



**Evaluation of the Lewisham People's Parliament on
'My Benefits'**

April 12th 2019



Report on the April 2018 Parliament on 'My Benefits'

This report gives feedback on the Lewisham People's Parliament on 'My Benefits' on April 12th, 2019. 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.

Benefits and the many changes that have been brought in by government has been a big issue for disabled people over the last few years. Many disabled people's organisations have campaigned against changes in Personal Independence Payments (PIP). There has been a lot of media coverage about the roll out of Universal Credit (UC) and the negative effects on some people's lives. We know from our own 1-2-1 advocacy service that many people have had their PIP Benefits removed completely. These are often restored when we support people to appeal.

The voice of people with learning disability has not been heard enough on this subject. People often raise the issue of Benefits with Lewisham Speaking Up, both in terms of individual problems with Benefits and as a subject that they want to talk about in general.

Our People's Parliament reps decided this would be a good issue to talk about. We also wanted to have another London wide People's Parliament where we invited self-advocacy groups from around London. We tried this in 2018 with our 'Our Voice' Parliament where we talked about the state of self-advocacy and had people with learning disabilities from 9 different London boroughs.

At the 'My Benefits' People's Parliament we had people with learning disability from 8 boroughs, representing a quarter of London's areas. We were pleased to be supported at this People's Parliament by representatives from DWP, Royal Mencap Society and Disability Rights UK.



The People's Parliament listening to guest speakers

The Parliament was chaired and opened by Aisha, one of our six elected people's parliament reps. To set the scene for the day we invited 3 guest speakers who would help people to think about Benefits and some of the issues involved.



Dr Annabel Head from Lewisham

Our first guest was Dr Annabel Head from the Lewisham mental health in learning disabilities team. Annabel spoke about how difficult it can be for people with learning disability to understand and cope with the Benefits system. This was reflected by the audience with people joining in with comments like 'I'm on ESA, people write me letters and I don't understand them' and 'some say you're acting disabled

and put you down'. Annabel told us about some research that one of her colleagues will be doing. This will be looking at the effects of Benefit changes on people with learning disability. Annabel said that some research has been done with people with physical disabilities but not with people with learning disability. Annabel asked if people would be interested in taking part. Several people said they would be interested. Annabel said the research hasn't started yet, but that she would come back and say more at a future People's Parliament.



Our second guest was Rob Holland from the Royal Mencap Society. Rob told us about Mencap's campaign asking the government to make changes to the plans for Universal Credit. Rob gave some background information about Universal Credit and the numbers of people involved. Eventually most people on Benefits will moved to Universal Credit. Rob said that quite a lot of disabled people could be worse off. Mencap thinks this is not fair and that no one should be worse off.

Rob Holland from Mencap

Rob also said it was very difficult for people with learning disability to apply online for Universal Credit. At the moment this is the only way to apply and Mencap says there should be other ways to apply.

The final guest speaker was Jaspaul Vilkhū from Speak Out in Hounslow. Jaspaul told us about his experiences in applying for Personal Independence Payment (PIP). Jaspaul said that he found the form for PIP very long and difficult to understand.



Jaspaul from Speak Out in Hounslow

He said that he contacted the DWP and asked for help with the form. He waited for six weeks and got no reply.

Eventually, Jaspaul had to ask a work colleague for help to complete the form. He didn't really want to do this, but felt that he had no choice.

When Jaspaul went for his assessment interview, he had to wait for an hour before he was seen. When the assessment did happen, Jaspaul said that he was asked lots of complex questions that he found hard to understand. He said that the person interviewing him used lots of jargon words. At the end Jaspaul did not get the points he needed to get PIP and he did not get the Benefit.

After we had heard from our guests, people were asked to join the workshops that they had chosen when they arrived.

The workshops and what people said

There were four workshops at the 'My Benefits' parliament.

- **Universal Credit (UC)** with Rob Holland from Mencap and Lewisham Speaking Up staff
- **Personal Independence Payment (PIP)** with Michael Paul from Disability Rights UK and Lewisham Speaking Up staff
- **Working and Benefits** with Emma Gillson, South London partnership advisor, DWP, and Elizabeth Akinsanya, Disability Employment Advisor, DWP, and Lewisham Speaking Up staff
- **General issues with benefits and Job Centres** with Benny Nwadiashi, Disability Employment Advisor, DWP, and Lewisham Speaking Up staff

Each workshop began with a discussion on the main topic and then notes were taken on what people said – ‘What we say’. The aim was for each workshop to come up with at least 4 changes that they want to see – ‘what we want’. Each workshop then gave feedback on their main points to the whole People’s Parliament. This is what people with learning disability had to say at each workshop.

Universal Credit workshop – ‘what we say’

- We don’t want to lose money
- Worried about getting in debt and the effects on mental health/stress
- Fear of eviction and homelessness
- It’s confusing, the information is bad, and people are bad at explaining
- Worried about waiting a long time, 5 weeks, to get it. Will I be without a benefit?
- Paid monthly not fortnightly so it’s hard to budget
- What if you have not got a computer?
- Fear about journal/diary responsibility
- The easy read literature is from 2010 and is outdated
- Only 5 out of 20 people with learning disability have a computer or access to the internet
- Lots of us can’t read
- Bank statement isn’t clear about payments

Universal Credit workshop – ‘what we want’

- We want the government to make it easier to understand. People to be friendly and understanding and information to be in easy read
- We want the DWP to use the information they already know about us

- We want people to be automatically transferred from ESA etc. to Universal Credit
- We want a personal benefits advocate for people who have no support. It should be a person who knows you, who is independent and who helps you through it all

Personal Independence Payment (PIP) workshop – ‘what we say’

- There should be more time to appeal. Appeals process should be more than a month
- Family members don't always understand someone's learning disability or the assessment, so cannot describe it well and get the wrong result
- It's too much to be asked in again (for assessment)
- (There are) lots of changes, worrying that benefits might go down
- We should be given more time to fill in the form. We should be allowed to fill in one bit at a time
- Questions are hard that they ask on the phone, but they don't like you having someone to help
- They try and trick you
- There shouldn't be a points system

Personal Independence Payment (PIP) workshop – ‘what we want’

- We want to tell assessors what they need to know about learning disabilities
- We want assessors to know about learning disability if that is why the person has applied for PIP
- We want assessors to ask the right questions
- We want more easy read forms
- We want more advocates to help us

- We want time scales to be longer
- We want people with learning disability not to be called back to be reassessed

Working and benefits – ‘what we say’

- A lot of us have got jobs but we would like more paid work
- The rules around working and benefits are complicated
- You can have your money stopped for doing too many hours and it takes ages to get it started again
- You can only work for 16 hours a week on benefits
- Universal credit can be better if you are working because the rules are different

Working and benefits – ‘what we want’

- We want simpler rules about benefits
- We want more help to understand the rules
- We want to work as many hours as we like without affecting our benefits
- We want more work coaches at the job centre
- We want to be allowed to bring an advocate with us to the job centre
- We want more easy read leaflets like the new access to work one
- We want more supported employment programmes for people with learning disability
- We want more employers to understand what people with learning disability can do

General issues with Benefits and the Job Centre – ‘what we say’

- The Citizen's Advice people can help with using a computer
- You need to say that you have a disability to get the right support
- There should be support away from the job centre like CV help and IT skills

General issues with Benefits and the Job Centre – ‘what we want’

- We want the information to be simpler
- We want people at the job centre to be calmer and take more time
- We want more time and help with filling in forms
- We want help with the journal
- We want more help on computers for people with visual impairment
- We want more courses and to be made more aware of what is available

Conclusions

It is clear that people are worried about Universal Credit. Concerns include how to maintain a work journal, how to manage money when paid monthly and importantly, fears about being worse off under Universal Credit. We think it would be grossly unfair for any person with a learning disability to lose money by transferring to Universal Credit. Many people do not have access to a computer or well developed IT skills. It is good that Citizen's Advice are able to support people to make new claims, but there are concerns that they will not be able to give people ongoing support with maintaining a journal. There are lots of people with mild to moderate learning disabilities that no longer receive support and it would not be right for them to be sanctioned for not keeping an online journal up to date.

People feel that the current system for PIP is unfair. They feel that assessors do not have a good understanding of learning disability and are sometimes deliberately trying to 'trick' people. We know from our own experience of supporting people through 1:1 advocacy that cases are easily overturned on appeal. Many people with learning disability do not wish to appear vulnerable and do not like to focus on what they cannot do. Attending assessments on their own can leave them with very few points awarded as they 'talk down' their disability. We would like to see more advocacy support for people with learning disability around PIP assessments.

People also felt that they should not be reassessed when they have a lifelong condition. Having a learning disability is not a health condition that gets better. We would like to see people who are assessed as needing PIP be given lifelong or at least long term awards.

It is well known that employment rates for people with learning disability are shockingly low, whilst the number of people who want to work is high. We know that supported employment programmes are effective in getting people work and importantly in keeping a job when issues come up. People with learning disability want more supported employment opportunities.

People with a learning disability feel the rules around benefits and working are overly complicated. There are some good changes happening within the DWP and Job Centres such as more easy read materials and quiet time sessions. Universal Credit also has some upsides for people with learning disability in that it can allow people to work more hours and still keep their Benefits. However people still need more support and opportunities to find work in the first place. The Job Centre coaches can only deal with people who are 'work ready'. We would like to see more specialist supported employment for people with learning disabilities.

We would also like to see a change in public attitudes towards people with learning disability as this will mean more employers talking on people who really want the chance to have a job.

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 'My Benefits' Parliament.

We will be asking to meet with Lewisham MPs Vicky Foxcroft and Janet Daby to ask them what they plan to do about the things raised in this report.

We will also be sharing the report with

- Department for Work and Pensions (DWP)
- Disability Rights UK
- Learning Disability England
- Royal Mencap Society
- Lewisham commissioners
- All the groups who came to the 'My Benefits' parliament
- Service providers in our area

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.

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.

The attendance at this Parliament was very good at 71 people with learning disability. As usual, there were fewer women than men and most people were in the 25 – 64 age range.

Numbers of people at the Parliament

Ages	Numbers at Parliament
Age 18 -24	4
Age 25 - 64	69
Age 65+	1
Total	74
Gender	Numbers at Parliament
Female	29
Male	45
Total	74

What did people think about the Parliament?

At the end of the workshops, people with a learning disability 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.

60 stickers were put on the flip chart. This means that 81% of people with a learning disability who came put up a sticker. 58 people said the Parliament was good (96.6%) and 1 person said the Parliament was bad (1.6%). 1 person said the Parliament was neither good nor bad (1.6%)

The table below shows what people thought about the 'My Benefits' Parliament.

Stickers	Number of stickers
Yellow smiley face (good)  =	58
Red sad face (bad)  =	1
Blue face (half and half)  =	1
Total of all stickers  +  +  =	60

If you would like to discuss this report or have any questions please contact us: marlin.stitchman@lsup.org.uk 020 8692 1862



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