



**'Self-Advocacy
Past, Present and Future'
Report of the Lewisham People's
Parliament June 2024**

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 by the City Bridge Foundation.

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 Self Advocacy

This Lewisham People's Parliament was held to find out what people think about self advocacy, in Lewisham and across the UK. Lewisham Speaking Up will be electing their new People's Parliament reps in September, so it was a good time to talk about how self advocates can make a difference for people with learning disabilities.

The Lewisham Learning Disability Partnership Board has recently been relaunched. The first meeting was shortly after our People's Parliament, on the 24th June. This will help people with learning disabilities to be involved in decisions made about them in Lewisham.

There are lots of self advocacy groups around the country, and they work together to campaign on wider issues and share ideas. However, there is no national forum anymore for self advocacy groups, and the London forum is not currently running. Some self advocacy groups have lost their funding, which is worrying for people with learning disabilities. We wanted to talk about the challenges and worries for self advocates, and what groups should focus on in the future.

Lewisham Speaking Up are working with Entelechy Arts to make our self advocacy work more inclusive for people with profound and multiple learning disabilities (PMLD). We wanted to talk about why this is important, and how self advocacy can be more inclusive for everyone with a learning disability.

We want to thank:

- councillors Edison Huynh, Aliya Sheikh and Jacq Paschoud for speaking to us about how people with learning disabilities can make a difference in their community
- Brighton and Hove Speak Out for allowing us to use their video, "50 years of Speaking Up"
- Entelechy Arts for speaking to us about how people with PMLD can speak up for themselves without language, and sharing these skills in a workshop
- Lewisham Wellbeing Hub for leading a workshop on self advocacy and wellbeing.

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.



Sam chairing the meeting

We invited people to join us on 7th June and 51 people with learning disabilities came in person.

This included guests from Lambeth Assembly, One Place East, Generate, Bemix and Hackney. We would like to thank them for joining us to talk about self-advocacy.

The meeting was chaired by People's Parliament rep Samuel Attah.

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

Sam said that we would be talking about:

- The history of self advocacy
- What we want the future of self advocacy to look like
- Why should we speak up for ourselves and other people with learning disabilities?

Sam said that as self advocates, we want to make people's lives better. He talked about how he became a People's Parliament rep because he wants people with learning disabilities to have a choice about how they live their life.

Sam speaks up about issues like day centres staying open, so that people with learning disabilities can choose how they spend their day. He speaks up for himself when he goes to appointments, to make sure he has the reasonable adjustments that he needs.

Sam also said that it is important that we speak up for those who cannot speak up for themselves.

He said that we can all be leaders, and that as leaders, it is important that we don't give up when things get difficult.

Sam introduced our first guest speakers for the day, Councillors Edison Huynh, Aliya Sheikh and Jacq Paschoud.



The councillors spoke about what it means to represent their communities.

Edison told us that he became a councillor because he didn't see anyone who looked like him in politics. During the pandemic, he saw a rise in anti-Asian hate, and saw that no one was speaking about it. He decided it was time to become a councillor and speak up about issues that were important to him and his community.

Aliya told us that she is going to start chairing the Healthier Communities Select Committee. The committee will make sure that local health matters are addressed properly. They will work with the NHS to make sure that our health is taken care of. Aliya would like to know what we think about health services in Lewisham.



Jacq told us about her drop in sessions at St Dunstan's Church Hall in Bellingham on the second Saturday of each month. She said that people can come to talk to her about issues they are having. She said that lots of people come and talk to her about the big issues they are having, but sometimes it's the little issues that have the biggest impact on our wellbeing.



Jacq also talked about why it is important to listen to people, even if we don't understand them at first. She spoke about her daughter's speech and language therapy. She said that when the therapist asked her what "explode" meant, she used the example of an egg! This wasn't what the therapist expected her to say, but it is still right. Sometimes people don't explain things how we expect them to, but it doesn't mean it is wrong.

Then Sam introduced the video 50 Years of Speaking Up, by Brighton and Hove Speak Out

The video told us about the history of self advocacy in the UK. It talked about how 50 years ago, people with learning disabilities did not have much choice about how they lived, and most people with learning disabilities lived in secure hospitals.

In 1972, the first recorded self advocacy meeting took place, at a secure hospital, where people with learning disabilities told their staff what they wanted to change about their living situations. The video shows how self advocacy groups developed from this meeting to what we have today.

In the video, self advocates around the country share why self advocacy is important today, and what they would like to see in the future. This includes some of our People's Parliament reps!

You can watch the video here:

<https://www.youtube.com/watch?v=PHqR0KES5bs&t=10s>

Finally, Sam introduced Mike Brooks and Rebecca Swift from Entelechy Arts.

Mike and Rebecca told us about how people with profound and multiple learning disabilities can communicate their choices without words. They run a group called ambient jam, where people with profound and multiple learning disabilities take part in movement workshops. They told us about how their members communicate their feelings and their choices through things like movement, music or touch.

They told us that people often think it would be difficult to know what people with PMLD think and feel, but if we spend some time with a person with PMLD, we can learn to communicate very well with them.

They also told us that actually, we all communicate without words. 70% of communication is through our body language, like how we stand and our facial expressions.

It is just as important for people with PMLD to have a choice about how they live their lives as anyone else.

Sam then invited everyone to join one of three workshops:

- A workshop on 'self advocacy through movement and senses' by Entelechy Arts
- A workshop on 'self advocacy and wellbeing' by Lewisham Wellbeing Hub
- A workshop on 'the future of self advocacy' by Lewisham Speaking Up.

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



Workshop 1: self advocacy through movement and senses

This workshop was supported by Entelechy Arts.

We talked about ways of communicating our thoughts and feelings without language.

When we talk to people, 93% of our communication is through our body and vocal tone, and only 7% is through the words we say.

Gestures

We took turns showing a gesture that expressed how we feel.

Breathing

We spent 1 minute breathing peacefully.

Afterwards, we talked about what we heard. People heard traffic, snoring, and their own breath.

We talked about how breathing helps us keep a rhythm. Rhythm is the basis of language, and helps us learn to speak. It also is the basis of our communication through gestures. The rhythm of our gestures affect what they mean to other people.

Smell

We tried smelling some mint, and talked about how it made us feel. We said it was very relaxing!

Sound

We tried making different sounds with our mouths and bodies, and talked about what they might mean. We also tried making the sounds with gestures too

Touch

We talked about how people with PMLD who come to Ambient Jam sessions at Entelechy Arts often communicate through touch. We tried different ways of using our hands and fingers to express how we felt. We also tried touching each other's hands, and putting different pressures to express how we are feeling and to connect with each other.

We ended the session with some Tai Chi exercises, where we used our hands and our breathing to relax.

What we say:

- We think it is important for people to practise communicating without words.
- It is good for us to try this, because it helps us to relax. Focusing on our breathing, movement and senses helps us to feel less anxious.
- It is important because it helps us to understand people who don't speak when they express their feelings.
- As self advocates, we want to understand people with learning disabilities who don't speak. We want to be able to represent their needs and wishes in our work.
- We think that decision makers should be more confident in communicating with people without language, so that they understand people who don't speak.



Workshop 2: 'The Power of Self Advocacy', Self Advocacy and Wellbeing

This workshop was supported by Lewisham Wellbeing Hub
We talked about how self advocacy affects us and our lives.

What we say:

- Speaking up for ourselves gives us power
- Self advocacy has given us the skills and the confidence to do other things, like speaking to members of the public at work
- Speaking up for ourselves and being listened to helps us to fight for social justice
- Self advocacy makes life better for us and those around us
- People's parliament gives us a voice to talk about what is important to us
- It is important for us to get together and hear what others are saying. It makes us feel like part of a community
- Big institutions are not good places for people to live. We should live as part of the community where we can advocate for ourselves and be listened to
- With great power, comes great responsibility! When we have power, we should remember to speak up for others too
- It's important to work together, and to look out for each other
- It's important that people from the same groups get to see and speak to each other, and share issues

What do we want to change?

- We want people to listen to us when we advocate for ourselves
- We want to be part of the community, so that we can share what we need
- We want opportunities to speak to other people with learning disabilities about issues, like People's Parliament
- We want to know where we can find people when we need them. For example, we want to know where we can find the police to keep us safe on the streets

- We want to be involved in decisions that affect us. We want decision makers to listen to our needs and wishes before making changes about our lives.



Workshop 3: The future of self advocacy

This workshop was supported by Lewisham Speaking Up. We talked about what we want the future of self advocacy to look like.

What we say

- When I moved to Lewisham, I discovered self advocacy, which I didn't know about before. It has taught me new skills
- Self advocacy is great because it gives a voice to the voiceless. However, the speaking up group in Southwark was closed, which made us feel cut off
- We work with self advocacy groups in other areas, but some places don't have them
- The national forum lost its funding, and London doesn't have a voice nationally
- I think self advocacy in Lewisham is quite good, but not perfect. The government don't want to listen to people with learning disabilities
- They don't hear our voices because we don't always have computer skills. We need extra help with accessibility
- Self advocacy is brilliant but it is a skill you need to learn. It needs funding and support to make it happen

- Self advocacy makes us feel:
 - Happy and powerful
 - Like we are listened to
 - Like we are someone
 - Like a human being
 - Important in the community
 - Passionate about what I do
- People don't feel listened to. They feel patronised and not respected
- We are worried about the cuts to benefits and the government's plans
- We know what we want to say but we need support to get our voice across



What do we want to change? / How do we get stronger?

- Involve the council, NHS, police, mayor of London and learning disability services
- There is a lot of lip service but not enough action
- There needs to be self advocacy groups in every area
- There should be a national forum
- Self advocacy groups should work together so that we are stronger. We should present a united front to the government.



- Get professionals to really listen to us
- Have more meetings with MPs, or bring them to our groups
- Raise awareness of learning disability
- We need to network with other services in our area, not just learning disability services
- We need more funding for self advocacy groups
- We want more training programmes for self advocates
- There should be a government minister for learning disability



Participants sharing their thoughts at the open mic



Summary

Self advocacy is life-changing for people with learning disabilities. It allows them to make choices about their lives, which impacts everything. People with learning disabilities who come to People's Parliaments are very excited about the future of self advocacy, and hearing about the work of self advocates from all over the UK. There are lots of decision makers who are working hard to listen to people with learning disabilities.

However, they are also worried about the future of self advocacy. There is no longer a national forum for self advocates, and some other self advocacy groups have lost their funding. People with learning disabilities don't feel listened to by the government.

It was brilliant to have three Lewisham councilors who came to our People's Parliament to share how people with learning disabilities can speak to them and can make a difference in their community. They took the time to listen to people with learning disabilities, and we want all decision makers to do the same.

People with learning disabilities in Lewisham want to work with other self advocacy groups as much as possible, because we are stronger together. Working together helps us to present a united front to the government. This means that people with learning disabilities are not left behind when decisions are made. We want to be part of the decisions made about our lives. One person said, "nothing about us without us, because if it's without us, it's over".

We also talked about making sure that people with profound and multiple learning disabilities (PMLD) are involved in self advocacy too. Lewisham Speaking Up are working with Entelechy Arts to make sure that our work represents people with PMLD. We want other self advocacy groups and decision makers to develop skills in communicating without words so that they can better understand how people with PMLD think and feel. People with PMLD should be involved in decisions about their lives, even if they don't communicate with words.





During our open mic, lots of people talked about how important it is to keep speaking up for ourselves and other people with learning disabilities. People said not to give up, even when it feels like no one is listening.



What did people say about the Parliament?

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

We asked people with learning disabilities to rate the Parliament by choosing a face sticker. 38 out of 51 people (75%) put up a sticker. This is what they thought about the Parliament meeting:

| Stickers | | Number of stickers |
|---------------------------|---|--------------------|
| Yellow smiley face (good) |  = | 38 |
| Red sad face (bad) |  = | 0 |
| Total of all stickers |  +  = | 38 |

What Next?

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

- Send this report to Local Members of Parliament, Lewisham Council, NHS bosses, service providers in Lewisham and other people who may be interested
- Send this report to Learning Disability England and other self advocacy groups
- Work with the Lewisham Learning Disability Partnership Board. We will support people with learning disabilities to have their views heard at the Board. We will help them to understand what is going on in Lewisham
- Continue to work with Entelechy Arts to involve people with PMLD in self advocacy
- Work with other self advocacy groups on campaigns which are important to people with learning disability

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

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