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HS&DR Evidence Synthesis Centre Topic Report

Social Care Access for adult BAME and LGBT+ populations: a rapid realist review

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This report

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Abstract

Background

Awareness of, and access to, social care services within UK is particularly low among Black Asian and Minority Ethnic (BAME) and Lesbian Gay Bisexual and Transgender plus (LGBT+) adults. BAME adults may be unfamiliar with social care provision, may perceive that the service is “not for people like us” or may delay uptake of services until precipitated by a crisis.

Objectives

To identify and understand the contexts that affect access to social care services for BAME and LGBT+ adults in the United Kingdom.

Methods

We searched Ovid MEDLINE and Google for key empirical studies and reviews and engaged with the wider evidence base through supplementary searching. Following identification of initial programme theories (from the theoretical literature, empirical studies and insights from the public and patient involvement group) the review team developed an explanatory narrative referenced to the underpinning evidence base. An overarching adult social care pathway was generated and used to explore contexts, causal mechanisms and outcomes. Additional searches for mid-range and overarching theories were performed using Google Scholar.

Results

52 publications were used to generate 11 candidate programme theories Five prioritised programme theories were tested against 59 publications, . All items, with the exception of works contributing to theory originated from the UK. The majority of studies were qualitative in design and presented data by BAME (e.g. South Asians) or LGBT+ (e.g. older gay people) population subgroup. An adult social care pathway includes 7 steps (Recognition of Need; Decision to Seek Support; Identification of Social Care as a source of support; First Contact; Continuation of Contact; Ongoing social care relationship and Appropriate fulfilment of Needs). Prominent causal mechanisms were navigation, recognition of the caregiver role, and responsiveness to emergent needs.

Limitations

The research was conducted by a small team, according to a rapid realist methodology, and time and resources limited our ability to consult with diverse stakeholders. Evidence was largely qualitative and experiences of recent migrants were largely overlooked. The experiences of LGBT+ populations were poorly represented overall. Studies of transgender experiences in accessing services were poorly represented.

Conclusions

Although the total number of studies included in the review was relatively large, studies were unequally distributed across the subgroups of interest. Differences within groups are likely to be as important as between group differences. Findings affirm the value of person-centred adult social care.

Future work

Research should focus on differential responses to person-centred care, its costs and potential benefits. In addition, the evidence for matching care providers and service users according to racial or ethnic characteristics is, at best equivocal, and, as revealed by this review may result in many unintended consequences. The value of this strategy compared with, or combined with organisation-wide approaches to training in cultural awareness requires further exploration.

Funding

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Registration

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[425 words]

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Supplementary Material File 1: Context-Mechanism Outcome Configurations for five programme theories

Supplementary material can be found on the NIHR Funding and Awards report topic page https://doi.org/10.3310/hsdr-tr-130866
Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer-reviewed.

List of abbreviations

Acronym	**Definition**
BAME	Black, Asian and Minority Ethnic
BME	Black and Minority Ethnic (See BAME)
CMO	Context-Mechanism-Outcome
CMOC	Context-Mechanism-Outcome Configurations
DHSC	Department of Health and Social Care
LGB	Lesbian, Gay, Bisexual
LGBT	Lesbian, Gay, Bisexual, Transgender
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
PCC	Person-Centred Care
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses [Reporting Standards for Systematic Reviews]
PROSPERO	Database of Review Protocols

Acronym	**Definition**
RAMESES	Realist And Meta-narrative Evidence Syntheses: Evolving Standards [Reporting Standards for Realist Syntheses]
RETREAT	Research question – Epistemology – Time – Resources – Expertise Audience and purpose-Type of data [Selection method for review types]
ScHARR	School of Health and Related Research, University of Sheffield
SCIE	Social Care Institute for Excellence
SCK	Shared Cultural Knowledge approach
USA	United States of America
VIP	Visually Impaired Person
VIPS	V = Values people; I = Individual needs; P = Perspective of service user; S = Supportive social psychology

Plain English Summary

Social care provides support for those who need help with day-to-day activities of daily living, such as getting dressed or cooking meals, and should target those who need it most. However, some adults don’t get the services that they need. People who are black, Asian or from another ethnic group (BAME) or those who identify as lesbian, gay, bisexual, or transgender (LGBT+) often express that they feel that they miss out on services they need. By thinking how you can make services better for these people you can make services better for everyone.

This research reviewed published papers to understand how adults find out about and use social care services. We found papers where people said whether social care had worked for them or not. People also suggested how to make services welcoming and friendly. We listed eleven ideas from the papers we found for how services might work. We asked the public and members of the Department of Health and Social Care to choose five ideas to study. We looked for papers that backed up or questioned these ideas.

Social care organisations should put adults at the centre of planning services. Finding out exactly what users want, pointing them to the right service and making sure that services fit with what family and friends are offering are important. Rather than treating everybody in the same way, services should try to give people what they need. Each person will feel respected and take the help they really need. Some need help to translate what they want into English. Others want to be looked after by someone from the same background, although this isn’t always the best idea. Treating people with respect, keeping them up-to-date, and being ready to make changes when needed, help to ensure that they get what they need.

Word count: 294

Scientific Summary

Background

Black Asian Minority Ethnic communities feature among those in heaviest need of social care and yet their awareness of services is demonstrably low. Inequalities of access may be exacerbated by affordability and by criteria imposed by local authorities for eligibility to receive state support. Lesbian Gay Bisexual and Transgender users may prove to be reluctant to access social care because of a perception that social care providers will be discriminatory in the language used and in the quality of service offered. Improving the social care response to BAME and LGBT+ groups not only tackles established inequalities but, offers a lens by which to explore the needs of other minority groups.

Objectives

This rapid realist literature review examined the research evidence exploring access to social care services by Black Asian and Minority Ethnic communities and Lesbian Gay Bisexual and Transgender users and evaluated a pathway that sought to identify systemic challenges in seeking an appropriate response to social care needs.

The specific objectives of the current study were:

- to explore the experiences and needs of Black Asian and Minority Ethnic communities and Lesbian Gay Bisexual and Transgender users when seeking to access social care services;
- to describe the current experience of social care services for service users and their informal caregivers, including the potential adoption of person-centred care;
- to evaluate five important components of successful access to social care services in relation to what works for whom in which contexts.

Methods

The research project was a rapid realist synthesis divided into four parts:

1. Scoping of the evidence relating to the experience of accessing social care services from the perspective of BAME and LGBT+ populations;

2. Creation of a Pathway to Adult Social Care against which to map available evidence;
3. Exploration of five prioritised programme theories against the available evidence; and
4. Initial identification of mid-range and overarching theories against which to explore future intervention design.

52 papers were identified for the scoping review. These papers were used to generate 11 candidate programme theories. The candidate theories were examined analytically (See: Report Supplementary Material File 1 - Context-Mechanism Outcome Configurations for five programme theories) to produce a collective pathway to social care. Five of the eleven programme theories were prioritised and identified by the Department of Health and Social Care for further exploration and testing. A further 8 studies were identified for the realist synthesis to make a total of 59 included papers. We produced a descriptive summary of key characteristics of the body of included papers. Thirty-four studies used qualitative research and a further four miscellaneous research studies were included. Four studies involved some type of literature review; two simply described themselves as literature reviews, one was a scoping review and one was mentioned above alongside a qualitative study. Eighteen papers were discursive. Data was extracted into purpose-designed data extraction forms in order to clearly identify the contribution of each included study to each of the five programme theories. Additional searches for mid-range and overarching theories were performed using Google Scholar.

Programme theories

We identified five programme theory components to explain why BAME and LGBT+ service users may not access social services according to their need:

> IF social care service users are aware of adult social care services and how to access them THEN social care service users access adult social care services as needed LEADING TO social care staff providing appropriate care/social care service users receiving appropriate care **[PT1].**
>
> IF social care service users perceive that adult social care services complement and augment informal and/or family support THEN social care service users feel able to

access adult social care LEADING TO social care service users feeling that their holistic needs are being fulfilled **[PT2]**

IF social care staff are sensitive to differences between different and within minority groups THEN staff personalise their response to each social care service user LEADING TO social care service users feeling welcomed and respected **[PT3]**

IF adult social care services use interpreters THEN social care staff and social care service users communicate more effectively LEADING TO social care staff providing appropriate care/social care service users receiving appropriate care **[PT4]**

IF Social Care Services recruit or use staff with expertise in engaging with minority groups THEN social care staff create a bridge between themselves and social care service users LEADING TO social care service users from minority backgrounds being supported in trusting and accessing social care services **[PT5]**

The programme theories were shared and discussed with the Department of Health and Social Care and endorsed by our public involvement group. We found evidence to support all five programme theories.

Results

Number of relevant papers differed greatly across programme theories but for all five BAME papers were more plentiful than LGBT+ and qualitative studies were more plentiful than other study and publication types. **Expertise with Minority Groups (PT5)** was the programme theory with most studies (BAME – 27 studies; LGBT+ - 9 studies). **Complementarity to Informal Care (PT2)** (BAME – 10 studies; LGBT+ - 3 studies) was the least populated programme theory. Corresponding figures for other programme theories were BAME – 21 studies; LGBT+ - 3 studies for **Awareness of Services (PT1)** and BAME – 21 studies; LGBT+ - 3 studies for **Sensitivity to Differences (PT3). Use of Interpreters (PT4)** only applied to the BAME populations and included 18 studies. Successful access to social care requires recognition of need, awareness of services, access to specific services and an ongoing, continually evolving relationship between care provider and service user. Qualitatively, access to social care requires an ongoing communication (including active listening and individualised questioning) and trust, that facilitates disclosure of important individual and personal characteristics. Within this positive environment the relationship between service user, care provider and informal caregiver is critical. Clear delineation of roles, with explicit expectations from the caregiver and the service, is key and this three-way relationship must continually evolve as new needs emerge.

Pathway of Adult Social Care

We explored the proposed pathway of adult social care against the available data. In comparison with a primary care pathway, more emphasis fell on the process leading to first contact. Our adult social care pathway complements the NICE social care pathway, which focuses on the process following assessment, by revealing the importance of processes that precede assessment. For both social care pathways, the assessment process presents a key milestone and opportunity, both instrumentally as a listening opportunity and, symbolically, as a potential taster for what is to follow. An invisible, but important feature of the adult social care pathway, is a process, analogous to contemplation, where the potential service user makes an informal hassle/benefit analysis in deciding whether to pursue access. Social care users from minority backgrounds frequently describe choosing to delay access. As a consequence, potential users may only contact services when they reach a crisis point.

Programme Theories

Programme Theory One (Awareness of Services) found that potential service users may delay access to care even when they have gained an awareness of services and even how to access them. They may seek validation of social service use from family or may have concerns about whether the organisation will be culturally appropriate and respectful of their preferred orientation. Consequently, they may delay presentation to the services until precipitated by a crisis.

Considering **Programme Theory Two (Complementarity to Informal Care)**, we found substantive variation between BAME populations in how they conceived the role of informal caregiver and in their expectations of formal care. For LGBT+ service users the concept of “family of choice” was considered important in recognising the extended networks upon which they might draw. Some LGBT+ service users sought to minimise future dependence on formal care by making arrangements before their capacity deteriorated.

For **Programme Theory Three (Sensitivity to Difference)** we found evidence of generalisation and stereotyping whereby care providers might feel that they are being culturally sensitive but miss important individual differences. Active listening and other communication skills associated with person-centred care are seen as important in ensuring that care is appropriately individualised. Above all, treating everybody the same was revealed as an inappropriate response potentially resulting in important individual care needs not being met.

Programme Theory Four (Use of Interpreters) relates to resources by which individuals might meet their need for communication. Resources includes the role of family members in translating forms and letters through access to formal interpreters. Concerns about translation include whether an interpreter is competent and whether they choose to be accurate. The potential negative role of translators in connection with those less able to speak for themselves is examined. Use of children for translating was also seen to hold potential pitfalls. However, the ideal demands for the service often have to compromised due to practical concerns about urgency and the availability of the interpreters. Ongoing needs continue to evolve and so access to an interpreter may persist through the lifespan of the social care contact.

While direct evidence was identified to inform **Programme Theory Five (Expertise with Minority Groups)** the evidence proved more equivocal. Strategies to deploy such expertise included embedding cultural awareness and competence throughout the organisation and also the matching of care provider to service user by ethnicity, race or sexual orientation. Some communities seemed to prefer matching by race and ethnicity (for example Pakistani and Bangladeshi service users) although shared language seemed to be the salient feature. We found no evidence for similar preferences in the LGBT+ community where considerations of the knowledge of the service user built up over time, as secured by personal budgets, seems to be the important feature. Importantly, we also found numerous instances of adverse effects of matching for service user and their caregiver (for example in having their goodwill taken advantage of in delayed arrival and early departure, for example) and for the career development of the care provider (in being assigned to limited stereotypical cases and being viewed as the “race expert”). Again, **Programme Theory Five** emphasised the importance of an individualised, personalised approach and of communication of individual needs.

Mid-range and overarching theories

In addition to the programme theories, we found diverse examples of mid-range theories relevant to the programme theory components under review. The data confirmed the value of the a priori theories highlighted as a result of the scoping work (namely, Aday and Andersen's Framework for the Study of Access and Dixon-Woods theory of candidacy. However other valuable insights were drawn from the Cultural Competency model and Leventhal's Self-Regulation Model of Illness, among others. Also of value were overarching theories that crossed two or more of the programme theory components, namely, ‘Othering’, Treating Everybody the Same, Invisibilisation and Minority Stress Theory. However, the uniting thread across all five components was a focus on Person-Centred Care. Adoption of such an approach, as modelled, for example, within the field of dementia care offers a counterpoint to many of the issues unearthed from the data. The overarching theories and the uniting person-centred care thread may be considered as more exploratory than the programme and mid-range theories.

Limitations

This review has several limitations: the time and resource constraints and the prevailing pandemic environment limited the extent of consultation with care providers and service users. The UK focus limited the coverage of potential service responses but strengthened the relevance to commissioners of UK social care. The review necessarily prioritised programme theory components and was only able to identify, and not fully explore, potentially relevant programme theories.

Conclusions

Although specific responses were identified for several programme theory components the overarching programme theory suggests that a person-centred approach offers a ubiquitous response to many of the identified issues. However, person-centred care does not necessarily correspond to the branded version recommended for dementia. Features of person-centred care relate to how a service is delivered rather than to specific intervention components. The Health Foundation identifies four principles key to person-centred care: (i) Affording people dignity, compassion and respect; (ii) Offering coordinated care, support or treatment; (iii) Offering personalised care, support or treatment, and (iv) Supporting people to recognise and develop their own strengths and abilities, enabling them to live an independent, fulfilling life.

Overall, access to social care by BAME and LGBT+ populations appears to be favoured by:

- a textual, visual and verbal identity that is inclusive and avoids heteronormative assumptions, generalisations and stereotypes;
- Support for services that complement individual cultural caregiver roles and values constructed within a context of informal care;
- Recognition of individual difference and an approach that privileges active listening to elicit actual needs;
- Support for interpreter and translation functions, whether formal, through family or social support networks to facilitate navigation through the system and ongoing responsiveness to emerging needs; and
- Support for cultural competence and cultural sensitivity, with appropriate matching of care provider and service user only where this results in a mutually beneficial and productive ongoing relationship.

Future work

Research should focus on understanding how different subpopulations respond to person-centred care, its costs and potential measurable benefits. The potential to learn lessons for m extensive work using the approach in dementia should be fully explored. In addition, the evidence for matching care providers and service users according to racial or ethnic characteristics is, at best equivocal, and, as revealed by this review may result in many unintended consequences. Specifically, unintended impacts of matching on professional development and on cultural sensitivity at an organisation-wide level should be explored. The value of this strategy compared with, or combined with organisation-wide approaches to training in cultural awareness requires further exploration.

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Registration

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Chapter 1 - Introduction and Background

Reasons for low access to services are complex and multifaceted. Some health conditions encounter more intense stigma within particular cultures.[1] This, in turn, may impact upon health and social care service uptake.[2] In the UK, carers from BAME groups provide proportionally more care than white British carers.[3] These carers are also more likely to suffer from ill health.[3] Evidence from the US suggests that compared to their white counterparts, BAME carers are less likely to use formal services.[4] This finding persists even though BAME carers express a greater need for support.[2 5]

Commentators have attempted to explain why carers might fail to access and engage with services. Some cultures may have a heightened sense of self-reliance and duty. Practical explanations, perhaps linked to other socio-demographic variables, may also play a role.[1] For example, BAME carers are more likely to be struggling financially and are more likely than majority white carers to care for 20 or more hours a week.[6]

Access difficulties may persist across all ethnic groups. However, their impact may be exacerbated for some BAME communities by language difficulties or information provision that is seen to be culturally inappropriate.[7 8] Higher levels of isolation have been reported for Pakistani and Bangladeshi carers.[3] Greater anxiety and depression have also been identified for British Indian carers.[9]

It is widely recognised that it is challenging to form definitive conclusions about whether those in minority ethnic groups experience greater challenges associated with low uptake than those in majority groups; research consistently fails to include majority groups for comparison.[1]

Similar challenges may persist for the LGBT+ communities; individuals may be reluctant to self identify in particular care settings, particularly if they anticipate a differential response from staff or fellow residents. Services may be perceived as orientated to particular norms of what is understood by “family” or “carer”. While it is challenging to disentangle the exact nature of challenges in accessing services the important fact remains for both BAME and

LGBT+ communities, namely that there is a strong and persistent perception that these challenges pose a substantive obstacle to the quality of their care.

Context for the Report

The Department of Health and Social Care (DHSC) and the National Institute for Health Research (NIHR) identified "inequalities within adult social care" as a priority research area and commissioned the School of Health and Related Research (ScHARR) at the University of Sheffield to deliver this work under the National Institute for Health Research (NIHR) Evidence Synthesis Centre contract. The DHSC has asked ScHARR to produce an evidence review to support primary research and evaluation of ethnic differences in provision and experience of adult social care in England. The research request from NIHR was "Addressing diversity and inequalities in access to social care services". Further discussion between ScHARR and DHSC explored a range of groups who could potentially have unequal access to social care, and identified two specific population groups of interest – people who are from BAME backgrounds and people who are LGBT+.

Definitions

Social Care

We are using the definition of social care from the Health Foundation "…care and support for people who need it because of age, illness, disability or other circumstances. It ranges from help with essential daily activities, such as eating and washing, to participation in all aspects of life, such as work or socializing. Social care can be provided in people's homes, to enable independent living or help with recovery after illness and, if home care is no longer an option, provide a safe space for people to live in supported housing, residential or nursing homes"[10].In addition to this definition, as part of our wider consideration of access issues, we will also look at wider support for accessing social care, such as information, support and signposting. We acknowledge that social care provision in its widest sense relates to far more than the provision of services by formal social care services. Social care relates to any activity that helps individuals with their personal care and to maintain their independence. This includes provision by formal and informal providers, from statutory services, family members, voluntary organisations and community members as well as from a wide range of agencies and organisations.

Access

The review will consider access in terms of the notion of candidacy[11] and not consider access to be a static and fixed relationship. "Candidacy describes the ways in which people's eligibility for … attention and intervention is jointly negotiated between individuals and … services… Candidacy is managed in the context of operating conditions that are influenced by individuals, the setting and environment in which care takes place, situated activity, the dynamics of face-to-face activity, and aspects of self (such as gender), the typefications staff use in categorising people and diseases, availability of economic and other resources such as time, local pressures, and policy imperatives."[11] This definition derives from healthcare access and we acknowledge that it may be less relevant when considering social care access - in particular the role of the identification and definition of social care needs by individuals, as opposed to the diagnosis of healthcare needs in a healthcare setting. In the review we will address whether individuals recognise a need for social care (as per the expanded definition above) (either themselves, informal or formal caregivers or health/social care professionals), the availability of care, awareness of services and eligibility (which may include local authority/NHS recognition, assessment processes, navigation). In addition, the review will also consider that access touches upon issues of provision, experience and satisfaction and that these issues may help to explain further access.

Inequalities

Under the Equality Act 2010, we understand the following characteristics to be protected from discrimination in the workplace and wider society - age, sex, gender reassignment, disability, ethnicity, sexuality, religion, pregnancy and marriage. There is also an intersection between these characteristics that frequently enhances discrimination and inequalities. In terms of access to healthcare, evidence has often focused on inequalities of access and outcomes for groups such as children, older people, members of minority ethnicities, men/women, and socio-economically disadvantaged people[11]. This review uses evidence relating to two specific groups (BAME and LGBT+) but may reference other protected characteristics.

Black, Asian and Minority Ethnic (BAME)

In this review, we use the most broadly held definition of BAME (Black, Asian and Minority Ethnic) to describe all ethnic groups that are non-white. Within the Office for National Statistics classifications, there are a number of White ethnic groups within the UK. The focus of the review is on non-White ethnic groups in the United Kingdom.

Lesbian, Gay, Bisexual, Trans (LGBT+)

LGBT is an acronym to describe people who define as one or more of the following: Lesbian, Gay, Bisexual, Trans. Trans is a broader term than 'transgender' and people who define as trans, are people whose gender does not match the sex that they were assigned at birth.

Hypotheses tested in the review (research questions)

The research aim is to use rapid realist review methods to explore the contexts that influence access to social care for two specific population groups. Specifically addressing the following research questions

(1) What are the barriers and facilitators to accessing social care for a) BAME and b) LGBT+ populations?

(2) Using IF-THEN-LEADING TO, or Context-Mechanism-Outcome configurations, can we map access to social care on existing access pathways to healthcare [12 13], to provide additional explanations for what influences access to social care for these two population groups?

Chapter 2 - Review methods

The review will be reported according to RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) [14] which is the standard reporting standards for this type of review.

Rapid realist review methods

Following discussion with the National Institute for Health Research and the Department of Health and Social Care we identified the need to conduct a rapid realist review. In this context rapid does not apply solely to the speed with which the realist review was conducted. The term further indicates that the scope of the review was carefully tailored to the needs of the commissioners to fit their policy window. It further indicates that the number of programme theories for exploration and the amounts of evidence assembled to explore each programme theory were constrained to acknowledge time and resource constraints.

The rationale for undertaking a rapid realist review is

1. Rapid realist methods have been specifically developed for work with policy makers[15]. Close working relationships between review producers (ScHARR) and customers (DHSC) were integral to the rapid realist review process.
2. The DHSC are already familiar with the evidence base for BAME populations, which is small (and we anticipated the same or similar for LGBT+ populations). In addition, the focus of the review was on the UK and England more specifically, thereby limiting the volume of evidence for potential inclusion in the review.
3. Realist methods have the potential to generate theories about policies and interventions and why they might work, for whom and in what context, which will be more informative than a conventional effectiveness review, drawing on a small number of studies which are generally not high quality.
4. By focusing on critical issues relating to access and prioritising them according to their potential to explain access, we can explore the pathways to access for these two population groups, in order to gain additional benefits from the evidence base.

5. Realist methods also allow us to look at the contexts of access to social care and the role of mechanisms in determining the outcomes around access.

Figure 1 describes our methods approach which is also described in more detail in the study protocol.

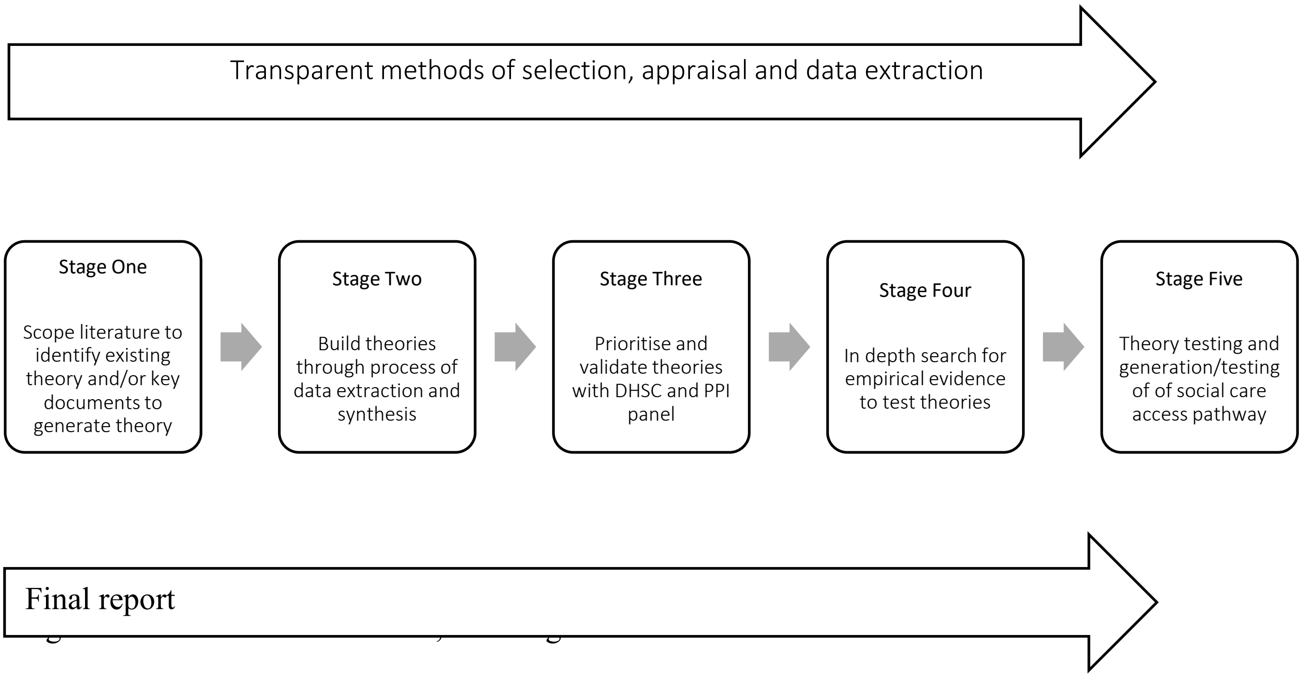


Figure 1 Methods approach

Stage 1 – Scoping the literature (searching and screening)

For this first stage we prioritised the rigour and relevance of conceptually rich evidence[16]. We focused on searching for evidence reviews and any existing theoretical work in the area which allowed us to generate hypothetical explanatory accounts.

Our initial source of evidence was a scoping review undertaken within the DHSC [internal document only] which reviewed existing evidence relating to access to social care. From this review of literature, several themes regarding reasons for unequal access to care for BAME groups emerged. These included (1) Lack of knowledge of services (2) Fear of discrimination

(3) A complex relationship between care delivered by family members and delayed access to social care and (4) A low uptake of personalisation. In addition, the review also identified three specific reasons for lower satisfaction with care, which may also relate in part to access issues. These are (1) linguistic and cultural barriers (2) Dissatisfaction with care received and (3) Diversity blindness – e.g. treating BAME people as a single group. Potential recommendations to better meet the needs of BAME social care service users that were identified in this review, included: community-based services and micro-providers, increase in uptake of personalised budgets, linguistic and communication improvements and person-centred care – e.g. to explore ethnic matching vs. non ethnic matching in care provision.

We then undertook a scoping search to identify key evidence and evidence reviews. This search is reported in Appendix 1. The search used MEDLINE via OVID SP and Google Scholar. The aim of the search was to identify both international evidence (within which UK studies were specifically included) and UK only evidence relating to social care including groups who identify as either BAME or LGBT. We therefore used a current published filter to limit to UK-relevant studies[17 18].

In contrast to later searches, our initial search was not limited by setting or date and the scope was wider than access to social care. Within this stage, we looked for evidence on theories of social care access and considered how they might inform the next stage of the review process.

Stage 2 – Building theory via IF-THEN-LEADING TO (extraction and synthesis of evidence)

The aim of this stage was to develop a greater understanding of the contexts that prevent and enable access to social care and the mechanisms that underlie this. We developed Context-Mechanism-Outcome configurations by directly analysing links as identified from a subset of between 10 and 12 papers selected for diversity and richness from our evidence set. In contrast with typical methods of qualitative data analysis, where themes are identified separately and then configured by the analyst, we coded elements as linked dyads and triads directly from the qualitative data in the studies.[19] The following elements were captured in the data extraction (Population, Subgroup, IF (Actors), IF (Context), THEN (Mechanisms), LEADING TO (Outcomes), location on patient pathway[12] and any relevant mid-range theories mentioned). These methods of coding and data extraction have previously been found to be appropriate in realist review activities.[20] We also listed population groups included in source documents to inform future searching. Any studies identified through the scoping search and not included in this stage were listed and reasons for their exclusion were noted.

Stage 3 – Validation and prioritisation of theories

From the data extracted, we articulated eleven initial programme theories (IPTs) (See table 19, appendix 2). We shared these with the DHSC for validation and sense check, and, given the rapid nature of the review, to allow them to prioritise the core areas of policy focus so that we could search for empirical evidence to test these. The purpose of this prioritisation was to choose 3-5 programme theories to test using evidence from BAME and LGBT+ groups. This exercise was undertaken in mid-December 2019.

We shared the emergent programme theories with the Sheffield Evidence Synthesis Centre Patient and Public Involvement panel for their comments. This took place in early December with our PPI panel.

Programme theories were selected with reference to the following guiding principles, developed by the research team and shared with the DHSC and the PPI panel prior to the meetings to validate and prioritise the theories:

- Whether programme theories relate to staff, service users, caregivers or a wider group?
- Which theories are the most ‘important’ versus which are the most ‘policy amenable’.
- Whether programme theories represent specific issues in access to social care for the BAME community or the LGBT community.
- Primary Support Reasons for accessing social care - physical support, sensory support, support with memory and cognition, learning disability support, mental health support, social support
- Access to care and support from the NICE Pathway[21]. Information should be provided on types of care and support available, how to access care and support (including

eligibility criteria), how to get financial advice about care and support, local safeguarding procedures, rights and entitlements to assessments, care and support services and personal budgets.

Stage 4 – Search for empirical evidence (searching and screening)

Following the selection of theories by the DHSC and discussion of these theories by the PPI panel, we undertook in depth searches to identify empirical evidence and supporting documents to refine and test the selected theories. The literature search was iterative and ongoing throughout the remainder of the project. A search was conducted of MEDLINE, Social Care Online and the King's Fund Library Catalogue, as well as through search engines, such as Google Scholar. Search terms from the scoping search were combined in multiple permutations with terms relating to the five specific programme theories in order to search the full-text of included documents. Candidate terms for inclusion are shown in Table 2. A "snowball" approach was also used in which citations from one reference were pursued using the *Publish or Perish* search software to retrieve citing references.

Searching - The first stage was a database search (January 2020)

Screening – Three reviewers (LP, EH and AB) undertook a test screen of records retrieved (n=100). Screening was undertaken according to inclusion criteria and there were three categories - include, exclude or query. Following the test screen, a discussion by consensus led to the following categories being developed and applied to all unique records identified via the search– include, exclude, evidence review, theory, park and follow up.

Our initial inclusion and exclusion criteria, prior to the test screen are shown in Table 1.

Table 1 - Inclusion criteria for the rapid realist review

Setting	Adult Social care
	Evidence from UK settings only, with an emphasis on evidence from England.
Population	Adults receiving social care Adults from a BAME group Adults who identify as LGBT+
Outcome	Included studies should have an outcome reporting a (positive or negative) change in access.
Date limits	2009-2019
Study Type	Any (peer reviewed and non-peer reviewed/grey literature)

Following the test screen, we refined the inclusion and exclusion criteria as follows:

- References that included social support with no reference to formal social care services were excluded.
- Refugees, Asylum Seekers and migrant workers are included within the BAME groups.
- Excluded studies from Ireland given explicit focus on England, Scotland, Wales and Northern Ireland (England and the devolved governments).

Following the refinement of the inclusion and exclusion criteria, full text screening was undertaken by one reviewer (LP or EH or AB) with a random sample of 25% checked by a second reviewer (EH, LP or AB).

Table 2 - Evidence Profile for the 5 Programme Theories

Programme Theory	**Relevant Search Terms**	**Included Studies - BAME**	**Included Studies – LGBT+**
PT1 – Awareness of Services	Aware*, Access*, Knowledge	21 studies (17 qualitative)	3 studies (2 qualitative)

PT2 – Complementarity to Informal Care	Informal care*, family care*	10 studies (8 qualitative)	3 studies (2 qualitative)
PT3 Sensitivity to Differences	Cultural* sensitiv*, cultural* aware*	20 studies (18 qualitative)	7 studies (5 qualitative)
PT4 Use of Interpreters	Interpret*, Translat*, Language difficulties, Non-English speak*	18 studies (15 qualitative)	Not relevant
PT5 – Expertise with Minority Groups	match*, shared ethnic*, shared background*	27 studies (23 qualitative)	9 studies (4 qualitative)

NB. All the above terms were combined with terms relating to "social care" and to the two population groups (BAME and LGBT+), limited to the United Kingdom.

Stage 5a – Theory testing (extraction and synthesis)

Based on our full search, and prompted by the approach used in the realist review on access to primary care for socioeconomically disadvantaged older people,[12] our review team gradually and iteratively refined the original social care pathway into a composite realist programme theory that included context-mechanism-outcome configurations (CMOCs) generated for each of the five programme theories.

The overarching patient pathway was developed from data extracted to a purpose-specific Google Forms data extraction form, with sections for the five candidate programme theory components Our analysis aimed to find data to corroborate, refute or refine the patient pathway into a realist programme theory. We accomplished this by gradually and iteratively building CMOCs for each of the five programme theory components and then mapping them onto the overall patient pathway. Figure 3 represents a simplified version of this pathway "map". The accompanying text summarises the process narratively; with further detail being present in the respective Results section for each programme theory.

Stage 5b – Mapping the theories to the access pathway

Using an existing review as a template,[12] we developed an access pathway for social care, which offered a structure for analysis and a series of focal points against which to map context, mechanisms and outcomes. To generate the context-mechanism-outcome configurations ("CMO configurations") for each programme theory component we analysed data and sections of text from the extraction phase as relating to context, mechanism or outcome. At least two of the three elements in the chain had to be present to be viable. In common with comparable realist syntheses many sections of text described only two parts of a CMO configuration, without exploring the underlying mechanism. Where possible we used supporting literature to generate or hypothesise missing components. Any substantive or formal "mid-range" theory identified during the process of search and data extraction was noted and discussed – first in each component section and then in a synthesis of underpinning theories.

An iterative, cyclical process was used to seek out data to enable judgements to be made about the 3Rs; namely, relevance (contribution to the research questions), rigour (the data used in programme theory development) and richness (the extent of the contribution of context and/or concepts). In other words, the analysis continually sought to establish whether data were sufficient to warrant modifying a CMO configuration, the pathway and/or the overall programme theory. Findings are reported in subsequent sections below in accordance with the RAMESES reporting standards[14].

Continuous – Involvement of stakeholders

Department of Health and Social Care (DHSC)

Throughout the review process, we held regular teleconferences with the DHSC, although these were interrupted by the Covid-19 pandemic. There was also regular email correspondence and, as previously detailed, the DHSC were involved in theory prioritisation, involvement in the peer review of the report and involvement in the development of bespoke strategies for dissemination to a social care audience.

PPI panel

The five programme theory components were also discussed with the Evidence Centre's standing PPI panel. At a regular face-to-face meeting in October 2019, we asked the panel to think about specific questions relating to social care access.

- What factors do you think might influence access to social care?
- Is there is a difference in accessing healthcare as opposed to social care?
- Have you had any experience of using social care for yourself or others?
- Can you think of any specific challenges for the two groups identified (BAME and LGBT+) in accessing social care? Again, are these particular to social care or would they be the same for healthcare?

The panel commented on the relevance of the review and indicated their interest in being involved throughout the review. As described above, at a meeting in early December 2019, we asked the panel to help with the prioritisation of theories in the form of IF-THEN-LEADING TO chains, in parallel with the prioritisation exercise with DHSC.

Our original intention was to validate findings from the realist review with a panel that was representative of the experience of social care, particularly in terms of membership of the two focal population groups. The impact of the pandemic upon the roles and personal circumstances of the project staff and, more specifically, on our efforts to broaden our standing PPI group representation meant that this was not possible.

Registration and outputs

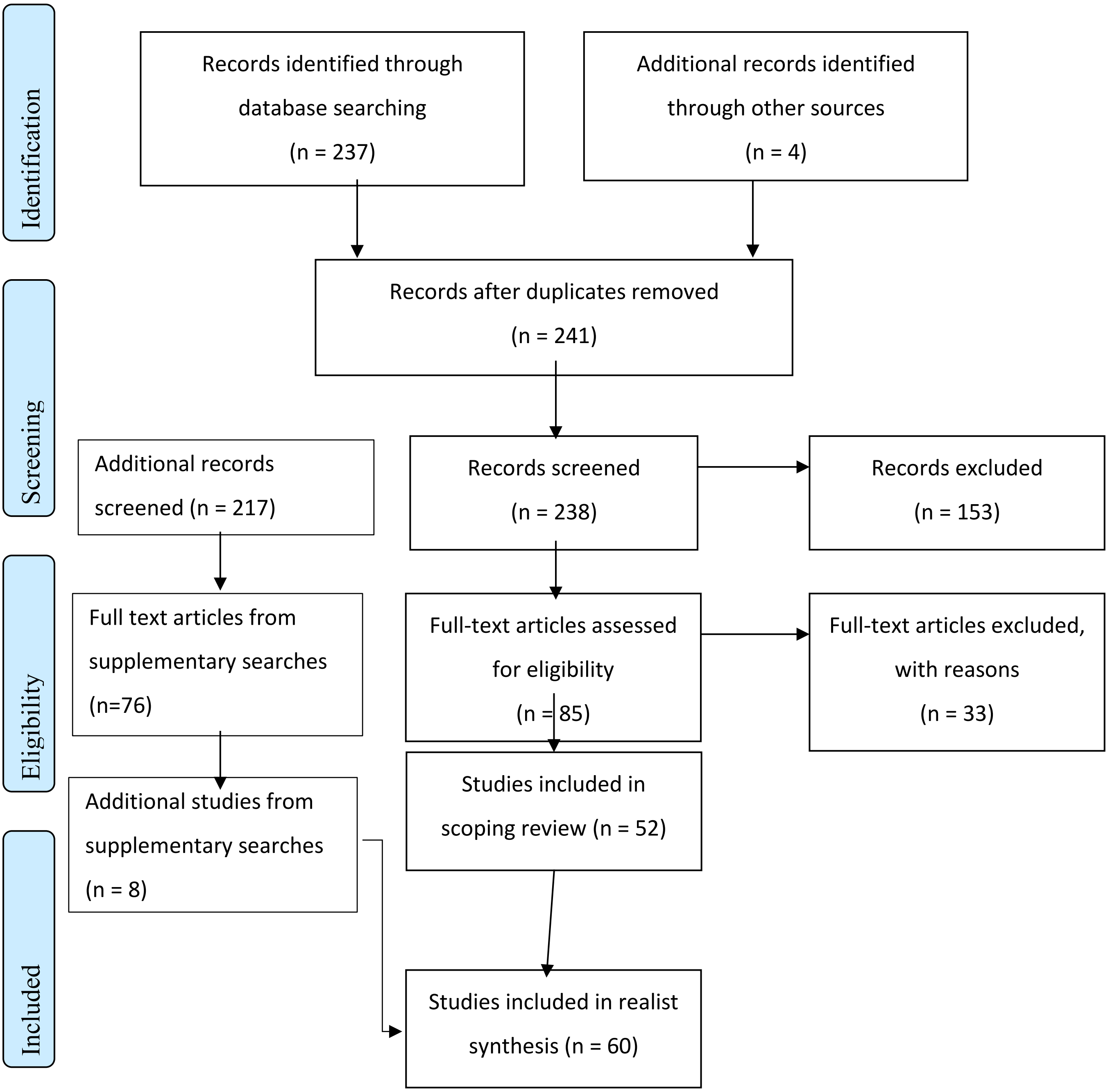
The protocol for the review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) in November 2019 and is record number CRD42019158250. In addition to the final report, we plan to produce outputs to meet the needs of the DHSC and the social care community more widely – as well as a peer reviewed journal article we plan to produce an evidence Briefing (a short, policy focused summary on what we have learnt from the review). This report and outputs will be reported according to RAMESES reporting guidelines[14].

Chapter 3 - Results of the Scoping Review

PRISMA (modified)

The PRISMA diagram (Figure 2) describes the evidence retrieved for inclusion in the review. Original sources from the scoping and theory generation stage are identified through the centre of the diagram. Additional sources identified from supplementary searching are identified in the left-hand column.

Figure 2 - PRISMA Flow Diagram



Theory building

We included a total of 52 documents in the theory building stage.

Theory testing

The Department of Health and Social Care prioritised five programme theories. The final list of programme theories represented a mix of staff and client/family related theories and included both formal and informal care and where these intersect. The second theory testing stage, included 76 documents initially tagged by at least one of the three reviewers as include or query. We did not review any documents with three excludes. We discussed all documents with at least one "include" or "query" and coded these against the additional categories of Review, Theory, Park or Follow up. From the literature searches we ultimately identified 59 references for the theory testing stage of the review as summarised in Table 2.

Description of Included Studies

We produced a descriptive summary of key characteristics of the body of 59 included papers. Thirty-four studies used qualitative research, 32 comprised the entire study, one was in conjunction with a literature review and one as part of a mixed-methods study. Four miscellaneous research studies were included; a secondary analysis of a national sample, a survey and two action research projects. Four studies involved some type of literature review; two simply described themselves as literature reviews, one was a scoping review and one was included alongside a qualitative study. Eighteen papers were discursive; 6 were discussion articles, 3 were conceptual papers, 3 were policy critiques, and 2 were briefing papers. The remaining papers comprised a case study, a commentary, and editorial, and a Royal College of Nursing discussion and guidance document.

Thirty-five papers covered the United Kingdom. Fourteen further papers specifically featured England, with four for Wales and three for Scotland. Of the remaining three papers one featured Scotland and the South East of England, one compared the UK with Australia and one compared England and Ireland.

Diverse terms were used to describe the populations under study. Thirteen papers defined the population by the sexuality of the person being cared for. Five studies were defined by religion (all Islamic). Five studies focused on a Chinese population and five populations were described as South Asian. Three studies specifically involved those from Bangladesh, two from Pakistan with one each from India and Somalia. Three populations involved people with dementia, two with stroke, two each with intellectual disabilities or physical disabilities and one with visual impairment. Sixteen of the studies specifically mentioned an older population, one referred to young adult asylum seekers and one to pregnant women. One study specifically targeted men and three focused on women.

Six included papers focused on issues for carers (BAME and White British carers of stroke survivors, Diverse ethnic group (Asian Indian, Asian Pakistani, black African, black Caribbean, white British) carers of stroke survivors, South Asian Muslim Parents, carers of UK Bangladeshi and Indian people with dementia, Older carers from diverse ethnic groups, and Gay and lesbian carers). Six studies involved social care or other workers (e.g. migrant or health workers). Three of these worked with refugees or asylum seekers, one study involved care home staff caring for old/er lesbian, gay, bisexual and transsexual residents and the remaining two featured palliative care professionals or social care staff working with different cultures.

In terms of the sectors of social care within which the papers were situated, 14 were located within social care services, 10 specifically within social work and 8 within health and social care. Of the remainder five were located within care homes, three each within mental health social work or dementia care, two in nursing homes, two in home care and two related to personalised care. Two papers were variously residential care and sheltered housing/other residential care, further two were end of life care/palliative care, and a single paper in long-term care services. The final six papers covered miscellaneous settings, namely statutory and voluntary-sector settings, social service providers, "caregivers, service providers and voluntary providers", caring relationships, midwifery students, and non-government organisations.

Finally, various terms were used to describe the phenomenon under investigation; by far the largest group (n = 12) focused on legal status (forced migrants/asylum seekers), some focused on citizenship (British…..), others variously invoked language challenges ("non-

English language speakers”), “marginalized communities” or cultural diversity . Several studies referred generically to BAME or LGBT+ populations highlighting a perceived commonality of experience.

As these descriptive analyses and the accompanying Table 2 make clear, many of the studies demonstrated intersectionality within the study population making identification of cross-cutting issues challenging.

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Table 3 - Studies contributing to the testing of programme theories

First Author	**Year**	**Method**	**Population Group**	**Setting/service**	**Country**
Badger[22]	2012	Survey	Minority ethnic residents	Nursing homes	England
Bailey[23]	2018	Qualitative study using participatory inquiry	Older South Asian Women	Health and social care	United Kingdom
Blake[24]	2017	Qualitative study	Bangladeshi and Pakistani users	Social care	United Kingdom
Cant[25]	2009	Policy analysis	LGBT	Health and social care	United Kingdom
Chantler[26]	2012	Policy critique	Asylum seekers	Mental health social work	United Kingdom
Chau[27]	2010	Discussion paper	Chinese Community	Health and social care	United Kingdom
Chau[28]	2011	Discussion paper	Chinese Community	Social work	United Kingdom
Cronin[29]	2011	Policy critique	Older lesbian, gay and bisexual people	Caring relationships	United Kingdom
Fell[30]	2014	Discussion Paper	Adult asylum seekers	Social work	United Kingdom
Fenge[31]	2014	Small explorative study	Bereaved older lesbian and gay people	Social work	United Kingdom
Fish[32]	2009	Discussion paper	Lesbian, Gay and Bisexual people	Social work and social care	United Kingdom

First Author	Year	Method	Population Group	Setting/service	Country
Fitzpatrick[33]	2012	Editorial	Minority ethnic people	Nursing Homes	United Kingdom
Gaveras[34]	2014	Qualitative study	South Asian Muslim Parents	End of life care	Scotland
Gill[35]	2014	Literature review; qualitative in-depth interviews	Pakistani, Bangladeshi and White British	Adult social care	United Kingdom
Giuntoli[36]	2012	Qualitative study	Older migrants	Social care and support services	United Kingdom
Greenwood[1]	2016	Qualitative focus group	Diverse ethnic groups carers of stroke survivors (Asian Indian, Asian Pakistani, black African, black Caribbean, white British)	Adult social care	United Kingdom
Greenwood[37]	2017	Qualitative study	BAME and White British carers of stroke survivors	Adult social care	England
Gunaratnam[38]	2011	Discussion article	Palliative care professionals	Palliative care	United Kingdom
Hafford-Letchfield[39]	2018	Evaluation of action research project	Older LGBT people	Residential care	United Kingdom
Haith Cooper[40]	2013	Qualitative study with focus groups	Pregnant asylum seekers	Midwifery students	United Kingdom

First Author	Year	Method	Population Group	Setting/service	Country
Heath[41]	2011	Royal College of Nursing discussion and guidance document	Older people (including LGBT+)	Care homes	United Kingdom
Herat-Gunaratne[42]	2019	Qualitative study with interviews	Family carers of UK Bangladeshi and Indian people with dementia	Home Care	United Kingdom
Higginbottom[43]	2014	Focused ethnography	Somali refugees with visual impairment	Caregivers, service providers and voluntary providers	United Kingdom
Hussein[44]	2011	Secondary analysis of national sample	Migrant workers (Refugees and asylum seekers)	Social care	England
Hussein[45]	2011	Qualitative study	Refugees and Asylum seekers	Social care	England
Irvine[46]	2017	Qualitative study	People from Chinese backgrounds	Personalised care	England
Jones[47]	2018	Qualitative study using interviews	Older bisexual people	Social work	England
Kakela[48]	2020	Qualitative element of mixed-methods study	Refugees and asylum seekers	Social work	Scotland

First Author	Year	Method	Population Group	Setting/service	Country
Larkin[49]	2018	Qualitative study	Adults with intellectual disabilities from minority ethnic groups	Social care	United Kingdom
Liu[50]	2017	Qualitative study with focus groups and interviews	Chinese older immigrants	Health and social care	United Kingdom
Macfarlane[51]	2009	Two action research studies	Non-English language speakers	Health and social care	Ireland and England
Malik[52]	2017	Qualitative study using interviews	British South Asian women with intellectual disabilities	Social care	United Kingdom
Manthorpe[53]	2012	Qualitative study using interviews	Older people from black and minority ethnic communities	Mental health services	United Kingdom
Martin[54]	2019	Scoping review	People with dementia	Care homes	Wales
Masocha[55]	2014	Qualitative study using interviews and discourse analysis	Asylum seekers	Mental health social work	England
Moriarty[56]	2008	Briefing Paper	Black and minority ethnic older people	Health and social care	United Kingdom

First Author	Year	Method	Population Group	Setting/service	Country
Moriarty[57]	2014	Briefing Paper	People from black and minority ethnic groups	Health and social care	United Kingdom
Mullay[58]	2011	Conceptual paper	Culturally diverse with dementia	Care homes	Scotland
Needham[59]	2015	Literature Review	Marginalized Communities	Social Care	United Kingdom
O'Brien[60]	2016	Conceptual paper	Lesbian, gay, bisexual and transgender people	Health and social care	United Kingdom
O'Higgins[61]	2012	Qualitative study - focus groups and interviews	Young refugees	Social service providers	United Kingdom
Ottosdottir[62]	2014	Qualitative study	Disabled forced migrants	Health and social care	England
Parveen[63]	2017	Scoping exercise using qualitative methods	Minority ethnic communities	Dementia services	United Kingdom
Peate[64]	2013	Commentary	Older lesbian, gay and bisexual people	Sheltered housing or other residential care	United Kingdom
Pound[65]	2016	Qualitative study	Older carers from diverse ethnic groups	Home care stroke services	England
Price[66]	2010	Qualitative study	Gay and lesbian carers	Dementia services	England

First Author	**Year**	**Method**	**Population Group**	**Setting/service**	**Country**
Regan[67]	2016	Case study	Muslim male	Dementia services	United Kingdom
Robinson[68]	2014	Qualitative study	Health and social workers working with refugees and asylum seekers	Non-government organisations	Australia and United Kingdom
Robinson[69]	2017	Qualitative study with interviews	Social workers working with asylum seekers	Statutory and voluntary-sector settings	Scotland and England
Scourfield[70]	2013	Qualitative study	British Muslim families	Social work	Wales
Simpson[71]	2017	Literature Review	Care home staff caring for old/er lesbian, gay, bisexual and trans residents	Care homes	England
Trotter[72]	2003	Discussion Paper	Sexuality	Social work	United Kingdom
Warden[73]	2017	Qualitative study with interviews	Islamic social work service users	Social work	Wales
Westwood[74]	2016	Qualitative study with interviews	Older LGB individuals	Care home	United Kingdom
Willis, P[75]	2016	Theoretical paper	South Asian and White British older people	Social care	United Kingdom

First Author	**Year**	**Method**	**Population Group**	**Setting/service**	**Country**
Willis, P[76]	2017	Qualitative study with survey and focus groups	Older lesbian, gay and bisexual adults	Long-term care	Wales
Willis, R[77].	2016	Qualitative study with interviews	South Asian and British White people	Adult social care	England
Willis, R[78]	2017	Qualitative study with interviews	Social care staff	Social care	England
Yeung[79]	2016	Qualitative study with interviews and focus groups	People from Chinese backgrounds with physical disabilities	Social care	England

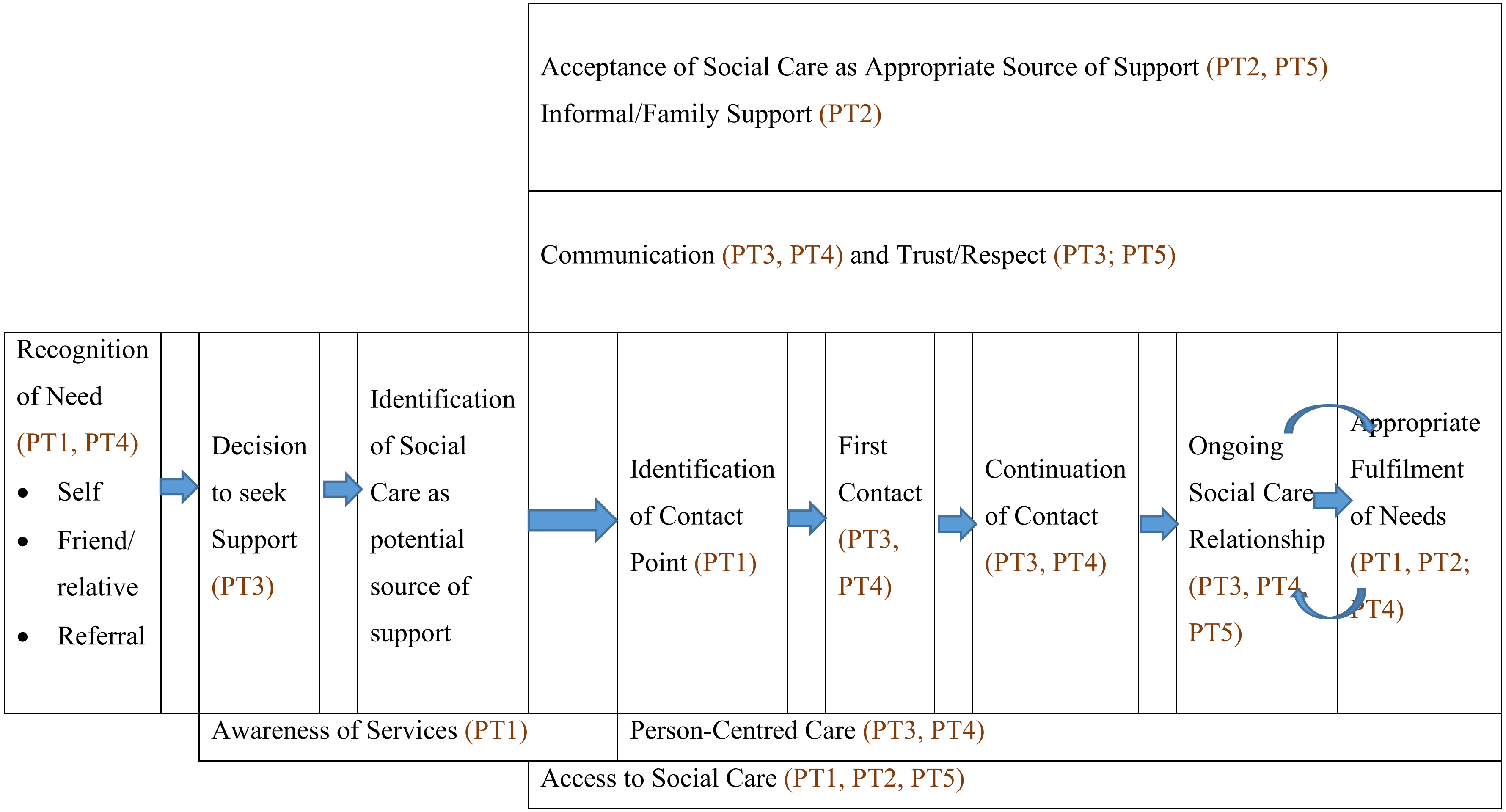
The Pathway to Adult Social Care

The Pathway

Increasingly health and social care services research adopts a whole systems lens to explore complex interventions and their equally complex relationship with and in their environment. Our initial scoping literature search did not reveal any studies that followed the service user through the adult social care system or mapped out access from recognition of need through to resolution of that need. As a next best alternative, we developed an adult social care pathway which (i) allows a targeted approach to address access issues at specific points of the pathway and; (ii) provides a coherent overview of access to adult social care provision. This adult social care pathway was therefore produced following initial reading of the scoping literature but before generation and prioritisation of the programme theories. It serves as a device against which to position the programme theories but does not constrain interpretation within each programme theory. Subsequently, individual studies may contribute to one or more stages of the pathway. Collectively, however, they can be pieced together to form an overall picture of the challenges faced by service users and/or informal caregivers in navigating around an adult social care organisation and along the pathway to resolution of their personalised needs.

In depicting an adult social care pathway we acknowledge that we have operationalised a choice between presenting data within a service user perspective and a service provider configuration. Following negotiation with the DHSC we proposed an equivalent to the primary care pathway that we have previously cited.[12] The intent is not to problematise the service user but to seek to model their progress, or lack of progress, along the pathway and then to explore reasons why. We also acknowledge that this particular lens could have been influential in leading towards a patient-centred perspective on care. However, the fact that the onus for creating a patient-centred care environment falls transparently on the service provider and the social care staff demonstrates that the complex nature of the problem, and the diverse data used to explore this, was more influential in shaping the review findings rather than the initial lens selected to explore it.

Figure 3 - Modified Adult Social Care Pathway (indicating positioning of Programme Theories)



Chapter 4 - Results of the Five Programme Theories

Programme Theory One (PT1) - Awareness of Services (Both Groups)

IF social care service users are aware of adult social care services and how to access them

THEN social care service users access adult social care services as needed

LEADING TO social care staff providing appropriate care/social care service users receiving appropriate care

Background

Many reasons for not accessing services are common across all service users and their caregivers. irrespective of ethnicity or the health condition concerned. However, poor access to services is often compounded for those from black and minority ethnic (BAME) groups[8]. BAME groups are more likely to suffer ill-health and poverty[80 81]. Language differences, cultural appropriateness of services and cultural notions of duty influence service uptake[7]. Inequality and racism[82] may further compound this disadvantage.

Available evidence consistently suggests that BAME groups and their informal caregivers are less likely to use formal services than their White counterparts[4 83] .This is despite the fact that BAME caregivers are more likely to express greater need for services than White caregivers[2]. In the United Kingdom, caregivers from BAME groups are known to provide more care than majority groups and are more likely to suffer from ill-health[84]. In the UK, BAME caregivers were more likely to say that they were not aware of services, that services were insensitive to their needs and that their use of services was restricted by lack of information, cost and lack of flexibility [85]. This situation is captured in one study where South Asian participants argue that they need to know what is available if they are to ask for something specifically. The full range of options was not offered to them:

> "There are so many things they [social services] provide, but we don't understand what is available and what is not available. There must be so many things we don't

> know yet. We don’t know what we are entitled to or not. How can we get things if we don’t know they exist? (p. 1372)" (SU 14, SA).[77]

Evidence Profile

The realist synthesis on **Awareness of Services** identified 21 studies exploring awareness in relation to Black and Minority Ethnic groups, of which 17 were qualitative (Table 3). One study was a literature review and three studies comprised other evidence (two briefing papers and one thesis). In comparison the literature relating to LGBT+ was less plentiful (Table 4). The literature search identified three studies, namely two qualitative studies and a narrative book chapter. Additional items were identified specifically in relation to dementia services, services that straddle the health and social care divide, and these offer a potentially productive line of future qualitative inquiry.

Table 4 - Summary of included studies (nos. of each type and references only):

	Black and Minority Ethnic Groups				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	**Other Evidence**
PT1: Awareness of Services IF social care service users are aware of adult social care services and how to access them THEN social care service users access adult social care services as needed LEADING TO social care service users utilising services appropriately	63 65	8 86		1 23 24 34 35; 37 42 43 46 50 63 65 67 75 79 87 88	56 63 89

Table 5 - Summary of included studies (nos. of each type and references only):

	LGBT+ Groups				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	**Other Evidence**
PT1: Awareness of Services IF social care service users are aware of adult social care services and how to access them THEN social care service users access adult social care services as needed LEADING TO social care service users utilising services appropriately	[90]	None	None	[31 32]	[74]

How interventions are believed to work

While the literature emphasises that ethnic minorities must not be stereotyped as cultures where children and extended family automatically "look after their own" it is important to recognise that this phenomenon may have multiple explanations (Table 5). For example, one Asian woman did not want her daughter in law to think that she was "going outside the family" as that might be interpreted as a sign that she did not feel she was being cared for[23]. In the absence of communication it may be difficult to identify where exactly the barriers to access are occurring and what is their precise cause. Specifically, in relation to access a lack of awareness of available services may be perceived as a neutral explanation that sidesteps difficult discussions.

BAME service users and their caregivers often share genuine bewilderment about (i) what they might be entitled to, (ii) what is available, and (iii) how to access such support[23]. Where lack of awareness is perceived as the specific cause for non-use substantial data suggest that others act as navigators or signposts, to available services:

> "This signposting role can be occupied by formal support, such as GPs or nurses, by informal carers such as family members or by charities".[23]

Potential beneficiaries from services "often said that they had known little or nothing about adult social care services until a third party, such as a neighbour, community worker or doctor, suggested that they get help".[35]

Another potential role might require some formal navigation service to assist those in the community with a particular condition to recognise and articulate their specific need. In the context of dementia one Muslim expressed a need to develop a 'platform for people to have their say'.[67] He further expressed a strong desire to assist in working alongside existing health and social care providers to generate a Muslim specific service: 'if I started something like that on my own and recruited people...go out there and promote the thing in some way'.[67] Creation of a social network, to act as a central hub about existing services and how to access them, offers one potential response:

> ‘there are people that need help, they don’t know where to go, so I think we need something for dementia, but as a whole, we need some sort of advisory network, where they are at least made aware of what type of help is available (pp.713-714).’[67]

This data extract highlights resource issues associated with intersectionality of minority group and condition. Can different networks (or hubs) for different communities be created or should provision be more generic, “lumped” either by condition or ethnic sub-population[67].

Andersen's Behavioral Model has been used extensively in studies investigating the use of health services[91]. Variables are characterised as predisposing, enabling, and need factors. Gender/sex and ethnicity typically feature as “predisposing factors”. Income/financial situation and having a usual source of care become “enabling factors”. Health status and self-reported health figure as “need factors”. By this model we recognise that an individual may hold back from using social services, perhaps because of cultural beliefs or norms, until their need becomes such as to trigger concern or anxiety. Usual sources of care, e.g. contact with existing service care provision, may act as a focus for information or encouragement when pursuing extra provision. This provision may be sought through private sources, where the potential service user possesses sufficient resources. Otherwise they may simply explore and, ultimately, access formal public provision. However, a counterbalance to this direction may be an inhibiting family culture that considers that “we look after our own”. Only when the need, as previously “absorbed” by the informal family caregiver, becomes sufficiently intense do they and the potential service user work together to explore entitlement.

Leventhal's Self-Regulation Model of Illness,[92] may help in understanding help-seeking behaviour in BAME communities[63]. The model suggests individuals acquire illness cognitions through exposure to the media, personal experience and their family and friends. Illness cognitions are defined as the individual's own common-sense beliefs about illness and provide a framework for understanding and coping with illness. If these cognitions do not accommodate awareness of available services then an individual’s coping response continues independent of these provisions. If the coping response is unsuccessful, then it is amended or the initial representation of the threat is revised. This either involves them considering that their situation is normal[77] and continuing without intervention, accessing friends and colleagues for suggestions on coping resources or trawling for information more widely themselves. Moriarty (2008) advocates for an integrated approach[56].

Table 6 - Putative mechanisms for intervention

Intervention Components	**Contextual Factors (Enabling)**
Information provision Cross-agency "joining up" "Discreet publicity" Inclusive publicity Navigation around organisation and to specific services	Family/Relatives with knowledge/experience of social care Health or other social care professionals/charities who signpost services Welcoming points of first contact An "every contact counts" philosophy
Potential Mechanisms **(Care Providers)**	**Potential Mechanisms** **(Service Users and Caregivers)**
Anticipation of emerging needs Identification with the whole social care organisation (not only their own service) Recognition of both potential service user and caregiver needs	Cultural validation and verification Family permission Being able to identify as a potential user of the service Recognition that services are not just for crises
Outcomes	**Leading To**
General awareness of service provision Awareness of specific services Identification of appropriate contact points for specific services	Specific awareness of entitlement, appropriateness and how to "trigger" services Reduction in delayed or crisis presentation to services

Mechanisms influencing the success of the intervention

A key determinant of access to adult social care services is past experience (See: Report Supplementary Material File 1 - Context-Mechanism Outcome Configurations for five programme theories). However, this can be seen to operate in diverse ways. For some the preconception of social care is formed from experience in their country of origin; both in how care is accessed and delivered and, specifically, relating to which specific services might be available. For example, one memorable article title reminds us that "In the Bengali Vocabulary, There Is No Such Word as Care Home":[42] Others may derive their awareness of adult social care services from the experience of family or relatives or from members of an extended social network or support group. Negative past experiences of the potential service user or of their contacts also play a major role.[46 47]

A further determinant relates to how the social care organisation is perceived – if publicity is inclusive and the accompanying text and imagery is perceived as welcoming then potential service users may see the service as being appropriate to their needs. The converse is true; heteronormative assumptions, carelessly used labels and even well-meaning but stereotypical assumptions about how race, ethnicity or sexual orientation translate into everyday behaviours and routines can cause users typically to delay, or even postpone indefinitely, their access to services. In this context, families may seek to carry the caregiving load as much as, and for as long as, possible and LGBT+ potential service users may make extensive arrangements to cover future contingencies to avoid dependence upon formal service provision.

The Context(s)

Social care agencies may assume that they are experienced as monolithic (i.e. that once the user finds out about their existence and their overall mission that awareness has been "sorted"). Instead it is helpful to see social care organisations as offering a suite of services when the service user may only be aware of, or only be aware of their need for, one service:

> "Some families had struggled for months or years without any form of social care and had not thought of contacting the local authority. Others had used one type of service (such as a day opportunities service) and had not known that other services (such as home care or home adaptations) might be available"[35].

Similarly, a study of the Chinese community reports differential awareness of specific services:

> "there is a notable information gap for people from Chinese backgrounds regarding personal budgets…this is the case for individuals who have managed to secure some access to social care services, often through a protracted process, and suggests that those who do not receive (but may be in need of) services are even less well informed about personal budgets" [46].

Supporting Evidence

One systematic review of quantitative and qualitative evidence examined barriers to access among BAME populations, specifically in relation to BAME caregivers. While the views of BAME service users and their caregivers are not synonymous they are likely to share similar views in terms of knowledge of available services and, subsequently, how they experience engagement with staff.

The review revealed no quantitative studies relating to whether non-awareness of available services was an explanation for relatively low levels of use among black and minority ethnic populations. Neither did the review identify any quantitative studies exploring non-awareness of services among LGBT populations.

Lack of awareness was mentioned frequently as a barrier in the included studies. However, close examination reveals that lack of awareness appears to operate at two levels; first, in general knowledge of what is available and how, generally to access these services[34] and second, in more instrumental details on how to initiate a response from a particular service. For example, a potential adult social care service user may first lack general knowledge that social services offer provision for those with limited mobility but then, once aware of this, may not know how to book a taxi or minibus pick up via that service: "the woman would also like more practical information and practical advice, such as how they might access a service or arrange shared transport" [23].

Operating behind both the general and the instrumental is a knowledge of entitlement; is this particular service available for, and appropriate to, my own needs? Finally, even when the potential service user is satisfied that they are entitled to use services and that they know how to interact with them a further consideration is whether such interaction will be "worth it": "a need to understand the paperwork, their commitment and whether there were 'strings attached'".[23] In some cases women "would take the information to their spouse and/or adult children" both in order to check not simply their understanding of the information but also as a form of "vetting": "We know that there are schemes, like when you look after someone you can get an allowance, but we need to be sure that it's all ok".[23] This expression may even convey the sense that the services on offer may be a lure by which they will be caught out, perhaps in undermining or disqualifying their current entitlement.[23] "Mistrust of healthcare providers" posed a barrier to access to related palliative care services.[34] Other users have expressed similar difficulties in knowing what is available:

> "I didn't know what service was available, I just knew that I could try but I didn't know what exactly I should be asking for." (Mr Lau)
>
> "I didn't get in touch with anyone because I didn't know where to go or how to get help ... I didn't know what I was entitled to." (Angela)[79]

Not knowing where and how to access social care was one reason for not getting support early[79]. Service users perceived that they had to wait for a crisis, such as their health deteriorating below a certain point, before support was offered from social care:

> "The only way you could get help was to be hospitalised and then you would have the service. You need to get into the system!"[79].

For users, as well as service providers, one of the challenges is benchmarking whether an individual's need had crossed a threshold of need, and how their need compared with that of others who were genuinely entitled to use the service.

> "You know, the system works like this. Your condition has to become very serious to warrant their intervention. However, only the sufferers know the seriousness of the situation, we live with it every day ... you know, they (social workers) actually don't understand."[79]

This statement suggests that service users and social workers work from different "thresholds of entitlement" which impairs communication and understanding[79]. Cultural expectations and unspoken assumptions combine to cause inertia and continuation of the status quo:

> Unfortunately, if people do not know that they have to ask for help, or even what service to ask for, this leaves them with unmet needs. Here, a South Asian participant reports that he was not offered any additional help to care for his father with dementia, and he did not know to ask for it because he assumed that was normal:
>
> "There was never any talk of any kind of additional care or respite or anything like that. We just took that as normal (p.1373)." (Carer 26, SA).[77]

Feeling uncertain about entitlement to services and being unfamiliar with the procedures involved impede help-seeking[79]. Many participants have to navigate through the healthcare system before reaching social care, causing delays in getting support and further confusions to their understanding of the organisation of social care. ([79], p. e147)

Modifying Evidence

Qualitative studies within the review revealed evidence that levels of awareness differ according to specific BAME subgroups. Multiple factors may combine to make the situation even more challenging; for example, certain communities are not only less likely to speak or understand English but may originate from countries that have no tradition of social services or where their model of social services differs from a Western UK-based model (e.g. Somalia [43], Bangladesh and Pakistan[35]. In contrast, Afro-Caribbean elders who had previously worked in health or social care might be familiar with what was available. These examples illustrate the need to avoid generalisations across a "BAME population" and attest to the influence of intersectionality, in this case language and culture, in determining actual awareness. Furthermore, older people and groups that have arrived in the UK more recently, such as some Somali and Yemeni people, may find it particularly difficult to find out about services[56]. More attention needs to be paid to ensuring that information is available in different languages and formats. This highlights the need for an integrated approach that includes written information, telephone helplines, outreach services and media campaigns[56] This attests to a need for multiple languages and formats. Within a BAME (specifically Bangladeshi and Pakistani) group: "negotiating the social care system was much easier for people who were highly educated, fluent in English and knowledgeable about the system". Literal language challenges and problems with literacy may be compounded by a lack of "service literacy", a social care equivalent of that manifested in the health service

> "knowing about services, accessing services, booking medical appointments, arranging transport to attend appointments, using services, and understanding information such as follow-up letters".[50]

The literature on LGBT+ experiences revealed different nuances from lack of awareness as expressed among BAME populations. In qualitative studies in LGBT+ populations, issues related more to a lack of awareness, or at least reassurance, that the available services are appropriate to the specific needs of the LGBT+ client. One study reveals a particular paradox; namely that acceptable services are required to be openly "gay friendly" but had to recognise that not all LGBT+ clients had revealed their sexual orientation and therefore require a discreet service. This may reveal further intersectionality in differences between younger and older LGBT+ populations and also between cultures that openly accept overt sexuality and those that continue to require such issues to remain hidden.

Some individuals need the service to have an identity or perspective to which they could relate, evidenced in a study of bereaved LGBT+ women: "it didn't feel it could be about me"[31]. In this same study a bereaved lesbian describes encountering great difficulty in trying to access support appropriate to her own needs, thus compounding feelings of loss and isolation: "I was looking for things to read just to identify with really and there was precious little. . . . There wasn't any specific support for gay people who were bereaved, and I did look." What "gay friendly" actually means is not always discernible from how services are delivered; instead it may include issues of continuity of care whereby a contact is aware of the client's individual identity. Continuity may take the form of Direct Care Payments, contrasting with the variable service offered by a care agency: "I live at home supported by people I recruit who I am very clear with who I am. They don't change every week and they are not all straight or gay. . .".

Summary of the Evidence Base

Issues of awareness tend to be "lumped" together as a single phenomenon. Included studies reveal that many issues are involved; awareness of general social care provision, awareness of specific services, awareness of entitlement and how to activate a social care response and awareness of whether the services are culturally appropriate and/or "gay friendly". Family support, validation or approbation are important when a potential service user is contemplating use of a service. We hypothesise that expressed unawareness of services might be a convenient explanation that avoids uncomfortable discussions with one's relatives, although this requires verification from the literature and further exploration.

Limitations of the Interventions

One study seemed to suggest that the artificial separation of services and entitlements across agencies (in this case social care, education and health care) adds further complexity for users from BAME populations [35]. One Pakistani mother of a disabled woman recounted that "she had not known about adult social care services, even though her daughter had attended a special school and received medical attention for multiple physical and mental health problems"[35]. Entitlement across agencies could be triggered by a set of associated circumstances making it difficult for a service user, or in this case a parent, to understand why being told about one service did not open up the possibility of finding out about related provision. In this case the mother found out about available services through a friend with similar circumstances who "urged her to contact a centre for people with learning difficulties"[35]. Service users from BAME groups may encounter "double discrimination" – not only are they not benefiting from the services but they also perceive themselves to be "last in the queue" to find out about their entitlements[35].

Limitations of the Evidence Base

The evidence base is overwhelmingly populated by qualitative research. The nature of this evidence base allows us to explore the assumptions that underpin the proposed programme theories but stops short of being able to establish these definitively. All observations and recommendations must be accompanied by this cautionary note. Although awareness of services features, to different degrees, as a consistent theme across almost the entire set of included studies coverage of particular groups is uneven. Within the overall BAME group the focus is largely on more established migrant populations, for example the experiences of the Bangladeshi and Pakistani populations, and South Asian respondents more generally, are comparatively well-represented. In contrast the experiences of those from the Balkans, Syria and the Horn of Africa (Ethiopia, Eritrea, Somalia) is comparatively poorly captured. In this context this omission represents a particular cause for concern because their experience in relation to awareness of services, language challenges, and the lack of cultural sensitivity is likely to be more acute and urgent.

Awareness of services appears to be less of an issue for LGBT+ service users. However, the composition of research samples from this group has been observed to be inordinately skewed to better educated LGBT+ users suggesting that the experience of those in more challenging social circumstances may be qualitatively different. As with all programme theories, coverage of the LGBT+ experience is less plentiful than for the BAME populations and tends to favour more easily accessed samples e.g. residents of care homes.

Key Considerations for BAME Service Users

Social care staff, and health professionals who may act in signposting adult social care provision, should be aware that aspects of UK social care may be unfamiliar to those from countries with different, or a complete absence of public, provision. They should not assume that (i) a user of one or more services is aware of and benefitting from, all available services; (ii) someone who is aware of social care services also holds a knowledge on how to activate service provision and (iii) someone who is aware of social care services is able to judge their own entitlement or the appropriateness of the services to their needs.

Key Considerations for LGBT+ Service Users

Social care staff should be aware that potential LGBT+ service users may want to establish whether a service is "for" people like themselves. This may present as checking out publicity and information about the service to evaluate whether they can identify with persons being depicted or described. However, being "gay friendly" may involve being aware that not all service users are comfortable with being overtly identified with non-heterosexist provision. It also involves acquiring a knowledge of the specific individual needs of the client, perhaps compiled over a period of time and acquired through continuity of care.

Programme Theory Two (PT2) - Complementarity to Informal Care

IF social care service users perceive that adult social care services complement and augment informal and/or family support

THEN social care service users feel able to access adult social care

LEADING TO social care service users feeling that their holistic needs are being fulfilled

Background

In England alone, five million carers (known in this report as ‘caregivers’), defined as “family members, friends or other informal networks who are not formally employed to provide care”, help with personal care or everyday tasks[6]. If interaction between formal and informal care is to be managed effectively then service users and their informal caregivers must be aware of what services are available and what their entitlement is. Programme Theory 2 on Awareness of Services can be seen as prerequisite to Programme Theory 3 on Informal Support. All care groups, whether supported by informal caregivers or not, need to be aware of the services available and how to access them. Those with caregivers and those who do not share a common need to identify diverse areas of support that they personally need and to map how this support might be delivered, whether exclusively through formal provision or as an optimal blend of formal and informal support. A third group relates to those who prefer to be largely as self-reliant as possible and who seek to choose the care that they perceive themselves to require[46]. Personalisation, and, specifically, personal care plans and personal budgets are thus required to facilitate this perceived self-reliance[46].

Evidence Profile

The realist synthesis on Complementarity to Informal Care identified 10 studies exploring awareness in relation to Black and Minority Ethnic groups, of which 1 was quantitative, 8 were qualitative, 1 was both quantitative and qualitative and one study offered other evidence (Table 6). In comparison the literature relating to LGBT+ was less plentiful (Table 7). The literature search identified 3 studies, namely one review and two qualitative studies.

Table 7- Summary of included studies (nos. of each type and references only):

	Black Asian and Minority Ethnic (BAME)				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	Other Evidence
PT2: Complementarity to Informal Care IF social care service users perceive that adult social care services complement and augment informal and/or family support THEN social care service users feel able to access adult social care LEADING TO social care service users feeling that their holistic needs are being fulfilled			23	23 34-36 42 52 53 65 75	57

Table 8 - Summary of included studies (nos. of each type and references only):

	LGBT+				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	**Other Evidence**
PT2: Complementarity to Informal Care IF social care service users perceive that adult social care services complement and augment informal and/or family support THEN social care service users feel able to access adult social care LEADING TO adult social care service users feeling that their holistic needs are being fulfilled		59		29 47	

How interventions are believed to work

Informal care, whether delivered by family members or by other caregivers, is a heavily used resource within personal and social care. Informal care may extend from providing support and information, to practical assistance, through to helping the service user to manage their situation and increase their coping capacity (Table 8). However, the caregiver themselves has associated needs for information, support and coping resources in order to build up their own resilience, self-efficacy and coping strategies[93]. Otherwise stress and caregiver burnout may occur, ultimately reducing the caregiver quality of life and increasing the cumulative load on health and social care services[93]. Where informal caregiver support and support offered by formal services is truly complementary this results in appropriate utilisation of resources and ensures that no service user needs fall down a gap between formal and informal provision. Such complementarity can only be achieved in the presence of good three-way communication, accompanied by trust, between the service user, service provider and informal caregiver. One or more of these three stakeholders needs to monitor the situation to ensure that complementarity continues in the light of ongoing and often changing needs. Dissatisfaction may occur when services are slow to respond, in contrast satisfaction will occur when care is eventually received following long periods of coping without support[24]. Recognition of an informal caregiver's role by healthcare professionals may improve the caregiving experience and reduce crises or the need for respite[93].

Families and care providers may have different ideas about what constitutes best support, both from each other and from the service user. However, service providers should view families positively given the family understands the person from their own perspective[94]. As a consequence, service providers need to make a concerted effort to develop relationships with families. Stereotyping families as either ‘over-protective’ or ‘disinterested’ is detrimental to person-centred planning[94].

Table 9 - Putative mechanisms for intervention

Intervention Components	**Contextual Factors (Enabling)**

Personalisation of services (in blend between formal and informal care) Personalisation of services (in terms of dependence versus self reliance)	Trust Willingness to accept informal help Willingness to accept formal help
Potential Mechanisms (Care Providers) Communication Clarity of role(s) Recognition of informal caregiver role	**Potential Mechanisms** (Service Users and Caregivers) Communication (Service Users and Caregivers) Involvement in care planning decisions Clarity of role(s) (Caregivers) Recognition of informal caregiver role
Outcomes Perception of Self reliance and Autonomy Appropriate use of services according to eligibility Appropriate use of services according to unmet need (i.e. needs not met by informal support	**Leading To** Effective deployment of limited social care resources

Mechanisms influencing the success of the intervention

Successful interactions between normal care provision and informal care support and networks requires good communication and demarcation of roles (Table 9) (Also See: Report Supplementary Material File 1 - Context-Mechanism Outcome Configurations for five programme theories). However, delineation of roles is not sufficient; if a formal care provider is delayed or fails to turn up there must be flexibility in this combined care system to compensate for care otherwise left undone. Furthermore, the informal caregiver must feel able to trust the care provider to carry out their assigned tasks so that they feel able to achieve some respite or breathing space. Building up such trust is challenging, particularly where no initial rapport exists or where continuity of care is an issue with the service user and their caregiver seeing a succession of different individuals from an organisation or agency. This requirement for continuity of care does not emerge so prominently as for other settings, for example the continuity of seeing the same GP, but can nevertheless be detected in terms of "knowing" the care provider or their knowing what the service user and caregiver like/want. Such a relationship can also be observed from the data in symbolic ways, for example in stopping to play dominoes once formal care tasks are completed(27)(See PT5).

The Context(s)

Informal care plays an important part in social care provision. Unpaid caregivers, typically from friends or family, are an important source of mitigation of demand on formal social care services. However, informal care is largely unrecognised. Potentially, goodwill of families may be eroded if they feel that they are being required to compensate for deficiencies in investment in formal support structures and inadequate staffing levels. Family members may not be equipped for a caregiver role, in terms of practical skills, coping mechanisms or their other circumstances and responsibilities. Where caregiver stress precipitates a crisis intervention the outcomes may often be undesirable, given the lack of preparation and the need for an urgent response. This necessarily has implications for perceptions of formal care services. Where the system works well, care providers, service users and informal caregivers can anticipate and negotiate planned disruptions. Such a system will also be characterised by being responsive to changes in needs and actively monitoring the match of provision to need.

Supporting Evidence

Service users realise that informal caregivers have their own pressures and responsibilities[23]. They recognise that adult children have their own pressures; they do not wish to be a burden and value positive family support but worry this may also increase dependency:

> "I can't get out on my own so much." (Workshop 3: Services and Support);
>
> "Family are busy, they don't always have time to take me out". (Workshop 3: Services and Support)

Older respondents report feeling lonely, not seeing so many people, and not having places to go outside of the home. This was compared with when they were younger, busy, and engaged within the community:

> "We were busy [when younger], always busy and many of us worked outside the home [local factories, family businesses], we had the children, the cooking, the home, all the family matters, always something to plan" (Workshop 3: Services and Support) [23]..

Being able to "go out" and "get on with life" are ways in which service users can signal their own independence. However, family may be too busy to take them out [23]. Access to affordable and workable public transport, as a route away from the family network, and an outside location where they can "meet, socialise, and do something enjoyable" are ways that they can temporarily step outside their dependence on the family network[23]. Informal support is not necessarily seen only in practical support delivered around the home. Grown up children could be used to explain instructions on medication or other complex or critical topics; GPs can be asked to write details down at the time and then these are explained by the family member on a subsequent visit[23]. Where family members live far away a weekly social group may offer alternative help with getting official letters translated [23]. Others express difficulty when such ready access is not near at hand.[50]

Service users do not wish to rely on family members to "go out" and "get on with life". They need accessible, affordable, and workable public transport, and somewhere outside of family networks where they can meet, socialise, and do something enjoyable. Familiarity and feeling comfortable contribute to the perception of informal care. For many women it is important to stay in their home and place where they raised their children. They like their neighbours and communities. However, some talked about being "scattered", living with younger family members who have moved out of their familiar community.[23] One woman described feeling lonely even though she lives with her family:

> “They are out at work all day, so I get lonely but also, I can't get on with things so much, doing the washing or cooking, even going up and down the stairs it's difficult since the [hip replacement] (p.4)”.[23]

Confirming earlier research[8] caregivers demonstrate reticence in involving “outsiders”[23]. However, where the relationship between care provider and service user works well care workers are seen as one of the family:

> "She treated her like a mother because I think she had a bond with her, that love with her. (Sadar, Asian Indian) (p.1576)”[37]

Family may also be too busy, or absent from the home (e.g. at work) when they need instrumental help (e.g. they may have limited mobility or unable to perform activities of daily living[23]. Family caregivers may have other caring responsibilities (for example, a sick wife) and so service users may feel unwilling to add to this existing burden. This perception may be particularly felt when the informal caregiver lives in a different, separate home where external calls on their time and energies are seen by their relatives as more disruptive[23].

Clients do not wish to be a “burden” to their caregivers[23]. Conversely caregivers may feel ‘burdened” by the amount of care that they still have to provide despite the availability of formal care[75]. They may view this as either a shortage of hours assigned for formal care or as a shortfall of the tasks with which they require help[75]. In some cases, tasks may be limited by external constraints such as health and safety restrictions on lifting and carrying [75]. Family caregivers may also be expected to administer medical procedures when formal caregivers are not available; such as administer insulin or change a catheter[75]. “Burden” therefore seen in terms of time taken, physically demanding tasks or tasks that carry a heavy degree of responsibility[75].

Where it works well family caregivers see themselves as “sharing the load” with social care staff, working together to meet the needs of the cared-for person [75]. In contrast, some caregivers feel that services expect too much from family caregivers[75]. Sharing the load requires trust between the cared-for person and the formal care provider and between the informal caregiver and that care provider. A lack of trust, in some cases following previous unsatisfactory experiences of health or social care services, may lead the informal caregiver to feel that they are the best person to care for the cared-for person[65]. They may feel that this requires them to take on the full caring role even if their circumstances are not compatible with this; for example, if they are working full-time [65]. Similarly, the service user may feel that they only trust the family to look after their care:

> "If the government gave me money to hire someone to look after me, I will only hire my daughter ... I had negative experiences with care workers in the past ... I will only trust my daughter to look after me. (p.882)".[46]

Building up trust takes time and so new formal care providers may have to work over a period of time to build up a record of dependability, with the informal caregivers gradually being prepared to share or delegate their responsibilities. However, once this position of trust has been gained, and they were able to stand down from a position of "hyper-vigilance" informal caregivers describe a feeling of respite and relief [65]:

Where trust is high and caregivers feel the service user could be safely left alone with care workers, they gain precious moments of relief and respite that punctuate their concerned hyper-vigilance.

> "Because as long as he comes here I don't have to worry about Augustus until I'm ready to give him his breakfast." (Paulina: Black Caribbean, wife, 76–80, cohabiting) (p.1993)

Respite may come from feeling able to leave staff alone with their family member[35]. Such trust may stem from good communication between formal and informal cares and in working together to the benefit of the cared-for person[35]. Clients value positive family support[23] but also worry that availing themselves of informal support will increase their dependency [23].

For older gay or lesbian persons, care providers must ensure that they include family in care by being aware of the sexual identity of the individual, and recognising his or her partner as family, and perhaps other individuals as "families of choice"[95]. Jones describes how several older LGB people had devised concrete plans for when they became more frail that did not depend on birth families or partners. One bisexual service user had taught a friend to drive on the agreement that the friend would then drive her around once she could no longer drive herself. After major heart surgery, a male bisexual service user planned for future care needs in moving from a one bedroom flat to a two bedroom one with more options for friends to stay and also for future care.[47]

Modifying Evidence

As with other programme theories it is important to avoid generalisations or assumptions based on shared characteristics. For example, a study of Bangladeshi and Pakistani social care service users describes the "perception among local authorities, borne out in practice, that Bangladeshis and Pakistanis with care needs were more likely than other groups to live with their families. This led to an assumption of a preference for 'taking care of their own'"[24]. This perception was reinforced by other observations described above; "an expectation within these groups that the family should or would provide care, resistance to 'outsiders' providing care in the home and a perceived stigma associated with seeking care outside the family". These combine to become a self-fulfilling phenomenon in the "perceived and internalised obligation to provide care"[24] such that these groups were less likely than their white British counterparts to be aware of their entitlements to services:

> "I think within the Asian community, sometimes they don't ask for that extra help, because it's very much not seen as the done thing, really ... And the ones that then do have a carer coming in ... families have said they almost feel as though they're being watched, or they're almost labelled." (Senior manager, day opportunities provider)

Cultural beliefs also impact upon whether the family is able to manage the expectation of being the main resource for meeting the needs of the service user. For example, in some UK Chinese families, older people are regarded as the guest rather than the host of the family; in others, younger members of the family work long hours and thus have little time to look after the senior members.[27]

Greenwood and colleagues remind us that the prevailing narrative of “duty” must not eclipse recognition that many informal caregivers actually like to provide help and support to a loved family member, whether linked by blood ties or by socially-constructed linkages[1]. They found that caregivers from all ethnic groups, but particularly from BAME groups, emphasised not only their desire to look after the stroke survivor but also the perception that they were usually the best person to care. Contrasting themselves with paid care workers, these family members felt that they genuinely care:

> "But what you have to do for your wife and parents, no one can care…I have a son… he suffers from mental illness as well so I’m looking after two disabled people. But I’m happy. No complaints. I’m very, very happy. I’m doing something for my family. As Peter (another participant) said ‘What you can do for your relatives, no one else can do. They [care workers] have no feeling. (p. 4)" (Asian Indian male)[1]

A further nuance is that explanations for why different groups may be culturally and socially constructed and one should not confuse rationalisation with rationale. South Asian participants tended to highlight their culture or religion and emphasised family ‘duty’ as part of their culture or religion. Participants from other ethnic groups were more likely to suggest that this is simply what family members do for each other, rather than having an explicit cultural basis. Some BAME caregivers see their desire to care as culturally influenced.

> "We’re Muslims, so we do look after our elderly anyway at the end of the day. It’s only in extreme circumstances that they’ll be put in to care homes." (Omar, Asian Indian male)[1]

In truth reasons may be inextricable, such as the link specifically between love and cultural perceptions of family duty:

> "You worry for the partner. If one is weak, you have to look after the other one. To do with duty and love." (Raameen, Asian Pakistani female)[1]

However, not all expectations are cultural, some may represent family relationships, and therefore cut across BAME and non-BAME populations. An understanding of why or why not caregivers feel willing to access adult social care services must be grounded in an understanding of their different rationales, and explanations, for their caring role. Greenwood and colleagues conclude that "rather than emphasising ethnic differences, it is important to value what carers do, while recognising that many want the caring role and find it rewarding (p.6)".[1]

LGBT people, including bisexual people, often access support networks that extend beyond family of origin, partners, and adult children.[47] These may include friends and former partners to an extent considered unusual among heterosexual and cisgender people. Again, it is important to resist assumptions. Care staff workers should not assume that someone who discloses a bisexual history is non-monogamous. At the same time, they should remain alert to the possibility that they might be, and that these relationships may offer additional sources of support.[47]

Summary of the Evidence Base

The evidence base offers good representation of BAME populations although once again coverage is almost exclusively qualitative in nature. Many issues discussed relate to the "service user-informal caregiver-care provider triad" more generally and, although the specifics are race or ethnicity-oriented they relate to awareness and sensitivity to individual needs. Where a caregiver is involved this awareness and sensitivity should extend equally to their needs. The evidence base is almost exclusively populated by studies of South Asian care groups and is heavily dominated by Bangladeshi and Pakistani populations. Migrants from more recent conflicts and situations, such as those from Somalia and Ethiopia and those from the Balkans are conspicuous by their absence. The experiences of the latter are exclusively documented within this review in the specific context of dementia from within a Central and Eastern European group.[63]

In comparison very little evidence relates to the experience of LGBT+ populations. In particular, the transgender population figures as almost invisible in the research literature.

Nevertheless, the existing research does offer useful insights. LGB populations, while statistically more likely to live on their own, are often cared for by a wider network, or family of choice, which may include friends and former partners.[96]

Limitations of the Interventions

Although the triad service user-informal caregiver-care provider relationship is common and well-recognised within social care research, particularly where the service user has specific limitations e.g. cognitive impairment, it is not always explored as such. Research studies typically focus on one group or occasionally two. The relationship between formal and informal care is fluid and dynamic with little available data on how this evolves and how relationships between service user, informal caregiver and care provider adapt in response to changes in needs and circumstances. As a consequence, few interventions tackle shared access, by service user and informal caregiver, to information about services and to the services themselves.

Limitations of the Evidence Base

Research is typically cross-sectional in design when it is the longitudinal nature of the often triadic relationship that might be considered most interesting. A further complication is the difficulty in exploring the experiences of service users or informal caregivers early in their contact with the adult social care pathway. Non-users of adult social care services are also challenging to research, given the invisibility of caregivers perhaps up to the point of a crisis occurring. It is difficult to identify what the barriers to access are, unless their withdrawal from formal care provision has been precipitated by a critical incident which, by definition, is atypical. If non-users are recruited through support networks they too may be untypical of the caregiver experience; having either positively chosen alternative types of support as a care choice or having gravitated towards such networks and, through participation, become an “expert carer”.

Key Considerations for BAME Service Users

Key to the complementarity of formal and informal care for BAME service users is recognition that “carer” has different connotations for different communities. Care from formal care services may be stigmatised because of its source ("welfare") or it may be viewed as criticism that informal family-based support has proved unsatisfactory. Care providers may make assumptions about the levels of support that families from different BAME groups are willing and able to provide. Expectations from formal care services may be determined by adult social care models of provision/non-provision in the country of origin, by information received either from the service itself or through informal contacts or social networks, and by past experience from encounters with care services. Care needs are continually changing making ongoing communication and trust between service user, care provider and informal caregiver essential in managing a dynamic, not static, three-way relationship.

Key Considerations for LGBT+ Service Users

Key to the complementarity of formal and informal care for LGBT+ service users is recognition that informal care may look very different from that perpetuated by heteronormative assumptions. While some relationships may be identified using familiar terms, such as "husband", a "family of choice" may include an extended network of former friends or partners.[96] Potential LGBT+ service users may delay contact if they perceive a service to be discriminatory. Intersectionality may play a further role, in relation to LGBT+ service users with a specific racial, ethnic, cultural or religious background. Adult service users may prefer to tailor services to their own needs through the provision of personal budgets which offer deliberate selection of care providers and ensure a measure of continuity of contact. LGBT+ service users may be creative in devising care solutions and may seek to anticipate their own future deterioration by taking practical steps to limit their dependence upon formal care provision.

A further key consideration is the extent to which the service user feels comfortable about revealing their sexual orientation. This may be determined by personal preference, by personal characteristics such as age or by cultural or religious considerations. Continuous care provision, such as nursing homes, is a particular challenging context where non-disclosure is the preferred position. Although it might be assumed that care homes for LGBT+ residents may offer a comfortable environment, lesbians and gay men may not welcome being co-located and transgender individuals may experience transphobia from LGB communities.

Programme Theory Three (PT3) - Sensitivity to Differences

IF adult social care staff are sensitive to differences between different and within minority groups

THEN staff personalise their response to each adult social care service user

LEADING TO adult social care service users feeling welcomed and respected

Background

It is well documented that BAME and LGBT+ groups are less likely to access and use social care services than white, British, heterosexual cisgender people[86 97]. People from minority groups can perceive that a service is ‘not for them’[47 98 99], based on prior experience with services[46 47] and assumptions based on the way service providers present the services to prospective service users[98]. Providers treating all service users ‘the same’ regardless of ethnic background and offering inappropriate services present barriers for people from BAME backgrounds who require the use of services[100]. Thus, poor recognition of specific issues faced by service users from BAME and/or LGBT+ communities (and their caregivers) may alienate BAME and LGBT+ people and their families from accessing adult social care and thus having their care needs met.

Many issues identified occur at multiple points of the adult social care pathway, but some issues specifically relate to initiation. Initiation is linked to assessment, which can be an important opportunity for staff to display sensitivity to differences and ensure that service users feel welcomed and respected. Opportunities for staff and services to do this occur at initiation and through ongoing care.

Evidence Profile

The realist synthesis on **Sensitivity to Differences** identified 20 studies exploring sensitivity to differences in relation to Black and Minority Ethnic groups (Table 10), of which 18 were qualitative. Two study were literature reviews and one study comprised other evidence (an editorial). As with PT1, the literature relating to LGBT+ was less plentiful in comparison (Table 11). The literature search identified seven studies, namely five qualitative studies, one quantitative study and one literature review.

Table 10 - Summary of included studies relating to BAME Groups (nos. of each type and references only):

	Black and Minority Ethnic Groups				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	Other Evidence
PT3: Sensitivity to Differences IF adult social care staff are sensitive to differences between different and within minority groups THEN staff personalise their response to each adult social care service user LEADING TO adult social care service users feeling welcomed and respected	75	30 59		8 22 24 34-37 48 49 51-53 67 69 73 78	[33][Editorial]

Table 11 - Summary of included studies relating to LGBT+ Groups (nos. of each type and references only):

	LGBT+ Groups				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	Other Evidence
PT3: Sensitivity to Differences IF adult social care staff are sensitive to differences between different and within minority groups THEN staff personalise their response to each adult social care service user LEADING TO adult social care service users feeling welcomed and respected	66	25		29 31 47 66 74	

How interventions are believed to work

Personalisation, in recognising and valuing diversity, takes place at multiple levels. For a care provider this means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support. The traditional service-led approach often means that people are not able to shape the support they need, or receive the right help. Personalisation involves making sure there is an integrated, community-based approach for everyone. This involves building community capacity and local strategic commissioning so that people have a good choice of support, including that provided by user-led organisations. It means ensuring people can access universal services such as transport, leisure, education, housing, health and employment opportunities. All systems, processes, staff and services need to put people at the centre. Unfortunately, evidence suggests that individuals may encounter similar issues across diverse agencies such as housing, healthcare, social care and education, undergoing comparable assessment procedures within each context.[35]

Adult social care staff seem likely to be aware of differences between and within BAME groups if they are delivering services within an ethos of person-centred care. Such an ethos captures differences within and between minority groups through providers and staff treating service users as individuals and responding to their needs. This involves staff reporting "listening to the service user and what they need, on an individual basis, and not generalising (p. 1096)",[24] so one service user might want someone from their community due to similarities in language and culture (see Programme Theory 5), whereas another might find this intrusive. Examples of person-centred care provision include mealtime arrangements, ensuring religious needs are met, ensuring end-of-life care is appropriate and ensuring other cultural needs are met, for instance, skin care regimes.[22] Thus, although person-centred care could be central to care more generally, and is not necessarily specific to minority populations, its use can broadly address the care needs of service users from diverse minority groups, via individual tailoring of service provision and staff care. Interestingly, the literature on person-centred care is more plentiful around older people living with dementia than either of the two groups of interest. For example, Brooker breaks down person centred care (PCC) using the equation PCC = V + I + P + S[101 102]. These components are variously

V = Values people

I = Individuals needs

P = Perspective of service user

S = Supportive social psychology

This VIPS framework then translates to the questions in Box 1 which have been refashioned in more generic (i.e. non-dementia specific terms):

Box 1- VIPS framework[101 102]

- Do my actions **V**alue and honour service users?
- Do I recognise the **I**ndividual uniqueness of the people I work with?
- Do I make a serious attempt to see my actions from their **P**erspective or stand point?
- Do my actions provide the **S**upport for service users to feel socially confident and that they are not alone?

In comparison, researchers have not really recognised the importance of person-centred care in BAME and LGBT populations given its prominence in other care groups.

Person-centred care includes empowering service users through listening to their needs and promoting independence and shared decision-making, including "diversity of ethnicity, specifically with regard to, cultural beliefs and preferences, religious and spiritual preferences, language and communication, and intrinsic to all of these, independence and decision-making (p.241)".[33] Similarly, "Local authority and provider staff talked about the importance of listening to service users and involving them in decisions about their care".[35] Co-production programmes can be used to gather feedback from service users.[35]

Personalisation involves relationship-based working, co-production and establishing trust (Table 12). It values the contribution of both service user and informal caregiver. Practitioner education and training has been identified as having a critical role so that staff can challenge discriminatory behaviour by colleagues or people who use services. Inherent in a personalised approach is that social care providers avoid assumptions and generalisations about service users based on their ethnicity, sexuality or gender status. Where assumptions and generalisations occur, these can lead to clients or their caregivers being dissatisfied with care, including care being rearranged against service users' wishes: "we wanted respite care for the two weeks in June because it followed this pattern, but they just assumed that because it was Gay Pride in London, that we'd want this extra week… (p.164)".[66] or a service user receiving inappropriate mealtime provision: "One participant's mother lived in a culturally specific care home, but…the food that was served was appropriate to the majority group, not her group (p. 1377)".[77] As well as avoiding working from assumptions, service providers can also be aware of the importance of not imposing Western values onto culturally diverse service users; instead, staff can draw from community-based knowledge to work with service users' cultural values.[48]

Specific staff approaches can facilitate openness within person-centred care. For instance, staff may use open questions and inclusive language that doesn't assume heterosexuality or cisgender.[32 64 95] This can serve to facilitate a safe environment in which service users may feel able to disclose their sexuality and/or gender status, which can facilitate more personalised care.[47] Where service users have experienced biphobia, homophobia and/or transphobia in the past, they are reluctant to disclose their identity, and delay accessing services; staff facilitating a safe environment in this way can encourage such openness from service users.[47]

Holistic care can be useful approach in person-centred care, an important element of which requires service providers to recognise the legitimacy of concerns about potential discrimination.[47] Linked to this, staff engaging in holistic assessment offer a useful strand of person-centred care, particularly when engaging with asylum-seekers. A holistic approach "considers the totality of clients' lives and not just those problematic aspects that could be risk factors or symptomatic of a lack of 'coping' or 'resilience' (pp. 1328-9)".[30]

At the level of the service provision, service providers can monitor the quality of LGBT+ service users' experiences, thus providing a richer understanding of LGBT+ populations and issues.[25] “Monitoring can provide an opportunity to question and problematise the lack of awareness [of gay social networks among providers], rather than problematising the LGBT population” and can also give service providers with “opportunities to engage with the complex multiple identities of LGBT people, in terms of their ethnicity, their gender, their class and their local neighbourhood (pp. 6-7)”.[25] Thus, providers can tailor their services to LGBT+ individuals, leading to service users feeling welcomed and respected.[25]

In some cases, the programme theory operates at the levels of both the service and of care delivery. Through eliciting the narratives of older LGB service users, staff and service providers can gain a situated understanding of service users’ lives and identities[29], which can lead to person-centred care and satisfaction. Person-centred care may operate at the level of the service, within the context of service providers seeking to provide an inclusive service and thus specifically seeking to address inequalities in accessing adult social care among LGBT+ service users, however issue of sensitivity to differences may also operate at the level of care delivery, within the context of staff providing person-centred care. These two levels may both ensure that service providers and staff deliver care that is more inclusive and person-centred, whether aiming to explicitly and openly address the diverse needs of LGBT+ people, or providing a more subtle message that the care service is LGBT+ inclusive, thus catering for people who are both openly ‘out’ and not out in terms of their sexuality and/or gender status (see PT1 – **Awareness of services**).

The importance of sensitivity to differences also operates at both the level of the service and the level of care delivery in terms of the (lack of) support for same sex relationships. Where care workers and service providers recognise sex relationships, staff support the partners of LGBT+ service users and the partners of service users feel satisfied with the service [31]. However, where service providers do not view same sex relationships as viable, and consequently, staff lack understanding of service users’ same sex relationships, support from care staff to partners of LGBT+ service users is lacking, leading to the partners of service users feeling dissatisfied with the service they have received.[31] As previously with eliciting narratives, support for same sex relationships may be evidenced at the level of the service, in terms of service providers aiming to provide an inclusive service, and at the level of care delivery, with staff providing person-centred care, of which this is part. Tackling this within the service context would address concerns of service users (and their partners) who just want to know that the service is for them, whereas action at a care delivery context would satisfy the requirements of those who want to know that the service specifically meets their needs. This highlights how person-centred care, in addressing diversity within minority groups, can be contribute within both the background and foreground of service users' care experiences and can also be dealt with at a population and individual level.

In (partial) counter-argument to the person-centred approach, service providers need to recognise the wider social issues and processes that shape minority groups' experiences; "LGB people share a history of oppression that may invalidate more obvious social divisions… [T]hese social conditions…impact upon access to, and standards of, care, the potential for culturally sensitive care and the selection of research priorities (pp. 425-426)".[29] However, this viewpoint nevertheless gives scope for care to also be person-centred, and diversity within groups should still be considered: "health and social care services should not perceive LGB categories as prescriptive; rather, these categories are connected in only loose ways and may or, more importantly, may not, be the starting point for considering an individual's needs (pp. 425-426)".[29]

Three theoretical approaches to multiculturalism relate to how BAME and LGBT+ populations may see their role when engaging with adult social care services: conservative, liberal and critical.[103] The first (cultural knowledge about the 'other') stems from a conservative approach to multiculturalism. This approach emphasises how to assimilate and integrate the 'other' within mainstream society.[104] BAME and LGBT+ populations are required to adopt the labels and norms of the dominant society and, by doing so, risk losing contact with their own valued identity. Such an approach strengthens dominant discourses and hegemony. The second (sensitivity to cultural differences), evidenced in PT4, and the third (cultural competence) that forms the backdrop for PT5, stem from liberal conceptions of multiculturalism.[104] These approaches do not impose a one size fits all approach, but rather appreciate and celebrate diversity, and accept the otherness of the 'other'.[90] A final perspective (anti-oppressive, critical multiculturalism) stems from the critical approach to multiculturalism, which strives for social justice and equality[90]. Such a perspective argues that social justice and equality can be only achieved by engaging with deep questions within the wider socio-political context[103].

One way of understanding and dealing with diversity in the LGBT+ community can be consideration of disclosure – whether or not an individual is ‘out’, and whether this is explicit or implicit. Such a consideration holds implications for care delivery and service provision. The Hitchcock & Wilson (1992) model/framework of disclosure of sexuality to care providers can highlight of understanding the way that service users may present themselves to staff and providers. The categories in the framework range from active disclosure (directly informing staff/providers – ‘coming out’), through passive disclosure (implicit disclosure, related to the presence of clues) and passive nondisclosure (not challenging incorrect assumptions, avoiding discussion of sexuality), to active nondisclosure (passing as heterosexual). The implications are that service users presenting in the active disclosure category may require care that meets their specific needs in order to feel welcomed and respected, whereas service users in the passive and active nondisclosure categories may need to be certain that a service is ‘for them’.

Table 12 - Putative mechanisms for intervention

Intervention Components ‘Person-centred’ approach Joint decision-making Ask open questions Avoid making assumptions	**Contextual Factors (Enabling)** Engagement and openness (Lack of) worry about discrimination H&SC professionals who are aware of the importance of gay social networks H&SC professionals who are aware of the importance of the complex multiple identities of LGBT+ people
Potential Mechanisms (*Care Providers*) Avoid disproportionate interventions Meeting specific needs (e.g. relating to food or religion)	**Potential Mechanisms** (*Service Users and Caregivers*) Service users being ‘fully present’ in the consultation
Outcomes Service users feel their needs are being met Appropriate/inappropriate care provision	**Leading To** Satisfaction with services Service users’ needs being met

Mechanisms influencing the success of the intervention

Personalised approaches such as self directed support and personal budgets involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives (See: Report Supplementary Material File 1 - Context-Mechanism Outcome Configurations for five programme theories). People need access to information, advocacy and advice so they can make informed decisions. A study of awareness of the provision of personal budgets among the Chinese community revealed limited accessibility among participants[46]. The majority of participants did not refer to personal budgets, and when asked directly they indicated that they were not aware of the existence and/or the detail of such a service, hence accessibility was effectively blocked:

> "(I've) never heard of personal budgets."
>
> "No one ever mentioned personal budgets to me, the Chinese community worker never told me about this. (p.882)."[46]

For personalisation to work successfully users need to be aware of available specific provision (see Programme Theory 1). Where there is a notable information gap, for example for people from Chinese backgrounds regarding personal budgets, this prevents them from being able to consent to or take up the service nor to access a choice of providers. Even though individuals who have managed to secure access to adult social care services, often through a protracted process, also express the challenges of navigating the available service options, and suggests that those who do not receive (but may be in need of) services are even less well informed about personal budgets.[46]

Service providers should consider how to prioritise inclusive service provision. Such provision takes place against a historical backdrop of oppression on care access and standards and recognising, understanding and legitimising concerns about discrimination. These mechanisms were identified from literature on LGBT+ service users' experiences (and those of their caregivers), although they could equally apply to BAME service users (and caregivers). More specifically, in relation to LGBT+ service users in particular, service providers need to engage fully with the narratives of LGBT+ people, be aware of and make provision for certain specific needs of different LGBT+ service users, engender and enact support of and for same-sex relationships and monitor the quality of LGBT+ service users' experiences. In doing this, service providers need to acknowledge the wider social processes that shape LGBT+ people's experiences.

Considerations for staff broadly involve taking a person-centred approach to care that treats service users as individuals, listens to service users (and responding to their needs) and engages in shared decision-making. This implies avoiding assumptions and generalisations. Specifically, staff need to be sensitive to differences between and within groups by using inclusive language (e.g. using open questions and not assuming heterosexuality or cisgender), to seek to understand specific cultural practices, draw from community-based knowledge to support working practices and provide care and support to same-sex partners of LGBT+ service users. This process could involve holistic assessment that offers a holistic understanding of service users and their past lives. Eliciting narratives from service users offers insight into their care needs and support systems, to enable staff to engage in person-centred care.

The Context(s)

Adult social care services in the UK generally aim to be inclusive of BAME communities, and to provide appropriate care and a personalised approach[22 59], however the reality is that accessing adult social care can be challenging for people from BAME communities, partly due to the way that systems are set up; for instance, satisfaction surveys inadvertently exclude people from BAME communities[24]. The term 'BAME' may potentially mask considerable variation among and within different BAME communities, with varying degrees of Westernisation. Religion too varies within BAME communities, however religious concerns may be potentially more important for people from BAME communities than White British people, many of whom list their religion as Church of England but don't actively engage regularly in worship. Other religions, for instance, Islam or Sikhism, are more likely to be practiced devoutly by people who disclose their religion as Muslim or Sikh, and are therefore more likely to need access to appropriate facilities for prayer and facilitation of religious rituals, such as cleansing.

While adult social care services in the UK aim to be inclusive and provide personalised care, it is likely that much provision does not meet the needs of people from the LGBT+ community/ies, in particular older LGBT+ people[29]. Adult social care has typically taken a 'sexuality blind' approach, in which all service users are treated the same, and this can inadvertently exclude LGBT+ people. Quite often, service providers and staff will make assumptions that service users are heterosexual and cisgender[31], which can be problematic for LGBT+ service users and their caregivers. As with BAME communities, the term 'LGBT+' may be misleading as while LGBT+ individuals typically encounter common challenges, the collective term masks diverse communities such that catering for the needs of one group may exclude others. Older people may not even label themselves as 'lesbian', 'gay' or 'bisexual'[29]. Meanwhile, in addition to variation within categories, people may cut across categories (intersectionality), for instance, be trans and bisexual. Adult social care staff need to understand this variation if they seek to understand the diverse needs of LGBT+ service users.

Overall, then, while adult social care services in the UK seem to value inclusivity, provision often fails to recognise what is important to people from marginalised groups, such as people from BAME and LGBT+ communities, with a potential lack of awareness about how services exclude people through White-focused Westernised, heterosexual and/or cisgender-focused practices.

Adult social care services generally make efforts to meet the needs of BAME service users. Some service providers and staff use person-centred care and an approach centred on asking questions and active listening to the service user. However, sometimes service providers and staff make assumptions and generalisations about BAME and LGBT+ service users, without being fully sensitive to differences between and within minority groups. This may be due to the lack of a culture of person-centred care at an organisation, or a lack of recognition of the importance of providing an inclusive service

Social care services also seek to cater to the needs of LGBT+ service users. Person-centred care offers a response to these individuals, too. There is a particular need for an approach centred on asking questions and listening to the service user given the lack of visual cues about cultural needs and preferences. Assumptions and generalisations are no less common for LGBT+ service users. In fact, although the literature on the LGBT+ service experience is not as plentiful as for BAME populations, our analysis unearthed multiple examples of such assumptions and generalisations.

Supporting Evidence

Two narrative reviews examined sensitivity to differences among BAME populations. One discussed holistic assessment[30] and the other highlighted the impact of generalisations and assumptions on care outcomes and the need to understand diversity [59]. One narrative review examined sensitivity to differences among LGBT+ populations, in terms of service providers monitoring the quality of LGBT+ service users' experiences[25].

No quantitative studies were identified that examined sensitivity to differences among BAME or LGBT+ populations.

In terms of evidence at the level of the service provider, four qualitative studies highlighted how service providers perceive the importance of responding to individuals' needs [22 53 69 78]. Specifically, several studies identified the importance of service providers not treating LGB people as a homogenised group[29 66 74], not treating BAME people (or people from a particular community) as a homogenised group,[67] recognising the importance of religion and religious practices[36 73 75], being aware of the specific needs of different LGBT+ service users and making provision for their needs [47 74]. One qualitative study examined the importance of service providers having a richer understanding of LGBT+ populations and their issues, through monitoring the quality of LGBT+ service users' experience and engaging more fully with the narratives of LGBT+ people[29]; similarly one study highlighted the importance of service providers being supportive of same-sex relationships[31]. Another qualitative study suggested a need for service providers to legitimise concerns about discrimination among LGBT+ service users, in an attempt to address a reluctance to disclose a non-heterosexual/cisgender identity on the basis of past experience of biphobia, homophobia and/or transphobia [47]. The need for service providers to recognise the importance of a history of oppression among LGBT+ service users on care access and standards was mentioned in one qualitative study [29].

Many qualitative studies provided evidence relating specifically to adult social care staff practices. Several qualitative studies examined the need for staff to treat service users as individuals, [22 69 73 75 78] engage in person-centred care,[29 66 67 74] listen to service users and respond to their needs,[35 69 78] promote independence and decision-making in service users ([52 78] and avoid making assumptions and generalisations. [69 73 78] Several qualitative studies also highlighted the need for adult social care staff to avoid treating service users from particular minority groups as though they have fixed/unitary needs ([29 34 66 67 74 75]. Specifically, several qualitative studies examined the importance of staff understanding specific cultural practices [34 74 75], understanding service users' behaviour in the context of their past lives[48 69] and needs and desires around religious practices with service users[36 75] and engaging in holistic assessment [69]. Another qualitative study highlighted the need for staff to use inclusive language, to provide a safe environment for disclosure, as a way of addressing the reluctance of service users to disclose a bisexual identity when they have experienced biphobia, homophobia and/or transphobia in the past[47]. One qualitative study examined the importance of staff gaining a situated understanding of older LGB service users' lives and identities through eliciting their narratives[29]. Another study highlighted the importance of staff providing individualised care and support to same sex partners of LGBT+ service users[31]. The need for staff to draw on community-based knowledge to support working practices was expressed in one qualitative study[48].

Modifying Evidence

No reviews or quantitative studies were identified that examined sensitivity to differences.

That care staff tend to service users' personal hygiene frequently was important to service users and their caregivers from an Afro-Caribbean background[36]. Having personal hygiene maintained was also important to service users from Pakistani/Bangladesh Muslim backgrounds, but as part of a set of practices connected with religion (e.g. washing before prayer)[36 37].

Specific needs of BAME service users were mentioned, mainly in terms of food and eating practices (a preference for spicy food, eating Halal meat, not eating onions and garlic, jhootha ["avoiding contamination between food and mouth, usually through unwashed hands or cutlery (p.1378)".[75] The need to recognise other socio-cultural factors within their ethnic group was also important; “One participant’s mother lived in a culturally specific care home, but…the food that was served was appropriate to the majority group, not her group (p.1377)”.[77]

Some person-specific needs of LGBT+ patients were also mentioned, bisexual people needing to access pornography online, vegan foods, and retirement accommodation big enough for polyamorous relationships involving three people, as well as a trans woman needing care providers to consider issues important to her in aging, for example her susceptibility to prostate cancer[47]. Some lesbians and gay men expressed preferences for living in single-gendered accommodation; “One of the things about a gay man is that he probably prefers the company of other men. Yes, we have common interests, lesbians and gay men, because we’re fighting the same battles, the same prejudice and so on. But to meet socially, I can’t see why you should expect that (p. e160)”.[74]

Summary of the Evidence Base

Sensitivity to differences between and among minority groups implicates many complex issues. The literature reveals a conflict as to whether service providers and staff are or are not sensitive to differences. On the one hand, service providers and staff adopt person-centred care, which focuses on asking questions, listening to the service user, and, in some cases, empowering the service user and/or taking a holistic view of the service user in the context of their past, and leaves the service user feeling welcomed and respected. On the other hand, service providers and staff make assumptions and generalisations about what service users from BAME and/or LGBT+ groups need, leading to dissatisfaction and an avoidance of social care or delays in accessing services[47]. In addition to person-centred care, specific approaches are or can be adopted by some service providers and staff to accommodate particular needs that service users might have, and/or to provide a more inclusive service. Sensitivity to differences may originate from a culture of person-centred care at an organisational level, or a broad recognition of the importance of providing an inclusive service.

Limitations of the Interventions

Unless culturally-sensitive care is undertaken in a person-centred way, with asking questions, listening to the service user and responding to their needs at the heart of it, attempts to meet the specific needs of minority populations run the risk of being overly generalised, based on assumptions, and inappropriate. One caregiver to a service user described a lack of cultural sensitivity from a homecare attendant, "I asked her to take her shoes off and put some slippers on that we had, she didn't say a word, had some tea and went off after doing her work… I got rude phone call from her boss. "Excuse me, did you tell her to take her shoes off"? (p.7).".[34] An over-reliance on faith-based projects could also be problematic, as highlighted in a literature review; "for South Asian women's mental health 'misinformed ideas about "culturally sensitive services" in relation to religious faith and spirituality can lead to a denial of the issues of attempted suicide and self harm'(p.831)".[59] One gay caregiver recounted an instance of their respite care being moved by the agency without being asked to accommodate Pride[66]. One caregiver's mother in a culturally-specific home received food that was only appropriate to the majority, not to herself. Another caregiver recounted how his father's care providers did not understand the Hindi concept of jhootha (avoiding contamination through cleanliness/hygiene when preparing and serving food) and thus his father refused to eat the food they provided as "They had not washed their hands in between drinking a cup of coffee and before serving his food. (p.1378)".[75]

Limitations of the Evidence Base

Very little data referred to multiple points in the programme theory around sensitivity to differences, with much data referring to mechanisms but not necessarily linking these to contexts or outcomes.

A phenomenon of meta-study of how the research has done it is that the literature has primarily been examining the needs of particular groups more generally and so it is difficult to look at both the differential needs of both groups and to get comprehensive coverage of all the groups being handled by UK adult social care. Therefore, the review highlights richer accounts of some groups rather than others making it difficult to know whether we have simply captured issues that have been reported or whether this truly reflects important issues across the groups. Given that care providers can never learn everything possible about each group, the most feasible approach is for care providers and staff to engage in person-centred care, in seeking to provide culturally relevant care for each service user.

Key Considerations for BAME Service Users

Holistic assessment can be particularly useful, as it allows staff and service providers to view service users in the context of their background, experiences and history of migration. When conducted sensitively assessment can be an unobtrusive way of eliciting not only religious beliefs but, more importantly, how they might impact on day-to-day activities such as meals and personal care. Assessment may also be important more generally when dealing with any service users who are of a minority ethnic background, and service providers should avoid imposing Westernised views. Instead, staff and service providers can draw on knowledge from the relevant community to provide culturally relevant care.

Ensuring appropriate provision at mealtimes is important for BAME service users, and ensuring their particular religious needs are met. Using a person-centred approach, service providers and staff can ask service users and family members questions about specific needs, including socio-cultural differences that are not immediately apparent.

Key Considerations for LGBT+ Service Users

LGBT+ service users may be wary of disclosing their identity, due to past discrimination. Staff can facilitate a safe environment through the use of inclusive language to encourage openness, by giving service users the signal that the service is ‘for them’ and can potentially meet their needs.

Staff and service providers can also be aware of the social networks that support LGBT+ service users, as part of their person-centred care. Staff or service providers eliciting narratives from LGBT+ service users can be part of this process and can be another way of engaging with the LGBT+ community. Social networks could also be considered by service providers in the provision of retirement housing, which could diversify in terms of options to suit the specific preferences of LGBT+ people, including single-sex accommodation, internet that permits LGBT materials and pornography, and living options for bisexual people who are polyamorous. It is important that service providers treat same sex relationships as viable and are aware that trans people may experience complex age-related issues (e.g. prostate cancer risk in a trans woman).

Programme Theory Four (PT4) - Use of Interpreters

IF adult social care services use interpreters

THEN adult social care staff and social care service users communicate more effectively

LEADING TO adult social care staff providing appropriate care/social care service users receiving appropriate care

NB. This programme theory relates specifically to members of BAME communities who are unable to communicate effectively, or who feel uncomfortable with communicating, in English. However, use of interpreters represents a specific instrumental example within the overarching need for effective communication and trust between service providers, service users and their families. By extension, similar mechanisms may operate in wider populations, including the LGBT+ community, for example in the importance of using inclusive language in interactions with service users and to not alienate service users in choice of terminology[32 64 95]*. Furthermore, the need to take account of specific and very individualised requirements resonates with the overall emphasis on person-centred care.*

Background

The lack of a common language can present a significant barrier to accessing and using mainstream/statutory social care services among people from BAME communities in the UK [28 59 63 78]. If potential service users experience difficulties in finding out about services, due to not understanding the relevant literature on these services, this may cause a delay in seeking help, and service users only contacting social care at crisis point[79]. Similarly, if service users cannot communicate effectively with adult social care staff, then they cannot be fully involved during the assessment process and as a result can end up receiving care that does not meet their needs[79].

Many service providers and staff rely on interpreters for communicating with service users who are not fluent in English. The use of interpreters may help to ensure that service users' needs are met and that they receive appropriate care, however there may be issues in the use of interpreters that may impact on the standard of care given and received.

Many identified issues occur at multiple points of the adult social care pathway, of which some issues specifically relate to initiation of service use. Initiation is linked to the assessment, which can be an important opportunity for staff to use effective interpreters and ensure that adult social care staff and service users can communicate effectively and thus that appropriate care can be provided and received. Opportunities for staff and services to communicate begin from the point of service initiation and continue throughout the adult social care pathway.

Evidence Profile

The realist synthesis on Use of Interpreters identified 18 studies exploring the use of interpreters among Black and Minority Ethnic groups, of which 15 were qualitative (Table 13). Two studies were literature reviews and one study comprised other evidence (a briefing paper). This programme theory was not relevant to LGBT+ groups.

Table 13 - Summary of included studies relating to BAME Groups (nos. of each type and references only):

	Black and Minority Ethnic Groups				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	Other Evidence
PT4: Use of Interpreters IF adult social care services use interpreters THEN adult social care staff and social care service users communicate more effectively LEADING TO adult social care staff providing appropriate care/social care service users receiving appropriate care	28 63 75	28 59	None	22 24 35 36 42 43 46 50 51 53 63 65 75 77 79	56

How interventions are believed to work

Mainstream services within the UK are provided in English[51], meaning that people from the BAME community who do not speak English are unable to access and use these services without some form of language provision. Language provision may be arranged by the service providers (possibly, the staff themselves may have language competencies), or is arranged by the service users. Perceptions of the quality of adult social care are influenced by the extent to which a service user's specific linguistic, cultural, and other needs are met in the process of social care delivery (Table 14). Effectively meeting these needs increases the likelihood of achieving positive and appropriate outcomes. Interpreting or translating services can improve communication quality and service user, service provider and family caregiver satisfaction with communication. The quality of communication holds the potential to influence the appropriateness of service responses; timeliness in seeking support; identification of the appropriate intensity of care packages; the anticipation and prevention of acute needs or crises; and interaction with care services (e.g. appointment keeping). Timeliness and availability of interpreting and translation services is therefore critical to their success.

The context in which interpretation takes place can shape its effect, given different service settings and different target groups. Contextual factors may include interpreters' training experience; gender of the interpreter or gender disharmony between the interpreter and service user; age of service user; service user literacy; conditions or circumstances that require sexual/cultural sensitivity or privacy. Within a positive context, the arrangements that the service provider has in place lead to staff organising interpreters[22 51], which they use to pass on information to service users, so that service users can make decisions about their own care[35], and to engage in effective communication and shared understanding[36].

Where interpreters are provided through service providers, the provision of interpretation can vary. On a basic level, interpreters can vary in quality[56], which can potentially mean that care will be variable in these instances. The usefulness of interpreters to staff/service providers and service users can also depend on the emphasis of the conversation. Where there is an emphasis on physical aspects of care, interpretation can work well to aid communication, however interpretation works less well when the emphasis is on the social and emotional aspects of care, and "many general practitioners and service providers talked about the feeling that 'something is missing' in these interpreted consultations (p.207)". [51]

Despite service providers identifying a need for interpreters, there can be problems in terms of provision. Interpreters are not always available who speak the right language, or the right dialect[35]. Adult social care staff may also feel that interpreters are incompetent [35]. Where interpreters are offered, service users are uncomfortable with even the thought that an interpreter may be known to them, and this discomfort can manifest itself in being wary of sharing information on private health issues with staff during the interpreted consultation[51 63]: "Whenever [the women] go to [the] doctor's... they always say no [to an interpreter] because they don't know who's gonna turn up. If they know that lady from the community they will be embarrassed to talk about it in front of her..(p.208).".[51] Another potential issue arises where service providers only provide translators for the consultation, leaving service users' additional translation needs unmet, including before and after using a service: "Government, hospitals sent me letters, and I don't know what they talk about ... my son, daughter live outside [the city], when they are back, letters might already have become mouldy(p. 860)".[50] A need for assistance with written documents was particularly highlighted. When interpreters lack professionalism, service users can feel 'put down' by the interpreter [51]. Where services use paid interpreters only, a problem can arise when staff and service users have to wait for an interpreter to become available, leading to a delay in service provision and care [53].

At the most basic level, if service providers do not offer arrangements for interpreters, and staff do not use interpreters in their discussions with service users,[24 35 46 65 75 79] then staff and service users cannot communicate effectively with one another.[24 35 46] Such a lack of communication can result in inappropriate care (or no care) being provided,[24 35 46] or in service users being unable to access services in the first place[46 79] (which also relates to PT1, **Awareness of Services**). For instance, "One Urdu-speaking social worker said that he knew of a service user who did not speak English and had a social worker who never used an interpreter. He pointed out that if this service user were arrested by the police he would not be interviewed without an interpreter (p.46)".[35] Another consequence of not being able to access services is that service users are not able to complain about the service.[65] This inability to complain can disempower service users and fuel inadequate provision of care. One possibility for service users unable to access care due to language difficulties and a lack of provision for translation/interpretation is to seek out culturally specific services: “The language needs of some participants were not met within mainstream services, and so culturally specific day centres, lunch clubs, sheltered housing and care homes were preferred as a result, even if it meant going out of the local area (p.1377)”.[75]

If interpreters are not provided by the service, then service users identify interpreters who are often family members[24 28 35 51 53 77 79] and also friends [79]. Using family interpreters can enable communication between staff and services, enabling access to services[28] and appropriate care to be received. However, issues arising from the use of family interpreters, include family interpreters controlling the conversation and the information provided[35 79], for instance, “the risk that they might interpret selectively or inaccurately, for instance, if they were wary of a care package being recommended by a social worker because it required a financial contribution from the family (p.46).”.[35] Use of family interpreters can be problematic when discussing sensitive topics, as service users can be wary of sharing sensitive information in front of certain family members, for instance “one particular woman could discuss issues about contraception if she was by herself with him but not if her husband was also present”, and, more generally, “service providers emphasised the particular sensitivities involved in relation to domestic violence and mental health services and the challenges involved in getting the woman’s perspective rather than a spouse or family perspective (p.208).”.[51] If children are used as interpreters, there is a risk that inaccurate information is shared, as a result of children not fully understanding the details [51], leading to a lack of effective communication and thus lack of appropriate care/support provision. There is also the risk that social networks can become exhausted: “Previously when I met the social worker, a friend came and helped to translate ... she helped me many times, not just a couple of times, but now she stops coming (p.e148)”.[79] This could potentially exacerbate isolation among service users, in addition to reducing their access to services and/or quality of care.

Several additional strategies can be used to aid communication in the absence of a formal interpreter arranged by service providers and staff, which are mainly applicable to care homes in particular. Service providers employ multilingual staff, to cover many of the common languages requested, negating the need for an interpreter[22], although this may be circumstantial rather than deliberate. Family and friends of service users provide care staff with material (flash cards/a CD) with common phrases or food items to aid communication. This approach can work well on a day to day basis, but less well in an emergency situation[22]. Where there is no shared language at all, care workers and service users develop a rapport by using body language and signing to communicate, which led to service users being satisfied with the care provided[24].

The importance of bilingual advocates has also been highlighted. Bilingual advocates might be identified through service providers or by service users themselves, or from third party organisations, and fulfil the function of a 'bridge' between service users and service providers, including interpretation and advocacy.[50] Bilingual advocates can support service users in interpretation in a number of ways, including enabling service users to access information about services, explaining cultural issues to service providers and identifying service users' instrumental support needs.[50] One problem with using bilingual advocates, however, is that service users can feel dependent on bilingual volunteers for accessing services.[56]

One way of understanding how the use of interpreters serves BAME communities is the Shared Cultural Knowledge (SCK) approach, which conceptualises culture as essential, with members of the same minority group sharing commonality in terms of the way they engage with their culture through their practices, with the implication for practitioners being to ensure that service provision is based on the relevant cultural knowledge to meet the needs of each particular community[28]. In terms of the use of interpreters, this might involve service providers working with various communities to identify specific needs and issues around interpretation, for instance how to deal with the possibility that a professional interpreter might be known to the service user, or how to ensure family interpreters interpret accurately rather than controlling the conversation.

The Diversity Based (DB) approach takes a different view, and conceptualises culture as fluid, meaning that the ways that members of the same ethnic minority group may have very different ways of conceptualising and enacting their culture.[28] The implication is that practitioners need to deal with structural inequality and seek racial justice through recognising inequality and oppression, seeking differences as well as commonalities among each identified ethnic group, and ensure that service users and their caregivers have a voice in the nature of their care[28]. In terms of the use of interpreters, this might involve service providers and staff engaging in person-centred care (see PT3 **Sensitivity to Differences**) and working with each service user (and their wider family) to ensure that the interpretation provided meets their needs and enables them to receive appropriate care.

Leventhal's Self-Regulation Model of Illness[92] features in the previous section on **Awareness of Services** (PT1) but is repeated in this specific context. This model helps us to understand help-seeking behaviour in BAME communities by suggesting that individuals acquire illness cognitions through exposure to the media, personal experience and their family and friends.[63] Illness cognitions are defined as the individual's own common-sense beliefs about illness and provide a framework for understanding and coping with illness. If these cognitions do not accommodate awareness of available services then an individual will try to continue to cope using only their own resources. If they are unable to cope, then their coping framework is amended or the initial representation of the threat is revised. They may consider that their situation is normal[77], and continue without intervention. They may access friends and colleagues for advice on coping resources. Alternatively, they may trawl for information more widely themselves. Translation and interpreting services may help in accessing additional information and therefore lead to enhanced coping strategies, as well as to instrumental practical help. This requires that the need is articulated accurately so that the response matches the original perception of need. Moriarty advocates for an integrated approach[56].

A lifeworld-led approach[105] can also aid understanding. “A lifeworld-led approach is concerned with articulating the nature and practices of humanly sensitive care” and “champions the human individual and exposes practices that tend to depersonalise or dehumanise those receiving care. (pp.1988-9)". [65] Using this approach, caregivers can be viewed as both co-workers and co-clients in relation to the service provider. Interpreters, particularly family (or friend) interpreters, may similarly have multiple roles with which service providers need to negotiate. This approach considers the existential meaning of being someone who needs to access social care services and faces a language barrier, and implies that service providers need to provide humanising care that includes these eight dimensions [106]: agency; insiderness; uniqueness; togetherness; sense making; personal journey/loss of personal journey; sense of place; and embodiment (as opposed to passivity, objectification, homogenisation, isolation, loss of meaning, loss of personal journey, dislocation and a reductionist view of the body, which are dehumanising) [65].

Table 14 - Putative mechanisms for intervention

Intervention Components	**Contextual Factors (Enabling)**
Interpreters Translators Multi-lingual staff Bilingual advocates/volunteers Culturally-specific services	Services with non-English language provision (translation or delivery) Use of family members/friends Services with multilingual staff or advocates
Potential Mechanisms **(Care Providers)**	**Potential Mechanisms** **(Service Users and Caregivers)**
Passing on correct information Delivering appropriate services	Trust and shared understanding Shared decision-making Service users receive appropriate information
Outcomes	**Leading To**
Service users make an informed decision about their own care Staff provide appropriate care	Service users receiving appropriate care Satisfaction with services

Mechanisms influencing the success of the intervention

Service providers must ensure that they have clear arrangements and protocols in place for obtaining and using interpreters, so as to enable staff to arrange interpreters when needed (See: Report Supplementary Material File 1 - Context-Mechanism Outcome Configurations for five programme theories). Key to this is ensuring that the interpreters are available in a range of languages and dialects [35]and are suitable, which includes not being incompetent or poor quality[35], or indeed of variable quality[56]. Ensuring interpreters from outside the immediate community are used reduced the possibility of interpreters being known to service users, which can be a barrier to effective communication, particularly around sensitive issues[51 63]. Service providers could also use interpreters to help service users to complain about the service if they need to[65]. Service providers should consider providing translation services that extend beyond the consultation to meet service users' additional translation needs, including assistance with written English to enable service users to complete the written documents required by service providers[50].

Service providers' protocols need to weigh up the pros and cons of employing paid interpreters only, or also planning for the use of family interpreters, including a potential wait for a paid interpreter to be available[53], family interpreters controlling the conversation[35 53 79] and the use of children, who may not understand the information being shared[51]. Protocols could also consider a role for bilingual advocates, who can translate information, explain cultural issues to service providers and identify service users' need for instrumental support[50], while also being wary of service users feeling dependent on bilingual volunteers for accessing services[56]. Other strategies could be considered alongside the provision of interpretation/translation services, including employing multilingual staff[22], and obtaining key words/phrases from family members on flashcards or a CD/audio file, although this would make pose communication issues in emergency situations[22].

The considerations for staff are, broadly speaking, organising independent/professional interpreters[22 51], and using interpreters to pass on necessary information to service users[35] and develop a shared understanding with service users[35], allowing service users to make informed decisions about their own care[35]. Key to this is organising interpreters who speak the right language and dialect[35] and who are not known to the service user[51 63]. Staff could also ensure that service users don't feel 'put down' by interpreters[51]. Staff should consider that interpreters are more useful in conversations with an emphasis on the physical than on the social and emotional aspects of care, where some meaning may be lost[51]. Family interpreters may be useful for allowing service users to access care, however adult social care staff should be aware that certain issues may arise, including family interpreters controlling the conversation[35 53 79] and the use of children, who may not understand the information being shared[51]. Adult social care staff should ideally avoid encouraging the use of friends as interpreters due to the risk that service users' social networks may become exhausted[79]. Where there is no interpreter available or provided, staff could use body language and signing to communicate with service users[24].

The Context(s)

Adult social care services in the UK are provided in English and provision for service users from BAME groups who do not speak English is not yet standardised across social care.[8 37 107] Some service providers have put arrangements in place whereby interpreters are provided, whereas in other cases the onus is on service users and their caregivers to identify a suitable interpreter, and in some cases consultations go ahead with no interpreter.[35] Even when service providers use interpreters, this does not always cover translation of written documents.[50]

Supporting Evidence

Two narrative reviews examined use of interpreters among BAME populations. One highlighted the role of family interpreters for enabling service users to access services[28] and the other discussed issues of sensitivity and confidentiality in interpreters who may be known to service users[59].

No quantitative studies were identified that examined use of interpreters.

Multiple qualitative studies look at the usefulness of interpreters[35 36 50 51]. The consequences of using interpreters are reported in small numbers of studies, including staff delivering appropriate services[36], staff and service users sharing understanding and trust[36], service users making informed decisions about their own care[35]. One qualitative study reports on interpreters being more useful for consultations with an emphasis on the physical, rather than the social and emotional, aspects of care [51]. One qualitative study highlights the importance of interpreters being available for the right language and also speaking a particular dialect, and the same study also reports a problem with incompetence among interpreters provided by social workers [35]. Two studies report on the problem of interpreters being known to service users, which can make service users wary of sharing private health information[51 63], one study reports on the issue of translation services only being available for the consultation, with wider translation needs not met, including written translation[50]), and one study reports on service users feeling ‘put down’ by the interpreter [51]. One study highlights the issue of staff and service users having to wait for an interpreter, where service providers use paid interpreters only [53].

Several qualitative studies report that staff do not use interpreters in discussions with service users.[24 35 46] The consequences of not using interpreters are reported in small numbers of studies, including staff not providing appropriate care,[24 46] service users not receiving appropriate care,[46 65] service users not being able to complain about the service, [65] and service users seeking out and engaging with culturally specific services.

Several qualitative studies examine staff and service users’ use of family interpreters. Staff and service users use family members to interpret. [24 35 50 51 53 79] Again, the various consequences of this are each explored in small numbers of studies, including family interpreters controlling the conversation,[35 53 79] service users being wary of sharing information about sensitive topics,[51] service users’ social networks becoming exhausted[79] and children being used as interpreters, who lack understanding about the information being shared.[51]

One qualitative study explores the role of bilingual advocates, including enabling service users to access information, explaining cultural issues to service providers and identifying service users’ need for instrumental support.[50]

Two qualitative studies consider how staff and service users make use of other communication aids in the absence of an interpreter[22 24]. One study mentions how service providers make use of multilingual staff and how service users’ family members provide flashcards or CDs containing common phrases[22]. The other highlights the use of body language and signing between staff and service users to communicate and develop a rapport [24].

Modifying Evidence

One narrative review highlighted how family interpreters can enable service users from the Chinese community in the UK to access services[28]. Another narrative review discussed how confidentiality, trust and anonymity are important where the interpreter may be known to service users, as members of the same community, among people of Pakistani, Indian, Sri Lankan, Black African and Arab origin[59].

No quantitative studies were identified that examined use of interpreters.

Interpreters could lead to staff developing appropriate services and staff and users sharing understanding and trust in people over the age of 60 from migrant communities[36] and facilitate service users from Pakistani and Bangladeshi backgrounds in making informed decisions about their own care, although securing an interpreter who speaks the right dialect is a challenge and an important consideration [35].

Interpretation can be more useful in consultations that emphasise physical care than those that emphasise social and emotional care among service users of Pakistani, Indian, Sri Lankan, Black African and Arab origin[51]. The possibility that a service user might know the interpreter was an issue in terms of wariness of sharing private health information for service users of Pakistani, Indian, Sri Lankan, Black African and Arab origin[51] and from British Indian, African and Caribbean, and East and Central European communities in the UK [63]. A need for translation of written documents and interpretation/translation (related to service use) that extends beyond the consultation was highlighted among service users from older Chinese immigrants in the UK[50].

The issue of family interpreters controlling the conversation was identified in service users from Pakistani and Bangladeshi backgrounds[35] in BAME service users in rural communities, as identified by social care staff [53] and among people from Chinese backgrounds with physical disabilities[79]. This may be a particular issue where service users are particularly vulnerable or isolated. Service users of Pakistani, Indian, Sri Lankan, Black African and Arab origin shared a concern that child family interpreters lack understanding about the information being communicated [51]. Use of friends as interpreters leading to service users' social networks becoming exhausted was a concern among people from Chinese backgrounds with physical disabilities in the UK[79].

Bilingual advocates (including those sourced through the family, service providers and third party organisations) help older migrants to the UK to access information, have cultural issues explained to the service providers (by the bilingual advocates themselves) and have their need for instrumental support recognised[50].

Nursing home managers in England report the use of multilingual staff and flashcards or audio files containing common phrases helpful for enabling communication with BAME residents in the absence of interpreters[22]. Service users from the Pakistani and Bangladeshi community, and/or care staff who work with them, find body language and signing between staff and service users useful for communication and developing a rapport [24].

Summary of the Evidence Base

Generally, interpreters facilitate communication between service providers/staff and service users from BAME communities, where language is a barrier, which can lead to the delivery of appropriate care by service providers and staff and can empower service users to make decisions about their own care. There are some considerations that need to be borne in mind, however, when service providers plan the provision of interpreters. Paid professional interpreters can provide a greater quality service and have no motives to control the conversation, however there could be a long wait and if the interpreter happens to be known to the service user this may hinder the correct transfer of information, so ensuring confidentiality and anonymity is key. There is also a need among service users for wider translation services in some cases, including for helping them to complete written documents required to access some services. Family interpreters may be more convenient, however there may be problems with this arrangement, including family interpreters controlling the conversation and service users being wary of sharing sensitive information in the presence of certain members of their family. Where children are used as interpreters, information sharing may be compromised, and where friends are used, service users' social networks may become exhausted. Bilingual advocates may play a useful role as translators, providing additional support beyond interpretation, including advocacy and two-way translation of written materials. However, such a role risks service users becoming dependent on the bilingual advocate, which may have negative consequences for their wellbeing and access to services.

Limitations of the Interventions

Paid professional interpreters are often the preferred approach among service providers, due to their perceived neutrality. However, documented limitations include delays while waiting for an interpreter who speaks the right language and dialect to be available, the possibility that the interpreter may be known to the service user (which can lead to service users being wary of sharing private health information in their presence), and the fact that provision of translation is often limited to the time of consultation. Service users may require wider translation services in some cases, including written translation support to enable them to complete the written documents required to access some services.

Family interpreters may be convenient and easily available, however the limitations of using interpreters from within service users' families include the interpreter controlling the conversation based on their own motives rather than the best interests of the service user, service users being wary of sharing sensitive information in the presence of certain members of their family and the use of children from the family to interpret for the service user, when they may have limited understanding of the information exchanged. The main limitation of using service users' friends to interpret is that service users' social networks may become exhausted, leading to diminished ability to communicate with and access services, as well as potential isolation.

Bilingual advocates may play a useful role as translators. However, they carry an associated risk that service users may start to feel dependent on the bilingual advocate after a while. Such dependency may hold negative consequences for the wellbeing of service users and their access to services.

Limitations of the Evidence Base

Very little data referred to multiple points in the programme theory around the use of interpreters, with much data referring to mechanisms but not necessarily linking these to contexts or outcomes.

As the literature has primarily been examining the needs of particular groups more generally, it is difficult to look at the differential needs within the BAME group and to achieve comprehensive coverage of all BAME communities encountered within UK social care. Therefore, we have richer accounts of some BAME groups and not of others. This unevenness makes it difficult to know whether the review reflects issues that have been studied and reported in research or whether this relates the reality of important issues across these groups. We are never going to learn everything we can about each group, so the best approach would be for care providers and staff to weigh up the pros and cons that we have identified for each approach to interpretation and identify a solution with the best interests of the service user at heart.

Key Considerations for BAME Service Users

All findings were related exclusively to BAME service users.

Programme Theory Five (PT5) - Expertise with Minority Groups

IF Social Care Services recruit or use staff with expertise in engaging with minority groups

THEN social care staff create a bridge between themselves and social care service users

LEADING TO social care service users from minority backgrounds being supported in trusting and accessing social care services

Background

Social care may be structurally organised to meet the needs of a particular type of service user and therefore may appear unfriendly and unsupportive to users who do not conform to type. BAME caregivers tend to express need for greater support than white caregivers but receive it less often.[8] Language and concerns about services' cultural and religious appropriateness typically surface as the main perceived barriers to accessing social care.[8] Much can be attempted to reverse these preconceptions; from the way that services are promoted and their visual identity through to how, and by whom, services are delivered. This programme theory explores two aspects to staff engagement with minority groups. The first of these explores the homogeneity argument; by seeing that services are delivered (and also received) by those with whom the service user can identify, whether by ethnicity, by sexual orientation or by some other shared characteristic service users may feel that the service is for "people like us". The following explication demonstrates that, although easy to comprehend, the advantages and disadvantages of matching are more nuanced and complicated than might otherwise be thought. Furthermore, it demonstrates that the matching approach may carry adverse effects or, at the very least, unintended consequences. Second, is an approach that requires expertise to engage with minority groups is everyone's business and that every contact counts. This requires sensitivity to differences (See **Programme Theory 3**) at every level of the organisation. It may place a considerable overhead in terms of awareness raising, education and training. Nevertheless, the resultant benefits to the organisation can prove considerable especially if such approaches are included within a consolidated strategy for person-centred care.

Evidence Profile

The realist synthesis on Expertise with Minority Groups identified 27 studies exploring awareness in relation to Black and Minority Ethnic groups, of which none were quantitative, 23 were qualitative (Table 15). 3 studies were literature reviews and one study comprised other evidence. In comparison the literature relating to LGBT+ was less plentiful (Table 16). The literature search identified 9 studies, namely two reviews, four qualitative studies and three items of other evidence. Again, we were unable to identify relevant quantitative studies for this programme theory.

Table 15 - Summary of included studies (nos. of each type and references only):

	BAME				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	Other Evidence
Expertise with Minority Groups IF Social Care Services recruit or use staff with expertise in engaging with minority groups THEN social care staff create a bridge between themselves and social care service users LEADING TO social care service users from minority backgrounds being supported in trusting and accessing social care services		56 57 59		1 22 24 26 34-38 42 48 50 52-54 58 62 63 65 67 73 77 79	28

Table 16 - Summary of included studies (nos. of each type and references only):

	LGBT+				
	Existing Theory	**Reviews**	**Quantitative Studies**	**Qualitative Studies**	Other Evidence
Expertise with Minority Groups IF Social Care Services recruit or use staff with expertise in engaging with minority groups THEN social care staff create a bridge between themselves and social care service users LEADING TO social care service users from minority backgrounds being supported in trusting and accessing social care services		59 108		29 39 66 109	25 60 64

How interventions are believed to work

This programme theory centres on mechanisms related to empathy; either empathy drawn from shared experience, as with the matching of service user with care provider in relation to such aspects as racial identity, ethnic background or language (Table 17). Evidence suggests that the last of these serves both an instrumental (practical) and a symbolic function; the provider and user are able to understand each other more clearly and this signals a uniting bond between the two. Beyond matching empathy is achieved across a social care organisation by interpersonal skills such as active listening and questioning and by avoiding stereotyping. Other symbolic areas of the relationship between care providers and service users and their caregivers include food and recreation.

Across multiple cultures food occupies an important role, both practically and as a symbol of cultural sensitivity[79]. Food provision is particularly important for participants experiencing long term provision. Two Chinese men used the vivid metaphor that living in the care home was like "serving a life sentence in prison, as they were always surrounded by English-speaking people that they could not converse with"[79]. Chinese meals and an opportunity to mingle with other people who share their cultural identity offers substantial benefits in terms of both psychological well-being and service satisfaction levels (p.e150).[79]

> "In the care home, they only have western food. They give me a few chips and cold salad. The chips are very dry and I have to drink water to swallow them. I want our hot soup."
>
> "Our food is different from theirs (the English). At the end of the day, we are not used to what they eat. We like rice porridge, rice, noodles."[79]

Food plays an important role in Chinese culture and it serves to meet more than one's physical needs. The predominance of potato-based meals, bread and cold salad is a mismatch for Chinese people's staple diet. Participants reported that they favoured food that was prepared in Chinese ways.

Recreation is another social feature that can help the service user to feel that their culture is being recognised. A Chinese study mentions the role of Mahjong. Within a West Indian context, older males may view the role of dominoes similarly:

> "He loves to play dominoes, my husband, he sometimes he play by himself because there's nobody else to play with him. So one of the carers that comes, he's from Caribbean and he, he also love dominoes. So after he finish doing what he have to do for him, he'll sit with him, maybe just for fifteen minutes and play dominoes with him... And he's happy, you'll hear him laughing, you know,

bantering together, yeah he loves that. I like that (p.1994)." (Black African wife, 66–70, cohabiting).[65]

Table 17 - Putative mechanisms for intervention

Intervention Components *Meals* *Community groups/centres*	**Contextual Factors (Enabling)** *Being among other service users with shared cultural identity*
Potential Mechanisms (Care Providers) *Symbolic acknowledgement of other cultures*	**Potential Mechanisms (Service Users and Caregivers)** *Culturally recognisable symbols (e.g. food, recreation)* *Familiar surroundings offering comfort and reassurance*
Outcomes *Service user satisfaction*	**Leading To** *Service user wellbeing* *Respite for informal caregivers*

Mechanisms influencing the success of the intervention

While it is important not to assume that service providers and service users strike a natural rapport, simply because of a shared ethnic background or sexual orientation, evidence suggests important barriers with regard to trust where a service user does not feel that they can share information with their care provider (See: Report Supplementary Material File 1 - Context-Mechanism Outcome Configurations for five programme theories). Older LGB people can sometimes feel that those who provide services will not be able to understand and meet their needs[64 110]. Specifically, "three in five are not confident that paid carers or housing services would be able to understand and meet their needs... Approximately 50% report that they would be uncomfortable being open about their sexuality to care-home staff... One third would be uncomfortable with being open about their sexuality to a housing provider, member of hospital staff or a paid carer (p.373)".[110]

Further evidence suggests that shared ethnicity is advantageous but not sufficient in itself to create the necessary rapport. Listening skills and cultural sensitivity, attributes for which training can be provided, have also been identified as important when delivering a multi-racial service.[111]

The Context(s)

Many social care services employ staff with diverse backgrounds and so concordance between service user and service provider is stronger than it may have been in the past. However, the assumption that this automatically leads to more appropriate service provision is open to challenge. First, BAME groups are not monolithic; therefore, a shared cultural or ethnic background may mask wider differences that prove critical in the building up of trust and communication. Second, the corollary is that ethnicity and sexual orientation, although important protected characteristics, do not automatically represent the most salient characteristics against which individuals choose to consider themselves matched. So, for example, if care provider and service user both have a child of similar age, this may create a stronger bond of commonality than a shared ethnic identity. Third, practical difficulties around workload, availability of staff and the timing of requests may make it inevitable that care provider and service user cannot be matched. Care providers may seek to take advantage of their perceived common ties, for example, in regularly turning up late for their assigned duties or in leaving early.[1] Finally, where shared identity translates into shared community service users may feel uncomfortable for issues of privacy in sharing personal and private information with someone from within their community network:[112]: This need for privacy from within the community network is further expressed as "It's my private life. I don't want somebody to come in and intrude and ask me all questions about – where's your daughter? I don't want any of that so send me a care worker that's not from the community (p.1096)".[24]

Conversely, care providers may feel uncomfortable when dealing with the challenges faced by someone to whom they are personally known.

Supporting Evidence

In general, an accepted response to cultural diversity (by both providers and service users) is the matching of care providers to the cultural characteristics of service users[24]. Among the Asian participants, having cultural backgrounds and languages in common with care workers was perceived as facilitating communication and understanding. This made it easier for caregivers to express their needs, but it also influenced their trust in services.

> "There are more and more agencies coming in now and they know the need of the Asians, and the other peoples. So, they cater for the people… for instance my wife wants someone Urdu speaking, or as the sister said [indicating another participant] Gujarati speaking." (Abdul, Asian Indian male)[1]

However, beneath the surface, micro-level manifestations of "ethnic matching" were identified as being important[24]:

> A common language; appropriate and respectful forms of address (e.g. addressing older care users as 'aunty' instead of using first names); preparation of culturally appropriate food; the gender of care workers; religion (for support with ritual ablution for prayer); and a general cultural understanding to help build rapport and familiarity[24].:

This matching appears particularly important among Bangladeshi and Pakistani communities[35 37]. However, it is not clear whether this is simply a characteristic of populations that have been most studied or whether it represents a genuine cultural characteristic. In one study of the Bangladeshi and Pakistani community, homecare provider managers and care workers reported that it was standard practice to match on ethnicity, gender (one manager said that they always refused requests for opposite-sex care workers) and language, although this could cause delays. One local authority manager believed that matching on language was not essential for homecare. However, this view was not widely shared.[35] Other accounts suggest that it is the shared language characteristic that is most important as a key to communication and obtaining the services they need.[37]

Modifying Evidence

For some family caregivers, respect and an understanding of the cultural background of the service user is more important than being from the same ethnic background. Shared characteristics are not seen as necessary, provided that the care is culturally acceptable:

> "Interviewees described a willingness to accept care, provided this could be negotiated with the care recipient and provided care was culturally acceptable. However, carer guilt and sense of duty, reluctance of care recipients to accept nonfamilial care, and experiences that services were not always culturally appropriate…precluded higher levels of engagement with services (p.7)".[42]

Level of engagement with services might therefore be determined by such micro-factors as, for example, "where home care workers did not speak the same language as the service user or could not prepare culturally appropriate meals".[42]

> "But, actually, some of that food culture and calling her mum and that whole Eastern respect, South Asian respect, is an important aspect, I think, of how she operates as a person." Carer 8, Indian, son[42]

A qualitative study suggests that shared cultural identity and gender may give rise to families transferring their problems to the workers[111]. In this context, supervision and informal debriefing may constitute an important managerial response[111].

Resistance to being treated differently may also be expressed by service users who want mainstream integrated provision[74]. An interesting cross-fertilisation across the two target groups sees a metaphor from race being used to describe the LGBT+ experience:

> "I think care homes ought to be integrated otherwise you're going to get segregation." (Yvette, aged 69)
>
> "I don't want the LGBT community to be ghettoised. When I want extra care, I wouldn't want to be with just gay men. I've always seen myself as part of the wider community and want to remain there. As a gay man (p.e160)". (Graham, aged 70, living in sheltered accommodation)[74]

Summary of the Evidence Base

All included studies acknowledge a need to develop an appropriate response to handle the needs of minority groups. Differences in opinion exist in how best to meet these needs. Interventions may be "universal" in seeking to change the perceptions and culture across an organisation or "targeted" at particular service providers, populations or challenges. Most included papers recognise a need to operate through both types of approach. As discussed above, the approach of matching service provider with service user, although compelling, carries many unintended and/or undesirable consequences, either in how it might work practically or in the symbolic messages that it may convey to the general public, service users or to the service providers themselves. Awareness raising and training are most frequently considered as generalised strategies but hold implications for resource use, feasibility and prioritisation.

Limitations of the Interventions

While matching of care provider to service user according to ethnic or cultural background or sexual orientation ay appear attractive, it may prove challenging to achieve practically[1]. Furthermore, identification of the care provider with the service user may have consequences that require additional managerial support[111]. The family may transfer their problems to the care worker who may then require supervision and informal debriefing[111] in order to avoid this impairing their effectiveness. Other possible limitations are that BAME workers may only be assigned to stereotypical BAME issues (one example being "gangs") and may be limited with regard to professional development or in terms of demonstrating their potential by being only paired with BAME service users or assigned to a limited portfolio of social care issues[22 113]. Ahmed extends the discussion by claiming that assigning responsibilities on the basis of shared ethnicity may result in care providers from other backgrounds deciding "not to turn up" when issues associated with race are invoked[114]. An argument can be advanced that "practitioners need to achieve a degree of detachment from their own cultural background and gain insight into the nature of their beliefs, values and traditions and how these shape their worldviews and responses to others"[115]. Assigning care providers to service users on the basis of a shared characteristic, be it race or ethnicity, sexual orientation or some other characteristic, denies this opportunity both to those who are assigned and those who are not. Although matching care worker religion or ethnicity may be worth considering in relation to personal care and religious observances, this sort of matching may set up false expectations[1]. Several participants expressed disappointment when matched care workers failed to live up to expectations.[1]

Furthermore, recruiting BAME staff “not for their skills, professionalism and knowledge but because they are assumed to be best suited to deal with problematic service users and their issues within a multicultural society” may cause workers to struggle and become insecure about their capabilities. By expecting them to take ‘responsibility for tackling oppression on the people within the system who are being oppressed’ their managers are not understanding that “these same BME workers face the same types of oppression as the service users they are trying to help”[114].

Information and training are a mainstay of diversity provision in many organisations in seeking to ensure that expertise in engaging with minority groups is more pervasive through the organisation. However, decisions have to be made on which minorities will be the focus, how intersectionality is addressed, whether particular staff should be targeted by role or whether training should be generic, and whether a person-oriented philosophy of care, in general, may prove more effective than cumulative sensitisation across multiple individual minority groups..

Limitations of the Evidence Base

As with many topics covered by this review, more data is available on BAME populations than for the LGBT+ population. It is not possible to establish (a) whether shared racial and ethnicity characteristics are more important than shared sexual orientation or whether this is simply an artefact of research and/or reporting, (b) whether despite both being protected characteristics there is a discernible and important difference between a more apparent characteristic such as race or ethnicity, a semi-overt characteristic such as religion, and a private or personal characteristic such as sexuality and (c) whether shared ethnicity is more important for some ethnic groups than others and, more importantly, what factors determine this importance. These complexities, together with issues about matching as identified above, suggest that the more sustainable approach is to seek to improve cultural, ethnicity and other minority awareness across the organisation.

Key Considerations for BAME Service Users

One approach, attempted by many organisations, is the development of cultural awareness checklists. For example, in the context of healthcare a team from the USA has developed a Cultural Sensitivity and Awareness Checklist.[116] Early examples in social services date to the early 1990s.[117] Many such tools exist[118 119] and (i) resonate with findings from programme theories discussed above (e.g. regarding cultural sensitivity and the use of translators etcetera) (ii) provide a starting point for development of organisation-specific context-sensitive tools and (iii) are suitably generic to apply across diverse health and social care settings. While checklists may not be the most appropriate form for delivering this information, they offer a structure around which aspects of training could be mobilised, in diverse forms. More recent efforts have sought to target the desired values rather than desirable behaviours.[120]. Elements that might included are preferred communication methods, potential language barriers (verbal and nonverbal), the service user's culture, comprehension, religious/spiritual beliefs, trust, care package, diet, culturally sensitive assessments, and recognise care provider biases and prejudices.[116]

Key Considerations for LGBT+ Service Users

Findings for LGBT+ service users reveal that matching on sexual orientation between care provider and service user is not articulated as an important consideration. Indeed, it must be remembered that many care providers prefer to keep their sexual orientation private, or limited to close colleagues, and would not want to see this deliberative public/private choice subverted by the needs of matching. More important is sensitivity to discriminatory assumptions and care in the use of language within interactions. A sensitive and person-centred care assessment should be able to elicit many of the important features required to deliver appropriate care without focusing specifically on sexual orientation; for example, information on social support networks. Not all LGBT+ individuals are happy for their sexual orientation to be shared widely and considerations of age, cultural and religious backgrounds may lead an individual to consider this important information as "private".

Chapter 5 - Synthesis of findings: common mechanisms and links to mid-range theory

This chapter seeks to advance findings from the five individual programme theories by attempting cross-programme theory synthesis. In doing so, we aim to advance the discourse from the specifics of individual programme theory components to the identification of contexts and mechanisms that are likely to contribute to intended or unintended outcomes. Two approaches are used to facilitate synthesis of findings: (1). Evidence identified is mapped against the adult social care pathway of care, and (2) Evidence for the five individual programme theory components is interpreted within the context of wider mid-range theory. In each case, available data are constrained by a lack of detail in the supporting studies and, specifically, an overall lack of studies exploring access to social care by LGBT+ users.

Description of Pathway

The pathway begins (Figure 3) with someone (the potential service user, their informal caregiver, another friend, relative or acquaintance, or a health or social professional) recognising a situation that requires a service response **(Recognition of Need).** Once the potential service user or their caregiver decides to seek support **(Decision to Seek Support)** they engage with their existing knowledge or lack of knowledge about adult social care services and what they can provide **(Awareness of services)**.

Having identified that social care may offer potential support **(Identification of Social Care),** and possibly following delay depending upon whether it seems to offer an attractive and viable option, the potential service user/caregiver makes F**irst contact**. If that contact is satisfactory and productive then the contact continues (**Continuation of Contact**). Following a period of negotiation and establishing entitlement an **Ongoing social care relationship** is formed and the service user (and potentially their caregiver) receives **Appropriate fulfilment of their needs**.

All of the stages from identification of social care onwards require **Access to Social Care** (be it information, contact, referral or receipt of services). This needs to be delivered within an ethos of **Person-Centred Care** and accompanied by ongoing **Communication** and **Trust and Respect**. Both service user and caregiver must continue in their **Acceptance of social care as an appropriate source of support**. The interaction with **Informal/Family support** (where available) remains critical in delivering an integrated response to service user needs.

Recognition of need

A key assumption relates to whether the potential service user, their informal caregivers or even the formal care providers recognise a need for social care intervention. Data from this review establishes that the service user (or by implication, the informal caregiver) often finds it challenging to identify what is "normal" or "usual" in terms of need and provision[77]. The picture is complicated by cultural norms that cause either or both the service user and the informal caregiver to feel that the family should manage any needs as they arise[1 65]. These cultural norms may cause a care provider to assume that all people who share a particular culture prefer to care for a service user themselves within a family setting[24].

The pathway of care in Figure 3 is depicted in linear form but can be seen to be recursive as new needs arise. Unless changing needs are articulated by service user or informal caregiver, or the formal care provider observes a change in circumstance, all parties are "frozen" within the current situation. A further nuance identified from the data is that this same cycle of progress (or non-progression) from need to provision, together with potential gaps and obstacles, is enacted for comparable agencies e.g. for entitlements in education, housing and social care, with no joining up[35].

To exit the current situation ("unfreeze") usually requires a source of impetus. Some respondents describe how crises prompt a change in social care provision, initiated by the user, caregiver, care provider or an external provider (e.g. GP)[35]. Others describe how another individual prompted such change through discussion or provision of information e.g. a serendipitous conversation between caregivers with shared circumstances or a focused or informal discussion within a social network. Thus, recognition of need is prompted by personal challenges, the advice of a friend or relative (perhaps muted by cultural norms or pessimistic expectations of service provision) or by referral or self-referral instigated by a community worker, doctor or other professional[35].

Decision to seek Support

The decision to seek support by no means follows automatically from recognition of need. In some communities a relative may be sounded out as to whether social care is likely to be desirable, appropriate or useful. That individual acts therefore as a *de facto* gatekeeper to progress along the pathway. Mistrust of authorities may act as an impediment to making contact with the appropriate services[23 34]. Less tangibly, the family may oppose the idea of formal support, viewing it as recognition of a deficit in their own informal care. The family may propose strategies to obviate or simply delay the contact with formal services, whether these present as barriers or, more constructively, as an opportunity to discuss and renegotiate current informal provision. Part of this dialogue may revolve around either the potential user of care or their informal caregivers articulating the objection that formal services are "not for people like us". Such objections may relate to either the perceived culture or lack of sensitivity of the service or, more instrumentally, to perceptions of entitlement.

A persistent fear among LGBT people relates to discrimination leading to poorer care and support, both in community and residential settings. This fear may be particularly acute when their disability or health condition is attributed to sexual identity (for LGB people) or gender-affirming treatment for transgender people.[121] Further anxiety may relate to the confidentiality of records and who may access them.

These experiences can result in LGBT people delaying the seeking of support when they need it or finding care and support services inaccessible. This is particularly true of people with mental health problems and older people. LGBT people from different generations or cultural backgrounds may have varying degrees of confidence about being ‘out’ about their sexual identity/orientation or gender identity.

Identification of Social Care as potential source of support

Once the decision to seek support has been resolved a key issue is where that support will be obtained from. The evidence reveals different levels of awareness about adult social care among different groups. Some groups may be aware of friends or relatives who have worked in health or social services, or may even have done so themselves. Other potential users may originate from a country where adult social care provision is uncommon or may take a substantively different form from that in the UK. Service providers may not have communicated the availability of, or entitlement to adult social care services. [85] Particular difficulties may be encountered if information regarding the services available is not presented in the first language of the service user or in the absence of an interpreter to explain how services are organised and how they can be accessed. Again, a relative, possibly even a child, may find themselves as a de facto gatekeeper to the services on offer. This may add a further load beyond a simple understanding of the labels being used and the services to which these refer; in contrast to interpreting services or formal bilingual advocates an informal or family intermediary may not comprehend or be able to communicate the exact nature of the need.

Identification of Contact Point

Even after social care has been identified as a potential source of assistance individuals and their caregivers face the challenge of identifying exactly where to direct their need. While lay persons often refer to “social care” or “social services” as a single entity the experienced reality is that it is an amorphous organisation that requires identifying the appropriate “trigger point” in order to initiate an appropriate response. Prior familiarity with the organisation, a contact point who can enter as a gatekeeper to the organisation or, more generally, an individual or support organisation who can function as a “navigator”[23] are means by which individuals match their need to a response successfully. One commentator speaks of “the need to understand the system” in relation to South Asian clients[77].

Alternatively, a service user may delegate the task of navigating the organisation either to a friend or relative who already assumes other caregiver roles[93] or to an individual identified (or self nominated) for their communication abilities or other relevant skills. Where an individual does not have those resources within their social network they may rely on support services, for example translators when facing language difficulties or relying on support networks or family members to translate letters or forms.

For a contact point to be considered appropriate the individual initiating contact must believe that they will receive a respectful and useful response, that they will not be redirected inappropriately around the organisation and that the response will be understanding of, and sympathetic to, the expression of need.

First Contact

Once an individual, whether potential service user or informal caregiver, has identified a likely first point of contact then they are able to initiate that contact. Whether they follow this up immediately or on a future occasion depends upon the urgency of the need, their own self efficacy or that of the person nominated (or self-nominated) to make the contact, and their perception of the likely response. For example, if the organisation is seen to be discriminatory then an LGBT+ enquirer, whether potential service user or their caregiver, may delay or postpone contact[47].

Most included studies are drawn from settings where first contact is initiated either by a visit or a telephone call but increasingly emails or online forms are seen as an appropriate first point of contact. While this may make the task of triaging needs easier for the agency it may require a different set of competencies or confidences from the one initiating contact, adding computer literacy, and availability of equipment) to the requirements of functional literacy and health/social literacy. Such a load may be prohibitive among those who do not possess English language proficiency or who do not have access to a wider social support network. Translation or interpreter services may be required at the point of first contact. Potential service users have differing needs according to their own proficiency with spoken or written language, either in connection with English or in relation to being able to read their own language. Response formats and response times may shape the subsequent impression of the accessibility of the social care organisation.

Continuation of Contact

Anticipated concerns regarding respect, sympathy and discriminatory organisational cultures may either be modified or confirmed by continuing contact between the service user, their caregiver and the social care organisation. Continuing contact also reveals whether the initial response, whether positive or negative, was specific to the individual who was contacted or whether it serves as a barometer for the organisation as a whole. Although continued contact is presented as a linear sequence it comprises multiple contacts with different staff members and different parts of the organisation and holds the potential to be shared by one or more adverse interactions or by a cumulative series of micro-aggressions. Although this report concentrates on protected characteristics of race, sexual orientation and gender reassignment the fundamentally personal nature of social care means that individual interactions are closely associated with perceptions of the organisation as a whole. Some service users may feel that a negative response may completely rupture their relationship with a social care organisation[46] whereas others may try, and even be successful in "shopping around" until they achieve the desired relationship. Personal budgets are presented as one such provision that allows this type of relationship to be actively sought and secured. Ready access to translation or interpreter services may be required to ensure that needs are identified and responded too within an appropriate timeframe.

Processes

While the above features have focused on the episodic and staged characteristics of the adult social care pathway a further important consideration relates not simply to what is done but rather how it is done. The following features contribute to the quality of the interaction between service user, caregiver and social care provider. They typically require constant attention because any disruption may instantly threaten the relationship that may have been painstakingly built up and maintained over time.

Awareness of Services (PT1)

Awareness of services can be achieved in multiple forms. To a certain extent the degree to which they are considered appropriate depends upon the prior knowledge of the service user or informal caregiver as well as their preferences for information and support. Some prefer to "research" available support by navigating an organisation's Web pages whereas others may prefer a more direct approach, so that they end up pursuing an answer around an organisation until they feel it is satisfactorily resolved. Awareness of services operates at several levels. The first level relates to awareness of social care provision and what this covers and entails. Second, awareness relates to specific knowledge about an individual service, how it is offered and what types of help are available[67 79]. Finally, comes knowledge about entitlements including how to ensure that such entitlements are activated by personal circumstances[79]. These three issues are often conflated or confused which provides one explanation why poor awareness of social care may persist notwithstanding a good overall awareness of the existence of "social services" and despite often vigorous attempts to promote and publicise services.

Acceptance of Social Care as Appropriate Source of Support (PT2, PT5)

For services to be used requires potential service users and/or their informal caregivers to accept that social care provision is an appropriate source of support in meeting their needs. Several factors may act as barriers to such acceptance. For some, welfare provision continues to be associated with stigma[93]; requiring either that they do not avail themselves of legitimate provision or that they seek to make any support "invisible" within the community. Some pursue a rights-based approach to entitlement in pursuing whatever resources are available. For others, a lack of willingness to accept social care provision is associated with pride, personal autonomy and dignity; they do not want to be seen to be dependent upon others for basic activities of daily living. For yet others reliance on social care is seen as a potential criticism of the available informal care, typically provided by family members. These differing perspectives may not only exist *between* different BAME subpopulations but may also be evident from *within* group differences. Similarly, LGBT+ groups may exhibit different levels of need and demand, perhaps related to socioeconomic or cultural factors and attitudes.

Specific issues may relate to the perceptions of LGBT+ service users that services are "not for people like me". Mainstream services are not always welcoming to LGBT people, yet personalisation is about being able to choose appropriate mainstream community-based or residential care and support if you want or need to. Creating an environment where LGBT people feel safe to be themselves without censuring aspects of their lives can be partly achieved by images in publicity materials, posters and other documents which include LGB people[32]. Knowing where to access relevant information is important for making referrals to local support groups known to offer a welcoming service to LGB people.

Informal/Family Support (PT2)

A key issue for adult social care provision is the interaction and interrelationship between formal care and informal support provided by caregivers often including family members. For some families, social care is "triggered" only when the family and informal networks are no longer able to cope – a further reason why social care use is often associated with a crisis response. For others, there is a demarcation between those duties that are seen as personal care, which are handled within the family, and those that require professional intervention. In a medical context this might include administration of medication or changing of infusions or dressings. Asian participants reported being expected to manage medical procedures for their parents when care workers were not around, including injecting insulin[77]. One participant describes being required to fix a catheter:

> "If my Dad had a problem with his catheter say for example, they would, I mean the nurses would expect us to sort it out and I'm barely at home. My mum can barely speak English and it's just like they expect my mum to sort it out or us to learn it and it's like, it's not our job (p.1374)." (Carer 30, SA).[77]

However, the distinction between medical care and personal care represents a blurred demarcation with evidence that, where possible, informal caregivers may seek to reduce their dependence on sources from "outside the family".[24] In other circumstances informal caregivers may use a medical/personal care demarcation as a boundary marker which restricts either the extent or the nature of their personal involvement. Under such circumstances the learning of new skills may be undesirable as it holds the prospect of additional caregiver burden.

Communication (PT3, PT4)

Communication is key to the service user, care provider and informal caregiver triad. The relationship between these three parties is continually shifting and evolving. All three viewpoints may be shaped by the third party in the relationship; so, for example frustrations between care provider and service user may have to be managed by the informal caregiver. Alternatively, the care provider may witness a deterioration in the relationship between service user and their family caregiver. If emerging needs are to be identified at the point that they occur then ongoing communication is essential. One specific manifestation of the need for communication, namely the use of interpreters, is explored in PT5.

Trust/Respect (PT3; PT5)

Several factors impact on trust between service user and care provider. These include the building up of a relationship over time and satisfaction in previous tasks accomplished[65]. Once trust is built up the triadic relationship between service user, care provider and informal caregiver is strengthened and the caregiver can gain respite and delegate previous roles to the formal carer[35 65]. Trust operates at the level of the service (there can be mistrust about an agency's role in connection with immigration procedures, for example) and at an individual level, associated with dependability and reliability. Healthcare providers can be subject to mistrust by some BAME populations[34].

A common language; appropriate and respectful forms of address; preparation of culturally appropriate food; the gender of care workers; religion and a general cultural understanding help to build rapport and familiarity at this individual level(22): However, the two levels are interdependent so, for example, having cultural backgrounds and languages in common with care workers was perceived to influence caregiver trust in services:

"There are more and more agencies coming in now and they know the need of the Asians, and the other peoples. So, they cater for the people… for instance my wife wants someone Urdu speaking, or as the sister said [indicating another participant] Gujarati speaking." (Abdul, Asian Indian male)

Access to Social Care (PT1, PT2, PT5)

In the corresponding realist review of primary care utilization by older people (Ford) issues of access focused on gaining physical access. In the papers explored in this report the barriers to access appear to be more psychological, social and cultural. Several explanations can be advanced to suggest why this might be the case. First, primary care services employ a neighbourhood model; many people are within walking distance or a short journey of primary care provision. Where this expectation is denied then this may represent a substantive barrier to the service users' perception of availability. In contrast, adult social care services are often organised around a centralised model. First contact may be by phone or by a visit to a centralised hub. Impediments to accessing the service may therefore relate to the difficulty of navigating the social care system or in making time to access the service. Alternatively, the challenge may relate to use of such services if the services themselves or the community that they serve is seen as unreceptive or hostile. Other individuals link their challenges to knowing when and how to access social care, thereby linking to awareness of services[79].

Person-Centred Care (PT3, PT4, PT5)

Person-centred care involves focusing on the needs of individual. Ensuring that people's preferences, needs and values guide decisions in relation to their care, and providing care that is respectful of and responsive to them. It can be seen that this philosophy of care, with its focus on preferences and needs resonates with several programme theories explored in this report (PT3, PT4, PT5). Certain assumptions may be made with regard to provision of person-centred care; for example, that care providers matched with service users on shared characteristics of racial background or sexual orientation are more able to deliver person-centred care. Evidence identified for Programme Theory 5 reveals that the situation is more complex than might initially be assumed. Alternative solutions may involve increasing sensitivity to needs in general, and to the needs of particular individuals more specifically, across the care organisation as a whole. This involves listening to the service user and avoiding generalisations.[24] Person-centred care provision may include mealtime arrangements, ensuring end-of-life care is appropriate and ensuring religious and spiritual preferences and other cultural needs are met.[22] Person-centred care includes empowering service users through promoting independence and shared decision-making, in relation to such aspects as cultural beliefs and preferences, and language and communication[122]. Open questions and inclusive language may feature as a specific manifestation of person-centred care where the needs of the LGBT+ population are concerned[32 64 95]. Organisational mechanisms for delivering person centred care include a common assessment process of individual social care needs with greater emphasis on self assessment. This requires social workers to spend less time and effort on assessment and more on support, brokerage and advocacy[32]. Other such mechanisms include person-centred planning and self directed support, individually tailored support packages and personal budgets for those eligible for publicly funded adult social care support[32]. This offers the prospect, for service user and their informal caregiver, to occupy a shaping role in their own care, facilitated by personal budgets. Specifically, person-centred care may also involve interpreter and translation provision so that the care providers are able to understand and respond promptly to the service user's ongoing needs.

Outcomes

Adult social care may be characterised by a wide range of outcomes; personal, social and relating to health and quality of life experienced by service user, their informal caregiver and even by the care provider. This review does not explore achievement of all of these outcomes which would be the target for a conventional systematic review of effects. Instead the outcomes have been simplified qualitatively into two important qualitative outcomes; the quality of the ongoing relationship of the service user and their caregiver with social care services, whether at an organisational or individual, personal level and the appropriate fulfilment of their individual and collective needs. Achievement of these outcomes may or may equate to achievement of social care service objectives. For example, service user and caregiver may want a particular service to continue indefinitely whereas the service objective is time-limited before moving on to meet the needs of other service users. Furthermore, user satisfaction, whether for service user or informal caregiver, is complex and relates to the interplay of what the service user expects and what they receive. Unexpected withdrawal of an expected service may have an asymmetrically damaging impact on service user and caregiver satisfaction. While these issues require further exploration this review extends as far as the achievement of a satisfactory (ongoing) triadic relationship and the continuing and appropriate meeting of needs.

Ongoing Social Care Relationship (PT3, PT4, PT5)

In contrast to acute pathways of care, typically mapped for health services and primary care, the relationship between service user and care provider, whether person or organisation, is based on situations that may continue over the long term. Success may not be measured in terms of resolution of a specific episode but may require the maintenance of an ongoing social care relationship. The quality of this relationship has a direct bearing on the perception of satisfaction with care.

Appropriate Fulfilment of Needs (PT1, PT2; PT4)

Typically, fulfilment of social care needs is not seen as episodic, as is often the case with primary care contact, but relates to ongoing need. While "goodwill capital" may be built up over time through successful care provision this is dissipated quickly in instances of unsuccessful care. As mentioned earlier, successful communication, along with the facility of care provider, informal caregiver and service user to adapt to changing needs and circumstances, remains an ongoing challenge.

Summary

This adult social care pathway is transferable to most adult social care contexts, and to other adult social care target populations, although the concepts described above have been crafted specifically in relation to BAME and LGBT+ populations. The adult social care pathway is shown as a linear pathway for simplicity, but access to primary care is clearly complex and dynamic. For example, the informal caregiver may accompany the potential service user throughout some or all of the pathway, they may act as a representative, advocate or navigator through this process or they may become involved intermittently. Similarly, the adult social care pathway may be associated with a major decision such as entry into a residential home, with minor recursions and regressions; for example, in checking out a number of candidate homes. Alternatively, the pathway may operate incrementally; persons already in receipt of one or more social care services may need to find out about, make contact with and negotiate provision for an additional service. However, whatever the circumstance this pathway offers a useful analytical device for the synthesis and analysis to follow.

Programme theory – Awareness of Services

Programme Theory 2 stated that:

IF social care service users are aware of adult social care services and how to access them

THEN social care service users access adult social care services as needed

LEADING TO social care staff providing appropriate care/social care service users receiving appropriate care

Exploration of Programme Theory 2 revealed that awareness involves different requirements for different people. For some, perhaps from countries with a different approach to social welfare, it can relate to social care services and what they offer. For others awareness may involve knowing which entities within an overall social services care provider offer which services. For a further group it may relate to individual entitlement, or to relative personal advantage from accessing the services; a mental trade-off of benefit versus inconvenience.

A second strand revealed that different groups are more aware (of any, some or all of the above aspects of social care provision) than others. In some cases, service users or their caregivers may personally have worked in health or social care services, or they may have relatives who have done so. Relatives, friends or even casual encounters with people with shared circumstances may offer a resource for identifying and then navigating the social care system. However, it is important not to attribute the same levels of knowledge and ability revealed by research studies to the studied population as a whole. Those who have greatest difficulty in accessing services may also be those who are most challenging to access for research.[50 123 124] The overall situation is therefore likely to be worse than the picture revealed by research. At the same time the barriers and obstacles may only differ according to severity; the research may reveal the types of obstacle with fidelity (e.g. levels of health and functional literacy etc).

A key finding from this programme theory is a further intermediate, and yet largely invisible, step between knowledge of, and access to, social care that impacts upon users accessing services. Having gained a knowledge of what is on offer service users make a decision about whether it is timely or opportune to access a service at that point in time. BAME and LGBT+ users share a concern about whether the service is "for people like me". This can be addressed by information, images of and contact with services, or the visibility of, peers who use the services. They may also be encouraged by the visibility of care providers that share their same ethnicity, although evidence on this is equivocal (see Programme Theory 5). LGBT+ service users may fear that the service will not be "gay friendly" although what this means differs to different individuals. In some cases LGBT+ service users fear direct prejudice, in other cases they may detect microaggressions and, in yet other instances, they are made to feel uncomfortable by heteronormative assumptions about "husband", "wife" or "family".

Although the pathway of social care focused on discrete and visible steps in the pathway, alongside continuous care processes, we did identify an intermediate, and largely invisible step – that is the decision by the potential service user and/or their informal caregiver to initiate contact with the social care provider. To a certain extent this is comparable to "contemplation" stages of behavioural change models. Decisions to delay may be linked to concern that contact will signal a deficiency in the informal support being provided. Alternatively, a potential service user may be wary of inappropriate responses, either related to their minority status or more broadly associated with social care organisations being official entities. They may explore alternative arrangements or care providers. They may decide that the balance between "hassle", for example of navigating the organisation or the administration and associated paperwork did not merit pursuing the option at this time. As a consequence several users describe delaying such involvement until a "crisis", whether from their own choice or because the crisis commands the focused attention of the social care organisation.

Programme theory - Complementarity to Informal Care

Programme theory 3 stated that:

IF social care service users perceive that adult social care services complement and augment informal and/or family support

THEN social care service users feel able to access adult social care

LEADING TO social care service users feeling that their holistic needs are being fulfilled

Key to this programme theory is the relationship between the triad identified in this study as care provider, informal caregiver and service user. Findings from the populations found that different cultures and different individuals may possess different thresholds or boundaries beyond which the need for social care is triggered. So, for some this boundary relates to caregiver burden or service user functional capacity – this can be evidenced in a gradual build up of workload and stress or in an increasing perception of being unable to achieve certain activities of daily living. For others the demarcation between informal care and formal care elates to the nature of the tasks required – so changing a catheter is seen as clearly a task for social care staff. However, the actuality is that in cases of delay or non-attendance the informa caregiver would end up having to step in such tasks, at a cost of considerable resentment. For others boundaries are cultural; some cultures will only accept family members as caregivers whereas LGBT+ people may access a wider network of friends, former partners etcetera. It is key that care provider, caregiver and service user share a n understanding of what the caregiver role entails and who will fulfil it.

Other cultural influences or community expectations may influence access to social care. Different cultures associate needing formal care support with welfare provision and stigma is attached to those who are not self-reliant.

In all contexts trust and communication figure prominently, particularly given that service user needs may be constantly changing, thus requiring adjustments in care and, consequently, in roles. The care relationship must therefore be seen as a dynamic and interactive process that requires continual checking that requirements are still current and continue to be met.

Programme theory – Sensitivity to Differences

IF social care staff are sensitive to differences between different and within minority groups

THEN staff personalise their response to each social care service user

LEADING TO social care service users feeling welcomed and respected

This programme theory reveals that sensitivity to differences does not involve treating all people the same and that this does not relate to either generalisations or stereotypes. Instead it requires a personalised and individualised response, founded on a sound process rather than a set menu. Evidence reveals that person-centred approaches demand a heterogeneous response set, even when the circumstances, health conditions and backgrounds of the service users appear homogeneous. Importantly, even experienced care staff become attuned to listening to the needs of individual service users rather than basing the assessment of needs on what has been required before under comparable circumstances.

We have also seen that an approach that is sensitive to difference can apply at multiple levels; in an organisation that welcomes and values diversity and in care providers who demonstrate such sensitivity at an individual level through their interaction with the service user and their family. For this reason approaches to person-centred care are very much to be welcomed, not only as an overall philosophy of care but also through approaches aimed at personalisation – such as personal budgets that allow design of an acceptable care package. In addition to personal budgets, the assessment process is seen as a key approach to advancing personalisation. Other evidences of personalisation may operate more at a symbolic level, such as in the provision of food and in culturally-compatible recreation. These are not necessarily substantive in their own right but collectively combine to reinforce the impression of being understood and valued as an individual

Programme theory - Use of Interpreters

This programme theory states that:

IF adult social care services use interpreters

THEN social care staff and social care service users communicate more effectively

LEADING TO social care staff providing appropriate care/social care service users receiving appropriate care

The programme theory started by reminding us that although the emphasis of this theory relates to functional translation it shared a symbolic importance with the use of acceptable labels and concepts with the LGBT+ community. Findings reminded us too, that although challenges relate to both verbal proficiency and written literacy, they must not be allowed to eclipse other important considerations such as health/social care literacy. A service user may be able to understand the language of a leaflet but not be able to interpret its meaning and implications for them personally.

As with communication more widely the role of interpreter or translator shares a major interaction with the concept of trust. An interpreter must enjoy the confidence of the service user that they are communicating proficiently (i.e. as an accurate representation of need) and with integrity (i.e. as a reliable advocate for the voice of the service user). While interpreters are key to an initial assessment of need a major challenge relates to the fact that, as highlighted above, these needs are always emerging and changing and the interpreter service may not always be available at time and point of need. The evidence base also confirms the important role being played by the informal caregiver or other family members or social networks; whether that be in translating letters or forms or in contact during regular visits. A particular challenge is faced when a "child as parent" has to function as an interpreter and they may not be equipped with either the knowledge or the understanding to relay an accurate representation of need.

Programme theory - Expertise with Minority Groups

IF Social Care Services recruit or use staff with expertise in engaging with minority groups

THEN social care staff create a bridge between themselves and social care service users

LEADING TO social care service users from minority backgrounds being supported in trusting and accessing social care services

We found that because matching is primarily suggested in relation to protected characteristics this response may hold widespread implications for the care provider-service user relationship. Either care provider or service user may be unwilling to share a private part of their life for the sake of matching. Furthermore, the characteristic on which care provider and service user have been matched may not be the most salient one. Indeed, it may open up risks of stereotyping and generalisation rather than a more nuanced appreciation of individual need. Unintended consequences of matching can occur for the service user/informal caregiver (for example, in a lack of privacy within a closed community) and for the care provider (in terms of being stereotyped with particular types of client/problem and in denying exposure to wider contexts in order to broaden personal development. Difficulties for the organisation may result from over-identification of the care provider with the problems of the service user and in restricting cultural initiatives to "race experts". However the role of cultural and ethnic matching may be more important as symbolising recognition of need than for its practical benefits; with evidence that language matching may be more important, from a strictly practical angle.

In contrast. person-centred approaches are accessible to any member of a care organisation, reinforced by training and organisational communications such that "every context counts". The overwhelming message from evidence considered for both populations in this review conforms to the observations of a recent scoping review specifically of older LGBT service users in the UK, namely "the need for diversity in care options…, and a common standard around the provision of knowledgeable and respectful care"[125].

Insights from mid-range theory

We searched for papers describing conceptual models or frameworks relevant to each of the programme theory components included in the synthesis. For pragmatic reasons, we aimed to identify one or two theories per component, but, in some cases, multiple theories were identified. Theoretical/conceptual papers identified from any aspect of the five featured candidate programme theory components were examined for their specific application, together for their wider implications across the two specific populations of interest and, where appropriate, more widely across other care groups. Theories are summarised in Table 18 and mapped onto the social care pathway (Figure 4) as well as being briefly rehearsed narratively.

Three of the most resonant mid-range theories are:

Dixon-Woods model of candidacy probably represents the best fit for a conceptual model against the pathway of social care proposed earlier[11]. It identifies distinct factors that influence the behaviour of individuals, service professionals and systems at all points on the access route to services. Candidacy is considered across six dimensions:

Identification – how people recognise themselves as needing a service. From the pathway of social care this includes the recognition of need, the decision to seek support and the identification of social care as a potential source of support. Cultural conformity, fear of censure for inappropriate utilisation of social care and anticipation of a negative response from care providers may combine to contribute to delay or non-use. This may explain why potential service users describe not knowing that a service was for them (i.e. lacking a benchmark for appropriate usage) or validating the option with a family member or relative before pursuing social care as an option. It may also explain why potential social care service users may delay involvement until they reach a recognisable “crisis point”; recognisable both to themselves and their caregiver and to social care staff who gatekeep the pathway.

Navigation – awareness of the services on offer and the practicalities of accessing those services (including transport and physical accessibility). This is seen in “Awareness of Services and, more specifically, in Identification of Contact point from the Pathway.

Permeability – the ease with which people can use services. This focuses on both Access to Social Care and to the smoothness and alacrity of the link between Identification of Contact Point and First Contact.

Presentation – the ability to self¬present, communicate and articulate the ‘need’ or issue; relates also to the ability to voice concerns about the standard of service if those needs are not met. This relates to the last two boxes on the pathway and the iteration between them. It links the ongoing social care relationship to the continual reframing of needs in the expectation that emerging needs will be fulfilled and current ongoing needs will be protected.

Professional adjudication – professional perceptions that may disadvantage certain people. Primarily, this refers to the construction of the individual as ‘deserving’ or ‘undeserving’ and involves moral and social judgements on the part of the “service professional”, or gatekeeper. However, in the context of this review it may reflect the danger that an accurate representation and interpretation of legitimate needs will be eclipsed by prejudicial assumptions. Constructions of entitlement may relate to the whole person (as in racial prejudice or homophobia) or to the legitimacy of specific needs associated with their identity (as in treating everybody the same [see next section], stereotyping needs or failing to be sensitive to individual difference).

Operating Conditions – Candidacy is subject to multiple levels of influence at the societal and macro levels, depending on the political, economic and environmental context at the time of presentation. Racial tension, anti-migrant feeling or anti-gay bias may rise at specific points within society challenging the previous constructions of being “deserving”.

Aday and Andersen's Framework for the Study of Access[126] offers an approach, derived from within health care, to understanding how policy can be used to affects characteristics of the care delivery system and of the population at risk in order to bring about changes in the utilization of care services and in the satisfaction of consumers with those services. Factors impacting upon access can be divided into mutable factors such as lack of knowledge, lack of translation services etcetera and immutable factors such as age, gender, race and sexual orientation. Utilisation of services within the Aday and Andersen model relates to the availability of those services and the needs (both perceived and evaluated) of the service user. User satisfaction with services is a factor of how well the system fits with service user needs, resources (e.g. informal care support) and concerns (e.g. discrimination). Satisfaction with services then influences future utilisation. Limitations of the Aday and Andersen model include an emphasis on need factors and individual characteristics in preference to consideration for cultural and contextual factors. As a consequence, the Aday and Andersen model does not foresee a need for interventions tailored for vulnerable subpopulations such as minorities, older adults and individuals with disabilities.

The Cultural Competency model is a model that discusses how healthcare disparities arise. This model acknowledges the existence of disparities in health and healthcare and explains healthcare disparities as arising from cultural differences that often exist between providers and patients. Cross et al. define cultural competence as a "set of congruent behaviors, attitudes and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations"[127]. Recent years have seen the development of similar models in social care in relation to both BAME and LGBT+ populations. However, while the Cultural Competency model recognizes that racial/ethnic disparities in service provision are associated with factors such as low socioeconomic status, interventions suggested to address disparities focus only on the supply side of the equation, primarily by increasing the number of healthcare providers from racial and ethnic minority backgrounds. Social care has also proposed an alternative to the cultural competency, namely "a stance of informed not-knowing". This stance focuses on the skills of active listening, questioning and establishing need and is offered as an alternative to stereotyping. It involves letting the service user choose how they want to express their identity, even where service providers are experienced at interacting with minority clients.

Figure 4 - Social Care Pathway (indicating positioning of Programme Theories and Mid-Range Theories)

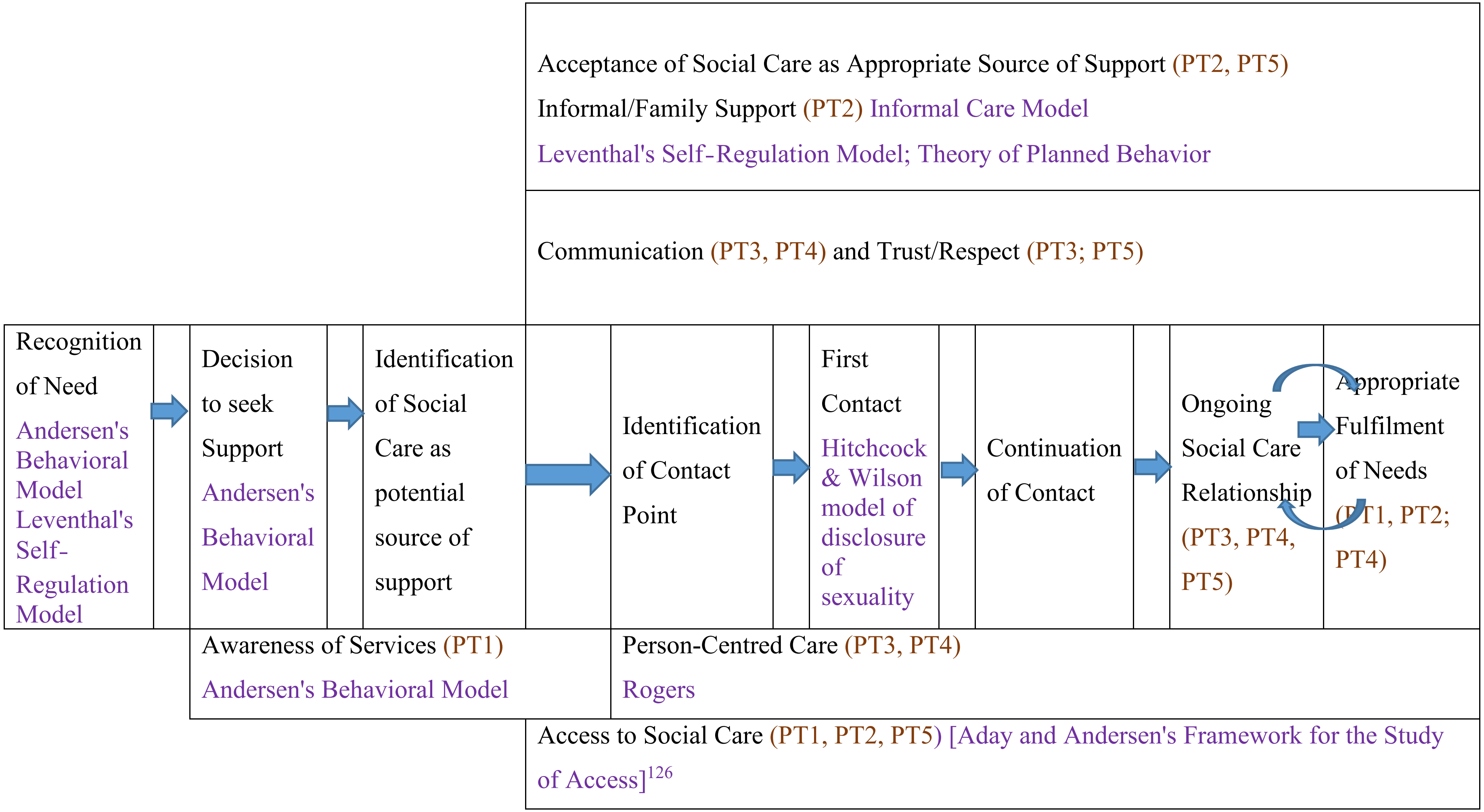


Table 18 - Mid-range theories associated with the five programme theory components

Programme Theory Label (Id No)	**Theory**	**Supporting References**
Awareness of Services (PT1)	Leventhal's Self-Regulation Model of Illness	63 92
	Andersen's Behavioral Model of Health Service Use	91 128
	Minority Stress Theory	129
	Aday and Andersen's Framework for the Study of Access	126
Complementarity to Informal Care (PT2)	Informal Care Model (ICM)	130
	Behavioral Model of Health Service Use	91 128
	Theory of Planned Behavior	131
Sensitivity to Differences (PT3)	Conservative, liberal and critical approaches to multiculturalism	90 103 104
	Hitchcock & Wilson (1992) model/framework of disclosure of sexuality to care providers	132
	Theories of heteronormativity	133 134
	Invisibilisation	135
Use of Interpreters (PT4)	Shared Cultural Knowledge (SCK) approach	28
	Diversity Based (DB) approach	28

	Leventhal's Self-Regulation Model of Illness	63 92
	Lifeworld approach	105
Expertise with Minority Groups (PT5)	Othering	136
	Treating everybody the same	90
	Cultural competency model	127

Overarching theories

Several areas of supporting theory may help to explain the phenomenon of unequal access to social care. We have focused on four lines of exploration: 1. Othering, 2. Treating everybody the same, 3. Invisibilisation, 4. Minority stress theory

Othering

The concept of ‘othering’ relates both to ‘race’[137]and sexual orientation[90]. Dominelli argues that:

> othering is an important aspect of the processes of oppression. (It) involves (exclusion) from the normal hierarchies of power and (being) labelled inferior or pathological … These (processes) create a “them–us” division which privileges those who are considered “us” … “Othering” is socially constructed through … the biological, social and political and/or economic domains (p. 18).[138]

LGB people are also located outside the legal, political, social and moral systems and therefore may be constituted as experiencing ‘othering’ which, historically, has deemed women, black people and ‘homosexuals’[139] as inferior. The concept of othering may, in part, explain why LGBT+ and BAME populations may consider that social care provision is “not for people like us”. It may require them either to adopt the prevailing heterosexual and white norms of UK society, to be characterised as stereotypically different (as with the all gay people attend Gay Pride stereotype[66]) or to face an ongoing challenge in conveying their individual and personal differences.

Treating Everybody the Same

Treating everybody the same is a basic democratic principle that places considerable emphasis on equal care: it implies parity in access to services. Many believe this to be an appropriate response to discrimination and injustice and in ensuring equitable care from health and social services. However, as commentators point out treating everyone the same assumes the need to preserve a level playing field. In reality, structural oppression operates in two ways: it assumes everybody is the same (e.g. people are offered the same services) and it compels disadvantaged groups to become similar to dominant groups[90]. These arguments relate to both BAME and LGBT+ populations but are less developed in relation to sexual orientation. Comparable analysis of racism in social care identified this as "the colour-blind approach" that fails to recognise the specific needs of BAME populations from social work[90]. These issues were explored earlier in relation to the need to be sensitive to differences within LGBT+ and BAME care groups for differentiated provision (PT3).

Many social care commissioners, providers and practitioners start by seeking to be inclusive by treating everybody in the same way. While this is a better starting point than following misperceptions and stereotypes, treating everybody in the same way does not demonstrate sensitivity to difference (PT3) and may not always make people feel comfortable. For example, referring to a husband or wife may not be appropriate for an LGB person, so using the term "partner" makes conversation more inclusive[121]. At the same type, other LGB persons may be comfortable with using the labels husband and wife. However, equating the acceptability of the label with the heterosexual norm that it conveys is equally inappropriate. One caregiver relates their experience from early contact with the Alzheimer's Society, in response to saying they were gay:

> 'Well we treat everyone the same, you won't find anyone who is prejudiced at the Alzheimer's Society' and I thought 'Er, well, I should hope not, but that wasn't exactly what I was saying – er – I do have some other needs actually, which are not the same as a husband or wife etc.' Anyway, I bit my tongue because I couldn't really articulate, to her, what her remarks signified (p.163)".[66]

Care providers should seek to be openly aware of how any service user self-references themselves, to enquire non-judgementally about preferred terms of address and to avoid generalisations within care groups. In cases of doubt, it may be appropriate either to elicit the preferred form or default to the most inclusive form, in this case “partner” until an opportunity to verify this presents itself.

Oppression theory posits that oppressed groups exhibit some deficit that leads to them being deemed inferior. This in turn demands that the oppressed group approximate the characteristics of the supposedly superior group. Concepts such as LGB parenting or family are patterned on heterosexual interpretations of parenthood and family requiring that LGB people who want acceptance feel “obliged to approximate heterosexuality”. By demonstrating conformity to heterosexual assumptions, some LGB individuals secure small-scale wins but at the cost of affirming heteronormative models. However, such conformity does not challenge institutionalised assumptions about care, particularly as it relates to the design of social care services. Such a phenomenon has also been reported in connection with the experience of BAME groups in which black people are expected to assimilate to white cultural norms: by wearing western clothes, eating western foods and by adopting Eurocentric traditions, values and ways of thinking. Inappropriate responses, microaggressions or even verbal abuse on the part of care providers, generate reduction in attendance and in seeking assistance. Double jeopardy requires that where minorities resemble the dominant group they lose their distinct identities; where they are different they are considered “inferior”.

As a consequence, LGBT potential users of care are afraid to reveal their sexual orientation to care providers in health or social care services, anticipating the negative impact that such an attitude can generate in the quality of care. As a result of the non-disclosure, the LGBT population is treated as straight. As a consequence, LGBT people prove to be dissatisfied with the care that they receive, being tailored to the needs of a heterosexual population and, thus, addressing neither their real needs nor desires.

The way that everyone should be treated the same is by viewing every person “as a unique individual within his/her own context”[140]. This requires aiming to treat every individual with the same level of dignity and respect; listening, understanding and responding to their unique needs.

Cultural sensitivity should not be 'relegated to an ethnic minority agenda'[141], but rather should be applicable to all individuals. The principles that govern the person-centred approach, are likely to take into account the particular needs of individuals, given the service is designed around individual circumstances and need. This acts as a counterpoint to the democratic view of the 'one size fits all' universal service, wherein cultural needs are inconvenient or overlooked.

Invisibilisation

A key characteristic in relation to LGBT+ access to, and use of, social care services is perceived "invisibility". In contrast to racial and ethnic identity which is accompanied by many visual and behavioural cues, LGB people (in this context transgender people may be considered a unique circumstance) can decide whether or not to disclose their sexual orientation. However, invisibility also extends to the overall absence of data and official statistics about the LGB population and, to a certain extent, to the comparatively thin research base for their access to social care services. This invisibility of a readily identifiable population can act as an impediment to improving access to services. For this reason, the potential contribution of LGB people is often overlooked when developing service provision. Similarly, LGBT caregivers and the "family of choice" may also experience invisibility,[142] either in not being acknowledged, not being acknowledged as a source of caring or by being "erased" in relation to assessments, forms or heteronormative language and assumptions. While invisibility is central to the experience of LGB service users, other groups included within this review also experience invisibility, for example BAME LGBT populations and older LGBT populations.

If they choose to LGB people, as individuals, are able to conceal their sexual identities from service providers and gain access to services as heterosexual[32]. However, this may place extra strain and anxiety on the individual and on the family of choice as they resort to circumlocution or subterfuge. This is expressed as a particular concern for those in residential care where a constant state of secrecy may be required. Older people may also be particularly reticent about being open about their sexuality. Factors that impact upon whether or not LGB people will disclose their sexual identity in social care settings include confidentiality, fear of lower standards of care, concern about the relevance of disclosure and fear of a negative or inappropriate response. Within society many people believe that a person's sexual orientation is private and not an issue they should be concerned about and this attitude may extend to care providers. The personal and private nature of sexual orientation may present a specific tension against a backdrop of public social care provision where open identification of expressed need is required to secure access to, and demonstrate entitlement to, available services. However, where relevant, this important feature of an LGB person’s life exerts a pervasive impact on their needs preferences and, for that reason merits inclusion in an individual’s care plan. Multiple reasons have been attributed to such a notion of privacy, both historical and contemporary, with many persisting particularly for those from outside the UK. Evidence suggests that many LGB people are now more willing to be open about their sexual identities, although barriers, particularly in institutional settings, continue to persist. In particular, more vulnerable LGB people living in care homes, day centres or other institutional settings (where they may encounter socially isolation), may prove much less likely to reveal their sexual orientation.

Common misconceptions about LGB people's use of social care services directly impact upon service provision. Prevalence of LGB people in the population is considered to be much lower than it is in reality. Data often are interpreted as meaning that no requirement exists for specific service provision. Planners may assume that no LGB people use their service, perhaps leading to them treating everybody the same as iscussed in the previous section. 008). Further misconceptions relate to particular groups of LGB people; for example, that disabled, older or BAME people cannot be LGB. Fish has pointed out that this notion of invisibility has consistently permeated the titles of social care research in LGB communities, such as ‘A Mighty Silence’, ‘Out of the Shadows’ and ‘Secret Loves, Hidden Lives’.

Minority Stress Theory

Kneale's scoping review of service provision to LGBT elders is one of many to invoke Minority Stress Theory as the theoretical basis for exploring sexuality-based health inequalities[125]. Minority Stress Theory starts from the premise that LGBT people are at an elevated risk of poorer health outcomes because of their greater exposure to chronic stress resulting from social stigmatisation and prejudice and stigma[143]. According to this model, such stress derives from both internalized homophobia (self-directed aversion), and stigma (expectation or fear of being rejected in society, with concealment of sexual orientation). These conditions are advanced as a possible explanation for the absence of demand for health and social care services.

Person Centred Care

Throughout this review person centred care has emerged as a counterpoint to many issues surfaced by the exploration of programme theory. In a sense therefore person-centred care becomes an overarching narrative that, while not strictly speaking a "theory", offers a continuous thread through the pathway of social care and through the original programme theories.

Person-centred care originates in humanistic psychotherapy. In the early 1960s, psychologist Carl Rogers was the first to use the term 'person-centred' in the early 1960s, in relation to psychotherapy. Today's person-centred care shares a concern with empathy – the professional's willingness to suspend judgement and appreciate a service user perspective. If we are loved, valued and respected, we feel worthy of love, value and respect. Rogers termed this unconditional positive regard. Conversely, if we are only valued for behaving in a certain way, we learn to hide some thoughts and behaviours. This conditional positive regard leads to a lack of congruence between the person we see ourselves as, and our ideal self. Seeing ourselves as a failure, we are afraid to 'be ourselves', preventing personal growth. Rogers believed we are capable of achieving personal growth through unconditional positive regard within trusting, genuine and open relationships, whatever our age[144].

The Health and Social Care Act 2012 imposes a legal duty for NHS England and clinical commissioning groups (CCGs) to involve patients in their care. A comparable patient focus is articulated in corresponding documents from the other UK constituencies.

Person-centred care involves knowledge of the individual as whole person, involving them – and where appropriate their family and friends (PT2) – in helping to assess their own needs and plan their own care. The opposite of this is a task-focused approach, which prioritises physical tasks over social care. In person-centred care, caring is central and relationships with the service user are fundamental to that individual's experiences of care[144]. The service user's role involves partnership, rather than being a passive receiver of care. A person-centred relationship promotes self-esteem (positive self-regard) and self-efficacy (a feeling of being able to achieve one's goals).[144]

The Health Foundation has identified four principles that identify person-centred care:[122]

1. Affording people dignity, compassion and respect.

2. Offering coordinated care, support or treatment.

3. Offering personalised care, support or treatment.

4. Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

Choice and education are core to person-centred care, which also relates to increased service user satisfaction. Humanistic concepts of "respect for persons, individual right to self-determination, mutual respect, and understanding"[145] underpin person-centred care.

Critics of the person-centred approach focus on it being resource intensive and time consuming. This may increase the strain on informal caregivers. It may also impact on the financial costs to provide services. Furthermore, the approach may allow an opportunity to blame the caregivers for any deterioration. Nevertheless, the focus of the Health Foundation on principles of care rather than a formal manualised approach offers the prospect of introducing a person-centred care approach more as a philosophy of care and, therefore, to titrate it according to the resources and associated commitment of the organisation.

Seemingly intractable problems may well be amenable to analytical lenses developed in alternative areas. Certainly the success of person-centred care within the specific context of dementia care, such that it has received official endorsement by the appropriate NICE guideline[146], offers an analogous template for its adoption more widely.

Chapter 6 - Discussion

Statement of principal findings

BAME and LGBT+ populations face personal, community and structural barriers that limit their access to social care services. Key contexts identified in this review were awareness of services, access to social care (information, contacts, referral and services), acceptance of social care as an appropriate source of support, communication, trust, and informal/family support. BAME and LGBT+ populations may share the perception that social care services are not offered for "people like us". They may also anticipate that services will be unsympathetic, or not understanding, of their specific needs. This may prompt delays in accessing services or exploration of alternative support mechanisms. As a consequence, they may seek to access social care services at times of crisis, resulting in an ill-considered or inappropriate response.

Prominent causal mechanisms were navigation to the appropriate point of inquiry, recognition of the different interpretations of the caregiver role, and the speed and appropriateness of responsiveness to emergent needs. Evidence for the value of the matching of care provider with service user by ethnicity is equivocal. It may even hold unintended consequences. The issue of matching was not raised as a concern within LGBT+ populations. As with the exemplar review in primary care[12], realist review has proved a useful approach for making sense of the complex and dynamic relationship of access to social care because it allowed us to explore underlying mechanisms.

Strengths and limitations

Strengths include a broad search strategy that retrieved multiple diverse settings for UK social care and a specific UK focus privileging relevance to the commissioner. As mentioned in our Methods, our original intention was to validate findings from the realist review with a panel that was representative of the experience of the focal populations. The rapid nature of this review means that we would have liked to have discussed our interpretations of Contexts, Mechanisms and Outcomes with social care service users and care providers to ensure there are no obvious gaps or inconsistencies. Although this was not possible, due to pandemic constraints on team roles and recruitment activities, the UK-specific literature and expert peer reviewer feedback suggests that findings resonate with current practice. However, further testing of the programme theories remains a task for subsequent dissemination of report findings.

The mid-range aspiration of the final theories, based on carefully-researched programme theories, means that it can extend to an understanding of access issues for other populations to help improve social care service design. Our review confirms the observation that, unlike most realist reviews and literature on realist methodologies which focus on a specific intervention or programme, realist reviews can be useful in developing programme theory to explore drivers and barriers of access to services.[12]

The main limitation was the lack of evidence specifically focusing on LGBT+ populations. While as a body of evidence these studies may hold analytical generalisability, the body of evidence had low levels of 'proximal generalisability'.[125] Reportedly, the voices of LGBT participants in research often favour well-educated white male middle class participants such that LGBT people from poorer backgrounds or LGBT people from Black and Minority Ethnic backgrounds are poorly represented by the findings[90]. This is despite the fact that the Department of Health and Social Care expressed particular interest in the intersectionality of BAME and LGBT+ populations. In common with other reviews we also found a shortage of representation of transgender people; absent from the majority of LGBT+ studies and understudied in separate studies. While exploring issues for BAME populations generally and LGBT+ populations generally has led to some useful insights the fact that, within both these groupings, certain constituencies figure prominently and others are almost completely invisible, should not be overlooked.

No comparative studies compared the access of BAME or LGBT+ populations to social services with the experience of the general population. Although realist approaches seek to optimise rigour and relevance, we did not undertake any formal assessment of the methodological rigour of each manuscript included in the review. However, we did make global judgements about the trustworthiness of data within documents or studies we used to support our inferences. Overall, we judged that the data was sufficiently robust to enable refinement of our programme theory.

A further limitation was the focus only on studies conducted within a UK context. One of the valued characteristics of realist approaches is their facility to engage at a theoretical level, meaning that valuable insights may be gained from other contexts. Our choice of a UK-focus was driven by two of the RETREAT criteria (Research question-Epistemology-Time/timing-Resources-Expertise-Audience and purpose-Type of data), namely Time and Audience and purpose[147]. Time constraints required that we conduct a rapid realist review that required (i) selection of priority populations; (ii) prioritisation of candidate programme theories; and (iii) privileging of specific information sources. The last of these was operationalised as a UK-only focus. Our intended Audience and purpose, namely to support Department of Health and Social Care decision-making in connection with service and research priorities added an imperative to focus on implications of relevance to a UK policy context. The Department of Health and Social Car was active in prioritising and shaping the focus of this rapid realist review. A specific benefit of the approach chosen relates to the BAME populations targeted by the review; namely populations most frequently encountered and studied within the UK and avoiding an anticipated predominance of studies of African-American and Hispanic populations had a more typical scope been implemented. However, there remains a strong case to be made for the inclusion of wider literature in relation to the LGBT+ research literature given the different stages of development of different countries in exploring and responding to issues of sexuality, gender and sexual orientation.

Comparisons with existing literature

Although several realist syntheses have been targeted at phenomena that lie on the borders of health and social care it remains relatively uncommon to use these methods within social care. Furthermore, realist syntheses tend to focus on interventions rather than to be population driven. The methods and approach of the realist review of access to primary care by socially disadvantaged groups has been influential in the design of this review. The shared focus on inequity and on a pathway of care has similarly proved critical. However, we have remained true to the distinctive nature of our data by surfacing different mechanisms and by engaging with different mid-range theories. Both the access to primary care and our own realist review derive insights from the Aday and Andersen Framework,22 . Similarities exist between our overall pathway of social care programme theory and the Aday and Andersen Framework. For example, most of our concepts could be categorised according to the description of predisposing, enabling and need factors, such as language proficiency (predisposing), interpreters (enabling) and emerging need (need). However, as with the previous synthesis our use of realist methodology, with its focus on exploring underlying mechanisms and identifying and understanding how contexts need to be modified by interventions so as to optimise the likelihood of desirable outcomes ads potentially valuable insights. The Aday and Andersen Framework lacked the additional level of detail demanded by our data as well as an understanding of the sociocultural influences on social care access and provision. Aside from this cornerstone work, other influential reviews include the critical interpretive synthesis on access to health care, with its important focus on candidacy[11], the topical overview on access to services by ethnic minorities and satisfaction[8] and, latterly the scoping review on inequalities experienced by LGBT elders.[125] These and other, largely primary literature, sources have collectively contributed a coherent and transferable explanation of the steps and causal processes (articulated as realist programme theory) of access to social care using the specific populations of BAME and LGBT+ people in the United Kingdom. This will help to inform future service provision, not only to these populations but, potentially, to other social care service users.

Chapter 7 – Conclusions

This realist synthesis was conducted to extend the evidence base explored by the DHSC initial literature search, to add explanations and nuances and to engage with a wider theoretical base. The focus was on identifying key explanations although the different study samples covered by included studies also allows observations about specific subgroups, circumstances and contexts. By focusing on a UK context we have optimised relevance but the field would benefit from further exploration of innovations and responses to the identified issues; at least from countries and contexts immediately comparable to the UK if not from a wider selection of high income countries.

This review found clear differences in the qualitative experience of satisfaction between BAME groups. However, this should not be articulated solely in terms of the ability of the services to meet needs but also reflects different cultural expectations of the caregiver role, assumptions from care providers of what family and informal caregivers wish to provide, and the role of different national origins in shaping the expectation of what social care will and won't provide.[77] Indeed, some care groups do not recognise informal care delivered by persons outside of the family (however "family" is defined)[1] while for some LGBT+ people the concept of the "family of choice", and extended support from ex-partners or friends is revealed as important.[96] Whilst avoiding overinterpretation of the data, one could view the greater satisfaction generally expressed by white British service users[37] as partly reflecting greater alignment of current caregiver roles, formal/informal care demarcations, and service provision with prior expectations.[77] Social care providers should do more than simply acknowledge and understand the expectations and preferences of other cultures by seeking to accommodate these expectations. Initiatives such as person-centred care may simultaneously tackle reasons for dissatisfaction from white British service users, in the sense that these are shared by all users of the service,[148] as well as addressing specific concerns of individual BAME or LGBT+ user groups.

White British service users may also possess an established understanding of social care provision and how to access services[77]. We found indications in the literature that this might be partly compensated for in BAME groups through prior contact and experience of the service user, caregiver or the extended family with social care provision, through navigation or referral from a health or social care professional, through opportunistic encounters with shared circumstances or through condition-specific or community-specific support networks.[67] At the same time prior familiarity with services, although offering improved ability to navigate the system, may also serve in reinforcing or imprinting negative experiences from past use in the minds of a potential service user.[46 47] We also observed within the literature relating to the experience of LGBT+ populations that samples tended to recruit those with higher levels of education and health literacy, perhaps meaning that difficulties in navigating services may be underreported in that community.[149]

Reasons for delay from potential LGBT+ users of care typically related to fears of an unwelcome reception or discrimination.[121] For some BAME users a second tier of filtering took place – once they were aware of available services they often sought "validation" from relatives or support networks that the assistance was "worth" pursuing, perhaps stemming from a mistrust of social services or of authorities more generally. [23] Other process delays may relate to language and literacy; in getting letters or forms translated by a friend or relative,[50] in waiting for a visit of a relative that could navigate phonelines etcetera. Movements towards Internet contact, through automated forms or emails, may add computer literacy requirements to existing challenges of language or literacy.

A key factor across all groups is what precipitates contact with the social care services. Some users may feel that making contact with formal social care constitutes being disloyal to their family support network. Some may delay because of the difficult conversations that contact may initiate in relation to their care and changing needs. Demand on social care may often be precipitated by a crisis, meaning that the prospective service user and their caregiver are ill-prepared for contact and that the service may be unable to offer a timely, satisfactory or complete response.

Throughout the report person-centred care surfaced as a potential response to unsatisfactory or inappropriate service response. However, such features as direct payments and personal budgets were often unknown or unclear to BAME groups; although positively received when explained. These specific features, offering the opportunity for individuals to arrange services that better fit with their values and preferences, were seen as particularly valuable for LGBT+ people.

Practical language barriers consistently figured as an important feature of the challenges facing BAME communities in accessing social care. Overcoming this barrier was prerequisite to tackling other important cultural barriers, such as assumptions, or lack of understanding, around cultural or religious practices. Assumption, itself a feature of lack of understanding, could persist among care providers to LGBT+ and BAME service users, even where they are very aware of potential sources of difference. It is not sufficient to know that a person has different requirements if the response does not meet the specific individual need (for example in acknowledging the different dietary preferences but being unaware of other socio-cultural factors)[77]. At the same time, increasingly, BAME potential service users possess or have ready access to necessary language skills but continue to encounter significant cultural barriers.

Throughout the report we have referred to a care "triad", largely for the sake of simplicity. However, service users may lack anyone in an informal caregiver role or, alternatively, this role may be shared among multiple family members, either by consanguinity (for some BAME groups) or as an extended "family of choice" (for some LGBT+ service users).[142] It is important to recognise that, firstly, achieving satisfaction amongst family members and informal caregivers may constitute an important part of the service response but, secondly, satisfaction of other parties is not always commensurate with the wishes and needs of the targeted service user. Indeed, the delivery of social care services may become an arena within which wider tensions or different aspirations between service user and informal caregivers may surface and become most visible.

Approaches to "diversity blindness" may risk homogenising BAME people and LGBT+ people as one group, or even adopting a homogenised approach to all minorities. Such approaches risk settling for an "average" for a satisfaction rating and limiting the extent to which mainstream services can adapt to respond in a culturally sensitive way or accommodate the needs of an individual[59]. Service providers must consider the extent to which they use "micro-providers" (service providers to a small number of users, targeted at specific groups) to improve the experience and provision of social care for BAME and/or LGBT+ groups while optimising mainstream service provision[59].

A specific focus of this report was on exploring the matching of service user and caregiver by ethnicity as “an accepted response to cultural diversity”[24]. This review extends the initial observations of the DHSC literature search. It has confirmed that language matching is more important than ethnic matching for some populations. It further finds that individuals may be matched on multiple characteristics and that different characteristics are salient for different individuals. Interestingly, it unearths various adverse effects or unintended consequences of such matching as experienced by the service user, the individual care provider and the organisation providing care. It finds that certain well-studied care groups, e.g. Bangladeshi and Pakistani service users and caregivers, may express stronger preferences for such matching than others. In contrast, such matching of care provider and service user is not articulated as being particularly important for LGBT+ groups. For all groups a respectful and supportive care provider relationship is considered more important than token matching – again confirming the importance of an organisational culture of person-centred care.

Implications for Social Care

Although issues around awareness of and access to social care services have been explored in this report through the lenses of needs associated with BAME and LGBT+ populations these offer a helpful analytical frame for considering the service as a whole in relation to the general population. These populations are particularly useful exemplars given how both engage differently with visual and verbal cues; in theory an individual may choose never to disclose their sexual identity whereas multiple physical, cultural and ethnic indicators (food, dress, household objects etc) exist to signify BAME origins and allegiances. Within group differences may prove as significant as between group differences. For all populations, needs are specific to each individual and constantly change, for better or for worse, in the light of interactions between service user, care provider and informal caregiver and the complex interplay between formal and informal care. Nevertheless, approaches such as person-centred care, and practical mechanisms to support these such as personal budgets, go some way towards meeting individual needs. So this report not only targets social care provision specific to the BAME and LGBT+ populations but also holds implications for all populations and services.

Some contexts identified in the review, such as religious beliefs and customs and the need for interpreting and translation services represent very specific needs in relation to specific population sub-groups. Nevertheless, these too operate at an "instrumental" (i.e. practical) and a symbolic level. Sensitivity to religious beliefs requires recognition that people have multiple world-views associated with belief and that imposing a single world-view risks alienation and resentment. A similar argument can be made against discriminatory assumptions of a heteronormative organisational culture. Similarly, the importance of communication, exemplified by the need for interpreters, extends beyond the physical limitations of language barriers to more symbolic language barriers such as the overt meanings or implicit assumptions carried by specific terms that may alienate LGBT+ populations. Indeed, even within the collective label of "LGBT+" different beliefs exist as to whether these subgroups are homogenous or whether differences between subgroups are more important than perceived similarities. For example, LGB-focused environments may be perceived by some transgender older people as being equally hostile to mixed sexuality environments due to transphobia from within the LGB community[150].

Implications for Social Care

We return to the model outlined in Figure 4 to highlight specific implications for social care providers (Box 2). Detailed findings underpinning each implication are provided by the evidence synthesis.

Box 2 - Questions to be asked by Social Care Providers

1. Is the scope and role of social care, specifically in connection with practical support available, clearly visible to local individuals, communities and support groups and networks?[46]
2. Are the visual identity (publicity materials, posters and other documents) and terms used in describing and promoting the service compatible with helping a potential

social care service user or their informal caregiver to feel that the service is for “people like us”?[151 152]

3. Does the service clearly communicate that its potential role relates to ongoing support and not just to crisis management?[153 154]
4. Is it clear to a potential service user how to access a particular service and which services meet which specific needs?[155]
5. Do all social care staff know how to refer a potential service user to a particular service and which services meet which specific needs?
6. Are the visual, vocal and textual cues offered by first points of contact for the service welcoming and would they help a potential social care service user or their informal caregiver feel that the service is for “people like us”?[151 152]
7. Are assessments conducted using gender neutral language and open questions and without assuming the gender or sexuality of users or that they possess specific cultural or religious characteristics?[32]
8. Do assessments include social interests, cultural needs, caregiver and family involvement and other social contacts and relationships?[29 156]
9. Do we have a clear understanding of how the potential relationship between formal and informal care is perceived by the potential service user and their informal caregiver?[157]
10. Do service users perceive that services are being delivered within a context of trust and respect? If not, are appropriate steps being taken to recreate such a context?[39 158]
11. How is the ongoing relationship between service user, care provider and informal caregiver being monitored?
12. How, and how often, are the ongoing and emerging needs of the service user, as identified by themselves, their informal caregiver, their care provider or other health or social care professionals being assessed?
13. To what extent has the design of current and future services been informed by service user involvement and consultation?
14. What provisions are available to demonstrate that the service user is receiving services within an ongoing context of person-centred care?

15. Have all social care staff received appropriate levels of training to raise awareness of needs, increase use of appropriate communication and to understand the discrimination faced by service users and informal caregivers

Recommendations for Research

Our realist review of access to social care for BAME and LGBT+ populations identified key contexts such as awareness of services, access to social care (information, contacts, referral and services), acceptance of social care as an appropriate source of support, communication, trust, and informal/family support. Notable among the omissions from the evidence base are the perspectives of more recent migrant populations such as those from the Balkans, Syria and the Horn of Africa. An important report finding is that specific differences between BAME groups can be as critical to the service response as the shared differences between BAME service users and those from other backgrounds. Exploring the particular needs and influences on satisfaction for these newer migrant groups is identified as a research priority.

A second priority relates to the importance of intersectionality in shaping personal care needs. An obvious starting point, given the focus of this report, is intersectionality between LGBT+ and BAME characteristics. By contrast to other areas of social care, there is comparatively little service improvement work in relation to LGB people from BAME communities[32]. Development work is required to raise awareness among care providers of issues for the LGB community in reconciling sexual orientation and religion and developing assessment guidelines to take account of these issues. Few projects are dedicated to meeting their needs. Furthermore, transgender issues require separate study given that gender represents a different protected characteristic from sexual orientation and the experience of transgender service users is likely to be substantively different from the LGB groups, let alone the wider population. Of course, intersectionality operates across multiple domains combinations of which could all be targeted for separate study. A feasible approach is to prioritise intersectionalities, according to the extent of existing research and according to their prevalence within the population and service, and to focus attention on the benefits of person-centred care approaches for different types of intersectionality. Every single individual is a complex example of intersectionalities.

A third workforce-related research priority relates to recognition that membership of a minority group does not automatically result in sympathy for or understanding of others either within our study groupings (for example, individuals or communities of established BAME populations may be antipathic to newer migrants, either generally or specific groups, and LGB individuals may hold negative views of transgender individuals) or across groupings (so social care staff may come from countries, cultures, or religious groupings that are homophobic). As the social care workforce continually changes in parallel to the composition of the UK population, identification of these issues, potentially resulting in different challenges and solutions, becomes an increasing priority.

In terms of the revised pathway of adult social care the section most in need of greater theorizing is that relating to expertise with minority groups (Programme Theory 5). While there remains almost universal acknowledgement that the approach of "Treating everybody the same"[90] cannot be appropriate until deeper determinants of inequity have been addressed little research exists to demonstrate how alternative approaches might be enacted in practice. In particular the role of the Cultural Competency Model[127] in day to day practice, as opposed to being simply a training and education device requires further exploration.

The review methodology facilitates the identification of further research gaps. One expert commentator has suggested that further work could focus on geographical inequalities, service availability and choice and income inequality (as important factors when accessing services across the UK). These factors combine to present important variability across the different ethnic groups and geographical areas included by this report. The implications of Coronavirus (COVID-19) for the programme theories and findings of this project remain unknown and, given its differential impact on BAME potential service users, require further exploration.

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Contributions of Authors

Louise Preston (Senior Research Fellow, Evidence Synthesis) led the literature search processes and project management during programme theory generation and empirical testing. In December 2019 Andrew Booth (Reader, Evidence Synthesis Methodologist) took over management of the review and led on data analysis. Louise Preston developed the realist synthesis protocol. Andrew Booth designed the working methods for the realist synthesis. Louise Preston, Lesley Uttley (Senior Research Fellow, Evidence Synthesis) and Andrew Booth generated the embryonic programme theory which was refined and finalised by all the review team. Andrew Booth and Emma Hock (Senior Research Fellow, Evidence Synthesis) conducted the analysis and writing of the final report. Louise Preston drafted the Methods chapter which was completed by Andrew Booth. All authors reviewed and commented on the final manuscript.

Data Sharing

All data requests should be submitted to the corresponding author for consideration. Access to available anonymised data may be granted following review.

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Appendices

Appendix 1 – MEDLINE search strategy

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) <1946 to November 19, 2019>

Search Strategy:

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1 (social adj (care or service* or work*)).ti,ab. (28197)

2 long term care.ti,ab. (19450)

3 (residential adj (care or home)).ti,ab. (3476)

4 ((help or care or nursing) adj home).ti,ab. (22652)

5 1 or 2 or 3 or 4 (69508)

6 (refugee* or asylum seeker* or (migrant* or immigrant* or emigrant*) or ("first generation" or "second generation") or race or nationali*).ti,ab. (185951)

7 (BME or black ethnic minorit* or black minorit* ethnic* or south asian* or bangladeshi* or pakistani* or indian* or sri lankan* or asian* or east asian* or chinese or taiwanese or vietnamese or korean* or Japanese or afro-caribbean* or african-caribbean* or caribbean or african* or black* or afro* or islam* or hindu* or Sikh* or buddhis* or muslim* or moslem* or christian* or catholic* or jew*).ti,ab. (815361)

8 6 or 7 (953288)

9 "Emigrants and Immigrants"/ (11383)

10 Refugees/ (9683)

11 8 or 9 or 10 (958335)

12 (LGBT or LGB or GLB or gay or lesbian or transgender* or transexual* or homosexual* or intersex or queer or sexual minorit* or sexual orientation).ti,ab. (32635)

13 exp United Kingdom/ (358299)

14 (national health service* or nhs*).ti,ab,in. (182131)

15 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (93071)

16 (gb or britain*).ti,ab,jw,in. (34887)

17 (british* not "british columbia").ti,ab,jw,in. (539096)

18 (uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in. (1493773)

19 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont

or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in. (1338245)

20 (bangor or "bangor’s" or cardiff or "cardiff’s" or newport or "newport’s" or st asaph or "st asaph’s" or st davids or swansea or "swansea’s").ti,ab,in. (52243)

21 (aberdeen or "aberdeen’s" or dundee or "dundee’s" or edinburgh or "edinburgh’s" or glasgow or "glasgow’s" or inverness or (perth not australia*) or ("perth’s" not australia*) or stirling or "stirling’s").ti,ab,in. (199340)

22 (armagh or "armagh’s" or belfast or "belfast’s" or lisburn or "lisburn’s" or londonderry or "londonderry’s" or derry or "derry’s" or newry or "newry’s").ti,ab,in. (24648)

23 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (2391733)

24 (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/) (2777270)

25 23 not 24 (2254040)

26 11 or 12 (986660)

27 5 and 26 (4904)

28 25 and 27 (365)

29 limit 28 to (english language and humans and yr="2010 -Current") (139)

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Appendix 2 – Theory generation

Table 19 - Initial Programme Theories (with final theories), examples and sources

	Programme Theory	**Examples**	**Sources**	**Potential resources and responses from the evidence base**
IPT1	IF social care service users believe that adult social care services are sensitive to their individual needs and circumstances THEN Clients access adult social care services as required LEADING TO appropriate service uptake	Default terminology or language used in assumptions of sexuality	32 64 95.	Using inclusive language in marketing and publicity of services Form re-design
		Fear of discrimination	1 8 59 159 160	
		Consideration of diversity in provision of food, assistance with personal care, such as bathing and dressing, and religious worship	161	User representation in social care staff or design of services
IPT2 **[Final Programme theory 1]**	IF social care service users are aware of adult social care services and how to access them THEN social care service users access adult social care services as needed LEADING TO social care service users utilising services appropriately	Lack of knowledge about services	7 8 85	Accessible information Provision
		Lack of clarity about costs	159	
IPT3 **[Final Programme Theory 2]**	IF social care service users perceive that adult social care services complement and augment informal and/or family support	Personalisation of services to empower BAME service users who prefer to be self-reliant to choose	46	Personalised care services Personal Care Plans

	Programme Theory	Examples	Sources	Potential resources and responses from the evidence base
	THEN social care service users feel able to access adult social care LEADING TO social care service users feeling that their holistic needs are being fulfilled	the care they require		
		Recognition by social care services of LGBT partners as family as advocates for the user	95	Inclusivity of 'families of choice'
IPT4	IF social care service users perceive, from their own experience and that of others, that adult social care services are unable to fulfil their needs THEN social care service users use alternative provision LEADING TO care not being appropriate for social care service user needs	Dissatisfaction with care received	8 36 85	Development of personal budgets to improve choice
		Lack of sensitivity to religious or cultural needs	8 162 163 164 5 99 165-168 169	
		Older LGBT not confident that paid carers or housing services would be able to meet their needs	1 64 110.	
IPT5	IF social care service users perceive that care is largely the responsibility of the family THEN social care service users do not access adult social care LEADING TO social care service users not having their needs met.	Cultural norms (e.g, religious coping strategies, fear of stigma) mean that only informal, as opposed to formal help is sought	23 67 79 159	
		Clarity about eligibility for support if already being supported by family	7 8 85 112 159 170 171	
IPT6 **[Final Programme Theory 3]**	IF social care staff are sensitive to differences between different and	Prioritise LGBT identity and sexuality issues	39 59 64 159	LGBT leadership and champion roles

	Programme Theory	**Examples**	**Sources**	**Potential resources and responses from the evidence base**
	within minority groups THEN staff personalise their response to each social care service user LEADING TO social care service users feeling welcomed and respected	within staff education and training Understanding differences affecting older vs younger ethnic minority groups		Personal Care Plans/Specialised services Ethnic matching in foster care placement
		Avoiding stereotypes of vulnerability when assessing need for support	8 56 61 172-174	Culturally specific residential care
		Ethnic representation of staff	74	
		Avoid assumption that all LGBT want to share residential homes. Some LGBT women prefer to not share residential homes with men	74	LGBT specific or gender-specific residential care
IPT7	IF Social care staff are not matched by language or culture to social care service users THEN social care service users and their caregivers face barriers to communication LEADING TO social care service users and their caregivers being	Language barriers Real or perceived differences in culture between staff and service users	8 85 162 163 164 165 99 166 167 5 168 175	Outreach services to address language barriers
		Ethnic representation of staff	176	Involve representatives in forums and strategic planning of services

	Programme Theory	Examples	Sources	Potential resources and responses from the evidence base
	unable to access adult social care.	Cultural competency of staff	65	
IPT8 **[Final Programme Theory 4]**	IF adult social care services use interpreters THEN social care staff and social care service users communicate more effectively LEADING TO social care staff providing appropriate care/social care service users receiving appropriate care	Provision of care with appropriate language support	159	Translation and Interpretation Services
		Clear language in assessments to avoid communication barriers when translating	65	Linguistic and cultural support with paperwork
IPT9	IF social care staff do not feel confident or experienced in engaging with social care service users from diverse backgrounds THEN adult social care services/staff do not find out social care service users' needs LEADING TO social care service users becoming disengaged	Lack of engagement with ethnic minorities e.g., in rural areas or Gypsy and Traveller communities	8 53	Training in Cultural Awareness for social work practitioners Training that recognises local contexts
		Heteronormative assumptions about client personal relationships	31 76	Pro-active recruitment of staff that represent underrepresented communities
		Job seeking process as a barrier to some BAME communities	45	Outreach services to address language barriers
		Policies to not use family members or friends as	176	Use of family members (rather than interpreters)

	Programme Theory	**Examples**	**Sources**	**Potential resources and responses from the evidence base**
		interpreters may be a barrier to service uptake		as interpreters to reduce miscommunication
IPT10 **[Final Programme Theory 5]**	IF Social Care Services recruit or use staff with expertise in engaging with minority groups THEN social care staff create a bridge between themselves and social care service users LEADING TO social care service users from minority backgrounds being supported in trusting and accessing social care services	Staff as "bridge people" with skills such as bilingualism and bicultural heritage to support older Chinese people in using social care services	[50]	Recruitment of a diverse workforce
		Education for social care staff in LGBT history	[76]	Community advisors to build LGBT understanding in social care staff
IPT11	IF other social care service users in close proximity hold biased opinions and attitudes THEN LGBT or BAME service users experience abuse or hostility from other social care service users LEADING TO isolation of LGBT or BAME social care service users	In residential homes, some care staff and other residents may foster discriminatory attitudes to LGBT people	[64 74]	Specialist housing options for older LGBT people
		LGBT often feel obliged to conceal their sexuality to avoid discrimination or negative responses from staff or others	[66 74 76]	Training in LGBT awareness for staff