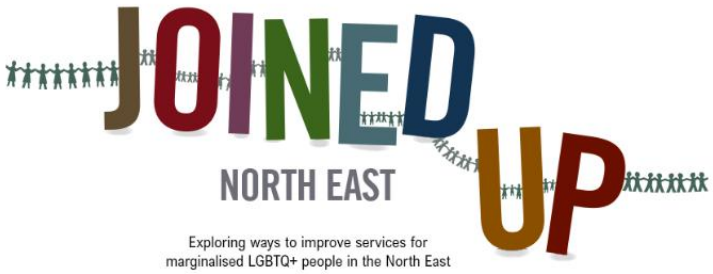
Focusing on all of us not us and them

Findings from the Joined Up North East study 2022-2024



This report is drawn from the PhD *'It's not what we would class as the front of our priority': a qualitative, intersectional perspective on LGBTQ+ disadvantage within health and social care service pathways in North East England*, which was awarded a Doctoral College Thesis Prize from Newcastle University.

Files from the study are stored on the Joined Up website and at the DOI 10.17605/OSF.IO/5RDCJ.

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RESEARCH CREDITS

Lead researcher: Mark Adley

Public Advisors: Kassim Ali, Liv Evans, Ellie Lowther, Karl Whillis

Supervisors: Prof. Amy O'Donnell, Dr Stephanie Scott

Examiners: Prof. Janice McLaughlin, Prof. Peter Matthews

Review panel: Prof. Sheena Ramsay, Dr Ryc Aquino

Artwork: Sarah Li

Design and graphics: Mark Adley

THANK YOU

First and foremost - to the study participants for sharing their stories and opening their hearts. Hopefully this has done you justice.

To the Public Advisors for their hard work and immense contributions, and to NIHR ARC North East and North Cumbria (NENC)for funding this project and the wider support.

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SUMMARY

WHY STUDY THIS?

LGBTQ+ people who face extra disadvantages such as homelessness, substance use, and involvement with the criminal justice system are often not seen by services.

The study's aim was therefore to find out how LGBTQ+ people in the North East who faced disadvantage experience health and social care services, what made it difficult or easy for them to get help, and to use this information to make suggestions for the future.

WHAT WE DID

We reviewed reports and papers on LGBTQ+ disadvantage in the UK and Ireland. This revealed patterns such as LGBTQ+ people being passed around services and moved 'out of the way'. They were described as causing problems for services and not fitting in with their **normal ways of working**.

Working closely with the study's advisors and local communities, we interviewed 72 people, (39 LGBTQ+ people and 33 professionals) with particular efforts made to reach people on the margins to find out about their experiences.

Illustration: Sarah Li (2024), "Benefits", pencil and pen drawing and digital collage.

WHAT WE FOUND

1. **The majority are the priority:** politics, policies, and funding all help to push minority groups further into the margins.
2. **Workplace cultures make a difference:** discriminatory language and behaviour, including jokes and banter, go unchallenged by staff and create services that are unsafe for LGBTQ+ and other minority groups.
3. **When poverty is viewed as the only 'real' form of disadvantage**, experiences of racism, sexism, and other forms of discrimination are not viewed as important.

WHAT THIS MEANS

Cuts to public spending hit minority groups hardest. Toxic culture wars and a lack of care about health inequalities at a national level also help to explain why services focus on majority groups.

However, we all can help to make things better. We found that collaborative working increased cultural awareness and improved engagement, with the voluntary sector often providing invaluable, gold standard care. This led to word of mouth recommendations, which boosted engagement with and use of services.

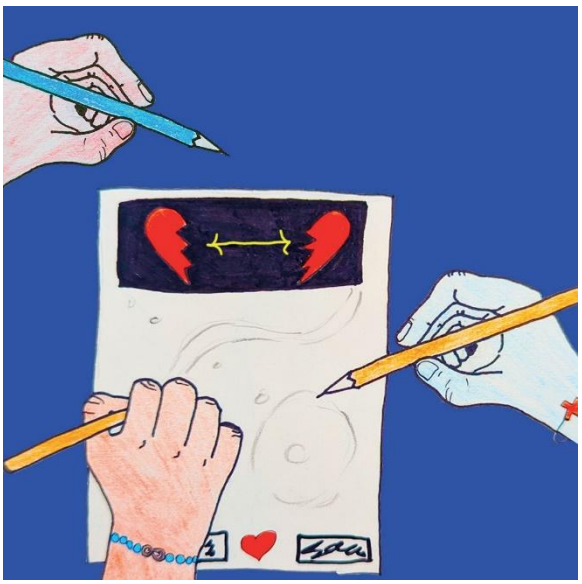


Illustration: Sarah Li (2024), "Ideal Service", pencil and pen drawing and digital collage.

INTRODUCTION

LGBTQ+ is used here to refer to people who are although not exclusively): lesbian, gay, bisexual, transgender, queer/genderqueer, questioning, intersex, agender, asexual, or pansexual.

While a term such as LGBTQ+ might suggest a common identity, any idea of a universal LGBTQ+ experience risks masking important individual or group experiences.

The concept of 'Gayness' has been, and perhaps still is implied as White, middle class, stylish, and tasteful[2-4].

LGBTQ+ lives have also been framed as uniformly "getting better"[5], which erases the experiences of those with less social privileges who are not able to access expanded legal rights[6 7].

Additionally, LGBTQ+ people who do not conform to normative 'Western gay values' such as coming out can experience stigma, discrimination and 'othering' from within LGBTQ+ organisations themselves[8 9].

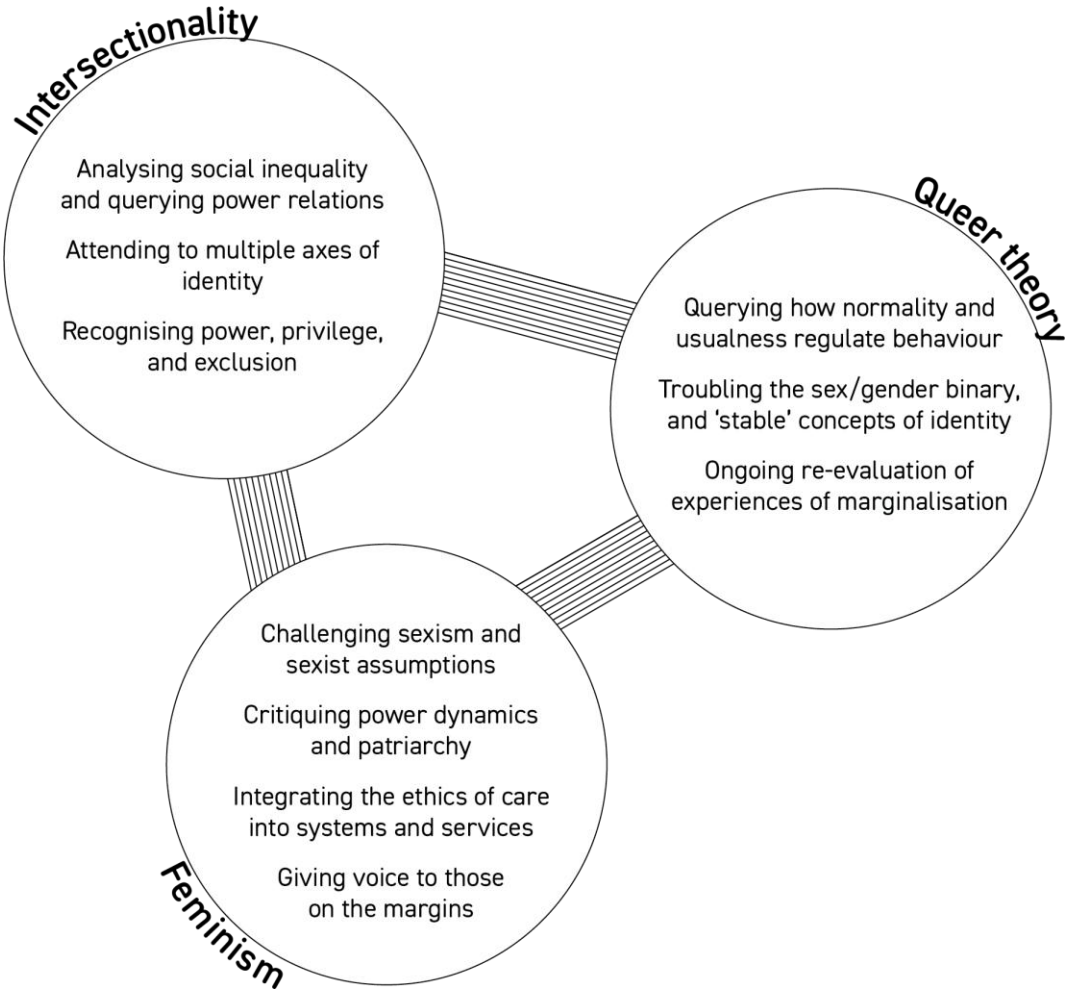
Stigma is unevenly distributed across LGBTQ+ populations. Experiences of discrimination vary widely according to any number of social positions, identities, histories, or personal life experiences.

BACKGROUND

People who experience severe and multiple disadvantage are those on the margins of society, whose social inequalities are made worse by stigma and discrimination.

The study drew from intersectionality, feminist, and queer theories which all question existing structures, from the perspective of those on the margins.

While intersectional population health research can highlight specific inequalities, intersectionality is more than a matter of considering **social identities**. Its focus is on **social inequalities**: the challenging of privilege and structures of oppression, the questioning of social inequity, and the search for social justice[10 11].



An Intersectional, Queer, Feminism. Illustration by Mark Adley

SCOPING REVIEW

Scoping reviews are useful in subject areas in which there are knowledge gaps, and where a broad sweep across the published and grey literature can help to map fields of study where it is hard to get a picture of the available research[12 13].

The study's scoping review sought to answer the question: **How do LGBTQ+ adults' experiences of homelessness, substance use, and criminal justice involvement impact upon their access to and use of health and social care services in the UK and Ireland?**

REVIEW FINDINGS

The scoping review findings centred around **normativity** and its impact upon LGBTQ+ adults facing multiple disadvantage. LGBTQ+ people were seen to be 'other than', and were moved out of the way so that **normal working practices** could continue. Discrimination and anticipation of stigma then acted as barriers to service access and use.

While the findings highlighted the **privilege given to dominant population groups in services**, this pattern was also seen across the research with LGBTQ+ populations.

For example, research with lesbians and bisexual women is generally absorbed within wider LGBTQ+ research[14]. In the scoping review, of the studies where participants' sex was identified, men† made up 64% of the 280 participants. Also, the majority of the studies also took place in more affluent urban areas such as London, Brighton, Dublin, and Manchester.

Only seven of the documents provided data on ethnicity. Of these 150 participants, **74% were White British**, 90% were White, and no people of Asian or Asian British ethnicity were included.

> The review identified specific gaps in the literature around the experiences of LGBTQ+ people of colour, sexual and gender minority women*, and people living outside of main 'gaybourhoods'.

† Assigned male at birth, or cis/cisgender male

* Assigned female at birth, or cis/cisgender female

STUDY METHODS

SETTING AND DESIGN

The study was set in the North East of England: the region of the country with the lowest life expectancy and greatest life expectancy inequalities in 2017-2019[15], and the **highest percentage of heterosexuals** in England and Wales (91%)[16].

There were 13 months of recruitment, starting in August 2022 and ending in August 2023, beginning with support from gatekeepers, with individual recruitment building through in-person contact, participation in community events, and word of mouth.

The study's website, leaflets, newsletter, and social media presence also promoted the study. Leaflets were translated, and multiple points of contact and information formats supported people with various communication styles.

Study leaflets in Arabic and Urdu, and a targeted flyer design

A qualitative study design was selected, which focused on participants' experiences, while also considering the impact of social and cultural factors such as gender and ethnicity.

Participants chose their preferred location, date, and time for interviews, which included evenings and weekends. Interviews took place either in person or over Zoom or Teams. Participants in rural locations were visited in person.

Interviews often took place within people's own communities. They were designed to be informal, relaxed, and to put people at ease. Refreshments were provided, where possible and appropriate. This approach aimed to capture people's 'natural attitude' within interviews.

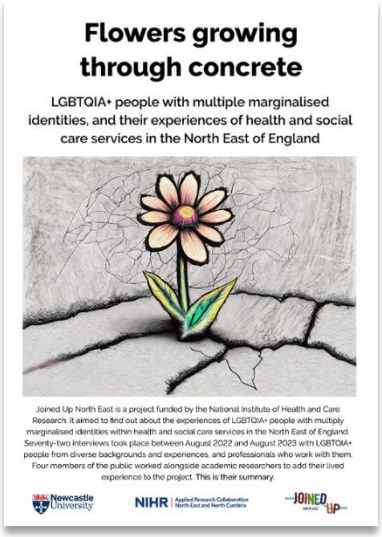
COMMUNITY INVOLVEMENT

The study's design was underpinned by its **ethos of community involvement** which ran through all aspects of the study. Knowledge was co-created by the lead researcher alongside community members.

The study took a co-operative approach to community involvement, aligned with the guiding principles put forward by the National Institute for Health and Care Research (NIHR)[17].

LGBTQ-specific groups and organisations had mentioned at the start of the study how they had been overloaded with requests to be interviewed for research. To address this the lead researcher helped services out where possible, for example taking part in community activities which offered no direct benefit for the study.

As the study progressed, the contributions of LGBTQ+ people with recent, relevant lived experience of social exclusion brought differing perspectives to the research. This learning was incorporated into the study's design, and these changes helped to further the study's reach into marginalised, multiply stigmatised communities.



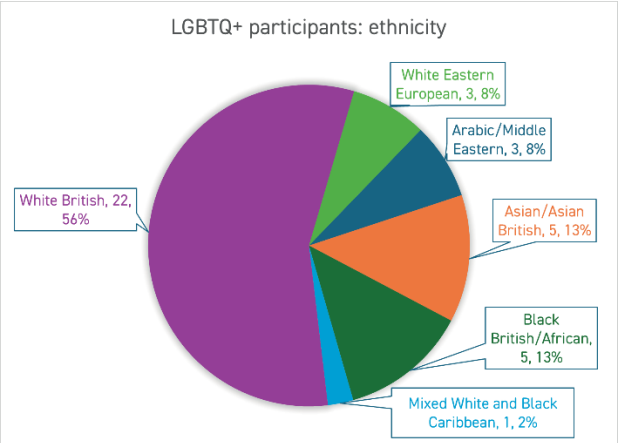
The Public Advisors' report: available from the Reports page of joinedupnortheast.co.uk

The study's four Public Advisors made invaluable contributions. They not only helped to shape the study, but they highlighted some of the lead researcher's 'blind spots' and areas of unconscious bias: both personally and within the study design.

They carried out their own analysis of the data, which is summarised in their report, *Flowers growing through concrete*, which can be downloaded from the study's website.

STUDY SAMPLE

A total of **72 people** aged above 18 years were interviewed, resulting in 66.5 hours of data: 33 interviews were with professionals from different areas of work (average interview length 50 minutes), and 39 interviews were with LGBTQ+ people who had experienced disadvantage (average interview length 59 minutes).



Detailed demographic data will be made available on the study's website: www.joinedupnortheast.co.uk

INTERVIEWS

The ways that services are funded reinforce the dominance of majority populations. Services focus on meeting targets and meeting the needs of their **core groups** of clients, often neglecting the concerns of marginalised 'others'.

LGBTQ+ people face social disadvantages that often go unrecognised due to a lack of awareness or understanding, especially around issues of gender, race, community and culture.

While some professionals and services show genuine interest in LGBTQ+ issues, for others this can be performative, masking underlying bias. There is a disconnection between services and marginalised LGBTQ+ people, leading to further stigma and exclusion.

When things work: when there is genuine interest in and engagement with those on the margins, the benefits can be seen for individuals, services, and across the wider system. There are many potential benefits to be gained from adopting an intersectional approach, and greater consideration of the inclusion of marginalised groups.

Illustration: Sarah Li (2024), "Challenges", pencil and pen drawing and digital collage.

THEME: CORE GROUPS

This comment by Katy (PR31) (female/cis/bisexual)reveals the collective direction that has been established within her service: to provide services to the majority **core group** of White men.

> *'And I think that there's not enough in place for us to go, "Right, let's target every minority community there is. Let's target every demographic that isn't White men". Like there's just not enough resources available'.*

Professionals interviewed highlighted the influence of funding requirements on the creation of 'core groups' of service users, who were then privileged within services.

Jackie (PR15) (female/cis/heterosexual) highlighted how funders contributed to the cycle of LGBTQ+ invisibility by not requiring data collection on sexual orientation and/or gender identity:

> *'It's not a question that we would ask, because a lot of the questions that we ask are skewed to what we're looking for funding for, and it's not a question that we have needed'.*

THEME: OTHERING

In some services it was standard practice to refer LGBTQ+ people to LGBTQ+ staff or allies. Claire (PR06) (female/undefined/queer) however questioned this:

> *'I shouldn't be the go-to person. My knowledge is not extensive. My knowledge just comes from compassion and wanting to make sure that I'm not discriminating against somebody. So I feel like my knowledge should be the standard. It shouldn't be the exception'.*

For LGBTQ+ people facing multiple disadvantage and marginalisation, being 'othered' and passed around services reinforced feelings of not belonging:

> *'So she (my GP) found this queer social worker who, like, helps queer people... but she couldn't, like, do counselling with me.... she did counsel from what I understood, other queer people. Just not queer people from my background... she kind of referred me to other services....' Amal (LG16) (unclassified/ non-binary/pansexual)*

As a young person of colour, Amal's later statement 'I was not designed to be part of society' suggests how stigma can be inherited as self-belief.

THEME: NORMATIVITY & INVISIBILITY

Police failed to recognise signs of the domestic abuse experienced by Rayan (LG09) (male/cis/gay), who is from a South Asian Muslim background. Having been 'outed' to the family against his will, he was then locked in his bedroom:

> *'that went on for like weeks and weeks... weeks, actually, that went on, where I was totally controlled... they took my phone and that's where things really started, you know, intensifying'.*

He ran away on several occasions and each time was found by police in a state of distress and brought home. Despite this distress, this abuse failed to be recognised as such.

The normative framework of services designed to support people facing disadvantage can render invisible the disadvantage experienced by LGBTQ+ people and other minoritised groups

By the age of 16 Max (LG35) (non-binary/cis/pansexual) had experienced homelessness, abusive relationships, problematic alcohol use, and mental ill health. However, Max only reached out to health and social care services when reaching crisis point years later:

> *'There's probably something about my sort of set of experiences that does pre-empt me from kind of accessing things... I don't tend to ask for help for things unless things are like pretty dire. And that, you know, in a way that probably does link to my queerness, my experience coming out and that sort of, being told over long term, like "hide this part of yourself" that's probably all filtered into kind of one'.*

It is not only external factors such as environment and social settings that can impact on help-seeking. Learned behaviour, such as the enforced hiding of identity, can also shape a person's capacity to reach out for support.

THEME: INTRAGROUP STIGMA

Ihsan (LG14) (non-binary/agender/multiple), who is from a British Pakistani and Muslim background, hoped to find a place within LGBTQ+ services, but instead experienced discrimination and stigma enacted along such cultural lines. Ihsan responded to the pressure to come out:

'Because it isn't a "This is who I am, get over it". It's, you know [pause] there's a whole load of education and colonialism that they've had to go through'.

Intersectional scholars cautions against 'Oppression Olympics' in which there is competition for which groups are most oppressed [1]. Instead, focus is placed on the systems of power that create the instances of social exclusion.

Yasmin (LG32) (female/cis/bisexual) commented that LGBTQ+ spaces were not always welcoming for her, as a person of colour. Yasmin shared how the rainbow branding associated with LGBTQ+ communities was not only not relevant to her, but instead signified a lack of representation of people of colour. Therefore, far from being a symbol of inclusivity it represented an identity 'other' than hers, and a community to which she did not belong:

'I feel like it's [the rainbow flag] not for me, but I don't actually know why, I can't think of why... Maybe it's just not seeing people that look like me that could be why most of the times, when I see a rainbow flag, I don't think "Oh, that's me". '

THEME: GENUINE, POSITIVE REGARD

When there was genuine concern, interest, and awareness, people felt seen, heard, and acknowledged. Marginalised people who had been stigmatised and othered, who felt as if they didn't 'fit', now began to feel safe and respected.

Kirsty (PR18) (female/cis/lesbian) shared an example of female-female domestic violence being acknowledged within a multi-agency setting:

'I think with the woman that I'm working with now, we have a really good team around her with probation, her housing officer, her drug and alcohol worker and myself. And when it came to the violence in the relationship, the support workers for her partner kind of, I think, acted similarly, and then we would share information when we needed to between the two teams around both people'.

Craig (LG07) (male/cis/bisexual) was sent to prison, and after his release he found employment supporting others with experience of the criminal justice system:

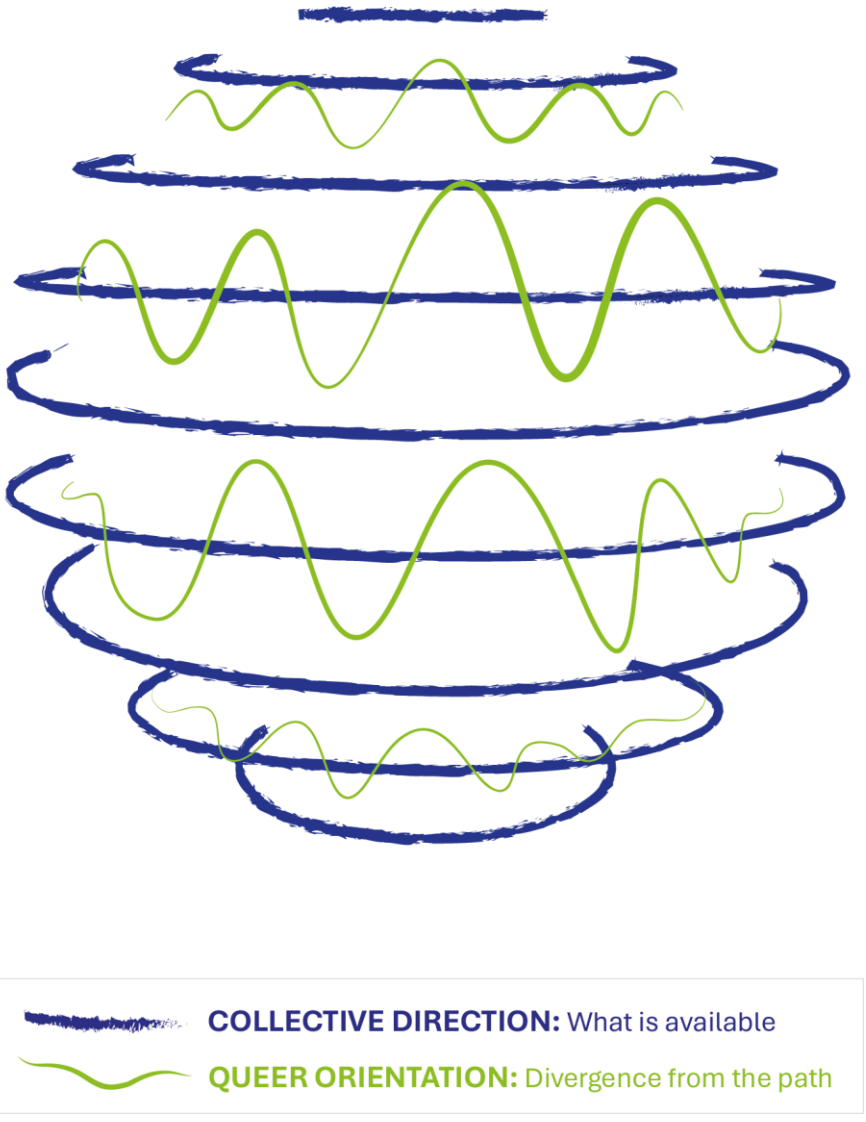
> *'So I think in me career, I think that's actually helped really well. You know, the fact that I work with ex-offenders, the fact that I work with people who, I've laid where they laid, I've ate where they ate, and shit where they shit. They understand, you know... I think you can only ever see the sides that I've seen if you've actually been in like our shoes.'*

Benefits of greater engagement with marginalised LGBTQ+ people identified within the study: illustration by Mark Adley

DISCUSSION

This final section draws together the findings from the scoping review and the study's interviews, and compares these against the literature. It also looks at the study's strengths and weaknesses, and whether the study met its aims.

In her book *Queer Phenomenology*, Sara Ahmed highlights how, in belonging to a group or community, we follow the path that others have trodden before us: the well-trodden path of collective direction[18]. In following this path, our alignment with the normative, collective direction is rendered invisible. It is only when our orientation is queer, when our positions in social space are twisted, that these lines of collective direction become visible.



Sara Ahmed's Queer Phenomenology, conceptualised and illustrated by Mark Adley

Interviews highlighted how **core groups** were perceived to be those most deserving of service provision. Issues relating to sexual orientation and/or gender identity were described in terms of disrupting normative service delivery or upsetting these core groups. The experiences and needs of people outside of these majority groups were at times blatantly dismissed as less important, or of less relevance.

The study also supported the claims made by Edith England[19] that displays of masculinity: the enactment and discrimination, aggression, or objectification towards women, LGBTQ+ or ethnically minoritised groups, were legitimised by staff within services.

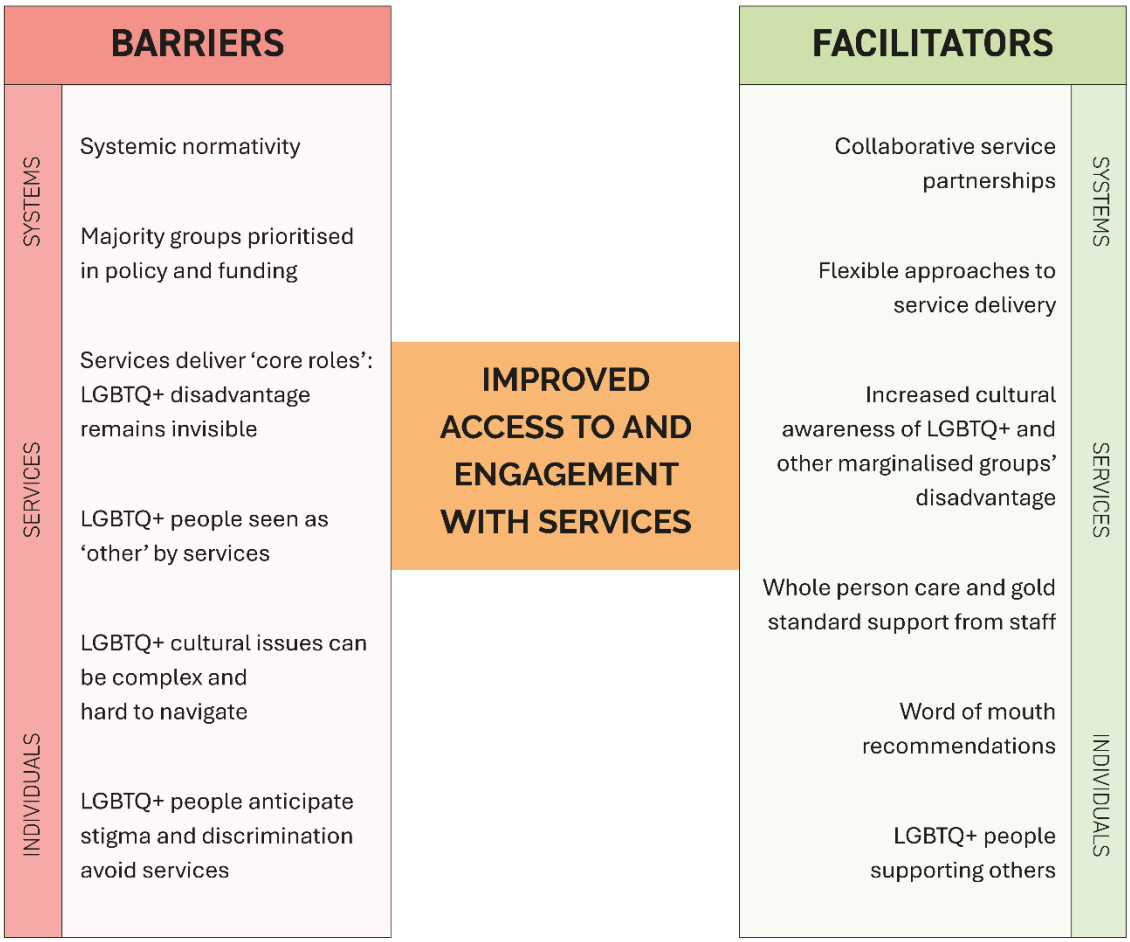
The study also found that there were privileged core group within LGBTQ+ structures themselves. This supported research highlighting racism within many LGBTQ+ organisations. For example, Muslims occupying an intersectional space between 'gay' and 'Muslim' identities have been treated with suspicion within LGBTQ+ organisations that are implicitly racialised White[8 20].

With the study's interviews, LGBTQ+ participants of colour described LGBTQ+ organisations as not being oriented towards them, with a lack of interest in or concern about their specific cultural needs.

Failing to check our ‘rear-view mirrors’, to consider our collective directions and blind spots can therefore contribute to the marginalisation of those ‘others’ who may be excluded from accessing or using our services.

Without creating time and space for reflections on our processes, practices, workplaces cultures, and shared beliefs, services risk reinforcing normative privilege.

Turning to face blind spots and questioning our collection directions therefore offers the potential for more equitable access to and use of health and social care services for those on their margins.



Barriers and facilitators to service access and use identified within the study: illustration by Mark Adley

STRENGTHS AND LIMITATIONS

STRENGTHS

This research is **timely**, as it addresses recommendations of more information on LGBTQ+ disadvantage and intersectionality, at a time of increasingly hostility towards many LGBTQ+ people.

Thirteen months of fieldwork, including engagement with local trans support groups, demonstrated rich **rigor**, and the recruitment of a diverse participant pool, including conservative views, added **context and credibility**. The study aimed for **resonance** by representing multiple groups and presenting findings in multiple forms.

Its **contribution** lies in adding depth to the understanding of LGBTQ+ disadvantage, particularly within the context of health and social care settings.

> The study addresses the health and social care pathways of disadvantaged LGBTQ+ individuals in North East England, set against a backdrop of increasing cultural opposition to LGBTQ+ symbols and events.

LIMITATIONS

In examining the health and social care pathways of disadvantaged LGBTQ+ individuals, the lead researcher at times questioned the worth of this topic over, for example the impacts of racism or sexism, or of economic deprivation.

The study's credibility is also impacted by the lack of representation from people from Chinese or other East Asian backgrounds. Its resonance is impacted by geographic limitations, with the majority of interviews conducted north of the river Tyne, and no participants from Teesside. Overall, while the study may contribute to the study of LGBTQ+ disadvantage, it may have limited impact upon those people with less interest in population groups on the margins of society.

FINDINGS

KEY FINDINGS	IMPLICATIONS	RECOMMENDATIONS
The majority are the priority Politics, policies, and how services are funded all help to push minority groups further into the margins.	Unchecked privilege within services can contribute to the marginalisation of LGBTQ+ and other minoritised groups.	Reflect upon organisational processes that may establish or reinforce core groups.
Workplace cultures make a difference Discriminatory language and behaviour, including jokes and banter, go unchallenged by staff and create services that are unsafe for LGBTQ+ and other minority groups.	Implementing processes that involve sexual orientation and/or gender identity might be met with resistance from staff.	Involve staff in new workplace processes relating to LGBTQ+ issues, and build in evaluation of how these are implemented.
When poverty is viewed as the only 'real' form of disadvantage Experiences of racism, sexism, and other forms of discrimination are not seen to be important.	The focus on economic disadvantage can mask social inequalities within minoritised groups and their impact on health.	Greater consideration of the impact of intersectionality within health and social care services and research.

QUERYING DISADVANTAGE

In the UK, discussion around multiple disadvantage has been dominated by definitions such as experiences of homelessness, substance use, and the criminal justice system, with data drawn from 'key datasets' [39].

However as widely identified in the study's interviews and scoping reviews, these definitions can render invisible the disadvantage experienced by LGBTQ+ and other minoritised groups, whose experiences of disadvantage might not fit into these categories and datasets.

Measuring disadvantage in terms of the number of people accessing services is based on the incorrect assumption that all groups have equitable access to those services.

LGBTQ+ people facing multiple disadvantage within this study were stigmatised, marginalised, or excluded – not only from mainstream services, but also from those services designed to support people excluded from mainstream provision.

CONCLUSION

LGBTQ+ people often face disadvantages that are not seen or addressed by regular policies and practices. This can lead to them avoiding early or preventative services and only reaching out for help in emergencies.

The study supports framing disadvantage and access to services in terms of all of us rather than us and them. Regardless of your belief system, increased costs to public services and the widening of health inequalities benefit no one.

'I think as far as commissioners go, they need to get underneath it and they need to look for some data and they need to stop saying things like, "Well, it's a very small cohort".

Who gives a **** if it's a small cohort because, do you know what, people kill themselves and people die, and people have horrible lives.

And that costs a lot... And if we look at the Inclusion Health groups, and we look at the social determinants of health, they're costing health way more than anything else.'

Phil (PR01) (male/cis/gay)

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