research article

Personalisation in racially minoritised groups within UK adult social care: a systematic review

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Although evidence shows that personalisation improves access to health and social care for UK's racially minoritised groups, research suggests that uptake is low due to racism, discrimination and negative experiences with mainstream services. A systematic literature review of 45 articles found that racially minoritised individuals choose personalisation for greater control and choice over their care but face systemic barriers, including a complicated adult social care system that fails to respond to cultural and linguistic values. Recommendations to improve uptake include involving racially minoritised communities in service planning, attracting a diverse workforce, tackling racism and discrimination, bridging the information gap, and funding racially minoritised community organisations.

Keywords: personalisation • racially minoritised • mainstream services • adult social care

Introduction

Personalisation is a social care strategy across the UK designed to empower individuals who receive care and support, along with their families, by offering them greater choice and control over the services they access (DH, 2007). This approach has become a fundamental aspect of how care is delivered across the UK's four nations, though specific methods and priorities vary regionally. Each nation has developed its own set of mechanisms and agendas to implement personalisation.

The concept of personalisation in social care has its roots in the disability rights movement. Since 1997, disabled people in the UK have had the option of 'direct payments', a cash sum instead of directly provided services, initially inspired by US initiatives. In the early 1990s, disabled people campaigned for the wider adoption of

direct payments, leading to their implementation after sustained advocacy (Glasby and Littlechild, 2009). Personalisation evolved from a broad policy vision to formal legal frameworks, such as that framed in the 2007 document 'Building on progress: public services' (Cabinet Office, 2007), which aimed to tailor services to individual preferences. This was further defined in the 'Putting People First' concordat, marking the formal adoption of personalisation in adult social care in England (DH, 2007).

Formalisation occurred through various legislative measures across the UK. In England, the Care Act 2014 enshrined personalisation in adult social care policy, while Wales incorporated it into the Social Care Services and Wellbeing Act 2014. Scotland established a legal basis for self-directed support with the Social Care (Self-directed Support) (Scotland) Act 2013. Northern Ireland emphasises independence and choice through health and social care trusts, institutionalising the principles of personalisation within legal frameworks.

Choice and control schemes have also grown across Europe, the US and Australia. For example, in Australia, the National Disability Insurance Scheme (NDIS) was created to give people with disabilities and their families and carers choice and control over the support they receive and how it is delivered and ensures that individuals receive the support they need over their lifetime (Wallace, 2018). In the US, the Cash and Counselling programme aims to give people who draw on care and support the option to manage their budget and live independently in their homes or communities (Robert Wood Johnson Foundation, 2006).

Personalisation policy across the UK aims to empower individuals by putting choice, power and control in their hands regarding care and support (SCIE, 2022). Key mechanisms underpinning personalisation include direct payments, personal budgets and individual service funds (ISFs). Direct payments enable individuals to receive a sum of money from local authorities to arrange their own care services, promoting independence and tailored care (DH, 2007). However, managing direct payments can be complex, especially for those lacking financial expertise or support, potentially deterring their use and perpetuating inequalities (Glasby and Littlechild, 2009). In contrast, personal budgets provide a predetermined amount of money calculated by local authorities to meet assessed care needs. Individuals can manage these budgets themselves or let their local authority do so on their behalf (DH, 2007). This approach offers a balance between autonomy and support, reducing administrative burdens if managed by local authorities. Nonetheless, the complexity of and potential lack of transparency in managing personal budgets can still create challenges for individuals trying to navigate the system effectively (Duffy, 2010).

ISFs involve service providers managing funds on behalf of individuals, enhancing choice in selecting service providers while simplifying financial management (Duffy, 2010). This model seeks to alleviate some burdens associated with direct payments by delegating financial oversight to service providers. However, ISFs may limit the degree of control individuals have over their care decisions compared to direct payments, potentially affecting the effectiveness of delivering personalised care (Yeandle and Steill, 2007).

There is substantial evidence showing that personalisation is popular among people who use care and support services, with many benefiting from involvement in planning their care (Yeandle and Steill, 2007; Baxter et al, 2020; SCIE, 2022). However, critics argue that despite its potential, personalisation often reinforces inequalities, especially for racially minoritised communities. Structural barriers like language difficulties,

cultural differences and limited awareness of available options prevent these groups from fully benefiting from personalised care (SCIE, 2022).

The success or otherwise of direct payments, personal budgets and ISFs in meeting the needs of racially minoritised communities is shaped by their implementation and the available support structures. Cultural and systemic barriers, such as language difficulties, cultural differences and institutional biases, can hinder the accessibility and effectiveness of these personalisation mechanisms (SCIE, 2022). It is essential to implement these mechanisms in a culturally competent and inclusive manner to address disparities and enhance effectiveness. Throughout this article, we use the term 'racially minoritised' instead of 'Black, Asian and minority ethnic' (BAME) to avoid limiting and problematic terminology. This choice acknowledges the social and political processes that contribute to minority status rather than implying that it is an inherent characteristic (Milner and Jumbe, 2020). By adopting this terminology, we aim to provide a more nuanced understanding of the complexities within these communities and how personalisation policies impact diverse experiences.

While personalisation holds the promise of transforming care for racially minoritised communities by offering culturally sensitive services (Moriarty, 2014; Irvine et al, 2016), these communities are significantly under-represented in schemes like direct payments and personal budgets (Needham and Carr, 2015). The limited research on personalisation for these groups often overlooks their specific needs. Nevertheless, studies suggest that racially minoritised individuals are generally willing to engage with personalisation when made aware of available options (Moriarty, 2014; TLAP, 2021). This highlights the need for better outreach, culturally competent support and systems that simplify access to personalised care for these communities. In light of the potential for personalisation to enhance adult social care access for racially minoritised communities, this review aims to identify evidence-based improvements in this area.

We address the following questions:

- What is known about racially minoritised communities taking up personalisation?
- What is the evidence about the reasons why racially minoritised communities choose personalisation?
- What are key recommendations to increase the uptake of personalisation in racially minoritised communities?

The review forms part of the programme of work of Improving Adult Care Together (IMPACT), the UK centre for implementing evidence in adult social care. 'Evidence' for IMPACT consists of insights from research, lived experience and practice knowledge (see Tawodzera and Glasby, 2024). In reviewing the literature, we seek to identify evidence-based recommendations that can be taken into policy and practice.

Methodology

A systematic review was conducted to identify any barriers to and facilitators of the uptake of personalisation by racially minoritised communities. While our literature search included the term 'BAME' due to its prevalent use in existing research, our analysis and discussion use the term 'racially minoritised groups' to provide a more inclusive and accurate representation of the populations discussed. A systematic electronic search was conducted between May and June 2022 in the Healthcare Management Information

Consortium (HMIC), Social Policy and Practice, Scopus and Web of Science databases to identify published papers and reports. These databases were chosen because they were deemed likely to catalogue articles and disciplines most relevant to the research questions and specific to the UK context. A Google search was also undertaken to identify further grey literature and other websites. Several combinations of keywords were used to search the databases; Table 1 shows the search terms.

Table 1: Review search terms

Area of interest	Search terms used
Racially minoritised communities	Exp black people, Minority groups, Asian people, ethnic groups, racialised, racially minoritised, Ethnic minorities$, Black Asian Minority Ethnic$, Black and minority ethnic$, Black people, Asian people, Black African$, African Caribbean$, BAME$, BME$, Mixed race, People of colour$
Personalisation	Exp personalisation, Personalisation$, individual health budget$, personal health budget$, person-centred care$, payment card$, self-directed support$, individuali?ed budget$, Individual service funds

Inclusion criteria

Searches were limited to English-language publications to control for international variation and yielded a total of 197 titles and abstracts from the database search and 19 from the grey literature for initial consideration. To provide a thorough summary of the subject, there were no limitations on the publication year. A review of the titles and abstracts was carried out by the primary reviewer to identify publications meeting the inclusion criteria, as follows:

- focuses on adult social care in the UK;
- includes discussion of racially minoritised communities in the UK; and
- includes discussion of personalisation.

Items that did not meet all three of these criteria were excluded at this stage.

Data extraction and quality assessment

Included items were then read and quality assessed by two members of the team. A standardised data extraction form was devised in Microsoft Office. The following descriptive data for the included articles were extracted:

- Study characteristics: authors, title and year of publication, type of study, target audience, the population of the study, and kinds of personalisation discussed.
- Authors' findings: conclusions, main recommendations, reasons for racially minoritised communities choosing personalisation, perspectives of choices of personalisation and how racially minoritised communities view mainstream services.
- Quality assessment: overall grading of quality, reasons for grade and identification of limitations.

The quality assessment used recognised criteria specific to the type of output and the research design used if the item reported research results. Both reviewers completed a pro forma, systematically recording the quality assessments in accordance with recommendations by Aromataris et al's (2015) manual for evidence synthesis and Lockwood et al's (2015) methodological guidance for systematic reviewers.

Descriptive analysis approach

A thematic analysis was conducted, focusing on the questions guiding the review. It should be noted that we do not subscribe to a hierarchy of evidence but consider the quality of contribution according to the design used (for research output) and the nature of the work conducted. Thus, we follow the recommendations of Nutley et al (2013) that in social care research, an accumulation of lower-quality or smaller-scale evidence can be brought together to produce useful and reliable recommendations for action. This is a pragmatic principle of consilience. For transparency, we indicate in presenting our results the quality assessment of each reference included in the review. 'H' denotes higher quality, 'M' medium quality and 'L' lower quality. Table 2 provides an overview of the research designs and types of items included in the review and the quality assessments.

Table 2: Overview of research designs and quality of items included

Research designs/types of publication of included items	Higher quality	Medium quality	Lower quality	Total
Review of two or more items, including systematic, rapid, scoping and realist reviews	2	2	1	5
A qualitative research study	9	2	3	14
A mixed-methods study	1	1		2
An expert opinion, including consensus statements, current discourse, personal commentary and so on	8	3		11
Another mainly descriptive item, including programmes and implementations, a description of policy processes, and systems reforms	5	4	4	13
Total	25	12	8	45

Table 2 shows that the majority of the evidence base is made up of qualitative research articles, expert opinions and other descriptive items. In terms of quality, there is a balance of higher-quality items, assessed using the established criteria. The intended audiences of the items included in the review were practice audiences (25 items), with 14 items for an academic audience and six for people who draw on care and support or who are carers.
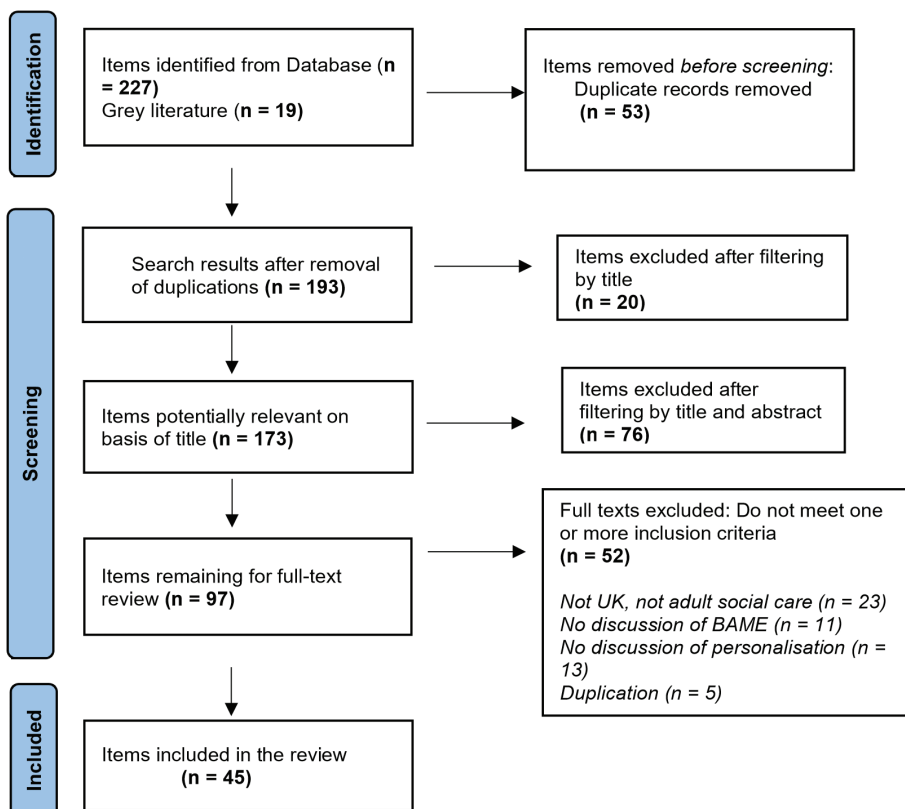
Results

Figure 1 provides the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flowchart (Moher et al, 2009). After screening for duplicates, 193 items were identified as potential items for inclusion. Of these, 20 were discarded by

study title and a further 76 were excluded by abstract. From the remaining 97 items, 50 were excluded based on full-text review because they did not meet the inclusion criteria. Finally, 45 items were included in the review.

Study characteristics

Ten high-quality and two medium-quality studies detail research based on interviews and focus groups with people who draw on care and support or their carers. A wide range of adult social care services is covered in the review, including mental health, disability, dementia, support for older people/long-term care and end-of-life care. Different groups are also represented, including African Caribbean (Healthwatch Sheffield, 2021), Chinese (Irvine et al, 2016) and East Asian people (Terashima, 2011), as well as different religious groups, such as Muslims and Sikhs (Jutla and Moreland, 2009; Jutlla, 2015). Five articles in the review include the perspectives of people who draw on care and carers (Newbigging and Lowe, 2005; Jutla and Moreland, 2009; Omotola, 2020). Two high-quality articles include the perspectives of social workers and those who work in mainstream services (Clark, 2001; Irvine et al, 2016). Also covered are the perspectives of members of faith organisations (Joannou et al, 2011) and volunteers in community organisations (SCIE, 2012; Stuart, 2012; TLAP, 2021), advocacy groups and other non-governmental organisations (Turning Point, 2010;

Figure 1: PRISMA flowchart

OPAAL, 2012). There are, however, no items covering the perspectives of front-line care workers or personal assistants employed by racially minoritised communities.

As identified in earlier literature (Phillips, 2007), research and commentary on care for racially minoritised communities have tended to be isolated from theoretical debates on caring. Included items did not generally offer a theoretical position, though most took an approach broadly emphasising social justice (Rummery and Fine, 2012) and focusing on inequalities and exclusion. Our discussion in the following reflects this emphasis (see Table 3).

Evidence about racially minoritised communities' views and experiences

Ability to purchase culturally appropriate services

The literature suggests that personalisation enables choice and control for racially minoritised communities and empowers them to purchase adult social care services that are tailor-made to their needs (Moriarty, 2014). The ability to purchase services that meet needs was identified as the major reason racially minoritised communities choose personalisation (Manthorpe et al, 2010; Terashima, 2011; Irvine et al, 2016; Omotola, 2020). Racially minoritised communities reported that personalisation allows them to arrange services that fit better with their ethnic, religious and cultural values and preferences. In particular, employing personal assistants from the same cultural background was seen as the most valuable use of personalisation and was argued to lead to better experiences among racially minoritised communities (Clark, 2001; Glasby and Littlechild, 2002; Lipman, 2015; Terashima, 2011; Omotola, 2020). Innes et al (2006) argue that employing a personal assistant who understands their language and has a better awareness of their care needs can take pressure off families and provide racially minoritised communities with more choices about how their service is delivered. This was seen as important for religious and spiritual well-being (Jutlla and Moreland, 2009; Jutlla, 2015; Irvine et al, 2016), as well as food and community connections (Lipman, 2015).

Ability to employ friends and relatives

Racially minoritised communities also welcomed the opportunity to employ a family member enabled by personalisation. While there is some evidence that this is not always allowed (CQC, 2016; Raghavan, 2016), the review shows that the chance to employ a close family member who is conscious of and better understands the care and support needs of the person drawing on care and support services was important for racially minoritised communities (Commission for Social Care Inspection, 2008; Moriarty, 2014). Employing a relative was also highlighted as important by the 2014 guidance and regulations underpinning social care (self-directed support) in Scotland (MECOPP, 2018). In some cases, it is cheaper for racially minoritised communities to employ a relative than to employ a care worker from agencies (Manthorpe et al, 2010).

Ability to purchase services from a provider of choice

Personalisation enables racially minoritised communities to arrange their own support from providers and organisations of their choice who can deliver more individualised, person-centred and culturally appropriate care (Health Commission, 2007; SCIE, 2012; Clayton et al, 2014; TLAP, 2021). In particular, voluntary, faith and community-based organisations were seen as important for racially minoritised communities.

Table 3: Study characteristics

Authors	Quality assessment	Year of publication	Population of interest
Bhattacharyya, S. and Benbow, S.M.	High	2013	Black and minority ethnic older people
Booth, A., Hock, E., Preston, L. and Uttley, L.	High	2021	Racially minoritised (BAME) older people and Lesbian, Bisexual, Gay, Transgender+ (LGBT+) community
Butt, J., Bignall, T. and Stone, E.	Medium	2000	Black and minority ethnic disabled people
Carers UK	High	2011	Racially minoritised carers
Clark, H.	High	2001	Older people
Clayton, K., Gardner, Z., Barrett, F.I. and Butt, J.	High	2014	Not applicable
Commission for Social Care Inspection	High	2008	People from Black and minority ethnic groups using services
CQC	Medium	2016	Racially minoritised older people receiving end-of-life care
DH	High	2001	People with learning disabilities
Glasby, J. and Littlechild, R.	High	2002	People receiving direct payments
Gregory, C.	High	2010	Racially minoritised carers
Health and Social Care Alliance Scotland	High	2020	Black and minority ethnic people
Healthcare Commission	Low	2007	People who use mental health services
Healthwatch Sheffield	High	2021	African Caribbean users and carers
Innes, A., MacPherson, S. and McCabe, L.	High	2006	Older people, disabled people and front-line workers
Irvine, F., Wah Yeung, E.Y., Partridge, M. and Simcock, P.	High	2016	Chinese adults with movement and/or visual impairments
Joannou, D., Fernando, M., Harrison-Read, C. and Wickramasinghe, N.	Low	2011	Minority ethnic people with mental health problems
Jutlla, K.	High	2013	People living with dementia and their family carers from racially minoritised communities in the UK
Jutlla, K.	High	2015	Sikh carers for an older person with dementia
Lipman, V.	Medium	2015	Racially minoritised older people
Manthorpe, J. and Bowes, A.	Low	2010	Black and minority ethnic older people
Manthorpe, J., Moriarty, J., Stevens, M., Sharif, N. and Hussein, S.	High	2010	Black and minority ethnic older people
MECOPP	High	2017	Racially minoritised people receiving self-directed support
Juttla, K. and Moreland, N.	Low	2009	Sikh carers for an older person with dementia
Moriaty, J.	High	2014	Black and minority ethnic people
Newbigging, K. and Lowe, J.	High	2005	Mental health service users

Table 3: Continued

Authors	Quality assessment	Year of publication	Population of interest
Omotola, E.	High	2020	People from Black and minority ethnic groups with mental health problems
OPAAL	High	2012	Older people
Poxton, R., Taylor, J., Brenner, D., Cole, A. and Burke, C.	High	2012	People with learning disabilities and their families
Raghavan, R.	Low	2016	People with intellectual disabilities from racially minoritised communities in the UK
SCIE	High	2012	Black and minority ethnic communities within Oldham
Smith, D.J. and Otter, P.	High	2014	Older people with dementia
Stuart, O.	High	2006	Racially minoritised service users and carers
Stuart, O.	High High	2012	Disabled people from Black and minority ethnic communities
Terashima, S.	Medium	2011	People with learning disabilities from South Asian communities
TLAP	High	2021	Racially minoritised people using personalisation
Turning Point	Medium	2010	Not applicable

For example, a report by Think Local Act Political (TLAP, 2021) highlights how these organisations are seen by communities as places where they will be culturally understood and provided with appropriate care. Joannou et al (2011) suggest that racially minoritised community organisations act as specialist service providers and broker services that are appropriate for communities.

Better quality-of-life outcomes

Several items indicated that personalisation improves racially minoritised communities' quality of life, confidence and chance to be at the heart of decision making about the care and support they receive (SCIE, 2012; Health and Social Care Alliance Scotland, 2020; TLAP, 2021). For example, TLAP (2021) reports on positive outcomes experienced by people who draw on care and support and their carers when accessing personalisation from small community organisations. The different organisations in the TLAP report help people with personalisation packages find opportunities for volunteering, training and employment, hence improving their well-being outcomes. People who wanted to age in their own homes were also being assisted to use their direct payments to stay connected with their families and community. A film by SCIE (2012) illustrates positive outcomes and experiences for people who draw on care and support and their carers. Attending luncheon clubs and getting language support and advice led to better well-being outcomes. These findings, though limited, highlight that personalisation can enable those from racially minoritised communities to improve their quality of life, increase choice and control, and receive more flexible and culturally responsive support that promotes inclusion.

Issues with services

Lack of uptake and appropriate information about personalisation

Despite consistent messages highlighting the benefits of personalisation for racially minoritised communities, there is low uptake of personalisation services by this group. The main reason noted for this is a lack of information regarding the existence and/ or details of such services (Newbigging and Lowe, 2005; Stuart, 2006; Irvine et al, 2016; Omotola, 2020). Most items in the review indicate that there is a lack of access to information about the choices regarding personalisation and that most racially minoritised families do not understand how systems work, particularly in relation to entitlement and how arrangements around personalisation affect family finances and entitlement to other benefits (Clark, 2001; Newbigging and Lowe, 2005; Manthorpe and Bowes, 2010; Poxton et al, 2012).

Language barriers

Practical language barriers consistently feature as a significant factor hindering receiving good, personalised care and making choices about care. Almost all the articles identify language as a practical barrier to the uptake of personalised services. It is argued that a number of racially minoritised communities fail to engage in personalisation because they have limited English-language proficiency and inadequate understanding of the complexity of available services (Manthorpe and Moriarty, 2009; Moreland and Jutlla, 2009; Manthorpe et al, 2010; Terashima, 2011; Irvine et al, 2016). Issues are further compounded by a lack of language support from mainstream services, which, by and large, makes it difficult for racially minoritised communities to navigate and negotiate the support they want (Commission for Social Care Inspection, 2008; Manthorpe et al, 2010; Bhattacharyya and Benbow, 2013; Booth et al, 2021).

Cultural barriers

Cultural barriers were also identified as important in hindering racially minoritised communities from accessing personalisation (Manthorpe and Moriarty, 2009; Bhattacharyya and Benbow, 2013; Booth et al, 2021). Articles highlight that mainstream services remain biased towards Western cultural norms and are not sensitive to the lifestyles of racially minoritised communities (Healthcare Commission, 2007; Gregory, 2010; Terashima, 2011; Jutlla, 2015; MECOPP, 2018). For example, personalisation promotes individualism, whereas some racially minoritised groups focus on family and community. More so, services are not adapting to meet the needs of racially minoritised communities; as a result, they remain Eurocentric and do not recognise the diversity of racially minoritised communities (Innes et al, 2006; Stuart, 2006). Cultural challenges are further exacerbated by assumptions in mainstream services that tend to view racially minoritised communities as homogeneous, hence overlooking the cultural diversity and differences in these communities (Jutlla and Moreland, 2009).

Racially minoritised communities indicate that access to personalisation is restricted by a failure to recognise and accommodate different cultural norms and expectations, particularly during assessment (Health and Social Care Alliance Scotland, 2020). As reported by Newbigging and Lowe (2005) and Innes et al (2006), assessments do not consider the background and requirements of racially minoritised communities, and there are no culturally and linguistically appropriate assessment tools. For example,

personalisation services focus on the individual, whereas many racially minoritised cultures give precedence to the family (Stuart, 2006; Terashima, 2011; Jutlla, 2015). This has led many racially minoritised communities to believe that mainstream services are not designed for them, do not understand their culture and would therefore not meet their needs.

Lack of diversity in the care workforce

Lack of care workers who could speak minority languages and understand the cultures of racially minoritised communities was also reported in seven articles (Clark, 2001; Glasby and Littlechild, 2002; Stuart, 2006; Commission for Social Care Inspection, 2008; Manthorpe et al, 2010; Moriarty, 2014). Evidence about the benefits of personalisation for racially minoritised communities points to the recruitment of personal assistants from the same background as an empowering aspect of personalisation (Commission for Social Care Inspection, 2008) However, recruiting and retaining suitable, culturally appropriate personal assistants is difficult. Racially minoritised communities find difficulty in having a choice in the market, particularly around choosing care assistants and agencies to work with or recruit from (Clark, 2001; Glasby and Littlechild, 2002; Stuart, 2012).

This lack of diversity in the workforce extends to mainstream service professionals. Racially minoritised communities report that the lack of diversity in mainstream professionals exemplifies the difficulties they have when liaising with staff who are not cognisant of their needs (Commission for Social Care Inspection; 2008; Ray et al, 2008; MECOPP, 2017; Health and Social Care Alliance Scotland, 2020). They reported that mainstream professionals are not sensitive to their needs and tend to view racially minoritised communities as not needing support due to the assumption/stereotype that they have a family to look after them, even though care and caring norms and notions about family vary between cultures (Carers UK, 2011; Poxton et al, 2012; Booth et al, 2021). This lack of recognition of different cultural norms and expectations is perceived by these authors to be a hindrance to the uptake of personalisation.

Austerity in racially minoritised organisations

It is reported that success in personalisation for racially minoritised communities is achieved through regular contact with community organisations and faith groups that meet their cultural and spiritual needs (TLAP, 2021). The roles identified for such organisations include being a conduit for disseminating information (Joannou et al, 2011), a means of identifying and contacting local families with members who need care and support (Poxton et al, 2012), and even the location of services (TLAP, 2021). However, government austerity since 2010 has affected these services (Gregory, 2010; Manthorpe et al, 2010; Moriarty, 2014). Community programmes and many faith groups have experienced unprecedented funding cuts, which have impacted the services they can provide (Lipman, 2015).

Improving personalisation uptake in racially minoritised communities

Avoiding assumptions

Several recommendations are made to improve the cultural appropriateness of mainstream services and to increase the uptake of personalised services. Items

repeatedly highlight that assumptions should not be made based on generalisations from existing research on particular racially minoritised communities. Commissioners and providers need to recognise the diversity and internal heterogeneity of minority ethnic and religious groups (Jutlla and Moreland, 2009; Jutlla, 2013; 2015).

People who need care and support should not be regarded as members of 'other' groups with collective norms but as individuals, with knowledge sought of the social and political influences on their lives (Jutlla, 2015). For personalisation to work well, it should focus on the whole person and holistic support (Poxton et al, 2012; TLAP, 2021), going beyond care itself to involve the whole family and community. Personalisation should build on people's assets (Clayton et al, 2014), as well as those of their families and communities (TLAP, 2021).

Carers

In line with this holistic approach, some items point to the need to support racially minoritised carers to understand the concept of independent living and make sense of personalisation (Glasby and Littlechild, 2002; Gregory, 2010; Poxton et al, 2012). Poxton et al (2012) point out that this is of particular importance for racially minoritised communities, which may face barriers to understanding the system and choices on offer. Jutlla and Moreland (2009) call for carers to be listened to carefully during assessment in order to ensure clarity about cultural issues. For Gregory (2010), support for these carers should be a mainstream issue.

Carers UK (2011) argues that personalisation offers an opportunity for racially minoritised carers to receive the right support but highlights that its success depends on the right brokerage and support mechanisms. It calls for local authorities to review their commissioning strategies to ensure that mainstream services offer better support for racially minoritised carers.

Employment and recruitment

With the literature demonstrating that a key benefit of personalisation for racially minoritised communities is the ability to employ personal assistants from the same cultural background, articles call for a more diverse, culturally aware and representative workforce (Ray et al, 2008; Healthwatch Sheffield, 2021). Terashima (2011) points to the need to maximise the employment of culturally matched care workers and calls for recruitment strategies to aim to achieve a gender balance.

Recommendations as to how to achieve a diverse workforce are, however, limited and tend instead to be confined to practical matters around training and cultural awareness. Terashima (2011) and the Commission for Social Care Inspection (2008) recommend that all staff receive training to enable them to improve their understanding of cultural differences and examine their values and attitudes, while MECOPP (2018) similarly calls for training for local authority care management on race equality issues. Butt et al (2000) call for racially minoritised disabled people to be involved in training

Involvement and peer support

Articles point to the need for racially minoritised communities and their carers/ families to be involved in the design of services from the outset (Clark, 2001; Terashima, 2011; Raghavan, 2016). As the Healthcare Commission (2007) points out, consultation is not enough; rather, there must be active engagement for this to be meaningful. Turning Point (2010) calls for new collaborative ways of working that support people to engage actively in the design, delivery and evaluation of services.

   One approach frequently cited as a model of good practice is that of peer support. Glasby and Littlechild (2002) and Clark (2001), for example, point to the importance of role models and peer support, as well as the involvement of local community leaders, as a means of enabling more racially minoritised communities to benefit from personalisation. Newbigging and Lowe (2005) similarly recommend recruiting members of the local community to disseminate information. This peer-mentoring approach is portrayed in a Social Care Institute for Excellence (SCIE, 2012) film, where experienced personal budget holders attend a luncheon club, providing language support and advice to those who are new to personalisation.

Addressing the information gap

With many articles attributing the low uptake of personalised services to a lack of clear information, the literature offers a number of recommendations to help overcome this barrier. Poxton et al (2012), for instance, recommend specific attention to ensuring that individuals and communities have relevant information about local services and how local decision-making processes work. Health and Social Care Alliance Scotland (2020) similarly suggests that racially minoritised groups should have equal access to face-to-face communication with social workers and high-quality information at an early stage to find out options before deciding how their support will be arranged.

   Most practically, the provision of accessible information in multiple languages and a range of formats is repeatedly highlighted as a means of raising awareness of personalised services (Butt et al, 2000; Newbigging and Lowe, 2005; SCIE, 2012). Clayton et al (2014) note the need for clearer, simpler language, suggesting that the term 'personalisation' may be regarded as jargon, and highlight the need for good case studies of personalisation working in practice, while Butt et al (2000) suggest that racially minoritised disabled people themselves should be involved in producing that information. Specialist support, such as access to interpreters (CQC, 2016; Raghavan, 2016) and advocates or support workers with specialist skills, are also recommended (Butt et al, 2000; MECOPP, 2017).

Outreach, community contacts and organisations

Butt et al (2000) state that information must be accompanied by outreach to those who need it. Crucial to all the recommendations discussed earlier is the role of outreach and the role of local community contacts and organisations in building trusting relationships with the local community. The Older People's Advocacy Alliance

(OPAAL, 2012) highlights the importance of patience, persistence and time in building up engagement with small minority organisations.

Items repeatedly highlight the importance of racially minoritised community organisations in helping their communities benefit from personalisation (Gregory, 2010; Manthorpe et al, 2010; Moriarty 2014; MECOPP, 2017). Carers UK (2011), for instance, argue that services need to be where people are and must work to build on strong and positive networks with, for example, faith-based, community or language-based groups.

In recommending targeted outreach and advocacy, Newbigging and Lowe (2005) suggest the novel approach of using such routes as poets, rappers and celebrities to raise awareness of direct payments. The APPG (2013) calls for organisations representing people with dementia and their carers, as well as racially minoritised groups, to work with specialist racially minoritised media in order to raise their awareness of dementia.

Specific recommendations have been made for commissioners, with the CQC (2016), for example, calling for commissioners and providers to engage with racially minoritised groups as part of their engagement with the whole community. Irvine et al (2016) similarly call for commissioners to consider how they can support racially minoritised groups and harness their expertise in order to understand their particular needs and facilitate engagement with mainstream services. For some articles, this has funding implications. Gregory (2010), for instance, calls for funding to allow racially minoritised voluntary sector organisations a strategic role in promoting participation and ensuring that inequalities experienced by carers are addressed. Lipman (2015) similarly calls for improved funding for voluntary groups that can support those communities most in need.

Data and research

Some researchers identify monitoring data as a key priority in enabling providers and commissioners to evaluate the success of their efforts in order to offer more culturally appropriate and personalised services. At the service level, the Healthcare Commission (2007), for instance, calls for services to develop performance information systems that audit, monitor and review the uptake of direct payments by age, gender and ethnicity. Recording ethnicity is identified as crucial to commissioning more culturally sensitive services. Lipman (2015) similarly recommends increased data gathering and analysis of uptake and outcomes for racially minoritised communities and recommends that practitioners should contribute to data collection about protected characteristics to establish if racially minoritised communities' needs are being assessed equitably, whether access to care and support is easy, and how markets at local levels can ensure a range of providers.

In terms of the wider research agenda, Innes et al (2006) identify a need for research that gathers a richer picture of service users' views and experiences of front-line care and support, examining diversities in the requirements of those who draw on care and support to build a better understanding of the complexity of delivering care and support packages in practice. According to Innes et al (2006), there is also a need for research exploring the motivations, satisfactions and frustrations of care workers' roles, in particular, focusing directly on the drivers and challenges facing front-line workers. Moriarty (2014) similarly identifies a need for more research on the impacts of personalisation for racially minoritised communities employed in social care.

The need for racially minoritised communities to be involved in research is identified by a limited number of sources: Butt et al (2000) notably call for racially minoritised disabled people to be involved in research and policy development; while Ray et al (2008) call for the involvement of people who use services and carers in promoting the knowledge and research base.

Tackling racism

Tackling racism and discrimination was discussed in tandem with issues of culture, language and religion. OPAAL (2012) states that organisations working with racially minoritised communities need to pay more attention to issues around race, culture and identity and to ensure that concerns about racism and exclusion from services are heard at a policy level. Similarly, Stuart (2012) calls for an alliance of racially minoritised and third–sector–led user groups to create more inclusive representation and points out that personalisation could fail racially minoritised groups if concerns about racism are not addressed. Manthorpe and Bowes (2010) recommend that in order to meet the protection and social inclusion needs of racially minoritised communities, public authorities should comply with some of the requirements of the Race Relations (Amendment) Act 2000, which emphasises promoting equal opportunities for people from diverse backgrounds.

Discussion and conclusions

This review has aimed to examine racially minoritised communities' experiences of and perspectives on personalisation in adult social care to identify barriers to and facilitators of improvement, with a view to making recommendations for action. The literature highlights the potential benefits of personalisation, suggesting that it offers a framework for accessing culturally and religiously appropriate care services (Moriarty, 2014). Research shows that mechanisms like direct payments and personal budgets can allow individuals to tailor care arrangements to their specific needs, including cultural and religious considerations (Islam et al, 2015). For instance, recruiting personal assistants from similar cultural backgrounds and providing culturally appropriate meals are crucial for these communities (Greenwood, 2018). However, our review confirms that racially minoritised communities are significantly under–represented among users of personalised care options (Memon et al, 2016).

Lack of information about personalisation options and entitlements is a key barrier. Studies indicate that many individuals from racially minoritised communities are unaware of their rights under the personalisation framework or of the different mechanisms available (Moriarty, 2014). This lack of information is compounded by the complexity of navigating the system, particularly for individuals who may face linguistic or cultural barriers (Islam et al, 2015). As a result, individuals who could benefit from personalisation may be excluded from doing so, simply because they are not sufficiently informed about their options or find the administrative processes too challenging to manage. This points to a broader systemic issue where personalisation policies, while theoretically inclusive, are not always accessible in practice.

Another significant barrier is the unavailability of culturally appropriate services within the personalisation framework. Although personalisation theoretically enables individuals to select services that meet their cultural and religious needs, the reality is that such services are often in short supply (Blake et al, 2017). For example, the recruitment of personal assistants from similar cultural backgrounds remains limited, as does the provision of services that adequately reflect diverse linguistic or religious practices (Memon et al, 2016). The failure to ensure the availability of such services undermines the core premise of personalisation − offering choice and control − by limiting the practical options available to individuals from racially minoritised backgrounds. This aligns with broader critiques of the personalisation agenda, which argue that the market-based mechanisms underlying the policy can exacerbate existing inequalities by privileging those who already have access to resources and knowledge (Greenwood, 2018).

Mistrust of mainstream social care services is a recurring theme, further compounding the barriers faced by racially minoritised communities. Several studies emphasise that historical experiences of exclusion and discrimination have led to a deep-seated mistrust of public services, with many individuals preferring to rely on family or community support networks rather than engage with formal care systems (Greenwood, 2018; Blake et al, 2017). This mistrust is often reinforced by ongoing negative experiences with social care providers, who are perceived as culturally insensitive or unresponsive to the needs of racially minoritised individuals (Islam et al, 2015). Our review shows that this mistrust poses a significant obstacle to the uptake of personalisation, as individuals may be reluctant to engage with a system that they perceive unlikely to meet their needs in a culturally competent manner.

The role of local community organisations in facilitating access to personalisation for racially minoritised communities is highlighted as a critical factor in the literature. These organisations often act as intermediaries, providing culturally relevant information and support that helps individuals understand and navigate the personalisation process (TLAP, 2021). Several studies note that community organisations are trusted sources of advice, particularly for individuals wary of mainstream services (Moriarty, 2014). However, the financial instability of these organisations is a significant challenge. With many facing funding cuts, their ability to continue providing support to racially minoritised communities is increasingly under threat. This undermines the effectiveness of personalisation by removing a vital support mechanism for individuals who are already marginalised within the system.

A striking gap in the literature is the lack of robust quantitative data on the uptake and experiences of personalisation among racially minoritised communities. While qualitative studies provide valuable insights into the barriers and challenges faced by these groups, there is a clear need for more systematic data collection to better understand the scale of the problem (Manthorpe and Bowes, 2010). Without such data, it is difficult to assess the effectiveness of personalisation policies in addressing the needs of diverse populations or to design targeted interventions that can improve access and outcomes for racially minoritised individuals.

Despite the unique challenges faced by racially minoritised communities, many of the barriers identified are shared by other marginalised groups. For example, individuals with disabilities or those from low socio-economic backgrounds also face systemic barriers, such as a lack of information, complex administrative processes and a failure

to account for diverse needs and preferences (Innes et al, 2006). This suggests that while the specific experiences of racially minoritised communities warrant particular attention, addressing the broader structural inequalities within the personalisation system is key to making the policy more inclusive for all.

Based on the review, several recommendations emerge. First, there is a clear need for improved information dissemination, ensuring that personalisation options and entitlements are communicated in ways that are accessible and culturally relevant. This includes providing information in multiple languages and formats and investing in targeted outreach to racially minoritised communities. Second, expanding the availability of culturally appropriate services is crucial to ensuring that personalisation delivers on its promise of choice and control. This will require investment in the recruitment and training of personal assistants from diverse backgrounds, as well as broader efforts to ensure that care providers are equipped to deliver culturally competent services. Third, community organisations must be adequately funded and supported to continue their essential role in bridging the gap between racially minoritised communities and the formal social care system. Finally, there is a pressing need for more robust research, particularly quantitative studies, to better understand the specific challenges and opportunities associated with personalisation for racially minoritised communities.

In conclusion, the reviewed literature highlights both the potential and the limitations of personalisation as a tool for improving adult social care for racially minoritised communities. While personalisation offers the promise of culturally appropriate, individualised care, significant barriers remain. Addressing these barriers will require a concerted effort to improve information, expand service options, rebuild trust and invest in community-led solutions. Only by tackling these challenges can the personalisation agenda become truly inclusive and empowering for all.

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Conflict of interest
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