

Better
Health
Briefing

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**Personalisation
for people from
black and
minority ethnic
groups**

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Key messages

- 1 Personalisation is a government policy aimed at giving people more choice and control over their lives. In the context of health and social care, it is about making services more tailored to people's individual needs using different mechanisms, including cash sums to purchase support for daily living activities (variously termed personal budgets, direct payments, or self-directed support) and other ways of managing assistance on behalf of individuals.
- 2 Personalisation potentially offers people from black and minority ethnic groups the opportunity to arrange services that fit better with their ethnic, cultural, religious values and preferences.
- 3 Unfortunately, research about personalisation is very variable in the extent to which it reports on service users' ethnicity. Although personalisation generally offers benefits for most service users in terms of greater choice and an increased sense of control, studies often fail to report if these experiences vary between different ethnic groups or if there are different outcomes.
- 4 The research that does exist suggests that people from black and minority ethnic backgrounds are generally willing to try personal budgets once they have been made aware of how they work.
- 5 The area in which we do have more information on differential uptake is in mental health. Uptake of personal budgets in mental health services appears to be low across all ethnic groups. Organisations advocating on behalf of people from black and minority ethnic groups with mental health problems argue that their negative experiences of mental health services may act as an additional disincentive towards trying personal budgets.
- 6 Black and minority ethnic community organisations play an important role in helping people from their communities benefit from personalisation. The impact of spending cuts on the sustainability of black and minority ethnic third sector organisations needs to be monitored to ensure that people from black and minority ethnic communities are able to benefit fully from personalisation.
- 7 There is a need for more research on the impacts that personalisation has had for black and minority ethnic people employed in the social care workforce.
- 8 Over time, the meaning of personalisation seems to have narrowed. Early arguments in favour of personalisation emphasised its benefits in terms of prevention and in the opportunities it gave for people using social care services to participate more fully in society as a whole. More recent experiences suggest that it has sometimes been operationalised in less flexible ways than those originally intended.

Introduction

Personalisation is about tailoring services to people's own circumstances and giving them more control over the amount and type of support they receive from public funds. This briefing is about personalisation in the context of adult social care where the Individual Budgets pilot (Glendinning *et al.*, 2008) represented the first attempt to combine different sources of funding to create greater choice for service users.

Since then, the term 'personalisation' has also been used for other government initiatives, all of which share a common purpose of streamlining and combining multiple sources of funding to give service users greater choice while making the process of applying for support less cumbersome. These include pilots of personal health budgets (Forder *et al.*, 2012), the Right to Control Trailblazers for people with disabilities of working age (Tu *et al.*, 2013), and help for people with learning disabilities to find paid employment (Stevens and Harris, 2013, Department of Health, 2011).

Devolution has accentuated differences in social care policy between each of the four constituent countries of the UK (Moriarty, 2010). While all share a common policy goal of achieving more personalised and tailored services, differences have emerged in how this goal is implemented (Manthorpe *et al.*, 2014).

A key feature of personalisation in social care in England is the development of personal budgets (sometimes terms vary locally). These cover services arranged by the local council (managed personal budgets), cash payments to individuals (or other people such as family carers) that enable them to purchase their own social care (direct payments), or a combination of both. Terms such as personal budgets, direct payments, and self-directed support are often used interchangeably, which can make it confusing for people using services and carers if no explanation of the term is given.

Despite the various types of personal budget that exist, most research has focused on people receiving individual direct payments, currently only used by a minority of service users. The majority of personal budget holders in England receive a 'managed personal budget' in which funds for their support are managed by their local council (Samuel, 2013). Another option is for providers to manage Individual Service Funds on behalf of individuals and to undertake to spend it in only ways chosen by those individuals.

In addition to receiving individual direct payments, people may choose to pool some, or all, of the funds they receive to purchase services collectively. This has enabled people to do things that had previously been inaccessible or to achieve economies of scale as integral part of local provider markets. Pooling can also lead to a review of how services are commissioned (Disability Rights UK and Shaping Our Lives, 2011).

The original vision for personalisation also included a focus on early intervention and prevention, building social resources, and improving access to 'universal services' such as leisure and transport, access to information and advice on care (Social Care Institute for Excellence/New Economics Foundation, 2011). However, these aspects are being emphasised less often as the impact of cuts to social care expenditure has begun to be felt (Brookes *et al.*, 2013). This has provoked criticism from some quarters that the concept of personalisation has become separated from progressive policies and is more about achieving reductions in social care expenditure (Zarb, 2013; Duffy, 2014; Slasberg *et al.*, 2012).

There have also been calls for an audit of money spent on personal budgets, with the suggestion that the sums are sometimes too small to make a positive difference to people's lives (NSUN network, 2012; Davie, 2012). These criticisms highlight the challenges that have been created by implementing personalisation at a time of reduced expenditure on social care at a time of increased demand. There is a risk that

personalisation will come to be associated with achieving cuts in expenditure and not on its potential to improve people's experiences of using services.

As well as offering greater choice for people using services, personalisation potentially offers greater choice and control for family carers about the ways in which they would like to be supported in their role (Carr, 2012). However, opportunities have been missed to achieve greater co-ordination between policies aimed at developing personalisation and policies aimed at achieving better support for carers (Glendinning *et al.*, 2013).

The Care Act 2014 establishes a policy preference for direct payments over managed personal budgets. It also places an emphasis on better preventive services and putting carers on an 'equal footing' with service users. At the time of writing, it is not possible to predict whether the Care Act 2014 and associated guidance will achieve the claim made by government that this legislation represents the 'most significant reform of care and support in more than 60 years.'

1 Can personalisation help people from black and minority ethnic groups?

Personalisation has been welcomed as an opportunity to resolve some of the entrenched problems of lack of access to culturally suitable services for people from black and minority ethnic groups. Recipients of personal budgets can choose whether they use mainstream services or culturally specific services or both; for example a person might choose to go to a day centre for people with dementia from all ethnic backgrounds or a day centre for people from their own ethnic or religious background. Personal budget holders are allowed to employ relatives to help them 'in exceptional circumstances'. This may be valued by both parties, although how the policy operates in practice varies between local councils. However, we continue to lack detailed information on the specific experiences of people from black and minority ethnic groups, which makes it difficult to draw firm conclusions on what is working well and where improvements need to be made.

2 Uptake of personal budgets

Uptake of personal budgets by people from black and minority ethnic people starts from a low base. Prior to personalisation, direct payments were the only alternative to traditional social care services arranged by the local council for those who lacked the resources to fund and arrange their own care. Uptake of direct payments was lower among people from black and minority ethnic groups, mainly because of barriers such as the lack of support to help people manage their payments and recruit suitable staff (Stuart, 2006). Research undertaken by organisations representing the interests of black and minority ethnic people suggests some of these barriers continue to exist (Voice4Change England, 2012; Vernon, 2011). They include:

- Confusion about personalisation, including fears that benefits and services will be cut or changed, and uncertainty about how direct payments can be used.
- A lack of accessible information about what support is available.
- A lack of advocacy and support services that could help people to apply for personal budgets.
- Reluctance among some groups to ask for an assessment, a necessary step to receiving a personal budget, because of pride or fear of stigma.

- Stereotyped ideas among professionals about the extent of family support available within families of people from black and minority ethnic groups.
- Difficulties in recruiting personal assistants who understand and can meet the needs of black and minority ethnic people.

Improving uptake

Examples of initiatives aimed at improving uptake of personal budgets among people from black and minority ethnic groups include:

- Funding for advocacy services who can advocate on behalf of people from black and minority ethnic groups (Stuart, 2006)
- Support for small community organisations providing workers who can deliver culturally suitable care (Carr, 2014),
- Dedicated outreach workers who can build up connections with local communities and groups (Edwards, 2009)
- Peer mentors who can tell other people in their community about their experiences of holding a personal budget (Social Care TV, Undated).

So far, there has yet to be any research systematically comparing the uptake of personal budgets across different ethnic groups. However, with the exception of personal health budgets for people entitled to NHS continuing healthcare where comparatively few people from black and minority ethnic backgrounds were recruited (Forder *et al.*, 2012), other studies are beginning to report similar, or even slightly higher proportions of people from black and minority ethnic groups using personal budgets, particularly direct payments, compared with their White British counterparts (Netten *et al.*, 2012; Hatton and Waters, 2011; Hatton and Waters, 2013; Purdon and Bryson, 2013; Woolham and Benton, 2012).

The exception to this picture is personal budgets for people using mental health services. Research has shown that comparatively few people with mental health problems use personal budgets, whatever their ethnic background (Webber *et al.*, 2014). Other studies have pointed to the complexity of making personal budgets for people with mental health work effectively across health and social care services and to the need for managers to 'sell' the concept more effectively and ensure a sense of ownership among their staff if they are to become more frequently used (Larsen *et al.*, 2013).

Even allowing for these factors, it is worth noting that the evaluation of individual budget pilots reported that proportionally fewer budget holders from a black and minority ethnic background were using mental health services (Netten *et al.*, 2012). A similar finding was reported earlier in a study that predated personalisation which found that comparatively fewer people from black and minority ethnic groups, especially men, were accessing direct payments (Spandler and Vick, 2005).

Mental health survivors (NSUN network, 2012; Davie, 2012) suggest that this under-representation is explained by the greater likelihood of mental health users from black and minority ethnic groups previously experiencing compulsory treatments, which in might make them less convinced that receipt of a personal budget could be an empowering experience for them. This suggests that further work is needed to ensure that equality of access is not being undermined by a history of poor experiences of mental health services over many years among people from black and minority ethnic groups.

3 Outcomes of personalisation

Overall, the main benefits reported by those using personalised services include a greater sense of control and empowerment, satisfaction, and improved quality of life (Webber *et al.*, 2014; Netten *et al.*; 2012, Hatton and Waters, 2011, 2013), although the quality of studies can be variable and these aspects are not always measured objectively (Webber *et al.*, 2014).

However, there is not enough information comparing these outcomes across different ethnic groups. In their national POET survey of personal budget holders and family carers, Hatton and Waters (2011) reported that responses to their survey of people holding personal budgets did not differ by ethnicity, although they emphasise that their survey was not nationally representative of all personal budget holders. Netten *et al.* (2012) found that outcomes for older people in general tended to be less positive for older people (their ethnicity is not reported). They suggested that this difference may have arisen because the older people had to use most of their budgets for personal care and so had fewer opportunities to undertake other social and leisure activities.

A small-scale study (Lipman, 2014) reported similar findings. Lipman quotes a provider from an organisation supporting older black and minority ethnic older people who pointed out that the amounts allocated to people as a personal budget were extremely low (around £50-100 per week). This meant that older people from black and minority ethnic groups were spending all their money on personal care and were unable to afford to come to a day centre run by the organisation where they would have been able to meet others from a similar background and take part in culturally acceptable activities.

4 Carers and personal budgets

There is a growing body of research highlighting the particular difficulties faced by carers of people from black and minority ethnic groups (Katbamna *et al.*, 2004; Afiya Trust, 2008). This has identified particular issues in terms of differing cultural expectations about asking for services and the lack of opportunities to get a break from caring.

A survey of Carers UK members showed that more carers from a black and minority ethnic than White British group thought direct payments were better than services arranged by the local council and that direct payments had increased the amount of time they had for themselves. However, slightly more White British respondents received financial compensation for the time they spent administering the direct payments. It was not clear whether this was because black and minority ethnic carers did not know that they could claim for this or if they had chosen not to (Carers UK, 2011). The overall number of respondents receiving direct payments was comparatively small and these respondents represent the much smaller group of carers receiving social care support compared with their numbers within the population as a whole.

A study of carers from Asian Pakistani and Asian Bangladeshi backgrounds found that they were very unlikely to see friends as an appropriate source of direct care (Victor *et al.*, 2011). The implications of this finding are extremely important. Although personalisation has brought advantages to people who can purchase care from family members, there is a danger that professionals will assume that the needs of all

people from a black and minority ethnic background can be met within the family or that they will be able to recruit personal assistants from within their wider social network. Where this is not possible, it is vital that people are given help in recruiting personal assistants and support workers (Stuart, 2006; Vernon, 2011). Otherwise there is a risk that too much responsibility will be placed on carers of people from black and minority groups for meeting all of a person's support needs.

5 Personalisation and the black and minority ethnic third sector

Many third sector (voluntary and not for profit) organisations for people from black and minority ethnic groups developed in response to marginalisation from mainstream statutory services (Butt and Mirza, 1996), leading Carr to describe them as a type of 'compensatory self-organisation' (Carr, 2014, p. 22).

People from black and minority ethnic groups meeting the eligibility requirements for social care, especially those who are socially isolated, who do not speak English fluently and who have limited knowledge of services, may be very dependent on these organisations to help them access support (Lipman, 2014). Without their help, there is a risk that health and social inequalities could increase.

Organisations representing people from black and minority ethnic groups generally view personalisation as offering both opportunities and threats. On the one hand, they can offer specific expertise in meeting the needs of the communities they represent. On the other, small black and minority ethnic organisations may struggle to compete on price with large private and voluntary organisations who can achieve greater economies of scale (Voice4Change England, 2010) and risk-averse local councils may prefer to contract with large organisations, especially when their budgets are reducing (Clayton *et al.*, 2014).

Commentators (Rochester, 2013; Milbourne, 2013) have argued that the decision by local councils to switch from giving third sector organisations block grants to provide a service to asking them to compete for contracts alongside other third sector organisations and private providers has posed challenges for the sector as a whole. This development slightly predates, but has been accelerated by, personalisation.

One important aspect of personalisation that appears to have had a direct impact on the voluntary sector is the closure of day centres and changes to contracts leading to many organisations now charging people the full economic cost of using day services. Various reasons for these closures and contractual changes have been given – including their perceived incompatibility with attempts to deliver personalised services.

We do not know the scale of these closures nor whether service users from black and minority ethnic groups and organisations for black and minority ethnic people have been differentially affected by these changes. The establishment of a number of day services run by the voluntary sector and specialising in supporting people from different ethnic groups (see, for example, Age Concern Support Services (Yorkshire and Humber), 2010) may have been one reason why earlier research suggested that day services appeared to be more popular with older people from black and minority ethnic groups than other traditional services (Manthorpe *et al.*, 2010; Moriarty *et al.*, 2011). However, few attempts appear to have been made to use an equalities framework from which to consider whether the closure of day centres impact differentially on people from black and minority ethnic groups (Manthorpe and Moriarty, 2013).

Furthermore, policies that assume everyone prefers to take part in 'mainstream' social activities will potentially disadvantage people who have limited spoken fluency in English, lesbian, gay, bisexual and

transgender people who feel unsafe in public settings, or those who have strong religious or cultural preferences that influence how and where they want to socialise.

Needham (2013) has also questioned whether the closure of buildings-based day services will affect local user-led organisations' abilities to access and resource collective spaces. This is not discussed in terms of the impact on individuals from black and minority ethnic groups or the black and minority third sector. However, while faith-based black and minority organisations based in a place of religious worship may not be particularly affected by these changes, it is possible that secular organisations and those supporting materially disadvantaged groups of people from black and minority ethnic groups, such as refugees and asylum seekers, may find that it is harder for them to continue their work.

Set against this picture of the negative impact of personalisation on organisations from black and minority ethnic groups, it is also important to see its potential. Carr (2012, 2014) has argued that because many third sector organisations supporting people from black and minority ethnic groups and other marginalised communities lack the resources and infrastructure to compete with large for-profit providers, a key role for commissioners is to consider ways in which they can support small specialist and community-based 'micro-providers' in order to ensure that service users and their families have a real 'market' from which to choose the type of support that they want.

In some places, large established voluntary organisations aimed at supporting people from all ethnicities are entering into partnerships with smaller local organisations representing black and minority ethnic older people to deliver services primarily aimed at improving take up of mainstream services or offering specialist services (Moriarty, 2013 unpublished). It may be that this model represents one way in which the black and minority ethnic third sector can continue to deliver services for the communities it aims to support.

Access for BAME Elders Project

Funded by the Big Lottery, the *Access for BAME [Black, Asian and Minority Ethnic] Elders* project run by Age UK Lewisham and Southwark supports older people from black and minority ethnic communities to access mainstream and culturally specific services with the help of a support planner.

Support planners are trained volunteers who use person-centred planning tools to help older people from black and minority ethnic groups living in the boroughs create a person-centred plan. The volunteers also help people develop the confidence to explain what is important to them and for them and to identify the necessary support available to help them achieve their goals.

As was mentioned earlier, the full potential for pooled personal budgets seems yet to be realised. However, they offer opportunities for third sector black and minority ethnic organisations to support people from black and minority ethnic communities in pooling their budgets to create and sustain bespoke services.

6 Personalisation and the workforce

It is important to consider the impact of personalisation policies on black and minority ethnic people within the workforce as well as on people using services and their carers. Skills for Care, the employer-led strategic body for workforce development in social care for adults in England, estimate that 10% of the adult social care workforce is now made up of personal assistants employed by people receiving a direct payment (Skills for Care, 2013a). The National Minimum Data Set for Social Care (NMDS-SC), which is completed by employers, shows that fewer Asian (1.3% compared with 4.8%) and black workers (3.8% compared with 7%) are employed as personal assistants compared with their representation within the workforce as a whole). Proportionally more personal assistants are from a mixed ethnicity (3.8% compared with 1.3%) but proportionally fewer people from black and minority ethnic backgrounds appear to be employed as personal assistants overall (Skills for Care, 2013b). While Skills for Care offer no explanation for these differences, it is clearly important that we look further to see why they should exist.

Hussein and colleagues (2014) undertook secondary analysis of the NMDS-SC data and concluded that, across the social care workforce as a whole (the data are not broken down by employment type), the proportion of British citizens from black and minority ethnic backgrounds working in social care is just 7.5%, lower than has been previously thought. By contrast, there are almost twice as many 'migrant' workers who are citizens of another country other than the UK within the workforce. They question whether the existence of a high proportion of migrant workers in the social care workforce has concealed a parallel under-representation of British citizens from black and minority ethnic groups within the workforce.

Beyond this, we know very little about how personalisation has affected the work experiences and employment conditions of people from black and minority ethnic groups. It is possible that working for someone receiving a direct payment might improve the position of individual workers, particularly in terms of reducing the likelihood of being a victim of institutional racism or racism from colleagues. At the same time, there is a risk that workers employed on a live-in basis by people on direct payments and in private arrangements may be at greater risk of exploitation (Kalyaan, 2009) than their counterparts employed in care homes or by an agency, particularly if their residence in the UK is dependent on being employed by a particular person.

Many social care workers from a black and minority ethnic group report experiencing racism in the workplace. Cangiano and colleagues (2009) have been particularly critical of the way the sector responds to these incidents and its failure to ensure that workers are aware of their possible legal rights to redress. However services are arranged and paid for, it is important that attempts to tackle racism in the workplace continue.

Conclusion

This briefing has highlighted that while there is a growing body of published research on personalisation, it has rarely focused in-depth on the experiences of people from black and minority ethnic groups. There is a particular shortage of research comparing the experiences of different types of service user and carer across different black and minority ethnic groups. Despite the diversity that exists within Britain's population from a minority ethnic background, research and resources about personalisation rarely discuss what the policy of personalisation means in terms of meeting the needs of service user and carers from different ethnic backgrounds and monitor if, and how, different ethnic groups have different experiences of personalisation.

Nevertheless, there are some tentative conclusions that can be drawn from this review. These suggest that the numbers of people from black and minority ethnic groups receiving personal budgets are increasing but that we know very little about whether certain types of service user and/or different ethnic groups are under-or over-represented.

People do not come to using services in a vacuum. Previous experiences of discrimination and poor treatment will influence their opinions about personalisation. These groups may need additional support and assistance in using personal budgets. Examples of good practice in improving awareness and uptake of personal budgets exist but we do not know how widespread they are.

Direct payments appear to be becoming more popular among people from black and minority ethnic groups but the lack of comparative information about other types of personal budget means that we do not know whether there are other forms of support that would meet their needs and preferences better.

Research with carers (Alzheimer's Society, 2011a, 2011b; Mitchell *et al.*, 2013) has suggested that some carers of people who lack capacity to run their own personal budget can find it an additional burden if it is assumed that they will manage direct payments on behalf of the person for whom they care. This highlights the need for better support for people in managing their own support. Carers from black and minority ethnic groups are already at greater risk of being stereotyped in terms of the support they provide and it is important that this tendency does not increase in any way.

There is a strong inter-connection between the black and minority ethnic third sector and the interests of people from black and minority ethnic groups. There is an urgent need to find out if cuts to social care expenditure are impacting differentially on this sector and to consider if this has negative implications for the successful delivery of personalised services to people from black and minority ethnic backgrounds.

Resources

Afiya Trust

www.afiya-trust.org/index.php/resources/publications.html

Afiya Trust website has a number of resources relating to health and social inequalities:

Disability Rights UK and Shaping Our Lives

<http://disabilityrightsuk.org/policy-campaigns/health-and-social-care-reforms/user-driven-commissioning-building-%E2%80%98lived-experience>

Disability Rights UK and Shaping Our Lives have undertaken a programme on user-driven commissioning which features pooled personal budgets: MECOPP: MECOPP works with black and minority ethnic carers in Scotland. A section of their website covers self-directed support:

www.mecopp.org.uk/services-self_directed_support.php?section_id=321

Race Equality Foundation

<http://www.raceequalityfoundation.org.uk/resources/downloads/personalisation-and-equalities>

Report of a learning event held by Disability Rights UK, the Race Equality Foundation and the LGB&T Partnership, in conjunction with the Department of Health, Public Health England and NHS England.

Social Care Institute for Excellence: SCIE

www.scie.org.uk/topic/keyissues/personalisation

Social Care Institute for Excellence: SCIE has a range of resources on personalisation, including reports and Social Care TV episodes.

Social Care Institute for Excellence Social Care

www.scie.org.uk/socialcaretv/video-player.asp?guid=4286962f-9825-4322-81c7-a87253c347a4

Social Care Institute for Excellence Social Care TV video on personalisation – making it happen in black and minority ethnic communities discusses work of Oldham Link Service which offers advice, guidance and support to people from local black and minority ethnic (BME) communities who use services.

Think Local, Act Personal

www.thinklocalactpersonal.org.uk/Browse/Co-production/Equalities/BME/?parent=8597&child=6515

Think Local, Act Personal website includes a range of resources on personalisation, including ideas about improving uptake of personal budgets among people from black and minority ethnic backgrounds.

Whose Shoes

Whose Shoes® is a board game to help individuals and organisations work together on developing more personalised approaches. There is also an electronic version: <http://nutshellcomms.co.uk/about/>

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