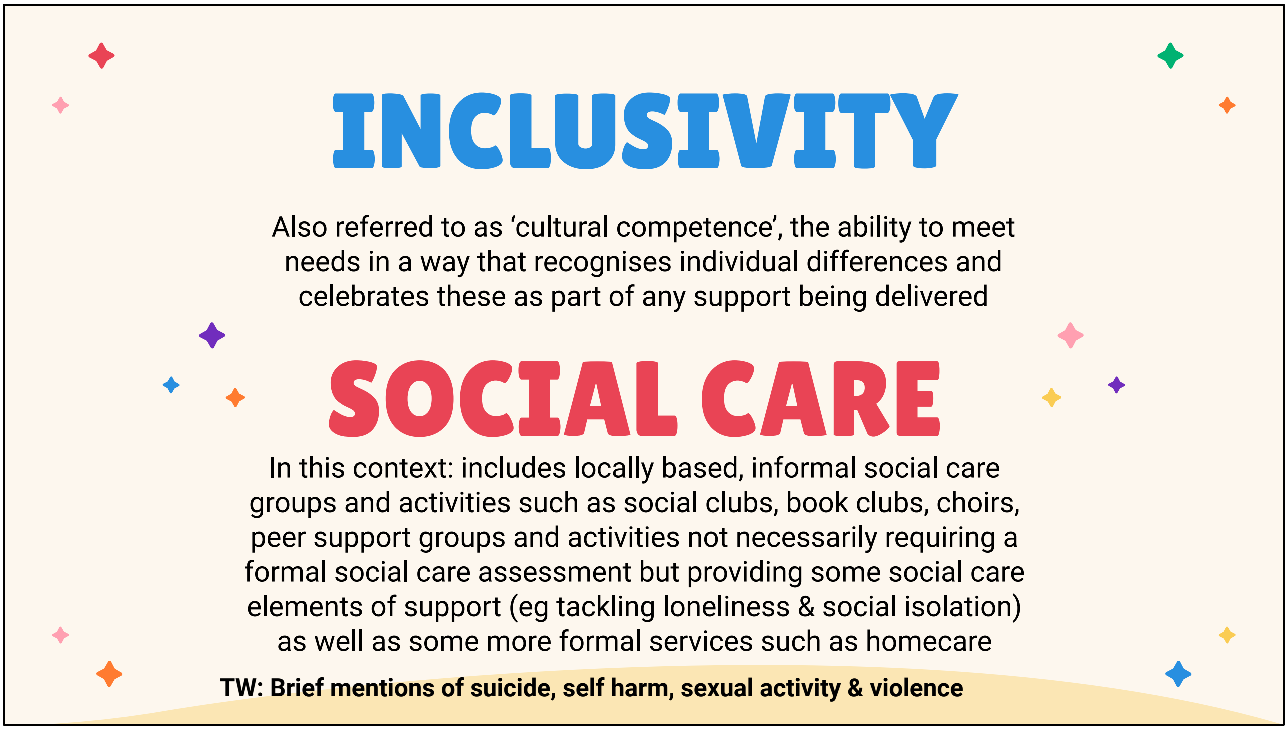
Proceedings Paper:
Wands-Murray, Elizabeth orcid.org/0000-0002-1892-2404 (2023) Inclusivity of community based social care for older LGBT+ adults:Early findings from my PhD study. In: NIHR SSCR Annual Conference 2023. NIHR School for Social Care Research (SSCR) annual conference 2023, 18-19 Apr 2023 , GBR

INCLUSIVITY OF COMMUNITY SOCIAL CARE FOR OLDER LGBTQ+ ADULTS

Liz Wands-Murray

NIHR | School for Social Care Research

UNIVERSITY of York



INCLUSIVITY

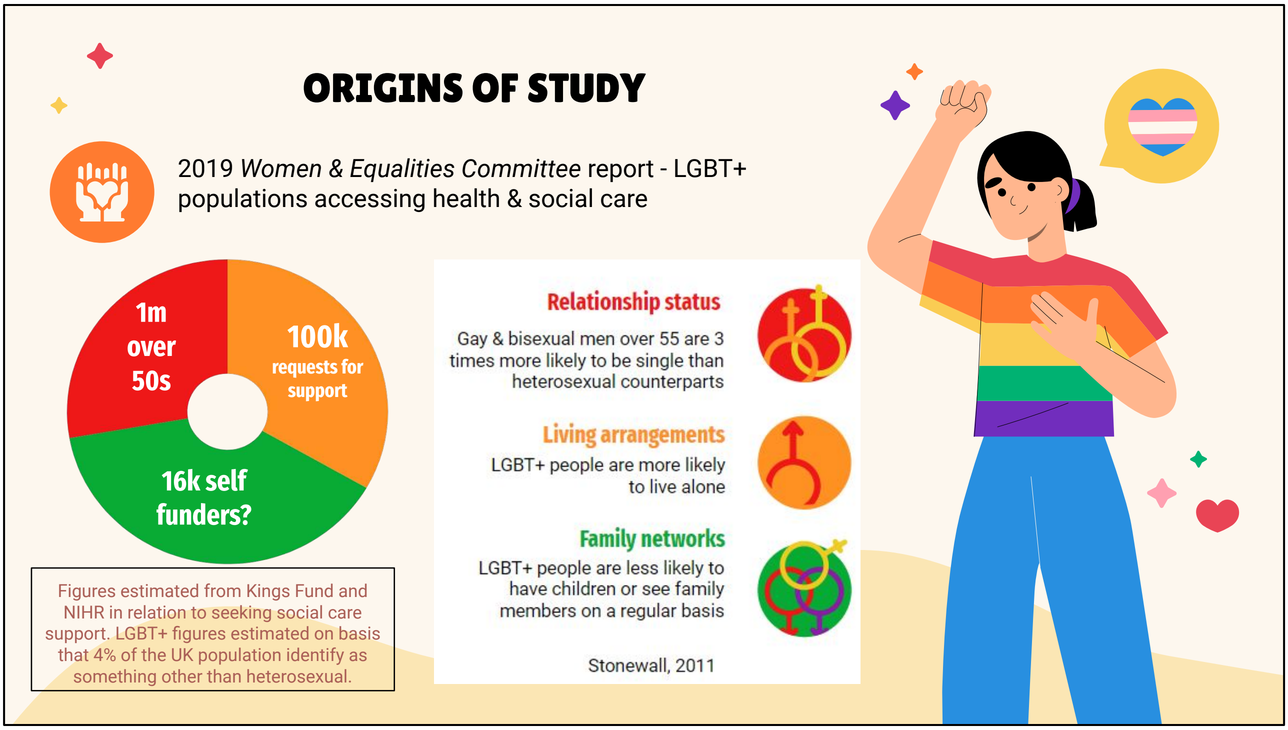
Also referred to as ‘cultural competence’, the ability to meet needs in a way that recognises individual differences and celebrates these as part of any support being delivered

SOCIAL CARE

In this context: includes locally based, informal social care groups and activities such as social clubs, book clubs, choirs, peer support groups and activities not necessarily requiring a formal social care assessment but providing some social care elements of support (eg tackling loneliness & social isolation) as well as some more formal services such as homecare

TW: Brief mentions of suicide, self harm, sexual activity & violence

Inclusivity, also referred to as ‘cultural competence’, is the ability to meet needs in a way that recognises individual differences and celebrates these as part of any support being delivered. In this context Social Care includes locally based, informal social care groups and activities such as social clubs, book clubs, choirs, peer support groups and activities not necessarily requiring a formal social care assessment but providing some social care elements of support (eg tackling loneliness & social isolation) as well as more formal provision such as homecare
TW: Brief mentions of suicide, self harm, sexual activity & violence.



ORIGINS OF STUDY

2019 *Women & Equalities Committee* report - LGBT+ populations accessing health & social care

1m over 50s

100k requests for support

16k self funders?

Figures estimated from Kings Fund and NIHR in relation to seeking social care support. LGBT+ figures estimated on basis that 4% of the UK population identify as something other than heterosexual.

Relationship status

Gay & bisexual men over 55 are 3 times more likely to be single than heterosexual counterparts

Living arrangements

LGBT+ people are more likely to live alone

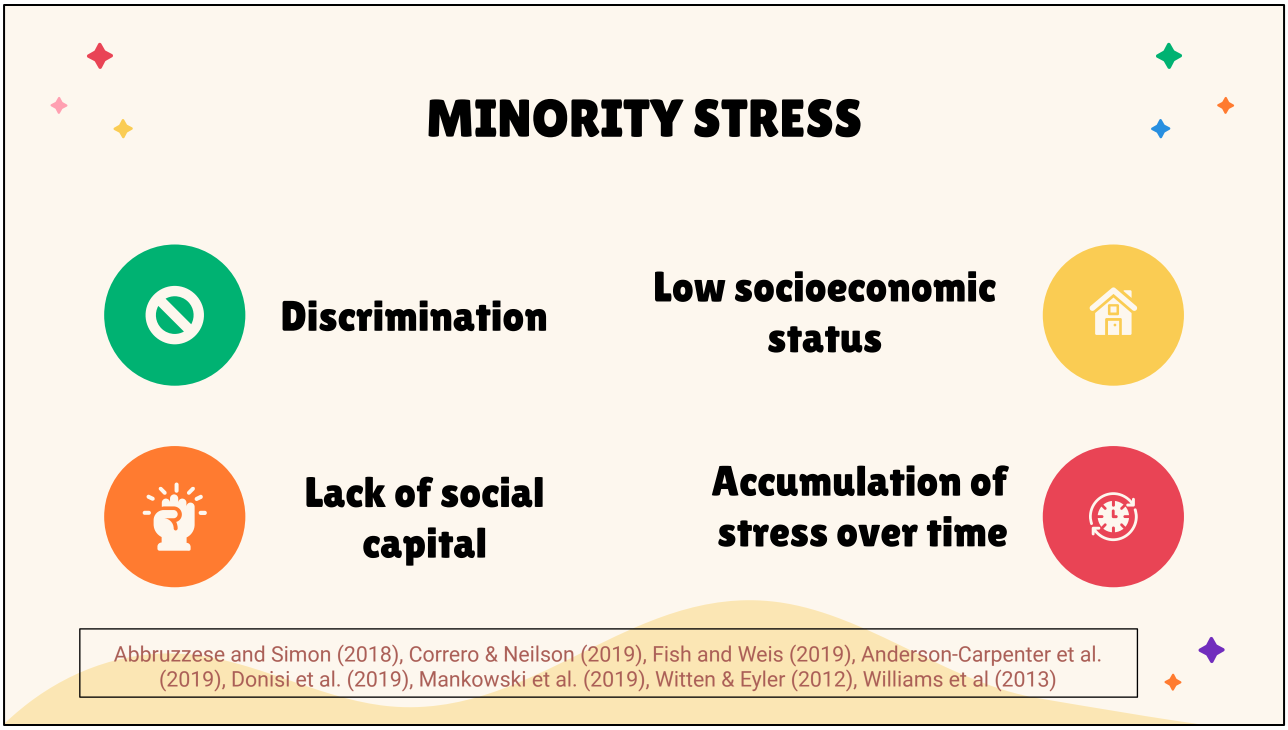
Family networks

LGBT+ people are less likely to have children or see family members on a regular basis

Stonewall, 2011

In 2019, the Women & Equalities Committee produced a report about access to and experiences of health and social care for the LGBT+ community. The report highlighted issues with unequal access and negative experiences and found LGBT+ people had similar health & social care needs to the general population but were often less healthy and did not receive the same levels of care, with a misaligned professional focus and conflation with sexual health. They concluded LGBT+ people needed to be treated equally but not identically to others.

To give further context, in the general population of the UK, over 21 million people are aged 50+. According to the 2021 census this would equate to roughly 1 million older LGBT+ people, potentially equating to 100k LGBT+ people assessed as needing publicly funded support, and 16k funding their own support. This doesn't include those who have not been formally assessed, have not actively sought support or do not recognise the issues they have as social care needs, so in reality the number is likely to be much higher.



MINORITY STRESS

Discrimination

Low socioeconomic status

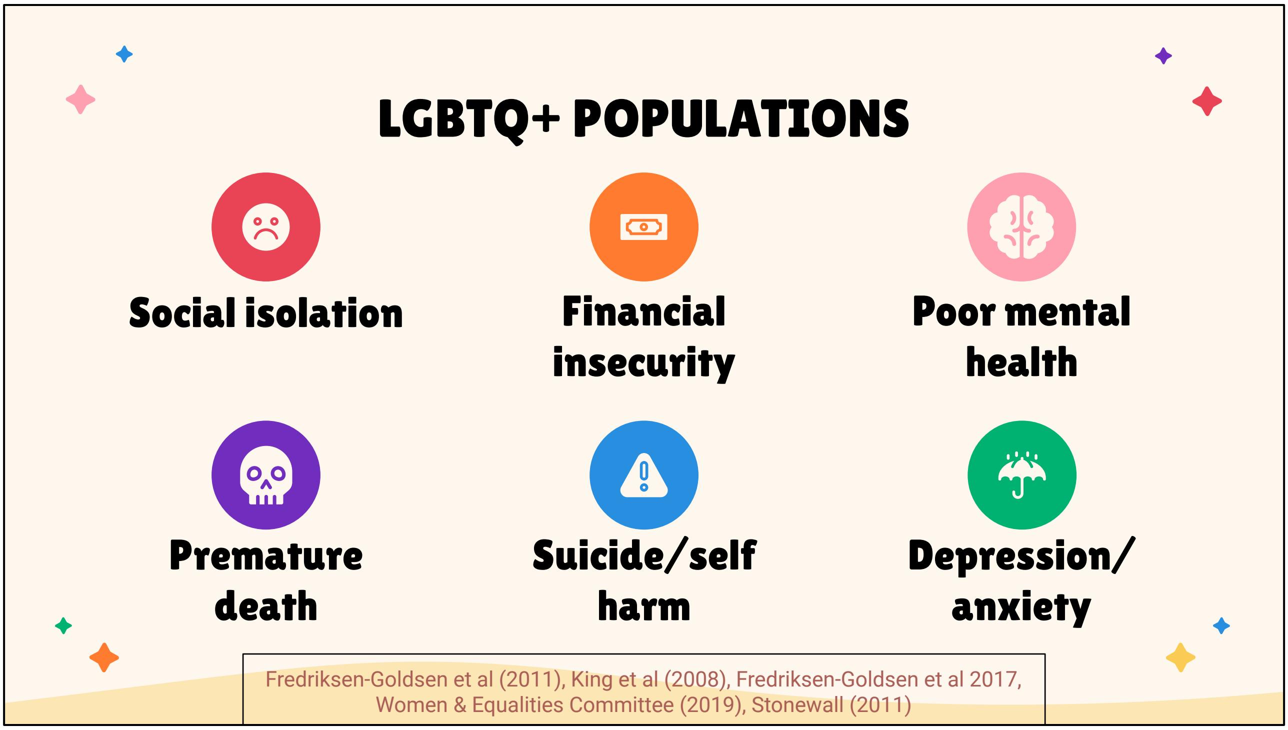
Lack of social capital

Accumulation of stress over time

Abbruzzese and Simon (2018), Correro & Neilson (2019), Fish and Weis (2019), Anderson-Carpenter et al. (2019), Donisi et al. (2019), Mankowski et al. (2019), Witten & Eyler (2012), Williams et al (2013)

One of the key theories going into the research was that of ‘Minority Stress’ - the theory that members of marginalised groups face additional stressors because of the discrimination they face, which is generally recognised as having both a physical and mental impact which accumulates over time. Research demonstrates that factors like lack of social capital, experience of negative treatment such as prejudice, and low socioeconomic status affect these groups, resulting in stress responses.

There are potential links between minority stress and depression, self-harm, drug and alcohol misuse, obesity and a range of other mental and physical conditions.



LGBTQ+ POPULATIONS

Social isolation

Financial insecurity

Poor mental health

Premature death

Suicide/self harm

Depression/ anxiety

Fredriksen-Goldsen et al (2011), King et al (2008), Fredriksen-Goldsen et al 2017, Women & Equalities Committee (2019), Stonewall (2011)

Broader research shows older LGBT+ adults are at much higher risk of mental distress than heterosexual counterparts, including depression, anxiety, self-harm and suicide. Socially, they are less likely to be married, partnered, see family of origin or have children and are more likely to live alone, resulting in lower levels of social support and financial security, in turn leading to elevated risk of social isolation, poorer mental health outcomes, cognitive impairment, and premature death as well as higher use of formal and informal support.

The Stonewall survey of LGBT+ people identified three in five respondents were not confident social care services would understand or meet their needs. 72% identified needing care as their biggest concern about ageing, 48% felt their sexual orientation already had, or would have a negative effect on them as they aged, and 65% anticipated hiding their sexuality if in residential care.

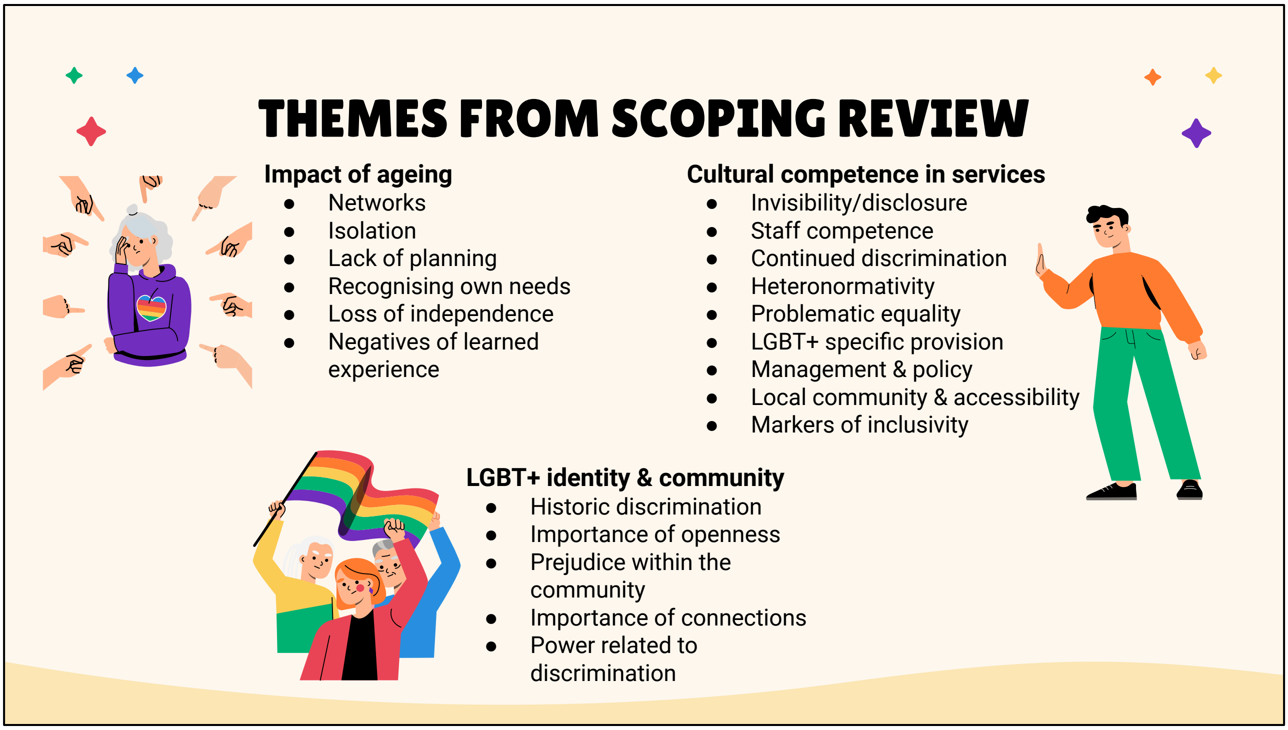
OVERVIEW

Scoping review

LGBT+ interviews

Provider focus groups

I wanted to understand the experiences and factors affecting choosing community based social care for older LGBT+ people to meet assessed or unassessed social care needs, as well as the perceived cultural competence within community social care, the signs and activities which foster inclusivity within services and the ways these can be more effectively implemented in services.
The study used qualitative methods including a scoping review, interviews with older LGBT+ people and service providers and focus groups with service providers. Following the collection of data, thematic analysis has been carried out following an iterative process to identify key areas for further discussion, and these analyses have fed into both the development of an inclusivity guide for services and my thesis.



THEMES FROM SCOPING REVIEW

Impact of ageing

- Networks
- Isolation
- Lack of planning
- Recognising own needs
- Loss of independence
- Negatives of learned experience

Cultural competence in services

- Invisibility/disclosure
- Staff competence
- Continued discrimination
- Heteronormativity
- Problematic equality
- LGBT+ specific provision
- Management & policy
- Local community & accessibility
- Markers of inclusivity

LGBT+ identity & community

- Historic discrimination
- Importance of openness
- Prejudice within the community
- Importance of connections
- Power related to discrimination

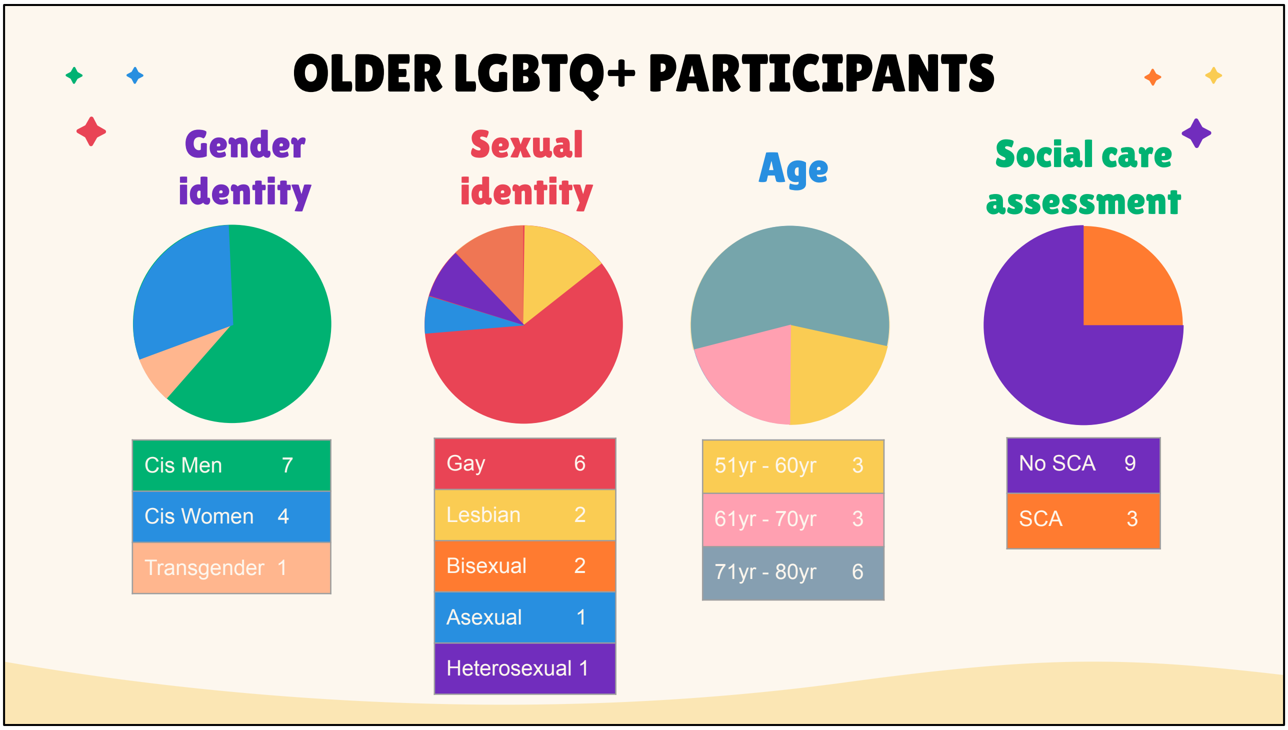
Three main themes came from my scoping review:
The first was LGBT+ identity and community - this included the importance of connections to the LGBT+ community, of belonging, sharing common experiences, culture, beliefs, politics, identity and being part of a ‘collective resistance’ which also contributed to building resilience.
LGBT+ identity was impacted by historic discrimination and this influenced decision making, attitudes and perspectives in everyday life.
There were clear accounts of the power discrimination gives and takes away - people were empowered by their activism, but also impacted by discrimination and related resilience (or lack of it as ageing occurred). There was a general recognition that being open was important if people wanted their life stories and lifestyles recognised and valued.
The second theme was around the impact of ageing. People formed strong networks or ‘families of choice’ and these were crucially important but didn’t always provide practical support, especially as they were rarely cross-generational.

People often felt their primary need was feeling isolated, however few planned for support in the future, and for those that did, it sometimes included drastic measures, with several studies demonstrating people felt euthanasia was a valid care choice or their best option to avoid poor treatment in old age. There was a marked loss of independence & connections were made between being LGBT+ and needing to be independent for most of their lives, which made it harder to admit or ask for help.

In relation to cultural competence in service delivery, people felt it was important to be open, but the need for repeated disclosure was problematic, leading to invisibility, and impacting on staff attitudes, with multiple studies including staff stating NO LGBT+ service users, so no need to consider this in the care and support. Studies showed that staff who treated everyone the same felt this somehow denoted inclusion.

People were impacted by both ongoing direct discrimination and indirectly via heteronormative systems and gender assumptive activities or interactions. Many, although not all, wanted LGBT+ specific services as they felt these would be safer. People wanted and needed local opportunities to engage with services and some studies noted simple markers of inclusivity. Staff training was inconsistent and staff often mistook person-centred care to mean focussing on daily routines and dietary preferences, with no recognition of sexual identity or life story.

Opportunities to use information as a source of knowledge and understanding and provide holistic support were missed. If services did not have support from management, or policies that supported culturally competent care it was extremely challenging to change things.



OLDER LGBTQ+ PARTICIPANTS

Gender identity

Cis Men	7
Cis Women	4
Transgender	1

Sexual identity

Gay	6
Lesbian	2
Bisexual	2
Asexual	1
Heterosexual	1

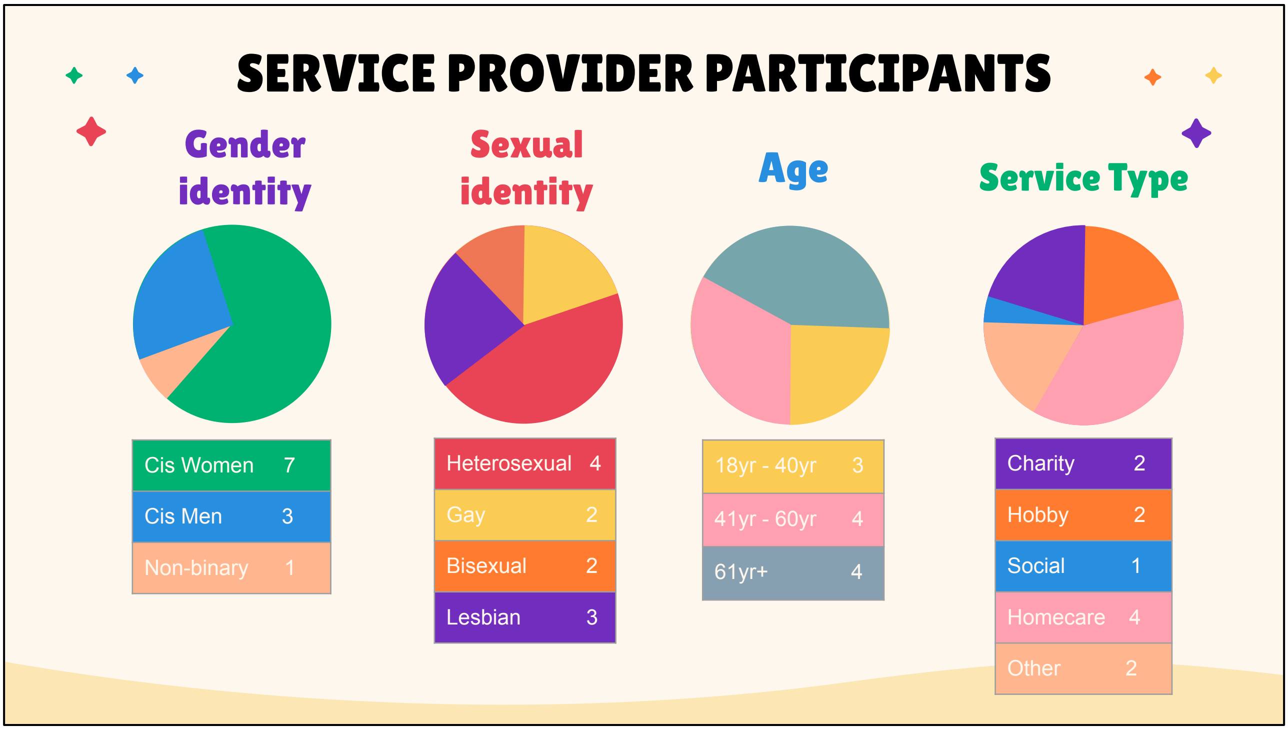
Age

51yr - 60yr	3
61yr - 70yr	3
71yr - 80yr	6

Social care assessment

No SCA	9
SCA	3

As part of my study, in total 12 older LGBT+ people were interviewed.
Some diversity was present within the group but there were gaps in the data collected, particularly around ethnic identity as all but one participant classed themselves as White, and only two as non-British.
As is common with these kinds of studies, Cis White Gay Men were the largest group. Half the group were aged 71 or older.
Only 3 had received any kind of formal social care assessment, which had not necessarily resulted in referral to formal social care provision.
Most had experience of using informal social care (all but one participant). Most were outwardly open about their sexual identity in their wider lives.



SERVICE PROVIDER PARTICIPANTS

Gender identity

Cis Women	7
Cis Men	3
Non-binary	1

Sexual identity

Heterosexual	4
Gay	2
Bisexual	2
Lesbian	3

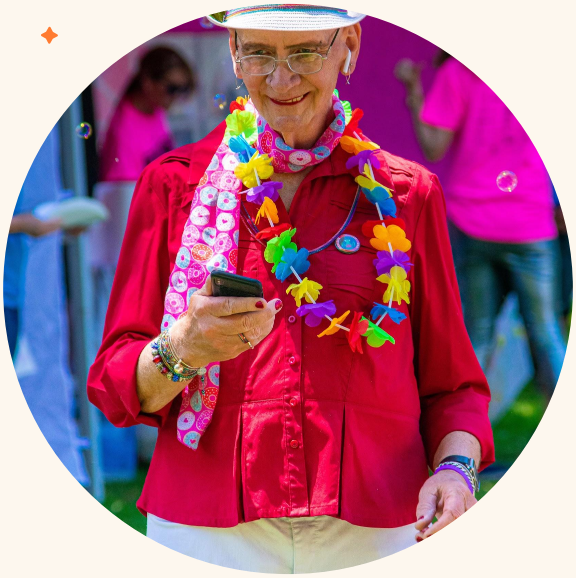
Age

18yr - 40yr	3
41yr - 60yr	4
61yr+	4

Service Type

Charity	2
Hobby	2
Social	1
Homecare	4
Other	2

Overall 11 service providers took part in the study.
I interviewed 4 service providers, who were all also members of the LGBT+ community.
The original plan had been to run focus groups with a combination of types of participant i.e. older people and providers, focussing on analysis and evaluation of the draft version of the guide. However, following the initial data collection and analysis it was clear that the focus and make up of those would need to be altered in order to gather more explicit data and to fully understand the complexities of the situation.
2 focus groups including a total of 7 service providers were carried out focussing on the data that had been collected from older LGBT+ people during interviews.
This provided the opportunity to discuss the implications of what the data was showing for service delivery.



IDENTITY & COMMUNITY

LGBT+ identity

Older person identity

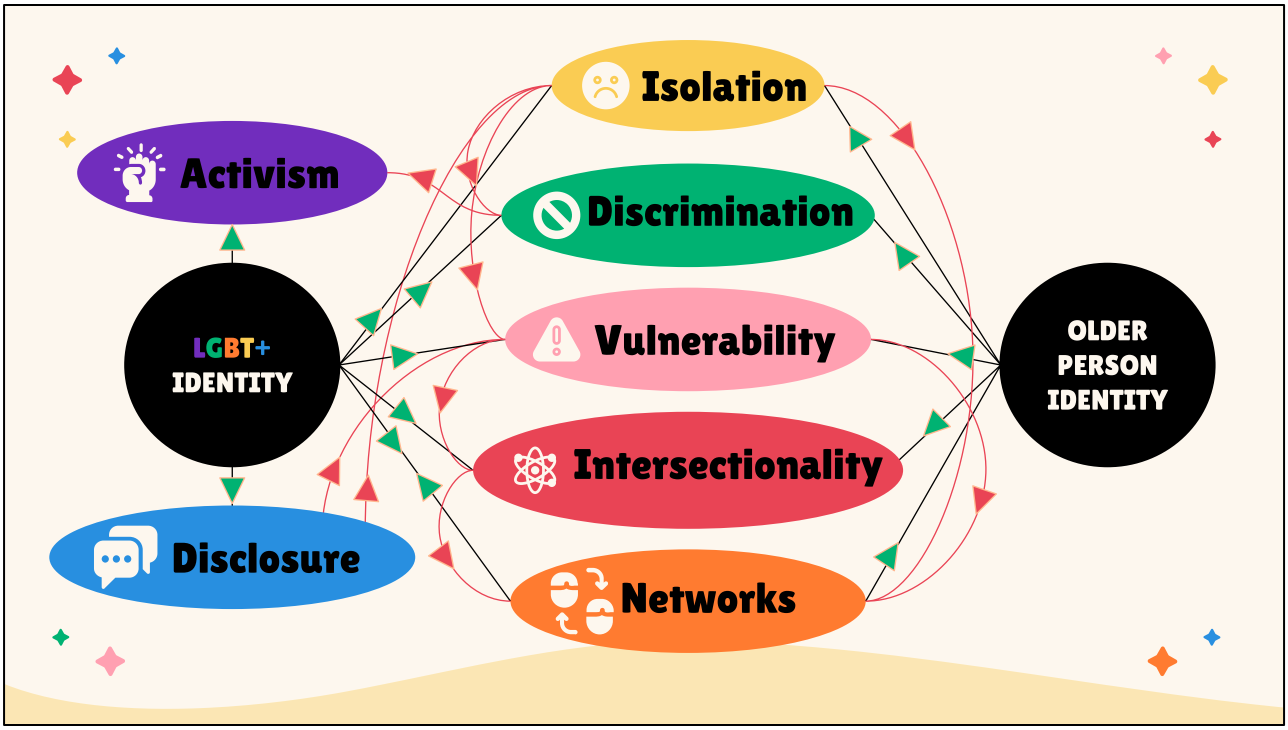
Linking to local & LGBT+ communities

Influence of history

Activism

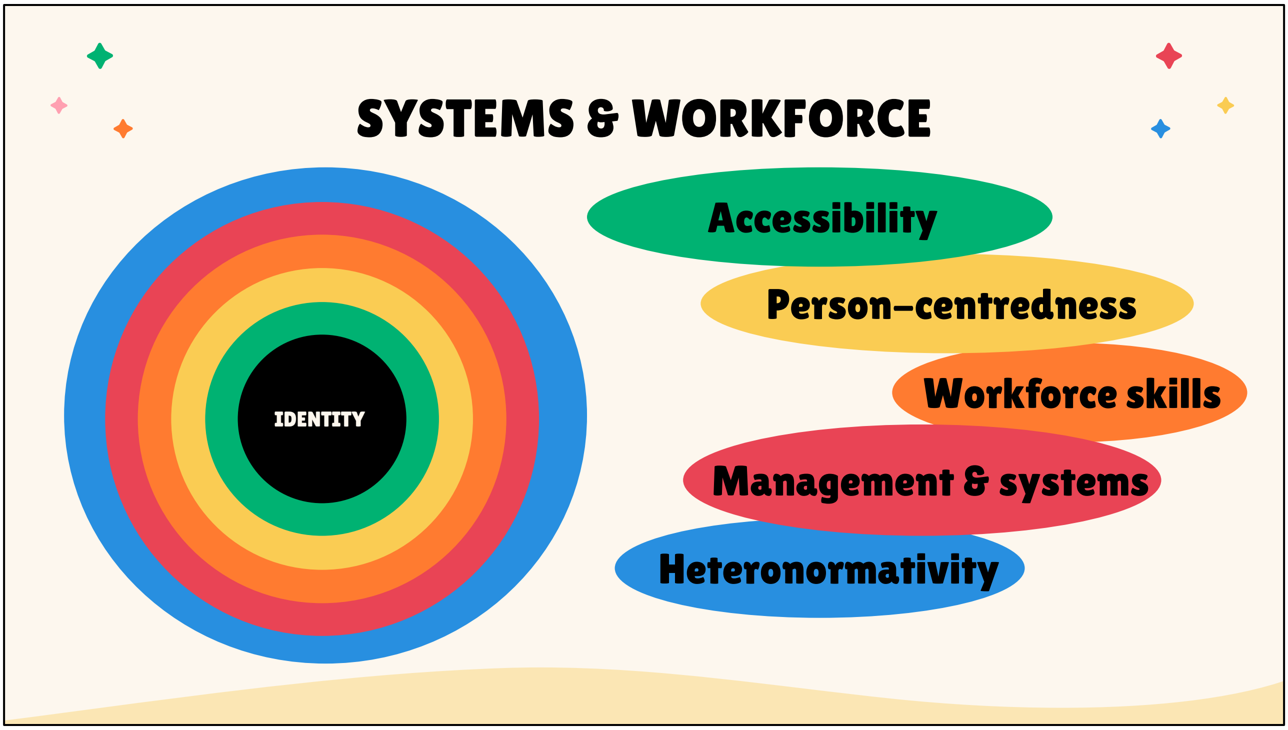
As had been the case with the scoping review, one of the key topics throughout the interviews was the importance and relevance of LGBT+ and older person identity as well as strong, tangible connections to these communities. Links to local communities, although important was in some ways more complex as it was defined by people's comfort with disclosing, perceived social acceptance and expectations about discrimination. There were many conversations about actions services could take and the signs people looked for to indicate an inclusive environment. However, the main wish people had was for their lives, life stories and identity to be recognised, valued and incorporated into approaches to delivering support.

The experiences many people had endured, which included conversion therapy, estrangement from families, physical violence both in services and in public, loss of jobs and livelihoods, and ostracisation from local communities, places of worship and local amenities had greatly impacted on their expectations going forward. Many had been involved in activism at the height of the fight for LGBT+ rights in the 70s & 80s and subsequently adapted happily to improved social acceptance, but still displayed decision making which was heavily influenced by fear and shame. When additionally considering their ageing status, this created feelings of vulnerability, less energy to advocate for themselves and expectations that rights, wishes and hopes would not be seen as relevant by services.



As can be seen here, the factors impacting on people's feelings about social care and inclusivity more broadly were complex. For participants, there were internal and external factors which influenced how they felt about themselves, made judgements about what would meet their needs, and how they evaluated whether something had been an inclusive experience. Because people were equally defined by their LGBT+ identity and ageing status, issues around vulnerability were more marked than people felt they had been in their younger years.

This waning resilience led to resignation about having their identity made invisible or viewed as irrelevant, despite feeling, in relation to social care, their LGBT+ identity was more relevant than it was in other areas of their lives. Because people also had other defining features or identities, such as race or disability, which can be more visible parts of a person's identity, there was frustration with the ongoing need to disclose and advocate for needs or methods of delivery of care which took sexual identity and lifestyle into account.



SYSTEMS & WORKFORCE

IDENTITY

Accessibility

Person-centredness

Workforce skills

Management & systems

Heteronormativity

There was a clear disconnect between older people and service providers in relation to the relevance and importance of someone’s sexual identity. This was frequently justified using the argument that if care is person-centred, then those things are accounted for in the individual transactions of delivering support. However, this was reliant on the older person indicating its importance, for example as part of their initial assessment.

Although many older LGBT+ people are accustomed to having to advocate for themselves, this expectation was felt to be exhausting and not inclusive. Older people wanted systems that recognised and valued sexual identity without them having to raise it themselves.

Many service providers expressed their reliance on management and organisational culture to support being more inclusive, in some cases stating they wouldn’t have the ‘authority’ to make changes, demonstrating both frustration and resignation.

Workforce skills and training were discussed with examples given of awareness raising and upskilling staff around EDI having a positive impact. Anecdotes included an example given of a woman in her 50s at a training session asking what a lesbian was (showing you should never assume people have knowledge and understanding) and a service provider who stated that their LGBT+ staff would be offended if made to attend EDI/LGBT+ training as they already knew everything they needed to about being gay.

A broader issue around the heteronormativity of systems, processes, and structures was identified, with this felt to be directly affecting personal attitudes and approaches in services and in wider society.

- Importance to service users
- Less relevance to service providers
- Bias impacting on appetite to change?
- Lack of understanding of impact

DISCLOSURE

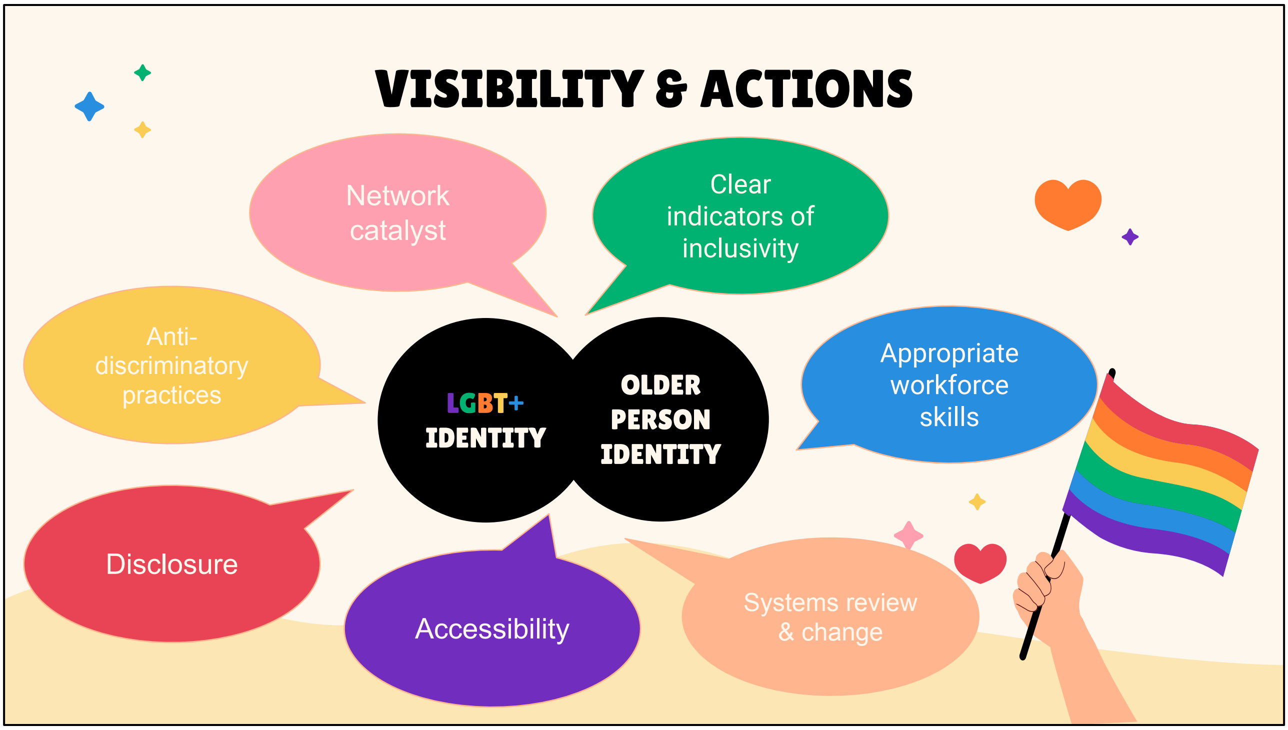
Across both groups, the issue of disclosure was discussed frequently.

Almost all participants felt that they would like to be open, and disclose their sexual identity within social care settings, as they felt it to be relevant to their support. This was a key finding. However, virtually none had been asked (1 participant gave one example of being asked) and many were frustrated by that. Equally, there was a vulnerability attached to disclosure as it could feasibly lead to discrimination.

Although most accepted things had changed, and services would be unlikely to discriminate on the basis of sexual identity, fears included hidden discrimination from staff, prejudice or bad treatment from other service users, or a lack of action from staff when discrimination was displayed. Despite this, they were still keen to ensure their sexual identity was known and accounted for within support.

For Service Providers who took part in the research, it was felt to be less relevant to care delivery on the whole, unless the person themselves chose to disclose it and express how it would influence or impact on their care. For providers, LGBT+ identity wasn’t seen as being connected to what good care might look like in the same way as older people expressed they felt it was.

There were also a range of concerns vocalised by providers, including that personal questions such as a person’s sexual identity were invasive, that heterosexual people may be offended by being asked the question (indicating a bias towards the majority) and assumptions that LGBT+ people may feel forced to disclose before being ready or comfortable to. There were various discussions within the group about when and how the topic should be raised. The conversations focussed on the difficulties that might be faced by services by asking the questions, with much less focus on how the answers might positively influence the way in which services and support were delivered.



VISIBILITY & ACTIONS

LGBT+ IDENTITY

OLDER PERSON IDENTITY

- Network catalyst
- Clear indicators of inclusivity
- Anti-discriminatory practices
- Appropriate workforce skills
- Disclosure
- Accessibility
- Systems review & change

Many participants from both groups felt services had a role in acting as a network or community catalyst. They felt if a service had links to more specialist provision, for example an LGBT+ peer support or advocacy group, this would serve to make them more inclusive, as well as potentially building knowledge and understanding through these connections.

As all the LGBT+ participants felt that connections to the LGBT+ community were important, but in general that LGBT+ specific social care was not needed or wanted, a service's efforts to make those local community links was viewed as extremely positive.

Participants also wanted more obvious signs of an inclusive approach, such as inclusion of rainbows or same sex couples in advertising materials.

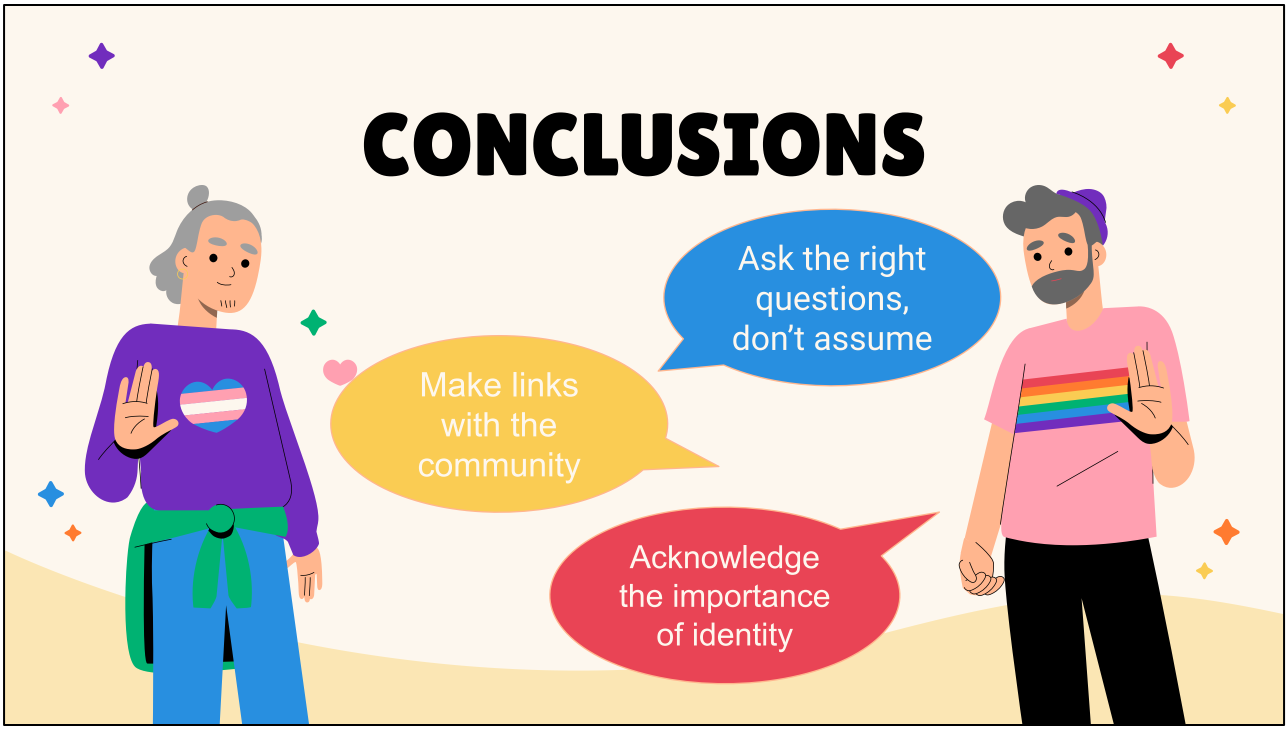
This was recognised by most as tokenistic, but it imbued affirmative action and was a quick and easy way to identify inclusive services.

Two participants talked about how initial, small 'token' changes often led over time to systematic culture shift through building understanding and being exposed to the marginalised groups who were engaging with the service on the basis of the tokenistic assurances.

Inevitably staff training, systems and processes and management were all felt to be key to good experiences within services. For some service providers it was not necessarily seen as fundamental, but all were able to recognise the value of reviewing and reflecting on where positive changes could be made.

Many older participants felt that many inclusivity issues would be eradicated if staff were appropriately trained and were also aware of and acted upon other’s prejudice and discrimination - the idea that being non-discriminatory was not enough and in fact anti-discrimination was required to shift negative cultures within staff teams and service user groups.

CONCLUSIONS



Overall, the data demonstrates that simple changes and indicators of inclusivity by service providers may have a meaningful impact on choosing services based on an assumption the service is inclusive because of external indicators.

This appears to be a good first step and something that is achievable for most types of service.

In order to make meaningful changes to how the service is experienced by older LGBT+ people, service providers need to consider systems of assessment, care planning and care delivery and acknowledge the importance of recognising and valuing sexual identity as a relevant factor in delivering services. Service providers also need to recognise the responsibility for disclosure should not be left to people themselves but rather should be a core part of how a service gets to know a person and subsequently plans person centred support.

Older LGBT+ people wanted to be asked this early in interactions to ensure it was considered throughout the contact. Staff knowledge and understanding need to be prioritised regardless of whether the service currently has LGBT+ service users, in order to address invisibility and because there are potentially wider benefits to being a culturally competent service provider beyond sexual identity.

The currently patchy application of EDI training and knowledge and the fact that sexual identity is not necessarily considered relevant to service delivery for providers is problematic and complex to address.

Ways to change systems to allow for more person-centred care as well as avoid heteronormativity are needed in order to start to shift things, although there will also be societal attitudes and current hot topics that will influence this (such as with the current hysteria around transgender people in the media).

Service providers also need to consider how they can become a catalyst for community connectedness, both with LGBT+ specific provision and wider, local and diverse provision which may help to address people’s needs more holistically. Ways to strengthen this, especially LGBT+ focussed links need to be explored to help build community and support networks where people feel comfortable and understood.

To make these changes both to systems and culturally is a complex task, but one that is both possible and has wider positive implications for all marginalised communities.

To finish, I want to share my favourite radical solution to getting support from a man in his 80s who took part in the research. He used a well known gay ‘dating’ app to recruit support for decorating, shopping and going out which had the benefit of him feeling safe with someone from the LGBT+ community and had the added benefit of it often being, in his words, very beautiful young men. Although this might be a push for UK social care system!

Inclusive Social Care

Guide for community based social care groups to be inclusive for older LGBT+ people

THANK YOU

This presentation summarises independent research funded by the National Institute for Health and Care Research School for Social Care Research. The views expressed are those of the author(s) and not necessarily those of the NIHR SSCR, the NIHR or the Department of Health and Social Care.

ANY QUESTIONS?

Why is it important to be inclusive?

There are an estimated 1.8million older LGBT+ people in the UK. Many have experienced a lifetime of discrimination and marginalisation. Ensuring they feel included and valued has an impact on health, wellbeing, mental health and quality of life.

What do older LGBT+ people think is important?

Overall, older LGBT+ people want their identity, life story and significant relationships recognised. They want to feel safe and protected from discrimination. They want services that listen to them, celebrate diversity and consider the ways in which they can be more inclusive.

What can social care groups and services do to be more inclusive?

Use LGBT+ images in advertising materials
Provide staff and volunteers with opportunities to learn about LGBT+ lives & history
Ask people about their lives and significant relationships
Consider if activities are stereotyping gender roles & interests
Address discrimination from other group members when needed
Celebrate LGBT+ lives (& other groups too!) through events and activities
Make links with local LGBT+ organisations and groups
Talk to your LGBT+ members about how to be more inclusive, be ready to learn