can make one and who could have copies of yours eg GP's/support workers / family members / Care Mgrs to make sure that the plans were carried out.

The group thought this was really good for people in Lewisham and Alison and Barley said they would make sure this was brought up in the health sub-group.

People also discussed having more good accessible information about staying healthy and health problems for self diagnosis of basic health issues. Group members also felt that people in Lewisham would benefit from accessible first aid information and training.

1 MP was able to feedback from people who use that service. They reported that they do, on the whole receive good quality primary health services and had a reasonable experience of UCL. They did not recall being spoken to about or have any knowledge of process of Health Action Planning.

Luke Williams, Senior Advocate, Lewisham Speaking Up

#### **Things that make us unhealthy**

- Smoking,
- Too much coffee
- Too much chocolate
- Too many fizzy drinks
- Not brushing teeth

#### **What can help us?**

- Health services talking to us
- Write to doctors and bosses

- Supporters and family need good information, easy read & leaflets
- Tell us about First Aid

### **Who helps us?**

- Doctors
- Trainer
- Nurse
- Key worker
- Dentist
- Physiotherapy
- Family
- Partners

### **What's in my Health Action Plan?**

- Eat fruit & vegetables
- Walking
- Water
- Dancing
- Dentist
- Sports
- Visit doctors quickly
  
- Holiday
- Swimming
- Gym
- Talk to people – if we feel worried or low
- Jogging
- Opticians
- Washing hands
  
- We need information
- Phone numbers

### ***My Local health services workshop 2***

#### **Workshop facilitator notes.**

Nick Llewellyn ran the group on 'My Local health services' with Magda Moorey, (Lewisham Primary Care Trust) and about 8 participants. We first talked about what a 'local health service' is doing a warm up game. We then talked about the questionnaires that people did in their day services and split people into pairs to do them themselves and then report back.

In 3 groups, we drew on large sheets of paper what we knew and thought about local services, paying attention to accessibility, inclusion, rights, choices and communication of people and buildings.

We then used this information to draw up what we wanted from our local health services. People wanted an accessible document so that they knew where their services were and knowledge of how to complain if they wanted to tell people if services were good and to train staff to Communicate with people with learning disabilities appropriately.

Nick Llewellyn, Self Advocacy Supporter, Lewisham Speaking Up

## **What we say**

- Sometimes they listen to us
- Some information we can't understand
- Sometimes I feel rushed
- The doctor is distracted sometimes
- Some staff are polite
- It is hard to make an appointment if the phone is busy
- I may feel scared
- I can feel like a child
- Talk to the supporter and not the person
- Not independent
- I don't always know where to go
- There is not enough time to talk
- They use jargon and big words
- My GP is close to home
- Its too long to wait for an appointment
- Staff are always different

## **What we think**

- Not enough time
- Good to walk to the doctor
- Waiting for an appointment
- Staff are always different
- The gobbledygook
- People feel scared
- Doctors learning Makaton
- Don't always know where services are
- Some people aren't independent enough to go on their own
- Talking to the support not me
- Staff not always friendly
- Noises at the GP
- Doctors are patient sometimes
- Always need to make an appointment to see GP
- Always polite at dentist and chiropodist
- My doctor listening to me is good
- I don't like tablets
- I don't like the noise of the dentists drill
- Posters I can't read
- The nurse is nice

## **What we want**

- To be able to walk in and see a doctor
- To sell services when they are good (make an award)
- To make complaining easy
- To make sure they use signs and easy words
- Long appointment times
- Talk to me

- Show our new (Doctors & Nurses) video to staff for their training
- Easy guide to where services are
- Use easy English

### **My Hospital services workshop 3**

#### **Workshop facilitator notes.**

The group was comprised of approx 8 participants of whom 6 are serving MP's . The session was supported/facilitated by Jane and Angelika from Speaking Up and was joined by Joy Ellery from Lewisham Hospital and Miriam Long from the Link.

Firstly group members introduced themselves and talked about something they did to stay healthy – like exercise, not smoking, eating fruit and vegetables. We then looked at the questionnaire the MPs had devised at their last training and which some MPs had taken to their services. Dennis fed back what he had found out:

- Some people would like more pictures to explain what is going to happen eg in an operation
- Some people would like to see their GP more often
- Some doctors talk over our heads and don't look at us and need to speak more slowly.
- We should be told the truth and doctors should use language we understand.

We used the questionnaire to get us talking about general issues about health services as a big group.

Then we split into two groups and looked at some more questions that Joy and Miriam had brought to find out about our experiences at Lewisham hospital. We got lots of ideas of things which are good about the hospital and things that could be better. Peter, Susan and Stefan offered to feedback in the afternoon.

Jane Abraham and Angelika Welzel Self Advocacy Supporters, Lewisham Speaking Up

#### **What we say (These are good things)**

- The food is good – I can choose and the staff help me with the menu
- Doctors explain the treatment
- Being shown the things they use to do an operation
- Nurses on the ward are friendly
- Toilet signs
- The wards are clean
- Visiting times and rest times are about right

#### **What we say (These are bad things)**

- When doctors & staff talk to key worker and not me
- When words are hard to understand
- When staff say this won't hurt and it does
- Noise on the ward at night
- Not being respected – getting a male staff when I want a female
- Not getting help to get dressed
- Not being asked if I need help to eat
- Not being asked if I am hurting
- If you are quiet you may get ignored
- Signs at the hospital are hard to understand
- Key worker came into my meeting with the doctor although I did not want it

## What we want

- Staff training so they know how to communicate
- Use of photos and pictures
- Staff to keep all disabilities in mind
- Hospital letters to have a photo of the hospital on them and the doctor and the time and date
- If people are scared please listen better

## Easy Read Health Questionnaires [some completed before the meeting].

### **Local Health Services**

#### **Question 1. Are your local health services friendly?**

Yes 5  
No  
Don't know 1

#### **Question 2. Does your local health service listen to you?**

Yes 4  
No 1  
Don't know 1

#### **Question 3. Is your local health service easy to understand?**

Yes 2  
No 3  
Don't know 1

### **Your Local Hospital**

#### **Question 1. Are hospital staff, doctors and nurses friendly?**

Yes 4  
No  
Don't know 1

#### **Question 2. Do staff, doctors and nurses at the hospital listen to you?**

Yes 4  
No  
Don't know 1

#### **Question 3. Does the hospital make things easy to understand?**

Yes 1  
No 4  
Don't know

## Notes from Nexus Service.



In Nexus, Dinesh asked Debbie and Phillip what they thought about health services. This is what they said: -

- They have plans and people to help them to stay healthy
- Staff in local health services are not always friendly and it is not always easy to understand the service
- At Lewisham Hospital:-
  - Not all of the staff are friendly and some do not listen to you.
  - The staff speak to carers not the patient.
  - Staff lack understanding of people with learning disabilities
  - Staff do not always listen or make things easy to understand.

Other things that need to get better: -

- Local services need to be more respectful to people with learning disabilities
- They need to be more patient
- They need more training in dealing with people with learning disabilities and other ranges of disabilities
- Buildings need to be more accessible for wheelchair users
- Need to provide weighing scales in the local clinics, GP's and hospitals where wheelchair users don't have to stand
- Services need to respond to home visits as soon as possible
- GP's need to link up with chemists to provide correct medicines
- Agency GP's need to familiarise themselves with service user health issues before visits
- Local health services need to provide a plunge pool with assisted hoist.

**Dinesh is currently learning about what it would mean to be an MP for people who use Nexus services.**

Our thanks and appreciation go to all the participants and supporters who made the Parliament about health possible. A special thank you goes to our Health Bosses, who were;

Joy Ellery, Director of Knowledge, Governance & Communications Lewisham Hospital.  
Miriam Long, Lewisham local involvement network LINK.  
Alison Keens, Southwark P.C.T. and Partnership Board Health Sub Group.  
Magda Moorey, Lewisham PCT, Chair. Professional Executive Committee  
Barley Oliver, Consultant Psychologist and Chair, Partnership Board Health Sub Group.