Community Change Lab - research by the people for the people

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What is a Community Change Lab?

The Community Change Lab is an inclusive space where people with learning disabilities plan and conduct research alongside people without learning disabilities. this type of work is sometimes called ‘co-design’, ‘co-research’ or ‘participatory research’.

This overview is drawn from work by an advisory group which has people with learning disabilities, staf of People First, academics and funders discussing how we should set the Community Change Lab up. The Community Change Lab is co-designed by this group of people.

Why are we setting this up now?

- People with learning disabilities are not well supported
- People with learning disabilities are excluded from co-designing services
- People with learning disabilities are excluded from decisions about research
- We believe research BY people with learning disabilities is important
- We think people with learning disabilities have unique knowledge
- This knowledge will improve research, services and lives.

Our Vision

We want to see a world where people with learning disabilities can thrive, where they are involved in decisions and research, and where they can live without discriminations.

We think we can create that world through research by people with learning disabilities.

Our Objectives

We will:

- Make sure people with learning disabilities design and doresearch on things that are important to them
- Make services better for people with learning disabilities
- Improve the lives of people with learning disabilities
- Show other organisations how to make research accessible to everyone

Our Research

Research means collecting information to answer a question or to create new knowledge. We will research things that can improve the lives of people with learning disabilities. this may often include topics relevant to health and social care services.

What does ‘planning and doing’ research involve?

There are ten stages in planning and doing research. We want everyone to e as involved in each peoject and support everyone to choose which stages they want to be involved in.

The diagram below shows the stages of research.

Types of research

Research means finding things out. there are three different ways research can be planned as shown in the diagram below.

Type A - ON people	Type B - WITH people	Type C - By people
Research is planned by academics and done ON people with lived experience. People with learning disabilities just give their data. This is the most common type of research.	Research is planned WITH people with learning disabilities and done ON them. People with lived experience give their views of the research plan. This happens some of the time.	Research is planned BY people with learning disabilities and done by people with learning disabilities. People with lived experiences are full co-researchers. This rarely happens.

The Community Change Lab is mainly interested in Type C research, where people with lived experience lead their own research, supported by practitioners and academics without learning disabilities. This approach benefits people with learning disabilities the most, and also supports researchers, participants, and society.

The Community Change Lab may also take part in Type A research planned by academics, and will support Type B research by reviewing plans created by academics. By reviewing research plans, we will help ensure that research involving people with learning disabilities is high-quality, meaningful, fairly paid, and properly recognised.

How we will work together

The way we will work together is grounded in the People First values:

Inclusion - we will make sure everyone has a meaningful role in the Community Change Lab
Rights - we will fight for the rights of people with lived experience in research
Independence - we will do research in a new ways, and we will support other organisations to do the same
Impact - we will make a difference, and this will help other people can see the value of co-research

We have agreed a set of principles to work to:

- Build trusting and respectful relationships
- Offer people choices about what they do in every research project
- Avoid making assumptions about what anyone can or can’t do
- Make all communication accessible
- Give the right support so everyone can take part
- Help people to do research without putting them at risk
- Be careful when researching sensitive topics and offer follow up support afterwards
- Flip the usual power dynamics with academics supporting people with learning disabilities
- Do research that makes a difference in 1 or 2 years
- Pay people with lived experience for their time in the right way.

How we are set up

Our scope

We will start our research from Cumbria as this is the place where Peopl First is based and we will start our co-research with people with learning disabilities as this builds on existing strengths.

Our team of co-researchers includes:

- Anyone over 18 who says they have a learning disability
- Any academics with expertise in learning disabilty research
- And any practitioner or manager with expertise in deliveringservices for people with learning disabilities.

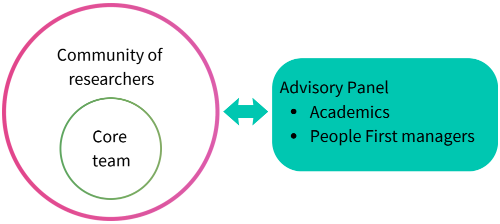
People who take part in our research can be of any age.

In the future we hope to cover the North of England.

Our structure

The Community Change Lab has three parts:

1. Core team
2. Community of researchers
3. Advisory panel



The **Core Team** manages the work of the Community Change Lab. This team of up to 14 people meet monthly for two hours.

The members include:

- People with lived experience and their support staff
- Staff from People First
- Academics
- Practitioners from services for people with learning disabilities
- A researcher from the National Institute for Health and Social Care Research

The **Core Team** decides:

- What research we want to plan and do
- How to make the research good quality and safe
- How to make sure people read the research we do
- How to fund the work we want to do
- Whether to take part in other people’s research from invitations they recive
- How to keep people engaged in the wider Community of researchers

The Community Change Lab also has a wider **Community of Researchers** who are people who would like to be involved in different stages or research projects. the community of researchers will include people with learning disabilities, academics and practitioners from health and social care organisations.

The community of researchers will meet every three months where we will discuss progress on projects so far and next steps.

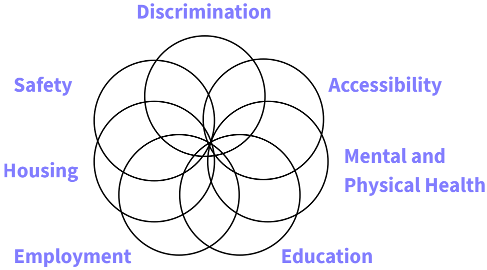
The community of researchers will be offered roles in research projects they will be paiud for this work. Smaller research project teams are likely to meet weekly.

The Community Change Lab **Advisory Panel** is designed to help us do high quality research that is safe for everyone. The advisory panel will meet about six times a year to support the Core Team. the advisory panel is made up of academics with experiences of learning disabilitiy research and managers from People First who are families with People First’s policies, structures and resources.

What will we research?

Our Core Team found 7 problems that people with learning disabilities experience:

- Accessibility
- Mental and pyhiscal health
- Education
- Employment
- Housing
- Feeling unsafe
- Discrimination



We have thought of all the things that create these problems and all the issues these problems cause for people with learning disabilities (please see the Community Change Lab Research Trees.

There are so many things we could research. We take things slowly and decide on one thingto research at a time. We choose what to research by working out:

- What is most interesting to us
- What we have the skills to research
- What funding might be available

We always check that research projects :

- Are useful to people with learning disabilities
- Are not repeating something that has already been done
- Are possible in one to two years
- Can be funded
- Are useful to services in Cumbria
- Offer meaningful work for our Core Team and wider community.

High quality and safe research

How do we make sure our research is ethical?
Research ethics are rules to make sure research is safe for everyone, it is good quality and it does not break any laws.

We have used the 'Health and Care Professionals Councils Ethics Framework' for pracitioners and the 'UK Research Institute Research Ethics' to guide how we work.

This gives us 16 ethical guidelines:

Benefit - Research should benefit people and society and also reduce risk and harm as much as possible.

Respect - Respect everyone's rights, interests, values and diginity.

Fair - Making sure everyone who has the right to take part can doso, making sure everyone has the same service, and the personal beliefs do not change the way they treat people.

Accessible - Make sure people get information in a way they can use it.

Voluntary - Taking part in any research is always a free choice.

Consent - Making sure people know what they are getting involved in and agree to it.

Withdrawing - People should be able to stop taking part at anytime and should be able to take their information out of the research.

Professional - We are polite to everyone, we do what we say we will do and we do not develop personal relationships.

Skilled and trained - Everyone has the right training and support.

Keep information safe - Information is saved in a private secure place.

Keep everyone safe - Make sure people taking part in research and people doing research are all safe from harm. Harm could be physical or emotional. We must be careful is we are doing research online and when we are working with people who might be 'vulnerable' in some way.

Anonymous - We make sure people who take part in our research cannot be identified by their name, where they live, or any personal characteristics.
If something goes wrong - All issues and complaints are reported to the senior staff in People First.

Independent - The research should not be steered by anyone except the Core Team. We all say if we know something or someone in a research project.

We follow the law - The laws need to follow include:

- The Date Protection Act 2018
- The Freedom of Information Act 2000
- The Human Rights Act 1998
- The Mental capacity Act 2005

These laws are included in People First's Policies.

Ethical - When we design a research project we will discuss and write an Ethics Plan that covers all the points above. Our Advisory Panel will review the Ethics Plan and advise us to :

- Go ahead with the research
- Change our plans
- Seek ethicak approval from another organisation. This could be the University of Cumbria or the Health Research Authority
- Stop planning and doing the research.

High quality and safe research

How can people find out about what we are doing?

It is important that other people can access our research. We write our research in an easy read format and share it with as many people as possible.

We will also communicate through:

- A small website on People First's website called a 'mocrosire'
- Newsletters
- Collaboration with the Tulip Group and LARA Group
- Networking
- Going to conferences
- Our own annual event.

Glossary

Anonymous - Keeping a person’s name or identity secret

Co-design - A group of people with service expertise and lived experience who design services together.

Co-research - A group of people with research expertise and lived experience who do research together.

Conflict of interest - When someone’s personal interests - family, friendships, finacial, or social facotrs - could influence his her judgement, decisions, or actions in the workplace.

Date - Information, like num,bers, words, or pictures, that can be collected and organised to help us understand something.

Denocratic - Things that are democratic are ruled by the people, for the people. A common form of democracy is when everyone votes on what they think is best for the whole group.

Partipatory research - People with lived experience participating in the design of research rather than just the collection of data.

Research - Involves collecting data or evidence to answer a question or to create new knowledge.

Research Ethics - Set out rules for how people do research to make sure it is safe for everyone, it is good quality and it does not break any laws.

Research Plan - A document that describes what research we will do and how we will go about it.

Research Trees - Diagrams that help us explore important topics. the show what the topic is (what), what causes it to be a problem(why) and what problems the topic leads to(so what).

Stakeholder - Someone who has an interest in what we do, power over what we do. Stakeholders can be individual people or whole organisations.

Voluntary - Doing something becuase you choose to, not necause you have to.

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

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