

“Good support isn’t just about ‘services’ – it’s about having a life.”



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Executive Summary

- This evidence review has been prepared to support IMPACT’s project, ***Personalisation and People from Black, Asian and Minority Ethnic (BAME) Communities***, a year-long project based in Leicester, England, beginning in July 2022. The project aims to identify the experiences of direct payments in Black and Minority Ethnic communities locally. An IMPACT Facilitator has been based within Leicester City Council, leading an evidence-informed change project.
- The findings presented here are based on IMPACT’s review of the evidence relating to personalisation and BAME groups in the UK. ‘Evidence’ for IMPACT consists of insights from research, lived experience and practice knowledge. This **working document** also captures additional learning gleaned from implementing evidence-informed change at the local level.
- Personalisation is a social care approach that aims to enable individuals who draw on care and support and their families to have **choice and control over the care they receive**. It encompasses different mechanisms for paying for services, including direct payments, personal budgets and individual service funds.
- Despite the benefits of personalisation for BAME people, there is **low uptake** of personalised services across BAME groups. This is due to a range of **barriers**, including negative experiences of mainstream services; a lack of awareness or understanding of available services; as well as racism and discrimination.
- This guidance identifies **evidence-based improvements** for providers and practitioners wishing to enhance their provision of personalised adult social care services for people from BAME communities. This includes recommendations such as: providing culturally competent services; supporting BAME carers; overcoming the information gap; outreach; evaluation; and, overcoming racism and discrimination.

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Introduction

- Evidence has long shown that people from Black, Asian and Minority Ethnic (BAME) communities in the UK are disadvantaged in terms of access to health and social care services.¹ **Personalisation of services** has been presented as a possible solution for this problem.
- Personalisation is a social care approach that aims to enable individuals who draw on care and support and their families to have **choice and control over the care they receive**. It encompasses different mechanisms for paying for services, including direct payments, personal budgets and individual service funds.
- In **England**, personalisation is at the heart of the Care Act (2014); in **Wales**, it is well-embedded in the Social Services and Well-being (Wales) Act (2014). In **Scotland**, self-directed support (SDS) has its legal basis in the Social Care (Self-directed Support) (Scotland) Act 2013. In **Northern Ireland**, personalisation is described in terms of independence and choice, which is delivered through the joint Health and Social Care Trusts.

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- Despite growing evidence about the role of personalisation in improving access to health and social care for BAME people, there is **low uptake** of personalised services across BAME groups. This is due to a range of barriers, including negative experiences of mainstream services; a lack of awareness or understanding of available services; as well as racism and discrimination.
- This guidance identifies **evidence-based improvements** for providers and practitioners wishing to enhance their provision of personalised adult social care services for people from BAME communities.
- The findings presented here are based on IMPACT’s review of the evidence relating to personalisation and BAME groups in the UK, as well as insights from local implementation of evidence-informed change. ‘Evidence’ for IMPACT consists of insights from **research, lived experience and practice knowledge**. The Technical Appendix includes detail about how we conducted this review.

Benefits of personalisation

IMPACT’s review of the evidence identified a range of **benefits** of personalisation for people from BAME communities:

- The major reason BAME people choose personalisation is because it enables **choice and control** and empowers them to purchase social care services that are tailor-made to their needs². Personalisation allows BAME people to arrange services that fit better with their ethnic, religious and cultural values and preferences.
- The most valuable use of personalisation for BAME people was found to be **employing Personal Assistants (PAs) from the same cultural background**. Studies reported that this leads to better experiences among BAME people,³ as a PA who understands the individual’s language and has better awareness of their care needs, takes pressure off families. It also provides BAME people who draw on services with more choice about how their care is provided.⁴ This is important for religious and spiritual wellbeing,⁵ as well as food and community connections⁶.

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- Although not allowed in all services, the evidence shows that BAME people also welcome the opportunity to employ a close **family member**, who better understands the needs of the person requiring care and support⁷. Where there is limited availability of culturally appropriate services, employing a family member as a PA may be the only way to ensure the individual’s cultural, linguistic and spiritual needs are met. In some cases, it is cheaper for BAME people to employ a relative than to employ a care worker from agencies.⁸ Self-directed Support legislation in Scotland permits the employment of a relative in ‘appropriate circumstances’, and MECCOP’s **toolkit** provides an overview of the potential benefits, issues and risks that should be considered when employing a family member.⁹
- Personalisation also enables BAME people to **arrange support from providers and organisations of their choice**, who are able to deliver more individualised, person-centred and culturally-appropriate care.¹⁰ Voluntary, faith and community-based organisations are particularly important, being viewed by BAME people as places where they will be culturally understood and provided with the appropriate care.¹¹
- Evidence shows that personalisation improves BAME people’s **confidence** and their **chance to be at the heart of decision-making** about the care and support they receive.¹² Examples of BAME people who were using direct payments point to a better quality of life, greater choice and control, and more flexible and culturally-responsive support that **promotes inclusion**.¹³

Because of religious needs, food requirements, access to religious places and having family and friends around whom share these beliefs, direct payments make all the difference when it comes to having the care and help that meets my needs. It allows me to get that help from different sources.

Respondent quoted in TLAP (2021) p. 15

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What are the issues?

Despite these benefits, our review demonstrated that there is a **low uptake of personalised services** by BAME communities in the UK.

- The main reason is **an information gap** on the existence or details of such services to people from BAME communities. There is a lack of access to information and lack of understanding about how personalisation works¹⁴.
- Almost all the evidence identified **language barriers** as a challenge that hinders people from BAME communities from accessing personalised services and making choices about how they are cared for. While in some cases people may have limited language proficiency and understanding of the available services¹⁵, this barrier is compounded by a **lack of language support** from mainstream services¹⁶.

I feel depressed because I stay at home all day, I feel pressured and obliged to care and culturally it is not a man’s role.... They (health care professionals) never come with translators so we don’t know what they are saying and what forms we are asked we sign. They just tick boxes and go away.

Carer, quoted in Carers UK (2011), p. 11

- **Cultural barriers** also prevent BAME people from accessing personalised services.¹⁷ The personalisation agenda has been described as Eurocentric, biased to western cultural norms and not sensitive to the need of BAME people.¹⁸ This may be exacerbated by a tendency for mainstream services to be underpinned by assumptions that view BAME people as homogenous, and overlook the diversity and difference in BAME communities¹⁹.
- There tends to be a failure to recognise and accommodate different cultural norms, expectations and requirements during the **assessment process**, and there is a lack of cultural and linguistic appropriate assessment tools.²⁰ As a result many BAME people believe that mainstream services are not designed for them.

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- Lack of careworkers with relevant language skills and cultural knowledge is also an issue.²¹ While the evidence shows that employing personal assistants from the same background can be beneficial and empowering, recruiting and retaining suitable staff is problematic. BAME people experience a **lack of choice and diversity** in the market when choosing care assistants and agencies to work with.²²

“Also, when looking for carers, and something we haven’t really touched on, is having carers from your own community, who can speak your language – especially if you can’t speak the language. There is a lack of ethnic minority community carers”

Respondent in *My Support, My Choice*, 2020, p.33

- The **lack of diversity in the workforce** also applies in mainstream services. BAME people report that staff are not sensitive to their needs and tend to assume that BAME people do not need support due to the stereotype that they have family to look after them.²³
- **Community organisations and faith groups** that meet the cultural and spiritual needs of BAME people have a key role to play in enabling people to access personalised services. The services offered have, however, been severely impacted by **funding cuts** as a result of government austerity since 2010, which in turn seriously undermines the personalisation agenda for BAME people.²⁴

Recommendations

Within the literature, there are a range of recommendations for providers wishing to improve access to personalised services for people from BAME backgrounds. These implications for practice can be summarised as follows:

Providing culturally competent services

In order to provide **culturally competent** services (that is, services that are sensitive to people’s culture and/or heritage), providers should:

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- Recognise that there are differences within and between minority ethnic and religious groups, and not make assumptions or generalisations from existing research on particular BAME communities.²⁵

People have tried to understand my brother and our culture but it has never worked. Every ethnic minority is different. We need ethnic minority staff, but being Asian is just not enough. Staff need to be willing to adapt and make the effort to find the correct service and information that’s right for us.

Family member quoted in Poxton (2014) et al, p2.

- Avoid the assumption that family members of BAME people are able to provide unpaid care for them.²⁶
- **Understand the life histories and different migration experiences** of the individuals who draw on care and support, and their implications for care.²⁷ This recommendation has been supported by the IMPACT delivery project, where take-up of direct payments has been low amongst communities who have come from a totalitarian country. It is suggested that this lack of trust towards state authorities may translate into a mistrust of the local authority, including its offer of direct payments.
- **Provide appropriate training, co-produced with people from BAME communities**, for all staff and care management on issues including human rights, equalities, cultural differences, and conscious and unconscious bias.
- Ensure that personalised services focus on the **whole person** and **holistic support**²⁸ going beyond health and social care, to involve the whole family and community. Personalisation should build on peoples’ **assets** as well as those of their families and communities.²⁹
- TLAP’s 2021 report [Personalisation in Black, Asian and Minority Ethnic Communities](#) provides illuminating case studies of a number of providers and projects who operate in this way. The projects offer ease of contact and self-referral; they base their care and support on a holistic view of the person’s wellbeing; and they are informed by cultural understanding, including language support where necessary.

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Supporting BAME carers

As part of this holistic approach, providers should support **BAME carers**, by:

- Providing **support to understand the concept** of independent living and make sense of personalisation. This is of particular importance for people from BAME communities who may face barriers to understanding the system and choices on offer³⁰.
- Ensuring that carers are listened to carefully during **assessment**, in order to ensure clarity about cultural issues³¹. [Guidance for Families of People with Learning Disabilities and Practitioners in Developing Culturally Competent Planning](#), published by the Foundation for People with Learning Disabilities, provides a framework for undertaking person-centred planning with people from diverse communities, helping to ensure that the information that is important to those who need support and their families is included in planning.
- Ensure mainstream services offer better support for **BAME carers by reviewing commissioning strategies** – that is, the planning, purchasing and monitoring of services.³²
- Actively involve BAME people and their carers/families in the **design of services** from the outset, so that **co-production** becomes a central and consistent approach.³³ TLAP’s [Making it Real](#) framework is a valuable tool, underpinned by the principle of co-production, that can assist organisations in this process.

I’m a wife, mother, nurse, teacher, administrator, cook, cleaner, decorator, a great inventor and counsellor ... As my daughter’s needs grew, I tried to keep up without realising the unrealistic demands I placed on my mind, body and soul. It took a team of workers round the clock to fulfil all the roles. Then I understood what a “carer” is.

Asian mother of a disabled young person, quoted in NBCCWN, 2008a, p. 52) (From Gregory, 2010

Overcoming the information gap

In order to **overcome the information gap**, providers should:

- Provide **accessible information** in multiple languages and in a range of formats (e.g. hard copy and digital; face-to-face; foreign languages; large

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print; Braille; Easy Read; BSL). IMPACT’s delivery project found that members of a BAME community within Leicester favoured **“talking leaflets”** (audio versions of written information) as their preferred way of receiving information. This highlights the importance of eliciting information about people’s communication preferences.

- Likewise, **it is important to involve BAME people in co-producing that information.**³⁴ People may regard the term ‘personalisation’ as jargon³⁵ and find alternatives – such as Personal Budgets; Personalised care; Individual budgets; Individual Service Funds and, Self-Directed Support – to be clearer and simpler.
- Provide good **case studies** that show how personalisation leads to better outcomes for people who draw on care and support.
- Where possible, provide specialist support such as **access to interpreters**³⁶ and advocate or support workers with specialist skills³⁷. However, this recommendation should be viewed within the context of current budgetary pressures within adult social care, which place limits on what can be provided.

Outreach

Information should be accompanied by **outreach** in order to reach those who need it. Providers should:

- **Identify and map relevant BAME community organisations** within your area that can: help people benefit from personalisation; disseminate information; help identify people who need care and support; or even provide a location for services.
- Build adequate **time** into the planning process for developing **trusting relationships** and engagement with those BAME community organisations.³⁸
- **Review support (including financial support) for BAME community groups** to enable those groups to have a strategic role in promoting participation and facilitating engagement with mainstream services.³⁹
- Work with **specialist BAME media** in order to identify people who need care and support, and raise awareness of services.⁴⁰

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- Develop models of **peer support**, to enable more BAME people to benefit from personalisation. The way in which peer support models operate will vary according to local circumstances and need. These might involve **role models** and **local community leaders** or take the form of **local peer networks** (see case study).

Peer Support: Case Study

In the 2012 SCIE film [*Personalisation – making it happen: black and minority ethnic communities*](#), **experienced personal budget holders** attend a luncheon club, as part of Oldham’s Link Service, providing **language support and advice** to those who are new to personalisation. The film shows Musar Khan, who, after years, of being housebound, receives a personal budget and is able to employ a personal assistant who takes him to the gym and the mosque. Musar says that previously, “I didn’t go anywhere, actually I had no communication within ... but this has helped a lot”

Monitoring and evaluation

Providers should **evaluate the success** of their efforts to offer more culturally appropriate and personalised services by:

- Ensuring that performance information systems record ethnicity in order to **monitor and review the take-up of personalised services**
- Contributing to data collection about protected characteristics to assess **if BAME people’s needs are being assessed equitably**; as well as assessing ease of **access to care and support**.⁴¹

Tackling racism and discrimination

All parties need to **tackle concerns about racism and discrimination**. This may include:

- Developing a mechanism for ensuring that concerns about racism and exclusion from services are heard at a policy level⁴²

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- Developing an alliance of BAME and third sector-led groups to create more inclusive representation⁴³
- Ensuring that safeguarding policies are culturally competent and sensitive to issues affecting BAME older people. This should be viewed within the context of the Race Relations (Amendment) Act 2000, which placed a duty on public authorities to promote *equality of opportunity* for people of different racial backgrounds.⁴⁴

Conclusion

This evidence review has supported IMPACT’s delivery project, *Personalisation and People from BAME Communities*, hosted by Leicester City Council. We undertook a systematic review of the academic and grey literature (including insights from lived experience and practice knowledge) to identify barriers to and facilitators of uptake of personalisation by people from BAME communities.

The review found that there are a range of benefits for BAME people in accessing personalised services – including increased choice and control; improved quality of life; and the ability to access more culturally-sensitive and flexible support that promotes inclusion. Despite these benefits, the evidence shows that uptake of personalised services is low across BAME groups. This is due to a range of challenges, including language and cultural barriers; lack of choice and diversity in the workforce and market; as well as fundings cuts to BAME organisations.

The evidence contains a range of useful recommendations for providers wishing to overcome these barriers and improve access to personalised services. These range from how providers might improve the cultural competence of their services; to how best to support BAME carers; and how to improve outreach and access to information; as well as considerations around monitoring and evaluation, and tackling racism and discrimination.

Equally, experience of local implementation highlights the need to be mindful of the local context and the realities of pressures within the social care sector. Some recommendations will be more feasible and applicable in some locations than others. Nevertheless, what all of them have in common is that they should be underpinned by co-production. Working together with people who draw on

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care and support, and their families, is crucial to determine local priorities for improving access to personalised services.

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Appendix 1: Approach to reviewing the evidence

IMPACT conducted a systematic review of articles, reports and other sources in order to:

- Assess why people from BAME communities choose personalisation;
- Identify barriers to access to personalised services for BAME people; and
- Identify BAME people’s perspectives about mainstream social care services.

Between May and June 2022, we carried out a systematic electronic search of research databases to identify published papers and reports, and conducted a Google search to identify further grey literature and relevant websites. To be included in our review, items had to meet our three inclusion criteria:

- They focused on adult social care in the UK;
- They included discussion of BAME communities in UK; and,
- They included discussion of personalisation

We assessed the quality of each contribution according to its research design and the nature of the work, using recognised criteria.⁴⁵ In keeping with the IMPACT approach to evidence, this included considering whether the item included the practice knowledge of people who work in adult social care, as well as the perspectives of carers and people who draw on care and support. We follow the principle that in social care research, an accumulation of lower-quality or smaller-scale evidence can together produce useful and reliable recommendations for action⁴⁶.

Endnotes

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- ¹ Booth et al, 2021.
- ² Manthorpe et al, 2010; Terashima, 2011; Moriarty, 2014; Irvine, et al., 2016; Omotola, 2020;
- ³ Clark, 2001; Glasby and Littlechild, 2002; Lipman, 2005; Terashima, 2011; Omotola, 2020;
- ⁴ Innes et al, 2006.
- ⁵ Moreland and Jutlla, 2009; Jutlla, 2015; Irvine et al, 2016;
- ⁶ Lipman, 2015.
- ⁷ Commission for Social care Inspection, 2008; Moriarty, 2014.
- ⁸ Manthorpe et al, 2010.
- ⁹ MECCOP, 2019
- ¹⁰ Healthcare Commission, 2007; Clayton et al, 2014; TLAP, 202.
- ¹¹ TLAP, 2021
- ¹² Health and Social Care Alliance Scotland, 2020; TLAP, 2021; SCIE, 2012
- ¹³ TLAP, 2021.
- ¹⁴ Newbigging and Lowe, 2005; Manthorpe and Bowes, 2010; Poxton et al, 2012.
- ¹⁵ Moreland and Jutlla, 2009; Manthorpe and Moriarty, 2009; Manthorpe et al, 2010; Terashima, 2011; Irvine et al, 2016;
- ¹⁶ Commission for Social Care Inspection, 2008; Manthorpe et al, 2010; Battacharyy and Benbow, 2013;
- ¹⁷ Manthorpe and Moriarty, 2009; Bhattacharyy and Benbow, 2013;; Booth et al, 2021.
- ¹⁸ Stuart, 2006; Innes et al., 2006; Health Care Commission, 2007; Gregory, 2010; Terashima, 2011; Jutlla, 2015; MECOPP, 2018.
- ¹⁹ Moreland and Jutlla, 2009.
- ²⁰ Newbigging and Lowe, 2005; Innes et al, 2006; Health and Social Care Alliance Scotland, 2020.
- ²¹ Clark, 2001; Glasby and Littlechild, 2002; Stuart, 2006; Commission for Social Care Inspection, 2008; Manthorpe et al., 2010; Moriarty, 2014.
- ²² Clark, 2001; Glasby and Littlechild, 2002; Stuart, 2012.
- ²³ Carers UK, 2011; Poxton et al., 2012; Booth et al., 2021.
- ²⁴ Manthorpe et al., 2010; Gregory, 2010; Joannou et al, 2011; Poxton, 2012; Moriarty, 2014; TLAP, 2021.
- ²⁵ Moreland and Jutlla, 2009; Jutlla, 2013; Jutlla 2015.
- ²⁶ Carers UK, 2011; Poxton et al., 2012; Booth et al., 2021.
- ²⁷ Jutlla and Moreland, 2009; Jutlla, 2013; Jutlla, 2015.
- ²⁸ Poxton et al, 2012; TLAP, 2021.
- ²⁹ Clayton et al, 2014; TLAP, 2021.
- ³⁰ Glasby and Littlechild, 2002; Gregory, 2012; Poxton et al, 2012.
- ³¹ Moreland and Jutlla, 2009.
- ³² Carers UK, 2011
- ³³ Clark 2001; Healthcare Commission, 2007; Turning Point, 2010; Terashima, 2011; Raghavan, 2016.
- ³⁴ Butt et al, 2000; Newbigging and Lowe, 2005; SCIE, 2012; Health and Social Care Alliance, 2020
- ³⁵ Clayton et al, 2014
- ³⁶ Care Quality Commission, 2016; Raghavan, 2016
- ³⁷ MECCOP, 2018; Butt et al, 2000.
- ³⁸ OPAAL, 2012
- ³⁹ Gregory, 2010; Irvine et al, 2016
- ⁴⁰ All Party Parliamentary Group, 2013
- ⁴¹ Lipman, 2015.
- ⁴² OPAAL, 2012
- ⁴³ Stewart, 2012
- ⁴⁴ Manthorpe and Bowes, 2010
- ⁴⁵ Aromatis et al., 2015; Lockwood et al, 2015
- ⁴⁶ Nutley et al, 2013

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