



Photograph by Diego Maeso

Make Room!

Creative Conversation Workshops Researching LGBTQIA+ Accessibility

Community Fellows' Experiences and
Considerations for Disabled People led Research
March 2024

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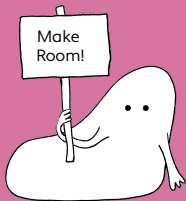
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Report Introduction

This report is one of five short reports sharing our findings on the Make Room! research project on LGBTQIA+ accessibility in the South West of England.

The focus of this report is to explain the role of Disabled led research from researchers from non-academic backgrounds within Make Room and We Are The People as a whole.

The report will also highlight key considerations for lived experience research projects led by and for Disabled people for anyone wishing to make their workplace more accessible.

Photograph by Gabriella Tigoglu



What is Make Room!?

Make Room! has been a six-month research project, led by Community Research Fellow Layla Taylor, running from October 2023 to March 2024 by We Are The People. Layla is themselves a queer, working class, Disabled performer, artists and creative therapeutic practitioner, and this creative ethos helped guide Make Room!

The project aimed to better understand experiences of accessibility for LGBTQIA+ Disabled people in the South West of England, particularly when engaging with LGBTQIA+ events and venues, drawing on creative methods of research practice to find out more, pose questions, and identify practical actions moving forward.

Photograph by Gabriella Tigoglu



Make Room! is one of three six-month Community Research strands launched for the 2023/2024 academic year by We Are The People, the other two being Disability and Activism, and Disabled People's Organisations.

Each research strand is led by a Community Research Fellow with lived experiences of Disability, and supported by an internal Research Fellow and project leader at Bath Spa University. For this project, Bethany Lamont was the internal Research Fellow and Ben Simmons was the project lead.

Our project consisted of two creative conversation workshops for Disabled LGBTQIA+ people and those who felt impacted by these themes, which included art making on LGBTQIA+ accessibility, as well as one to one and group interviews, alongside a small-scale survey for participants, and a working group to steer the project's direction and focus.

Photograph by Gabriella Tigoglu



What is We Are the People?

We Are the People (WATP for short) is a five year research project into Disabled people's experiences in the South West, which is based in Bath Spa University and funded by the Wellcome Trust.

We Are the People is made up of a passionate team of Disability advocates, comprising both of Disabled people and their allies.

Experiences in the team range from practising artists and museum workers to academic researchers in the field of social sciences, which is a kind of science that focuses particularly on people's life, their communities and the society around them.

Photograph by Gabriella Tigoglu





I joined the project because it really chimes with work I have been doing over many years which brings the knowledge, methods and rigour of academia and academic research into the voluntary sector, and Disabled People's Organisations in particular.

I love the fact that the project works with under-represented groups, who do not often have much of a voice within disability fields, and I love the fact that the project is working in ways that will present research and research findings in new ways to make the research accessible to new audiences.



-Theo Blackmore, Senior Research Fellow for We Are The People on the importance of lived experience research

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For me, the WATP project was shaped by a fundamental ethos of wanting to change how research happens between universities and disabled people.

WATP was informed by a culmination of other disability research grants the team have previously been involved with, such as ‘Getting Things Changed’ and ‘D4D’. However, WATP is a standalone piece of work shaped by the insights of disabled people and allies who want to make things better for disabled people.

”

-Stuart Read, Research Fellow for 'We Are the People' on changing how universities research about disability

Lived Experience Research in We Are the People

The team were interested in how they could approach academic research into Disabled people's experiences differently.

Questions they asked included:

- How could academic research into Disability promote leadership for Disabled people from non-academic backgrounds?
- How could academic teams recognise the value of lived experience, and not simply academic qualifications?
- How can the direction of what WATP researches be set by Disabled people?
- How can WATP ensure our findings are communicated accessibly to Disabled networks?

Photograph by Gabriella Tigoglu



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- How can we prioritise community impact, and ensure our findings aren't simply filed away in an unread report?
- How can we champion creative ways of research to promote accessibility and new discoveries?

This is how WATP came up with the Community Fellow model. They knew they would be running lots of research projects on different subjects related to Disability across the five years.

Here, they decided that each of these projects should be led by a Community Fellow, with lived experience of the subject they were researching.

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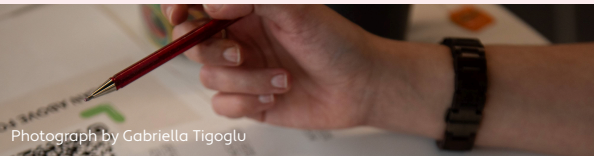
Key Objectives of We Are the People's Lived Experience Research:

The research development programme must:

- Lead to a significant and sustainable research agenda
- Develop the careers of the people in your research group
- Build a diverse and collaborative research community
- Explore and develop approaches to co-production in disability studies
- Develop 'inclusive' university practices
- Explore how universities can work with local communities to co-develop/run projects

Co-production: working with a particular community on a research project to ensure it meets their needs, and benefits them.

Photograph by Gabriella Tigoglu



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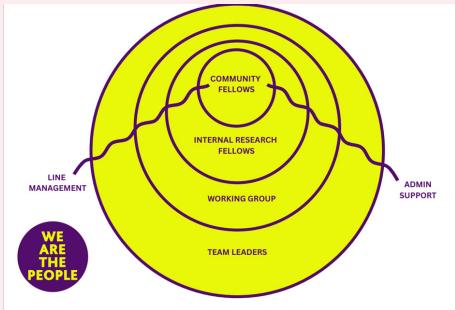
Phases of the Six Month Community Fellow Role:

1. Interviewing, onboarding, training
2. 'Getting to know'
3. Project planning
4. Running the project
5. 'Coming to an End'

Photograph by Gabriella Tigoglu



Photograph by Gabriella Tigoglu



Here is a diagram of We Are The People's working model for all their research projects, including Make Room. As you can see, Community Fellows are at the centre.

You might be wondering what the 'Working Group' is, this is a group of people in the South West with lived experiences of the research topic who offer feedback and guidance on the project. You can find out more about our working group in the Research Methods report.

In the next few pages, you can read quotes from the We Are The People team explaining why the Community Fellows are so important to the project.



The Community Research Fellows (CRFs) have lived experience of the issues they are researching. This brings a depth and breadth of understanding to the areas of research that other people might not be able to bring.

The concept of 'Nothing about us without us' has been the cornerstone of the disability rights movement since the 1970s, and should be a part of all disability research, and yet is rarely seen.



**-Theo Blackmore, Senior Research Fellow
for 'We Are The People on the
significance of the Community Fellows
model**



We wanted to ensure that disabled people who may not have previously worked with universities before had the chance to shape their own research and see themselves as researchers.

People who work in universities, even disabled people, do not necessarily know the issues that disabled people within the South West experience.

The Community Research Fellows are a chance for universities to see what the 'real world' issues are for disabled people, as well as recognise that there are other forms of knowledge besides academic knowledge.



-Stuart Read, Research Fellow for 'We Are The People on the significance of the Community Fellows model



Disabled People are still researched 'on', rather than 'with' or 'by'. This method of working is very immersive, and using disabled people as the Community Research Fellows offers the opportunity to unpick 'sticky', pervasive issues that others have not been able to unpick.

This way of working has the opportunity to be reflected across the board into other research fields to the benefit of research, as well as the topics being researched.~



-Theo Blackmore, Senior Research Fellow for We Are The People on the importance of the Community Research Fellows



In the early 1990s Professor Mike Oliver coined the term 'emancipatory disability research'. Mike felt that disability research had failed to make a positive difference to the lives of disabled people. He also said that disabled people felt alienated by traditional forms of research. I think the WATP project is very much influenced by this sentiment.

We want to explore how universities can work with local groups of disabled people to create meaningful projects. Or, in other words, we want to conduct research 'with' disabled people, not 'on' them.



-Dr Ben Simmons on the importance of collaboration with Disabled people for We Are The People

Emancipatory: To give someone freedom or social and political rights

“

Research that is led by universities to explore disability issues has traditionally been ‘on’ or ‘for’ disabled people, rather than ‘with’ them, whereby disabled people’s stories and wisdom is used for the benefit of furthering non-disabled people’s agendas. I have long been interested in how we reframe this power away from universities so that agendas of coproduction and social change are at the heart of any disability research.

”

-Stuart Read, Research Fellow for 'We Are The People on the significance of the Community Fellows model

What was it Like Being a Community Research Fellow?

In these next pages, Layla Taylor will share their experiences across the six months of Make Room! as a Community Research Fellow.

This will highlight key considerations for lived experience and Disabled people led research, key accessibility tips, and helpful resources.

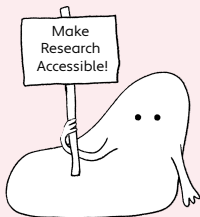
This is particularly important as this was the first time the Community Research Fellow scheme had run, so it's helpful to consider how it can be improved for the next round of Community Fellows.

Photograph by Gabriella Tigoglu



What Considerations Are Needed for Community Fellows?

- Lived experience roles require different consideration.
- Relevant cultural knowledge and understanding is essential.
- Academic culture feeds poor mental health/worklife balance, so always consider wellbeing in the workplace.
- Transparency on decisions made on the research model and ways of working is important.
- Make sure there is continuity post-project and for Community Fellow's future career prospects
- Accessibility!



Community Fellows: Access Tips

- Provide access riders at the start to establish needs and barriers.
- Accessibility 'scaffolding' - provide a designated and trained access lead to support on workload, and specialised academic elements.
- Need for accessible research training, including how to take care of yourself as a lived experience researcher. (Lived Experience Load/Crip Time)
- Significance/relevance of lived experience across team or outsourced.
- Consider realistic deadlines, flexibility and crip time.
- Consider necessary training for the role



What was it Like Being Part of a Neurodivergent Research Team?

In these next few pages, Bethany Lamont will share their experiences across the six months of the Make Room! project as an internal Research Fellow, and their experiences as a neurodivergent researcher working on a project on Disability.

This is important as the Make Room! research project was unique as both Layla and Bethany were coming from a lived experience perspective in regards to neurodivergence, mental health and LGBTQIA+ identity.

Photograph by Gabriella Tigoglu



Photograph by Gabriella Tigoglu

My Experience as a Neurodivergent Researcher

As a neurodivergent person who also has long term mental health struggles, and really struggles with fatigue, I spent a lot of time thinking about Disability and the workplace, and whether I really had a place in the world beyond my bed.

Not only was this my first experience working as part of a research team, but this was really my first experience of paid work which actively considered my own positionality in regards to Disability, as well as LGBTQIA+ identity.

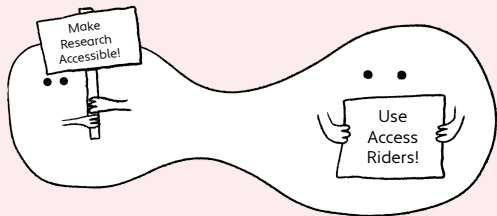
I learnt so much, including in regards to creating surveys and easy read formats, as well as learning about creative arts therapeutic practice from Layla, something I have fallen completely in love with!



I loved working with other creative people to invest in the relationship between arts, queer Disabled experience, advocacy and community. Whilst meeting all the incredible participants was an absolutely pleasure, there's so much shared work we can do in the future.

But there were challenges too. I am lucky to have support from Access to Work, including a lovely support worker. However, I think there's more specialised consideration for support that research teams could consider when working with Disabled people.

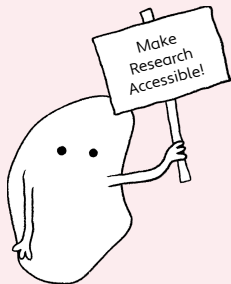
One interesting topic I learnt about through my research for this project was something called 'access riders.' These are basically templates to consider what a Disabled person might need in the workplace, and the organisation Unlimited offers really helpful guidance on this.



It could also be helpful to elect one person within the wider research team as the go to access person, for anyone who might be needing help.

As research projects such as this were so new to me, it could also be a helpful to provide a really clear individual starter pack, of the project, its aims and outputs so every new team member has the full picture on the project.

One thing I really struggle with is time management, if I'm creating a lecture I always make too much and need help cutting it down! So for neurodivergent people, or anyone else who finds this tricky, ensuring the project is viable for a smaller time scale is important, and making sure there are people who can help guide this.



I'm very aware of how academic workplaces themselves can be Disabling, in the sense that pressures and workloads can make academic workers physically and mentally unwell. Here I found myself asking some interesting questions, like: 'What actually makes a project on accessibility accessible?'

Outside of this project, I work as a Media Communications lecturer, including leading a module on Media Ethics, so ethics is definitely a big interest of mine.

However, a large scale project like this got me thinking about how ethics can be accessible to those who need it most. A long term question could definitely be: 'How can we make ethics accessible? How can it be about doing right by others, rather than just overwhelming them with word documents?'



The Value of Lived Experience Roles in Research :

Top Tips From the Make Room! Team

In the planning and delivery of Make Room! we believe lived experience was vital for this project to be sensitively culturally informed. 'Nothing about us without us' is a mantra we believe is essential when it comes to both Disability and LGBTQIA+ research as separate themes, and in this context when there are intersectional identities.

We believe our lived experience helped to foster an environment where participants felt more able to share honest and detailed experiences.

When considering running a lived experience research project, we believe it is important for an organisation to consider:

1. Commitment to meaningfully centering lived experience

Lived experience is celebrated, and everyone in a team is clear on why lived experience is so important.

2. Willingness to adapt and do things differently to be accessible

This could be thinking about overall project objectives, timing, formatting, etc. There is enough resources to best support a lived experience team, and an understanding on how lived experience can impact a project.

3. Realistic expectations and goals, curated with lived experience voices

It's better to do something to a smaller scale and do it well than be overambitious and overstretch a team, leading to burnout.

4. Lived experience informs all decisions effecting the role

We recommend this is included from the very beginning, considering lived experience voices on the job description and recruitment panel.

5. A focus on trust, relationship building and cultural acknowledgement

For example in an academic setting, many marginalised groups are shut out of opportunities in these fields, and sensitive approaches to this are paramount.

6. Curating a culture of openness and flexibility

Any approaches to lived experience should be constantly evolving, understanding that expectations an organisation may have about lived experience could be misinformed.

7. Be honest and transparent about the influence of a role

Clarity over the influence of the lived experience role on decision making to avoid disappointment and frustration.

8. Providing safer spaces

Considering accessibility based on the lived experience of the individual, and how this may differ person to person and with additional intersectional identities and needs.

9. Continuous commitment to learning, development and accountability

Being happy and willing to engage with critiques, learning from mistakes, and coming up with solutions together.

10 Cultural competency

Considering the use of appropriate training and knowledge building with the non-lived experience team members, and considering the use of jargon, tone and approaches that may be familiar to researchers already in the field but new to those with lived experience of marginalisation.

Inspired by LEAD – Lived Experience Advisory Directory: Centering Lived Experience: A strategic approach for leaders what does centering lived experience meaningfully look like?

Useful Resources:

On Access Riders:

'Creating your own Access Rider', Unlimited, link [here](#).

This page explains what an access rider is, and offers templates to make your own to ensure your accessibility needs are met at work.

On Lived Experience Research:

'My Voice Matters: A Guide For Lived Experience Research, Shaping Our Lives (2023), link [here](#)

This is a helpful guide to anyone looking into lived experience research. It explains what to expect, potential downsides and things to consider.

Lived Experience Advisory Directory (LEAD), link [here](#)

LEAD is a community network for people working in Lived Experience roles. LEAD's purpose is to improve accessibility and offer support and guidance.



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