Westmorland & Furness Council

NIHR | National Institute for Health and Care Research

People First

Community Change Lab

Easy Read Co-Evaluation of the Accessible Research Training Materials Project

Co-created by:
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Introduction

About this project

	Westmorland and Furness Council and People First in Carlisle applied for a National Institute for Health and Care grant for a Public and Community Partnership.
	We were awarded £10,000 to co-create research training that was accessible to people with learning disabilities.
	A team of seven people with learning disabilities and neurodiversity, one person from Westmorland and Furness Council and one person from People First worked together to test out accessible learning materials and to design this pack.

What is Co-Research

	Co-research is when people with lived experience do research with researchers. Co-research is an equal partnership. People do what they are able to and what they enjoy – no one has to take part in everything. Co-research can use any tools and techniques and its focus is making people's lives better.
	About 2.5% of the population have a learning disability, but only 1.4% of academic grants are spent on research about learning disability. Less than 1% of medical trials involve people with learning disabilities.

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	People with learning disabilities have live 19 years less than the rest of the population and 38% of their deaths are avoidable.
	This highlights the need for more research into the inequalities they experience, and people with learning disabilities are best placed to design and do this research.
	We believe, that with the right training and support, people with learning disabilities and other needs can design, conduct, analyse, write up and communicate research themselves. There are no excuses for not involving people with lived experience as co-researchers.
	This is what we set out do to in this project.

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Credits and thanks

NIHR | National Institute for Health and Care Research	Thanks to the National Institute for Health and Care Research Specialist Centre for Public Health for their Public Community Partnerships Research Grant.
Westmorland & Furness Council	Thank you to Westmorland and Furness Council for believing in the work and being lead partner in the grant process.
People First	Thank you to People First for providing all the venues, support, infrastructure and consultant time to make the project a reality.

Note:

This study/project is supported by the National Institute for Health and Care Research (NIHR) RSS Specialist Centre for Public Health (SCPH) (Grant Reference Number NIHR 205426-PH). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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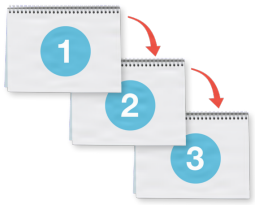
How we co-evaluated the project (our method)

	We had reflections from every sessions and evaluation forms to help us know whether we did a good job. We filled in the forms, worked out what they meant and wrote the evaluation together as a team.

Evaluation of **how** we co-designed the materials (our process)

How we did the project

	Kaz and Liz had written the grant application and this set out the structure of the project. We had ten sessions that covered each stage of the research process.
	Each week Kaz and Liz would design some activities and some information that would help people with learning disabilities to understand research.
	We would all try out the activities and read the information. We were very honest about what needed changing.

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	After each session Kaz wrote everything up into our accessible research training materials pack.
	Mark O'Farrell read everything to check we had used the right language and activities.
NIHR | Health Determinants Research Collaboration	When the pack was completed, we sent it to Cumberland Council Health Determinant Research Collaboration three Co-Researchers to review it.

What did we enjoy the most?

	- The role play activities (the bad interview, the bad focus group). - Interactive games (paper's got talent) - The opportunity to shape the materials - Kaz and Liz acting on our feedback. - Moving around and doing different things.

What went badly or was not enjoyable?

	- Nothing.

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Was the project accessible?



Yes, because:

- The building was easy to get into
- The resources were accessible
- The sessions were welcoming and let us be ourselves
- It was very flexible.

But:

- We were not sure what we were signing up to
- We didn't know why we were chosen to take part

Were the activities and project meaningful?



Yes, because:

- Everyone felt they were listened to
- We liked using our lived experience
- We felt we were making a difference
- Kaz and Liz changed things when we said they needed changing.

Did people have opportunity to be involved in different ways?



Yes, because:

- Everyone knew their roles
- Everyone had choices
- People never felt judged
- It was very varied.

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Was everyone supported well-enough?



Yes, because:

- We always started with check ins
- We used different ways of communicating
- Resources were accessible
- Fidget toys and snacks were helpful
- We could talk about anything we wanted to
- We got support when we needed it.

Were people paid and did they have their contributions recognized?



Yes, because:

- We were paid £27.50 per hour
- We were named as co-authors.

Was power shared in the project?



Yes, because:

- Kaz and Liz shared whenever they could and acted on what we said
- Everyone felt part of decision making
- Everyone felt they had been treated fairly.

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Evaluation of the **changes** the co-design project created (our impact)

The gains we experienced as individuals

What we gained	
	Communication / use of words
	Empathy for and understanding of other people
	How to do research and design work
	Hope things will change
	Confidence

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	Knowledge
	Fun
	Creativity
	Named as an author
	Friends / comrades
	Support / stability

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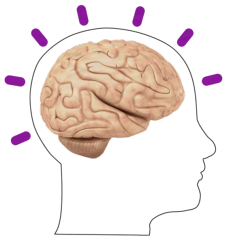
	Thinking outside the box
	Calmness / slowing down
	Sense of community / belonging
	Make less assumptions
	Using what I know

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Other wider impacts

	- Other people said these resources would be useful for everyone.
	- We made an Easy Read ethics form for the University of Cumbria.
	- Westmorland and Furness Council are going to use this work to help them make more things Easy Read and accessible.

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Conclusion

	- We worked together well and all enjoyed the process.
	- We all learned and gained things from the project.
	- We produced a research training pack other people can use.
	- We hope this will make accessible research more common.

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