

# **Community Change Lab - Launch event notes and resources**

## **June 2026**

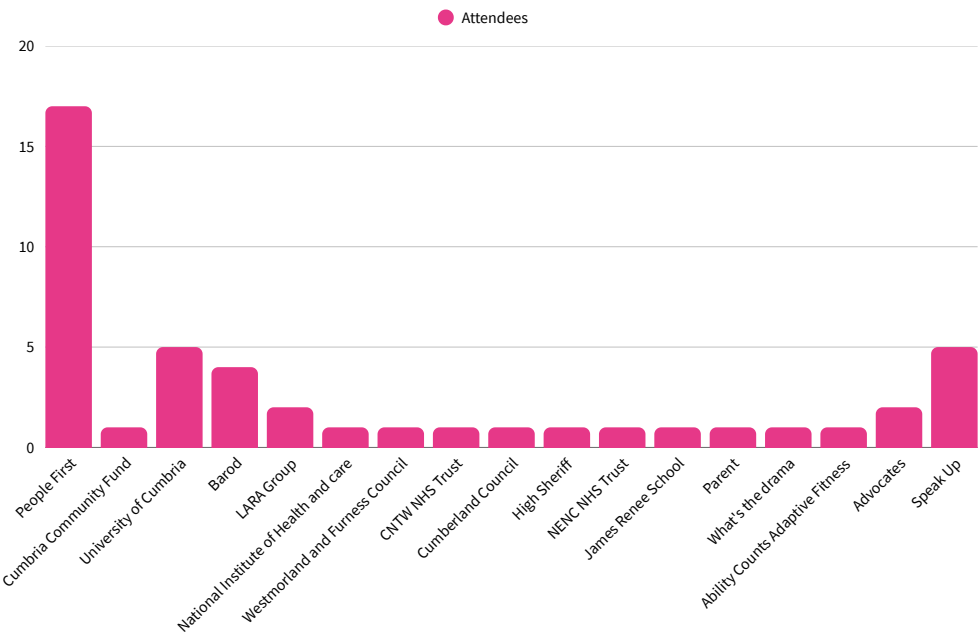
# Introduction

This document is a summary of all the information presented and collated at the launch of People First’s Community Change Lab – a co-research centre doing research in equal partnership with people with lived expertise.

## Who was here

There were 49 people at the event. We expected 43 – nine were not able to attend but 15 people attended who were not registered which was fantastic.

As you might expect there was a large number of people from People First itself (including people with lived expertise), but also people from a range of 16 different charitable and statutory organisations as shown in the chart below.



We were delighted to be able to engage in meaningful conversation with so many colleagues.

## About People First

- People First was set up 35 years ago
- We were first set up to advocate for people with learning disabilities
- We are experts in inclusion
- We believe nothing should be done about us without us
- We have a history of supporting people with learning disabilities to do research
- We believe research should be done with not on people with learning disabilities
- And so it made sense for People First to set up the Community Change Lab
- We are now a much bigger organisation
- We support people with learning disability, people experiencing addiction and people with care responsibilities
- We work across the North West
- Our Community Change Lab's will support all these groups to co-research
- Today we are celebrating the launch of our first Community Change Lab supporting people with learning disabilities.

## Inequality in Learning Disability Research

- About 2.5% of the population have a learning disability
- Only 1.4% of academic grants are spent on research about learning disability
- Most research focuses on why people with learning disabilities live 20 years less than everyone else and how to prevent avoidable deaths
- Despite the push for inclusion, populations with learning disabilities remain heavily underrepresented
- For example, less than 1% of medical trials include people with learning disabilities, despite them experiencing a significantly higher prevalence of many conditions
- And there are so many inequalities that could be researched, as we will explore this afternoon.

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## Why People First, and why now?

- We have the experience and expertise to do inclusive research well
- We know people with lived experience of learning disability and research
- Our independence affords us the opportunity to do research differently
- Our drive for equity and excellent connections across the North West will help us ensure this research makes positive change happen
- We hope you will support us on this journey.

## Getting to know one another

### How did we get started?

- Pam, Mark and Lou all had experience in research and wanted to help set up this new research centre
- People First were interested in setting up their own research centre
- We got together once a month for a year and talked about what we should do
- We chose our own name and decided how we would work together
- We applied for research grants to help us get started
- And here we are today, launching the Community Change Lab!

### Who are we, and how are we set up?

We have a core team who attend monthly meetings as regularly as they are able. It includes:

- Lived experience of learning disabilities
- Staff from People First
- Academics from the University of Cumbria and the National Institute for Health and Care Research
- Head of School from Sandgate School
- Representatives from Cumberland and Westmorland and Furness Councils
- We also have a wider community of practice who are people who want to be involved but not as regularly as the core team
- We welcome anyone to join our core team or wider community of practice – just come and see us or drop us a line.

## What do we do and how do we work together?

- We have a Core Team of people who meet every month online for two hours
- We always spend some time getting to know one another
- We also have an agenda of tasks to work through
- We made a set of ground rules we work to, for example, that everything must be in an Easy Read format
- We wrote our vision and objectives
- We plan what research to do, who will do it and how to fund it
- We also make sure there is time and support for everyone to take part in meetings.

## Our projects

### **Our first project is a National Institute for Health and Care Research Public and Community Partnership Grant**

- Westmorland and Furness Council won a £10K grant with People First
- The pays for us to co-design accessible, easy read research training materials
- These will be ready for anyone to use by the end of March 2027.

### **Our second project is a National Institute for Health and Care Research Methodological Innovation Grant**

- University of Cumbria won a £45k grant with People First
- We will co-research the barriers people with learning disabilities have in accessing health care
- We will test how easy it is to use surveys, interviews, focus groups and creative methods in co-research
- We will have guidance on how to do co-research and a set of research findings by the end of March 27.

### **Our third grant is £3k from the Rix Thompson-Rothenberg Foundation to do creative co-research with people with learning disabilities. This will start in November 2026.**

## Get involved!

- We have space for anyone over 18 with a learning disability to take part in either or both of these projects.
- Join our Community of Practice to keep in touch and to hear about future opportunities.
- We have space for more people to volunteer on our Core Team to help shape how the Community Change Lab develops.
- You might be a commissioner of research – and you can commission us to do your research in an inclusive way.
- You might be an academic - our team can offer advisory services, reviewing your research plans.
- And we are always open to offers of grants, funding, or support in kind!
- [research@wearepeoplefirst.co.uk](mailto:research@wearepeoplefirst.co.uk)

## Building our research agenda – research trees

- Our core team discussed the range of issues people with learning disabilities face
- We set these out as research questions in a tree format
- The issue is on the tree trunk
- The causes are shown on the roots
- The problems this issue leads to are shown on the branches.



We asked everyone to grow our trees, adding causes, symptoms, and connections to people or projects that answer some of these questions. The comments that were added to the trees are written in full on pages 9-

## Housing

- Quality of housing
- Support in supported accommodation – prevents free choice
- Have help with a social worker
- All options are given to a person, not just the easiest for the service
- Find out what is there already
- Look at housing options for people with LD
- Create connections to people with supported housing / living
- Make sure that people have a choice
- Make the rules and boundaries clear
- Let the providers know they are treating people unfairly

## Accessibility

- Funding is not equitable – it costs more to work with PWLD so fewer can take part
- Lack of consultation for people with disabilities
- Lack of guidance for physical / sensory accessibility
- Ableist thinking – thinking that disability access is an extra
- Design decisions are not inclusive – aging not considered in housing
- Services need to be explained so they have all the information possible
- When designing signage there is some research about the need for colours that signify things e.g. red for danger
- There is more room for research on universal design principles
- Need good design of unavoidable settings e.g. hospitals are bright, uncomfortable, uninclusive – add dimmable lights and quiet spaces
- Create a careers team – health and social care staff need to spend time with LD people – not just tick box training but something meaningful
- Inclusion should happen in all research
- Training made available for family members in supporting / carer role.

## Health

- Intersectionality
- Medical misogyny
- Race
- Health passports are a good start but not enough as a whole
- Health environments e.g. hospitals too distressing
- [Lynzee.mcshee@nhs.net](mailto:Lynzee.mcshee@nhs.net) has done some research in having services for people with learning disabilities. She walks around at the hospital in Sunderland
- Change the trunk question – people with LD have less chance to have good health
- Lack of continuity or consistency of care
- Lack of tailored communication - assumptions made
- Patient passports not fully used
- Lack of appropriate support to make good choices
- The system is difficult to navigate and complex and social inequalities are much sharper for families with less knowledge or lower socio-economic status.

## Education

- Karen McKenzie (2024) Screening for intellectual disability in mainstream schools
- Increase accessible courses to teach people to teach in inclusive ways
- Louise Townson OMMT
- Listening to talks from families and students have had support in education
- Wigham (2025) Developing a trauma checklist
- Teacher training focuses on content and not enough on conditions of young people
- Complex SEND process / EHCP to navigate – poor, slow, parents need to fight hard
- Lack of advocacy for individuals
- Expectations of what can be achieved by individuals are too low
- Education system has a narrow focus – obsession with assessments and exams without looking at underlying issues of poor wellbeing
- Stigma embedded within the education system.

## Employment

- Lack of suitable opportunities or creative approaches to creating job opportunities
- Prejudice
- Limiting beliefs
- Assumptions

## Discrimination

- Safe places for people with a learning disability
- Where do people feel safe?
- NE Library Service project – Safe Places North Tyneside
- Social bullying and hate crime
- Feel unsafe
- Misinterpretation of abilities
- Bias and stereotyping
- Society lacks knowledge and inadvertently discriminates due to lack of understanding
- Fear of knowing what to say or do
- Challenge focus on what people can't do rather than what they can do
- Can be hidden and invisible.

## Safety

- Victims of hate crime and mate crime
- Don't get on with neighbours – no community
- Name calling
- People struggling with addiction and begging makes the public feel unsafe and wary
- Lack of hate crime reporting centres
- Often moved around in housing
- Lack of support and basic needs prioritised
- Reduced funding and changes to care services e.g. police no longer have hate crime officers
- Risk of bullying and harassment due to mean people or lack of understanding

## **Keynote: Working together to improve inclusion of people with learning disabilities and autistic people in research – Anna Anderson and Janis Borquoi**

Janis and Anna explained the LARA group to us and introduced us to the ACCESS guide they have written by using a guessing game which we all really enjoyed.

### **The Community Change Lab Launch Event: LARA group slides**



These slides are just for your own use. Please do not share them publicly, such as on the Internet.



**Working together to  
improve inclusion of  
people with learning  
disabilities and autistic  
people in research**

Janis and Anna

## About our group

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LARA stands for Learning disability and Autism Research Access group.



We are a national group of people with lots of different experiences of learning disabilities and autism.

## Our aims

A



We aim to improve inclusion of people with learning disabilities and autistic people in health and social care research.



For example, by supporting people with and without lived experience of learning disabilities and autism to work together and co-produce research.

## Our top tips

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To help meet our aims, we developed top tips for working with people with learning disabilities and autistic people as research team members.



We grouped the tips into an **'ACCESS Guide'** to make them easier to remember.

## ACCESS Guide

J



## Our take-home messages

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The LARA group involves sharing, learning and working together.



We hope this will help improve inclusion of people with learning disabilities and autistic people in research.

## Our thank yous

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Thank you to all the LARA group members for being part of the group and helping to develop the ACCESS Guide.

Thinklusive

Thank you to the Thinklusive Advisory Group and designers for helping to develop the ACCESS Guide and our Easy Read documents.

## More thank yous

J



Thank you to the NIHR Biomedical Research Centres in Leeds and Oxford for funding the ACCESS Guide work.



Thank you for to People First for the invitation to talk today and thank you for listening!

If you want to know more about the LARA group, contact Anna via [A.Anderson@leeds.ac.uk](mailto:A.Anderson@leeds.ac.uk) or 0113 3436965 or visit our LARA group webpage: <https://medicinehealth.leeds.ac.uk/directory-record/1938/learning-disability-and-autism-research-access-lara>

A

**ACCESS Guide authors:** Anna M Anderson, Maximilian Clark, Amy M Russell, Angeli Vaid, Melissa Kirby, Elizabeth Atkinson, Amrit Chauhan.

**Funding:** This ACCESS Guide project was funded by the National Institute for Health and Care Research (NIHR) Biomedical Research Centre (BRC) Oxford and the NIHR BRC Leeds. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

**Images:** The images in this presentation are from Microsoft 365, Unsplash, and the Centre for Ageing Better Age Positive Image Library.

## Making co-research happen – overcoming barriers

Our core team identified a range of seven barriers to making co-research happen. We asked everyone at the launch event to think of solutions to overcome these barriers. People's responses are written out in full below.

### **There are too many rules that say 'no'**

- Find loopholes that aid research and that don't break the law
- Campaign to change the rules
- Involve all organisations to enhance compromise and flexibility
- What are the rules? Who has set them? Why are they holding people back?
- Make it the other way around – have to justify exclusion and high thresholds for acceptance
- Understand why the rule was made in the first place
- Co-produce rules that are safe and support not deter
- Try to talk to the people who make them
- Improve guidance for ethics committees on co-production
- Explain why people need to be involved and explain why the rules need to change
- Gather communities interest in research and things and share why things should change.

# Making co-research happen – overcoming barriers

## There is not enough time or money

- Co-create best practice templates to include PWLD in research
- Find someone to help you lead the work
- Gather positive data and info on why research is so valuable
- Find a sponsor
- Apply for funding
- Publish information from funders about the % of funding they have awarded to research including people with learning disabilities
- Develop a costing template that can be given to researchers who are co-writing grants
- Make it a part of what everyone does so its not extra money or time but part of core work.
- Lobby funders to include people with a learning disability
- Reciprocity
- Embed a culture where co-research is a priority
- Allocate a % of budget to co-research
- Give examples of timelines so people do not underestimate what is needed for this work
- Create guidelines for what is appropriate – what should indicative costs be?
- Ask family for help
- Try to make more time through funding
- Drive NIHR funding for co-production
- Involve retirees and people with time and wisdom.

# Making co-research happen – overcoming barriers

## Can't find people who want to take part

- Good zoom connections
- Create a buddy system
- Flexible offer
- Sort transport issues
- Greater advertising, awareness raising of all the opportunities
- Universities could hold a data base of people
- I'd love to take part
- Create a film about why research is important
- You're not trying hard enough
- Go where the people are
- Online facilitated meetings
- Social media
- Use art to engage researchers
- Make projects visible, report findings widely so people know and trust the team
- Involve VCSE organisations
- Give incentives and experience towards employment
- List the benefits and possible changes it could bring
- Media presentations that are accessible to all
- Share communication with local services and work together to spread the word.

# Making co-research happen – overcoming barriers

## It is too difficult getting people to meetings

- Pay for transport and include it in funding bids
- Go to them
- Include access costs in funding bids
- Walk-friendly spaces
- Sensory room options
- Explore why – what would make it more accessible, do you need to move the venue, provide inclusive technology etc.
- Join on phones
- Shared resources
- Online meetings or travel to community you want to engage with
- Make time for local meetings and then a spokesperson brings everything together
- Have infrequent but really FUN meetings
- Tag onto other events
- Hybrid options
- Write supporting letters for Now 247 card applications
- Give incentives to come to meetings
- Travel training
- Work with universities to make research more accessible and fun.

## Senior managers do not value co-production

- Introduce the need to justify if something is not co-produced so it has to become the norm
- Recruit trustees who do!
- Show / demonstrate the value of where it has worked elsewhere
- Employer training – get them involved
- Involve senior managers in the work
- Quick feedback why it is important, what improvements it can lead to
- Meet with managers and explain the benefits
- Find examples where co-production led to positive change and share.

## Making co-research happen – overcoming barriers

### **Organisations don't know how to make things Easy Read**

- Use AI
- Pictures are alright
- Provide Easy Read training
- Explore online widgets
- Get funding to develop Easy Read documents
- Understand and learn from individuals what communication needs they have – communication passports
- Co-produce to know what works best
- Build an easy read library
- Do a course
- Show people how to do it
- Talk to people who use it regularly.

### **Staff are not confident in leading co-production and / or research**

- Staff learning sessions
- Involve staff as co-participants
- Staff 'champion' or 'lead'
- Create points of contact with other staff with expertise
- Time to review and build confidence
- Mentors
- Offer more courses
- Buddy up
- Make time for people to come to speak to staff
- Co-produce training with staff and the public
- Offer courses and training
- Collect case studies showing actual work in progress and what can be achieved
- A register of people or organisations people can contact for help.

## Keynote: Barod CIC

Claudia Magwood, Simon Richards, Simon Rice and Mal Cansdale shared an overview of Barod CIC's research work with us and some tips on how to create some co-creation spaces.

You can watch the team's recording of their presentation here:  
<https://youtu.be/ktK3XNOmuhw>

## Sharing resources

We had intended to ask everyone to add to a shared resource bank- one a list of people working in this space and another a list of online resources. We have turned these into 'Miro boards' so everyone can add to these and access them remotely and so they can continue to build over time.

There are two sets of 'post it' notes – please add any resources you are aware of onto the notes so we can all use what is already out there!

**PEOPLE** - Who is doing co-research with people with learning disabilities?

**RESOURCES** - What electronic resources are there to support co-research with people with learning disabilities?

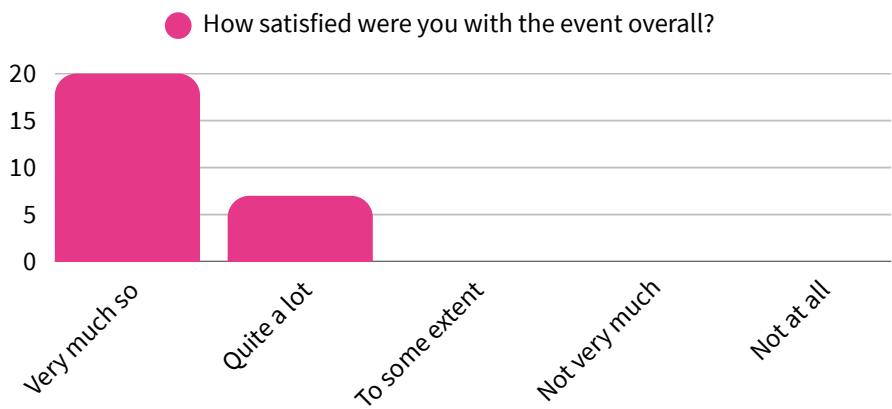
You can view and add to them by clicking here:

[We invited people to write thoughts and reflections on the table cloths and this is what we read](#)

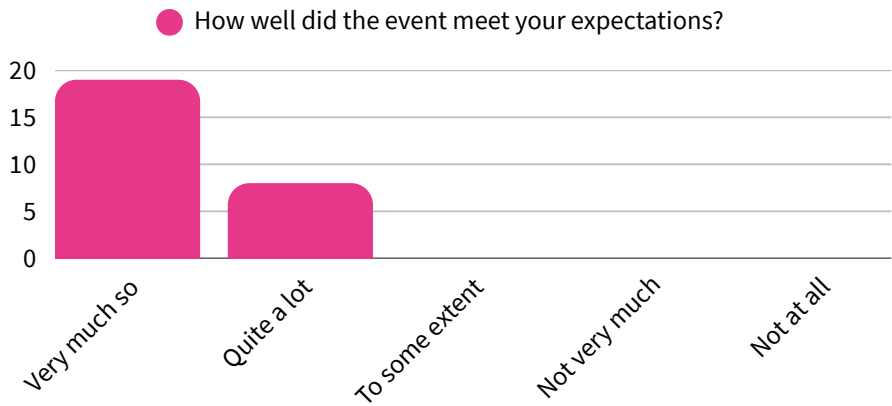
# Evaluation

We asked everyone to fill in an Easy Read evaluation form.  
We collected in 27 evaluation forms which meant 55% of the people there completed a form.

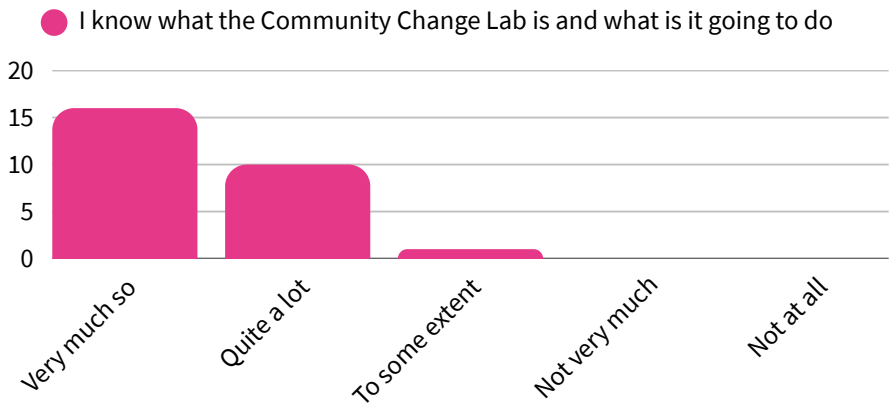
**We asked people how satisfied they were with the event and they were all very or quite satisfied with it.**



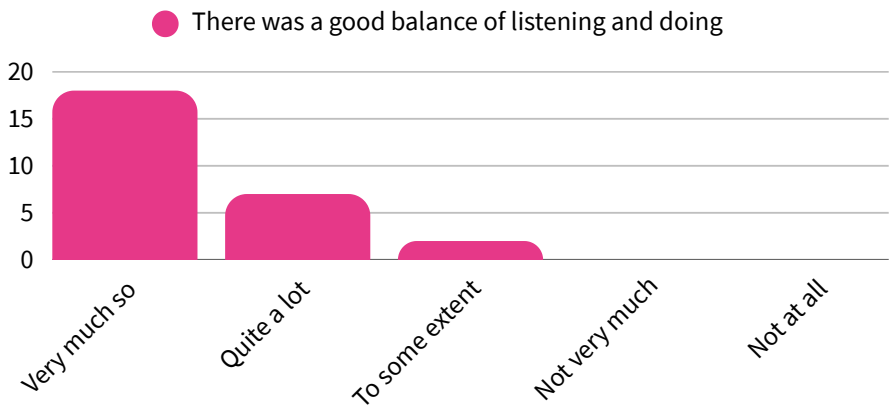
**We asked how well the event had met people’s expectations and everyone said it met their expectations very much or quite a lot.**



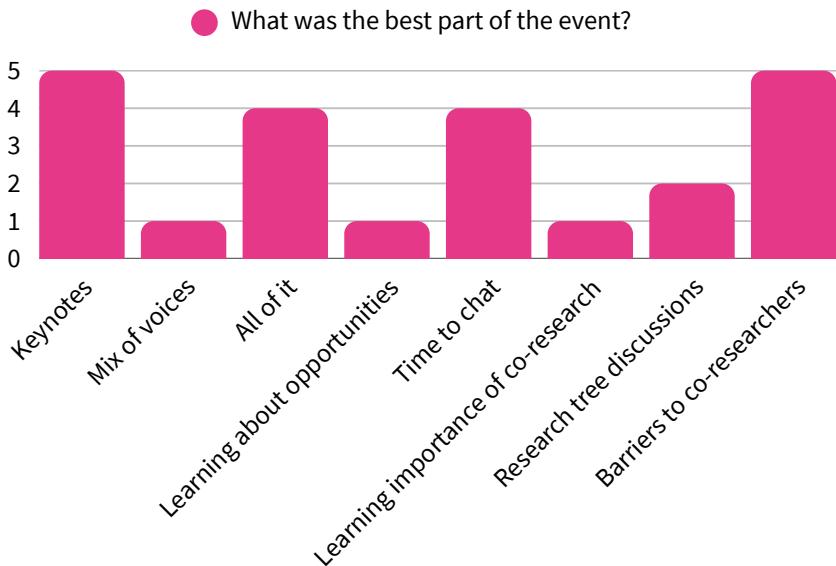
**We checked in to see if we had explained what the Community Change Lab does well enough. People said they understood it very much, quite a lot or to some extent.**



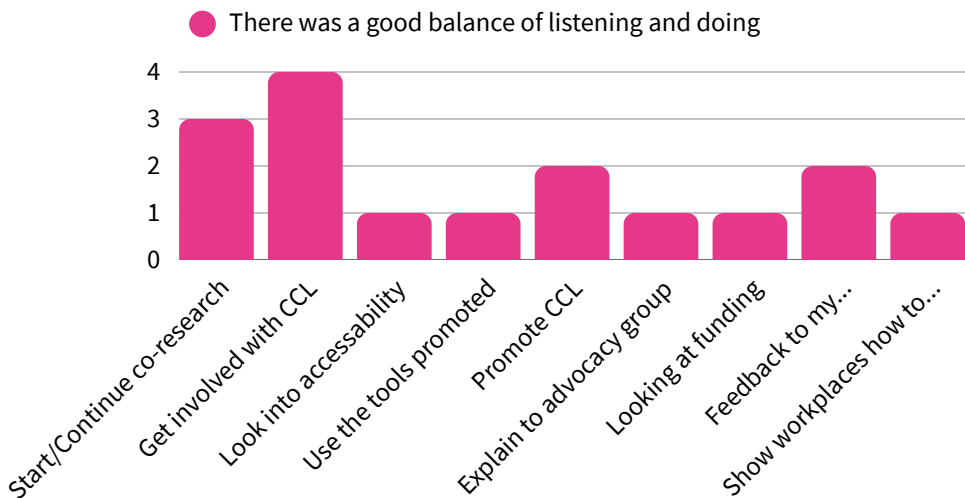
**We asked if there was the right balance of listening to presentations and doing activities. Everyone said there was a very good balance, quite a good balance or some balance between the two.**



**We asked whether we had provided enough time for connecting with other people. Every one said there was very much enough time, quite enough time or just enough time to connect with others.**



**We also asked everyone to commit to something they would do as a result of coming to the event. 16 people filled in this box and there were nine different things they committed to doing.**



**We are delighted the event had something for everyone, was enjoyable and meaningful and has promoted some future actions. We will consider how we can make future events even better from the feedback we have.**

## **Any questions?**

If you have questions about our Community Change Lab you can contact us



You can call us **0300 303 8037**



Or email **research@wearepeoplefirst.co.uk**



Or live chat **wearepeoplefirst.co.uk**

If you need this information in a different format please let us know

### **We are a charity**

People First Independent Advocacy are  
a Registered Charity. No 1184112



**wearepeoplefirst.co.uk**