



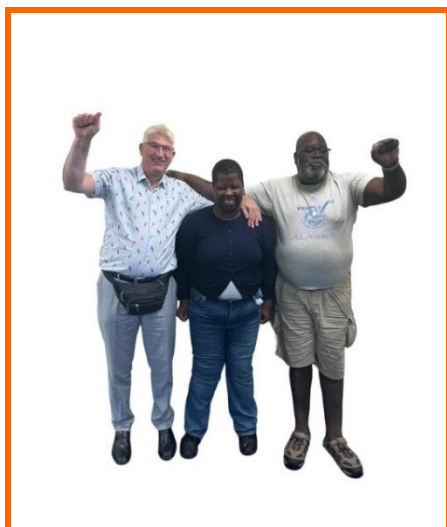
## London Campaign Network Meeting



**Friday 7<sup>th</sup> March 2025**

**11am – 3:30pm**

**King's Cross Methodist Church  
58a Birkenhead Street,  
London, WC1H 8BW**



### **1. Welcome and introductions**

Andrew Lee, Raymond Johnson and Samantha Johnson welcomed people to the second meeting of the meeting London Campaign Network.

We had 48 people at the meeting, representing 19 boroughs.



Everyone introduced themselves.

Our aim for the meeting was to start work on one of the three campaign priorities we set at our first meeting.

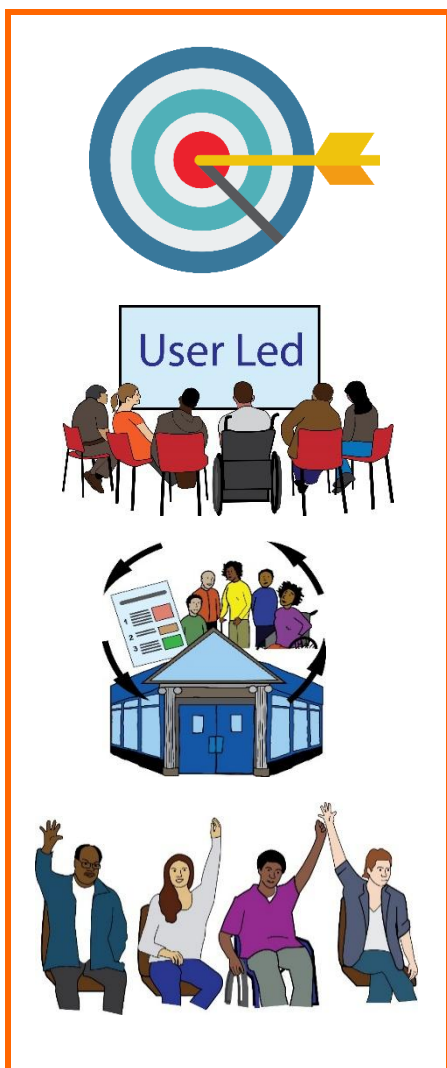
**Benefits and Money** was the focus of this meeting.



## Our Agreements for the day

Sam went through the agreements which are to help us to work well together:

- One person to speak at a time
- Phones off or on silent
- Respect everyone's points of view
- Keep to time
- Support and encourage each other



## Our 4 big aims

Andrew reminded people about the work of the network.

- To set up a 'London Campaign Network' for and run by self-advocates with learning difficulties/disabilities.
- To find opportunities to work together on campaigns that matter to us all.
- To influence the people that make decisions about us.
- To improve the lives of people with learning difficulties/disabilities across London.



## What we've done so far

We visited groups and organisations across London to talk about the London Campaign Network.

We found out what people were already working on and wanted to work on.

We had our first London Campaign Network meeting on the 1st November 2024. At the meeting we agreed our top 3 campaign priorities.

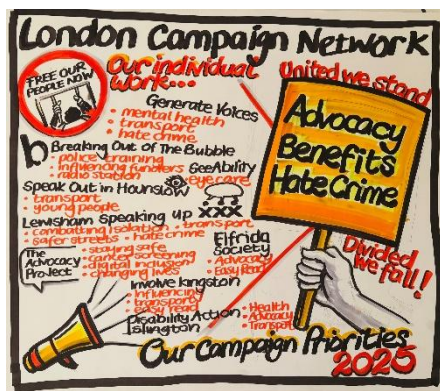
### Advocacy



### Benefits and Money



### Hate Crime



We produced a graphic at the meeting to remind us of what campaign priorities we agreed, and what everyone shared about their own work during the Soap Boxes.



## What we've done since the last meeting

We have been visiting and talking to people with learning difficulties and disabilities across London.

From what people told us we found out that **benefits and money** are the biggest concerns for people now.

That is why the focus of the second meeting is benefits and money.



## Soap Boxes

Everyone was offered a 5 minutes on the Soap Box to talk about their work.

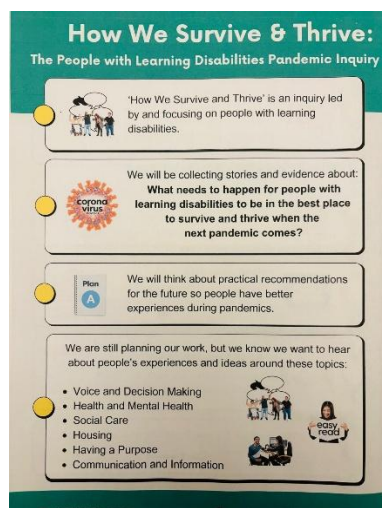


We heard from:

- **Dimensions** - Mark Brooks spoke about the 'My Vote My Voice' campaign. In 2025 the campaign wants to reach 2000 additional voter registrations of autistic adults and adults with learning disabilities.

<https://www.myvotemyvoice.org.uk/>





Mark also spoke about the Covid Inquiry project 'How We Survive & Thrive'. It is led by and focusing on people with learning disabilities. The commissioners are collecting stories and evidence about what needs to happen if and when another pandemic occurs. The topics are:

- Voice and Decision Making
- Health and Mental Health
- Social Care
- Housing
- Having a Purpose
- Communication and Information

- **Free Our People Now Campaign** - Simone Aspis spoke about the planned Day of Action on Tuesday 29<sup>th</sup> April at Westminster. A letter will be delivered to Baroness Barrington asking for the minimum amount of people to be in hospital.
- **Breaking Out of the Bubble** - Jen and Gina told us about their work with funders. They are working on a survey to find out how funders work with people with learning disabilities. They want funders to understand us and our organisations better, and to come out and meet us.



- **Advocacy for All** - Duncan spoke about ways of helping people access the Benefits assessment process including using Dictaphones and recording apps to help you remember things and manage money. He also spoke about contacting your MP for help when needed.
- **Robert, Jade and Ian** spoke the need for more accessible information about benefits. Also, the issue of 'claim and shame'. Not all of us are 'con artists' or 'benefit frauds'.
- **Mencap** - Vijay and Martin spoke about how people are supported to have a voice. They want to work in partnership with other organisations to campaign for better support and services.
- **SeeAbility** - Grace shared information about their work to raise awareness about good eye care for people with learning difficulties /disabilities. 'How to be eye care aware' guides for families and support workers were also shared.



- **The Advocacy Project** - Patrick spoke about the 'My Health My Choice' project in Brent. It is campaigning for Health Passports, Easy Read information, double appointments, registering with a GP, Annual Health Checks and reasonable adjustments.
- **Elfrida Society** - Martin, Rodney and Leon spoke about their work linking people to social services, working with Job Centre Plus, Debt Advice, and awareness of neurodiversity. They are also running user-led quality monitoring and holding quarterly meetings. Leon finished by saying that 'society is a double-edged sword, we're in chaos and need to change attitudes.' He also said that 'we should not suffer in silence and we should wake up, come together and challenge unethical and unfair wrongs.'
- **One Place East** – Kweku spoke about the work they were doing with health care professionals to help them understand the needs of people with learning difficulties.



**12:40pm – 1:40pm**

Lunch and Networking  
Information sharing



## **Welcome Back and Warm Up**

Ray asked everyone to do the campaign chant from our last meeting. We all sang together...

***'Get up stand up, stand up for our rights!'***



## **Workshop: Benefits and Money**

### **Barriers and Solutions**

At each table we talked about the barriers and challenges, and then we thought about the possible solutions.

Here is a summary of the feedback.

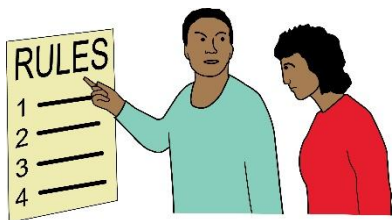


## Barriers



## Attitudes

- Stop trying to prove us wrong
- Claiming benefits should not feel like a crime
- Do not sweep us under the carpet
- The people making the rules are not affected by the rules they are making
- Government dictates what is socially acceptable and what is not
- Fear about doing the wrong thing so don't do anything
- Benefits are getting cut and changing too often
- All benefits going to Universal Credit
- Not being kept informed about the changes
- Big benefit shake up without much warning
- Attitude that Disabled people must stay poor
- Government is taking more money away from Disabled people



## Job Centres

- Lack of understanding of staff
- Lack of accessible (easy read) information
- Lack of suitable jobs for people with learning difficulties/disabilities
- Lack of long-term support in the workplace
- Rules can be overly strict such as long-term unemployment can result in being pushed to turn volunteer work into paid work or look for full-time work
- Must earn a certain amount before being able to stop going to report to the Job Centre
- Staff taking people off Permitted Work
- Lack of awareness of the day-to-day challenges we face
- Only able to work a certain number of hours (16) not flexible
- Reasonable adjustments are not put in place – the law needs to be applied to employment agencies
- People don't understand the changes made to benefits or the rules



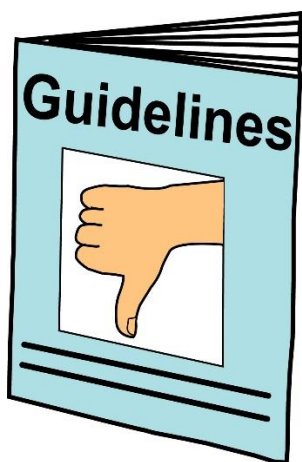
- Not enough time given to people with learning difficulties/disabilities
- Not enough job options that people have open to them
- Not enough training or courses available to people with learning disabilities (skills development & confidence building)



## Assessments

- No more Disability Benefit reassessment
- Questions can be triggering and patronising (e.g. who is the current prime minister? spelling tests etc)
- Not enough money to live on day-to-day – cost of living has gone up, benefits have not
- The higher you earn the lower the benefits
- Access to Work is difficult to apply for and can take a long time
- Stressful waiting for decisions
- Not enough support when living on your own to manage the assessment process
- Must prove you are eligible even when registered Disabled or have a lifelong condition that will not change



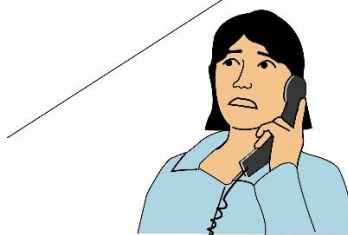
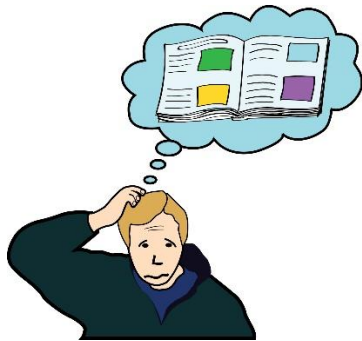


- Must reach certain criteria, but don't know what it is
- Stopping people with learning difficulties get a full-time job – we have to stay working part-time
- Lots of forms to fill in
- It's hard to get back on benefits if you come off them
- Things don't change automatically
- The amount we are assessed as needing is not enough to live on – we can't enjoy life properly
- Being changed from one benefit to another
- Not being given information about other support – local organisations who can help, food banks
- Too many hoops to jump through

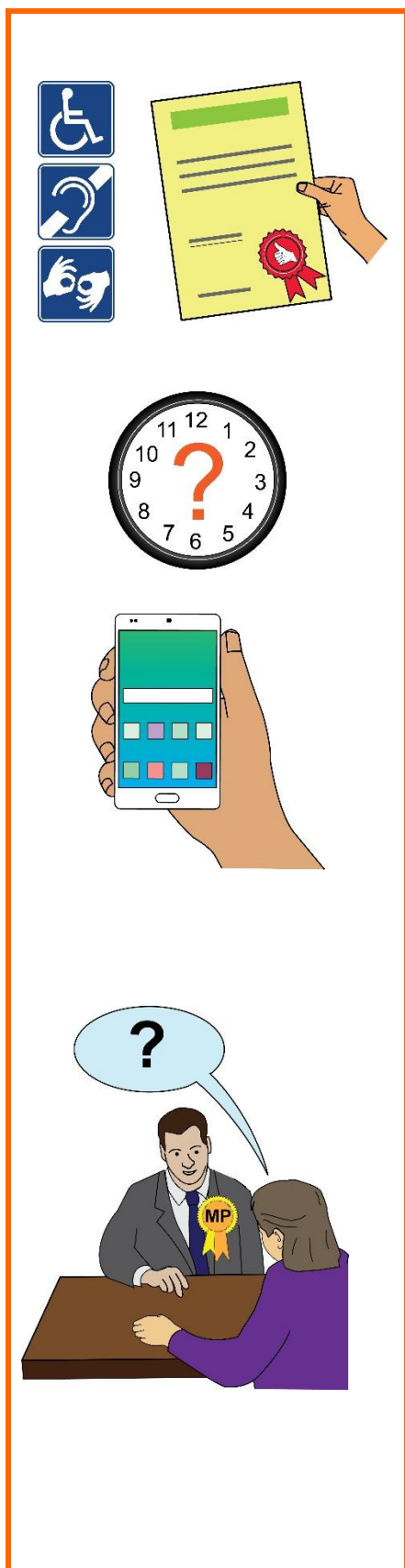
### Access issues

- Where do you go to get information – services have disappeared, support networks have disappeared – can only turn to family and friends, if you have them!
- Letters and forms not in easy read
- Too much jargon used





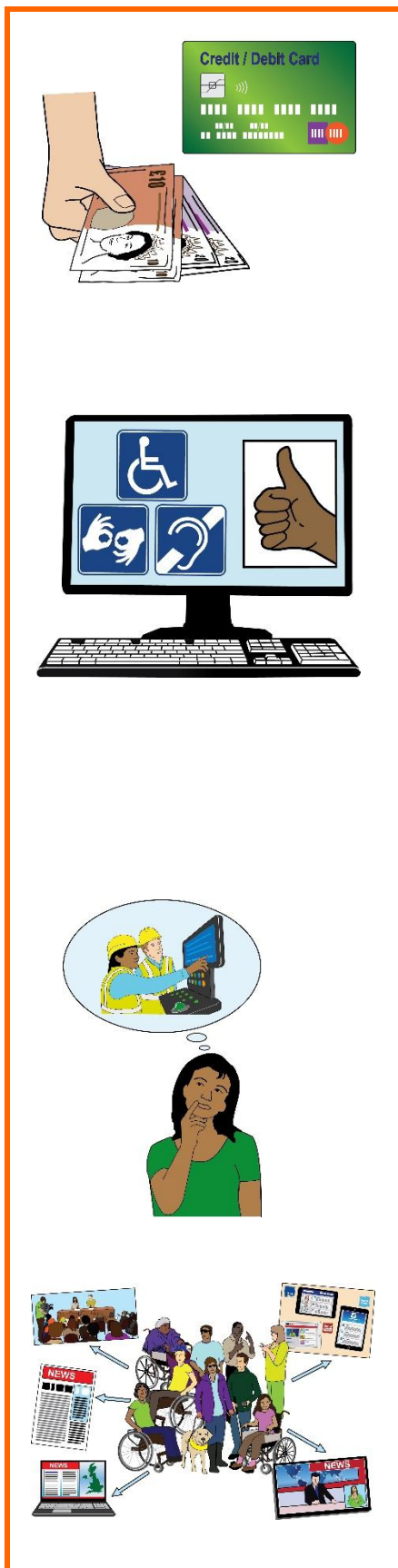
- Not being told what you are entitled to
- Information about benefits is not clear
- Long winded explanations about benefits
- Information is not always relevant and can be scary
- Digital exclusion - people not being able to use computer or not having smart phones
- Not able to manage the payment systems – cards, pin numbers etc
- Telephone calls inaccessible – staff hard to understand and speaking too quickly (inpatient)
- Long waiting times on the DWP phonenumber
- Hard to find out about benefits and what you are eligible for
- Hard to get the right support to get on benefits
- Too many types of benefits – too confusing
- Information unclear about what benefit you can go for
- Some people don't want to or can't use credit or debit cards – a lot of places don't take cash anymore



## Solutions

### Access issues

- Make information accessible to all
- Make Easy Read information we can understand about benefits
- Stop cutting time available to talk to people
- More accessible information on websites and apps
- Use text messages for reminders for appointments and other important information
- Have an option for a call back on the DWP phone line
- More face-to-face meetings about benefits
- Combine benefits to make it one benefit – easier to understand
- More explanation of the changes and why they are needed
- Speak to MPs about what would make it better for people with learning difficulties/disabilities
- Speak to people in power
- Talk to people about what they need and how much they need to live on
- Fund workshops on benefits



- Having a choice between using a money card and cash
- Have somewhere to go for face-to-face support and to talk to about your situation
- Fund organisations that can help people understand and get benefits
- Access to more financial and benefits advisors
- Make it easier for people to apply for benefits – not just online
- Forms. Letters and website information needs to be in easy read and a variety of different formats
- Need support to understand and keep to the rules

## Attitudes

- Offer options to work full-time if the person wants to, don't assume we can't or we won't
- Educate the public and press about the real issues
- More promotion and awareness of the issues we face
- See and value all people as people – not see Disabled people as a liability – respect everyone



- Make sure staff have a good understanding of the needs of people with learning difficulties/disabilities
- Train assessors on unseen/hidden disabilities
- Run seminars
- Redefine work (unpaid carers)
- Tax the rich – don't take off the poor (benefits cuts)

## Co-production

- Talk to the people getting benefits to understand more about what benefits they need – what works and what doesn't
- Staff to support you to do research into what you want to do and what your options are
- Include us in all decision making
- More recognition and support to be heard and listened to
- Talk to your local MP
- Organise protests
- Make an Easy Read video with people with learning difficulties





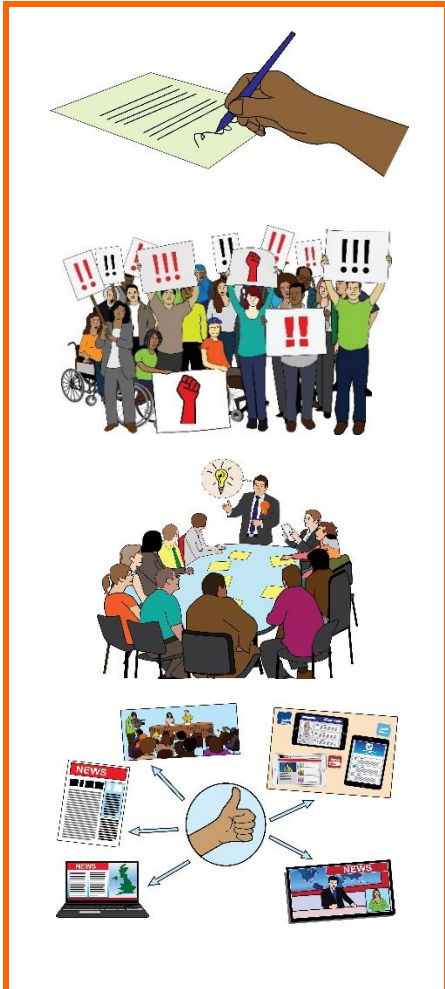
## Assessment

- More training for staff working in the benefits system
- It should not matter where you are - benefits should not change if you are in hospital
- Have the option to use your own Doctor, not theirs
- Gives people the chance to get jobs, if not successful can go back on benefits – flexible benefits
- Find out how and who can help people with the application and assessment process
- Have a 'Basic Citizen Income' that includes Disabled People
- Benefits should match potential earnings and not be decreased
- People should not be pushed to do more hours when taken off Permitted Work
- Benefits information should be personalised
- Any changes to the rules need to be sent to people in a way they can understand
- People should be able to work more than 16 hours if they want to and can



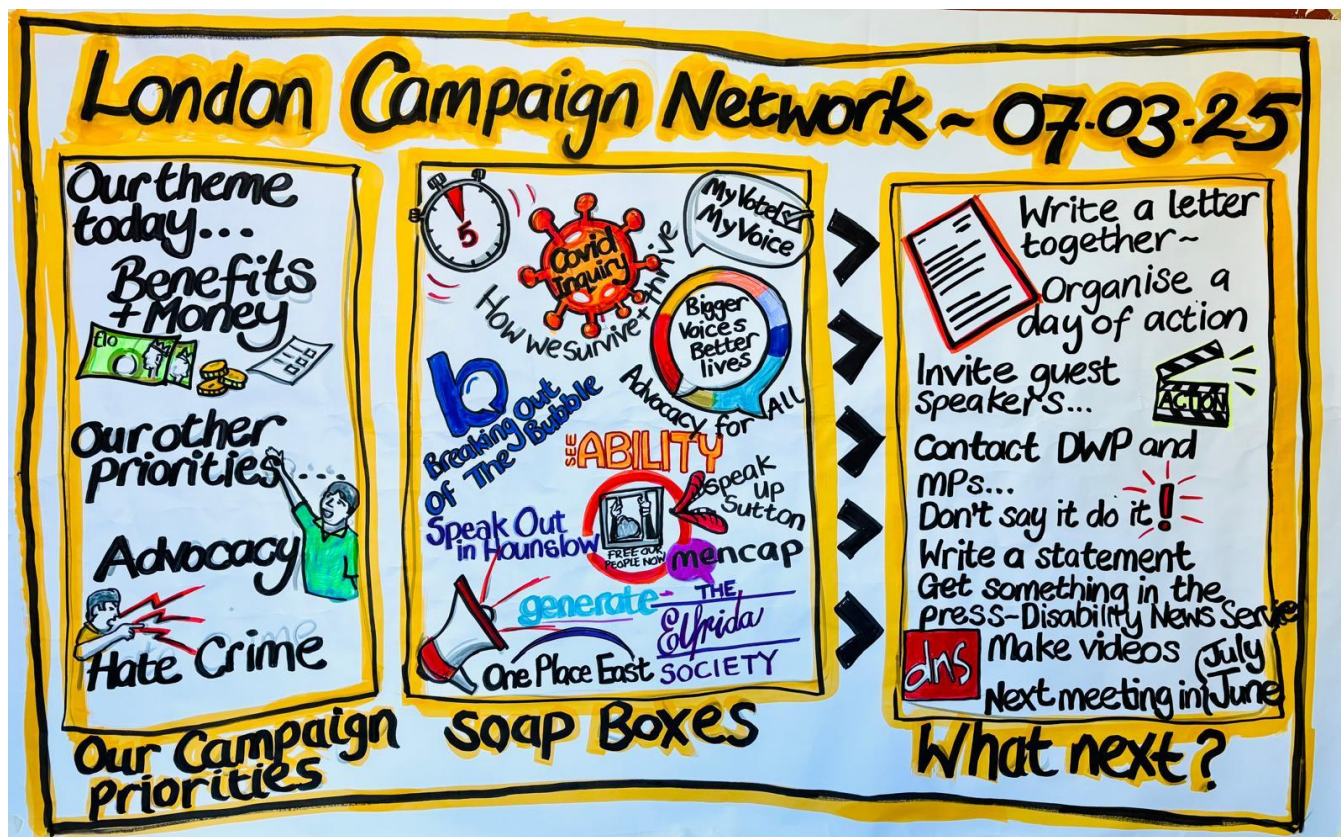
**2:40pm – 2:50pm**

Comfort Break

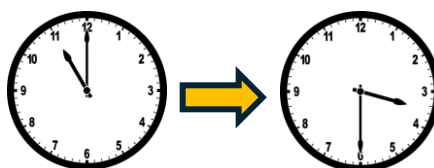


## What next?

- Write a letter and a statement based on all the feedback about barriers and solutions.
- Organise a day of action.
- Contact DWP
- Invite MPs to meet with us.
- Get something about our campaign in the press.
- Make videos.



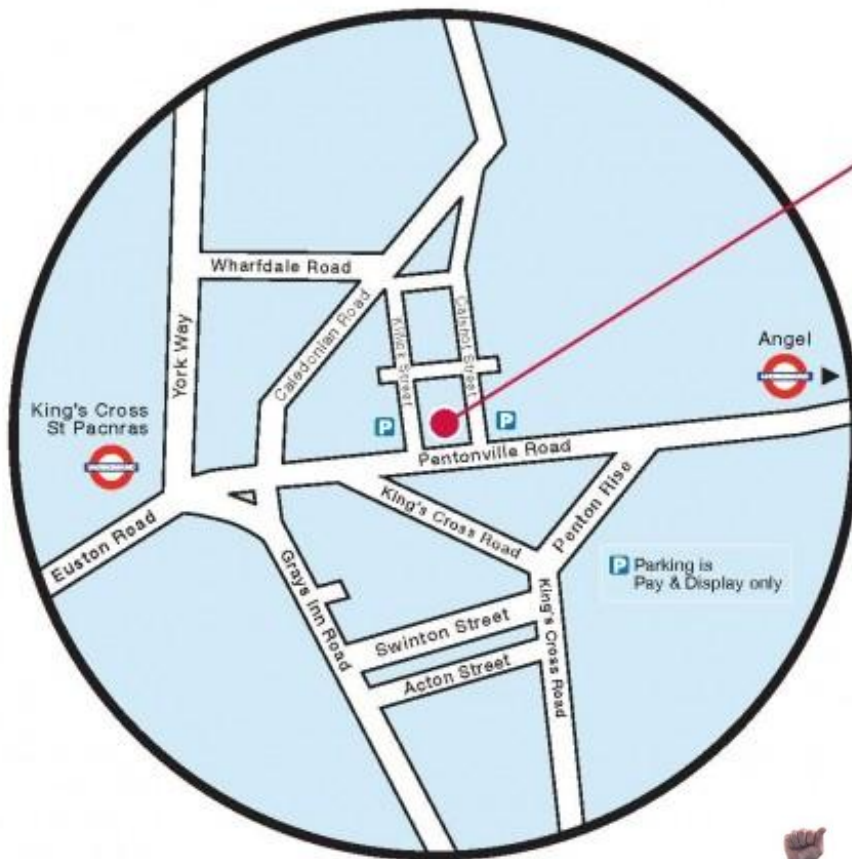
Friday 18th July 2024  
11am – 3:30pm



**Voluntary Action Islington**  
200a Pentonville Road  
(Near Kings Cross) London N1 9JP  
<https://vai.org.uk/contact-us/how-to-find-us/>



# DIRECTIONS



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**Contact us:**



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