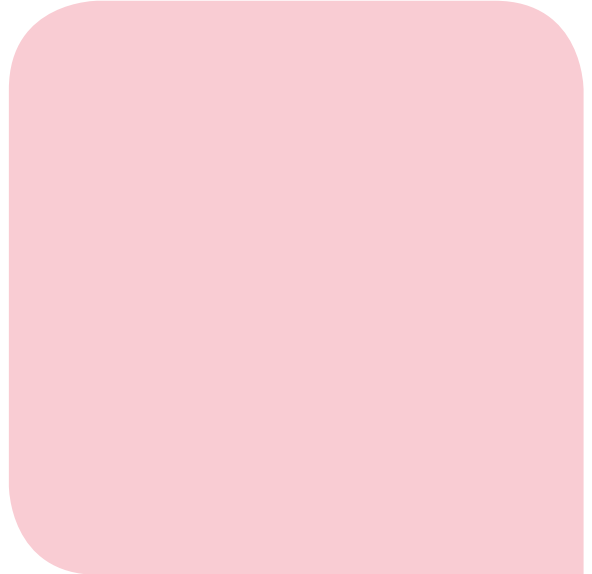


Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers?



Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers?

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Preface

The Social Care Institute for Excellence's (SCIE) aim is to improve the experience of people using social care services by developing and promoting best practice in service delivery. Since the *Race equality discussion papers* were published in June 2005, SCIE has hosted a seminar to discuss the issues raised in the papers. This was done to explore some of the challenges facing social care in providing accessible and appropriate services for black and minority ethnic people. The papers have been re-published, informed by the discussion at the seminar and the comments received.

As a result of the seminar there is a commitment to undertake a review that pulls together examples of social care working with refugees and asylum seekers. This is part of SCIE's work programme in 2006-07.

The seminar and the development of our race equality scheme have provided an opportunity to restate a commitment to embracing diversity as a core value at the heart of our work. The Social Care Institute for Excellence is committed to improving our knowledge and understanding of the needs and aspirations of black and minority ethnic service users, practitioners and other stakeholders. We will draw on the experience and expertise of people and organisations from black and minority ethnic communities and those undertaking race-specific work.

SCIE will also work with non-black and minority ethnic people and organisations to explore race equality issues within the context of social care when taking part in its work programmes.

Bill Kilgallon
Chief Executive
Social Care Institute for Excellence

Foreword

The Social Care Institute for Excellence's (SCIE) role is to develop and promote knowledge about best practice in social care. By working with people and organisations throughout the social care sector, it can identify useful information, research and examples of best practice. The information is used to produce free paper and web-based resources, which bring together existing knowledge about specific areas of social care, identifies gaps in knowledge and draws out key messages for best practice.

SCIE aims to improve the experience of people who use social care services by developing and promoting knowledge about best practice in social care in relation to equality and diversity.

Attention is being paid to race equality and the future challenges for social care. The needs of black and minority ethnic people have often been neglected or marginalised in the provision of social care services. On the one hand myths of black and minority ethnic communities 'looking after their own' prevail, on the other hand black and minority ethnic communities are over-represented in the acute psychiatric system.

Over the years concerns have been raised about inaccessible and inappropriate service provision. Also, changes in the demographic profile of the black and minority ethnic population, such as increasing numbers of older people and refugees and asylum seekers, have placed growing demands on the social care sector. The Race Relations (Amendment) Act 2000 outlaws discrimination in employment, in the provision of goods or services and in all the activities of public bodies. The challenge for policy makers and social care practitioners lies in tackling institutional racism and finding ways of responding to the needs of black and minority ethnic people in ways that value diversity, respect human rights and promote independence.

There is a body of knowledge that details the factors that hinder black and minority ethnic people from accessing services. However, there appears to be less knowledge and best practice on the organisational barriers and enablers that facilitate good access and delivery of services.

To start to explore and debate some of the future challenges for social care, SCIE has commissioned three discussion papers. These focus on:

- independent living
- refugees and asylum seekers
- characteristics of social care organisations that successfully promote diversity.

While the discussion papers only capture the tip of the iceberg in terms of key issues within social care, it is hoped that they will open up a much needed dialogue with a range of stakeholders on the challenges to be met.

The first edition of the race equality discussion papers formed the basis of SCIE's race equality seminar in July 2005. In light of discussions at the seminar, the papers have been revised. They will be used to set a context, stimulate debate and inform SCIE's

future work. For example, a project mapping best practice in meeting the social care needs of refugees and asylum seekers is in the pipeline. As with the first edition of the discussion papers, we welcome your comments or contributions.

Nasa Begum
Principal Adviser, Participation
Social Care Institute for Excellence

Summary

More people than ever before can now choose to have cash payments to purchase their own personal assistance rather than using services arranged for them by local authorities. This scheme is called 'direct payments'. New legislation has placed a mandatory duty on all care managers to offer service users and carers, with an assessed need for services, cash payments.

This new flexibility has been welcomed by disabled people after decades of campaigning to be given choice and control over their lives. The direct payments scheme is seen as an important step towards the goal of achieving independent living. Unfortunately, one group has failed to benefit from the choice and flexibility offered by direct payments: black and minority ethnic communities. Local authorities have a history of consistently failing to provide black and minority ethnic communities equal access to direct services. And there is a growing body of evidence that black and minority ethnic service users will also be under-represented in direct payments schemes.

The purpose of this discussion paper is threefold:

- First, it will explain the latest legislation on direct payments and how it is meant to work.
- Second, it will summarise the growing research and secondary evidence that point to the inability of black and minority ethnic service users and carers to fully embrace direct payments.
- Third, it will pose a number of questions that will address ways in which direct payments services can be effective for black and minority ethnic service users and carers.

Direct payments

There are two key components to direct payments. The first is the care manager's assessment of the needs of service users and carers. The care manager must include direct payments as an option to secure direct services. They must also seek to offer the service in innovative ways. No service user can be forced to choose direct payments. The second component is the support services that will help users and carers manage their direct payments. The result is that a service user becomes an employer to their personal assistants. This means they will need help with taxation, payroll and other employer–employee matters. Support services can assist with this process while advocacy services can help service users choose the best option for them. The Department of Health (DH) believes support and advocacy services will overcome the one major weakness of direct payments – its complexity. The DH also believe that community-based support services are better placed to represent and assist black and minority ethnic service users and carers.

Black and minority ethnic service users' experience of direct payments

Despite the hopes of the DH, black and minority ethnic service users are faced with considerable barriers to accessing direct payments.

They include:

- confusion over the meaning of 'independent living'
- assessment processes not taking account of black and minority ethnic service users' backgrounds and requirements
- service users being unaware of how to access important information on direct payments
- lack of support for people to use the available information
- difficulties in recruiting personal assistants who can meet the cultural, linguistic and religious requirements of black and minority ethnic service users
- failing to consider using direct payments in more innovative and creative ways
- a shortage of appropriate advocacy and support services
- lack of resources for local schemes
- variable levels of commitment to direct payments among local authorities
- the possibility for confusion over the relatives' rules.

All together these barriers present a considerable challenge to local authorities. They require them to use imaginative and original methods to attract hard-to-reach groups. Training programmes for care managers need to reflect the socially inclusive goal of direct payments. The barriers also require local authorities to look carefully at the kinds of advocacy and support and services they have in place and to ask whether they represent the interests of all local users.

Local authorities have an opportunity to deliver innovative and flexible services to groups they have traditionally been unable to assist with direct services. There are going to be problems reaching some services users within this group. However, if the message – that direct payments can make a massive difference to the lives of service users and carers – is made to reach the target audience, then overcoming these problems will have been worthwhile.

Notes on the author

Ossie Stuart read for a Doctorate at the School of Oriental and African Studies, University of London, in 1989. From there he moved on to a research position at St Anthony's College, Oxford University and from there to the Social Policy Research Unit, University of York two years later. It was during this time that he was made aware that disability was not a condition but a question of rights. This coincided with his already quite extensive interest in 'race' and ethnicity. It was not long before he made an important contribution to disability theory by simplifying the discussion around 'race' and disability. He has also helped to give a voice to disabled people from black and minority ethnic communities.

After returning to London Ossie Stuart finally left academia in 2001 to work full time as a diversity consultant specialising in disability and ethnicity. He has worked with many organisations as a trainer in disability equality and ethnicity and disability. These include larger organisations such as the National Lottery, Royal College of Surgeons and Senate House, University of London, Imperial College and the University of Sussex. However, he has not neglected the much smaller voluntary sector organisations throughout London and has also done extensive training with these groups.

Between 2002 and 2004 Ossie Stuart has written or co-written three major reports on disability for the government, the Greater London Authority and the Metropolitan Police Authority. Ossie Stuart continues to make his expertise available for the benefit of disabled people.

Introduction

The Community Care (Direct Payments) Act 1996 and the more recent Health and Social Care Act 2001 created a social policy initiative whereby all local authorities in England, Scotland and Wales have a mandatory duty to provide cash to service users to allow them to purchase the services they need. For disabled people, the new direct payments legislation is a huge step towards 'independent living'. However, there is considerable evidence to suggest that this policy is not equally benefiting service users and carers from black and minority ethnic communities.¹ In fact, black and minority ethnic communities are the least likely to be offered the direct payments option by local authorities, despite their mandatory duty to do so.²

Aim of the discussion paper

Community-based support services are an essential part of the Department of Health's (DH's) strategy to bridge the gap in provision for black and minority ethnic service users and carers.³ It is reasonable to assume that support services that reflect a community's needs will help service users manage their own direct payments better than local authorities. However, there appears to be too few examples of the voluntary sector rising to the challenge where black and minority ethnic service users are concerned.

This discussion paper addresses the question of whether community-based services can achieve better results for black and minority ethnic service users and carers. What would enable good practice is perhaps the most important question as the reasons for the lack of black and minority ethnic service user participation in direct payments goes far beyond the kind of support services available, as this discussion paper will make clear.

This discussion paper seeks to do three things. First, it will explain the latest direct payments legislation and how it is meant to work. Second, it will summarise the growing research and secondary evidence that point to the inability of black and minority ethnic service users and carers to embrace direct payments fully. Third, it poses a number of questions that will point to ways in which direct payments services might be effective for black and minority ethnic service users and carers.

Who are black and minority ethnic service users and carers?

Behind the term 'black and minority ethnic' is a diverse and very loosely related group of people. People of African and South Asian origin are the predominant groups, especially the latter. Yet continued migration to the UK involves people from other parts of the world as well. As a result, the term can include residents of the UK who originate from as far apart as China and the Irish Republic. For the purpose of this discussion paper, however, it would be prudent to assume that the term 'black and minority ethnic' usually refers to the two main minority ethnic groups in the UK: members of the South Asian and African communities (also known as people of New Commonwealth origin). Other communities will be mentioned by name if and when it is appropriate to do so.

The legislation and background to direct payments

The legislation

Direct payments – that is, cash in lieu of social services – for adults of working age were introduced in April 1997 through the Community Care (Direct Payments) Act 1996. They were extended to older disabled people in 2000. Since April 2001, as a result of the Carers and Disabled Childrens Act 2000, direct payments have been available to carers and as of April 2003, local authorities are required to offer direct payments to people who have an assessed need and who are able to manage the payments (alone or with assistance).

Voluntary organisations are expected to bid for local authority projects to support the expansion of access to direct payments. The DH has assumed that this would be a key part of the delivery of and support for direct payments, and they see support and advocacy services overcoming the one major weakness of direct payments – its complexity. With this in mind, in 2002 the DH announced that, to support voluntary sector initiatives, it would provide a direct payments development fund of £3 million a year for the next three financial years.⁴

The Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005

In the past six years the government has updated two key pieces of legislation of particular interest to black and minority ethnic service users and carers – first, the amendment (in 2000) to the Race Relations Act 1976,⁵ and second, the update to the Disability Discrimination Act in April 2005.⁶ The significance of these two updates is that public bodies have new statutory duties to promote 'race' equality and disability equality.

The new duties to promote 'race' equality and disability equality will oblige local authorities to:

- consult communities from the so-called 'hard-to-reach' groups
- account for the quality of services used by black and minority ethnic service users and carers as well as the wider community
- state and monitor how services will be improved over the next three years for black and minority ethnic service users and carers.

As a result of these new duties local authorities are encouraged to look at diversity and service development in an holistic way. What this means is that disability isn't just about 'welfare' or that it is just the responsibility of social services departments, or that 'ethnicity' is just the responsibility of anti-discrimination local authority officers. In fact, a service user's ethnicity should be considered at every level of local authority policy and by all departments.

The establishment of 'race' equality schemes by local authorities will allow greater transparency in the collection of useful information on black and minority ethnic

communities who use social care services. Local authorities will also have to consult service users on how services are delivered and improved upon.

When it comes to direct payments, black and minority ethnic communities are under-represented as recipients, which reduces their chances of 'independent living'. The situation isn't helped by the lack of statistical clarity around the number of black and minority ethnic people who use direct payments. However, updated 'race' and disability legislation should enable greater understanding of their experiences when accessing services.

The figures

The Community Care (Direct Payments) (Scotland) Amendment Regulations 2000 allowed direct payments to be offered to older people.⁷ The Carers and Disabled Children Act 2000 expanded on previous direct payments legislation to include disabled people aged 16 and 17 who wished to receive direct payments, and people with parental responsibilities towards disabled children.⁸ The consequence of this has been a dramatic rise in the number of people opting for direct payments in England.

During 2003-04 the number of adults aged 18 and over receiving direct payments increased from 9,600 to 17,300 – an 80% rise on the previous year.⁹ Impressive though these figures appear, they are rather mediocre when compared to those of European neighbours who run similar schemes. For example, in 1999 there were over one million direct payments users in Germany and more than 43,000 in Sweden.¹⁰ We can safely assume that by 2004 these European figures will have increased as much as, if not more than, those in the UK. Despite the 80% increase in a year, the number of users of direct payments in the UK remains comparatively low.

Lack of official data on black and minority ethnic users of direct payments

Low uptake of direct payments has serious implications for service users and carers from black and minority ethnic communities. Historically, this section of the UK's population has received the poorest services from local authorities. Evidence suggests that their experience of direct payments has been equally poor when compared with the majority of disabled people who use the scheme. The fact that there is no official data on the number of black and minority ethnic users of direct payments is indicative of the general lack of attention paid to the welfare of black and minority ethnic service users. This has for too long characterised the delivery of social services in the UK.

What is the direct payments scheme?

Before considering the barriers that black and minority ethnic service users and carers face in accessing direct payments, let us consider what the direct payments scheme actually is.

Under the Health and Social Care Act 2001, a mandatory duty has been placed on local authorities to offer service users the option to use direct payments rather than a particular service.¹¹

As part of the care planning process, each eligible individual should be offered the choice of having their needs for a relevant service met through cash payments rather than through services provided or arranged by the local authority. The DH publication *Fair access to care services guidance* offers advice about care planning and how direct payments should be offered as part of this process.¹²

If individuals wish, local authorities can arrange mixed packages for them consisting of services provided by them as well as direct payments to meet different needs. Among other things, this can give a service user the opportunity to become familiar with the business of using a direct payment before taking on the responsibility for arranging services to meet all their needs.

The following groups of people may be eligible to receive direct payments:

- Older people (who despite being the largest single group of people using community care services, are the least likely to be offered and to receive direct payments).
- Disabled people aged 16 and over.
- A person with parental responsibility for a child. This may include a parent or others, such as a grandparent with parental responsibility for a disabled child. It may also include a disabled person with parental responsibility for a child.
- Carers aged 16 and over. That is, people whom the council decides need services because they provide or intend to provide a substantial amount of care on a regular basis for someone aged 18 or over. Carers (but not employees: people working under contract or for a voluntary organisation) may obtain direct payments in respect of their own needs for services but not for services in respect of the needs of the person they care for.

Who cannot receive direct payments?

Direct payments may not be made to certain people whose liberty to arrange their care is restricted by, for example, mental health or criminal justice legislation.

Another important exclusion relates to the use of close relatives as paid carers. To cite DH 2003 direct payments guidance:

Unless a council is satisfied that it is necessary to meet satisfactorily a person's needs, a council may not allow people to use direct payments to secure services from a spouse (husband or wife), from a partner (the other member of an unmarried couple with whom they live), or from a close relative (or their spouse or partner) who live in the same household as the direct payment recipient.¹³

Local authority responsibilities

There is not the space to describe in detail all the responsibilities that local authorities must adopt to ensure best practice in the delivery of direct payments. It is instructive, however, to outline their key responsibilities. What becomes quickly apparent is that direct payments present local authorities with a number of complex issues.

At the heart of the DH's 2003 guidance is the quality of the training that care managers receive. Their actions will make the difference between service users receiving or rejecting the direct payments option. They will also influence the relationship with services support, interpretation of the law, risk assessment, the experience of people with differing disabilities, competition from direct services and even how the service is advertised locally.

Despite obligations to provide direct payments, to some extent the success of the service is still dependent on the discretion and competence of care managers. It is precisely this discretionary nature that can mean the difference between black and minority ethnic service users using the system or not.

Barriers to accessing direct payments

It has been acknowledged that black and minority ethnic service users and carers are under-represented among users of direct payments. For example, DH guidelines stress that a special effort should be made to reach black and minority ethnic groups.¹⁴ This mirrors the findings of the Joseph Rowntree Foundation – their response to the Scottish Executive's initiative regarding direct payments also highlighted a lack of user demand from black and minority ethnic communities.¹⁵

This discussion paper identifies 10 key reasons why black and minority ethnic service users are under-represented as users of direct payments. Some of the reasons will apply to all potential service users and carers. However, they are most pertinent to users from black and minority ethnic communities.

1. Confusion over the meaning of 'independent living'

The key philosophy behind direct payments is that it will increase the independence of disabled people for whom receiving services from providers has always meant a lack of choice and a loss of independence.¹⁶ However, this is a Eurocentric interpretation of independence, where disabled people make decisions independently of carers and family. This term became part of a political campaign for disabled people throughout the 1980s and 1990s, which culminated in the direct payments legislation we have today.¹⁷

The highly politicised nature of direct payments influences the language most people use to describe them. DH 2003 guidance to local authorities quoted care managers describing direct payments as:

"People have a voice when they're in control of something ... I just feel [that] people [being] more in control gives them a better quality of life."

"It's great way to take hold of your own life,"

"It's so exciting! There's a massive sense of satisfaction."¹⁸

This political interpretation merely serves to confuse and create fear for potential black and minority ethnic service users and their families. This became apparent in a Joseph Rowntree Foundation research project¹⁹ where 44 young people of Asian, African and Caribbean origin were interviewed. The majority agreed with

the interpretation that independent living meant living on your own. Although the majority of the young men and women were living with their families, many felt that they exercised independence because they were making their own decisions. To what degree they were independent depended on circumstance, not choice. For many of the young people living independently, this involved living with or near their families, but being able to exercise control over decision making.

Similar findings were made by Joseph Rowntree Foundation research in West Yorkshire and the West Midlands by Hussain, Atkin and Ahmad (2002) at the Centre for Research in Primary Care, University of Leeds. The researchers stated that:

... not all young people and their families had a politicised view of disability. Gaining independence, leaving home, living separately or having personal control of resources did not always have the same significance to these young people as it did to their white counterparts. Young people tried to balance having control over their lives with taking an active role in their families and helping out family members.²⁰

But why is there a fear of independent living? There are concerns that direct payments will impose autonomous lifestyles on service users. This is something many members of black and minority ethnic communities would not choose. Care managers might emphasise 'independence' over dependence without properly explaining what this means, and this could put off potential direct payments users from black and minority ethnic communities.

2. Assessment processes do not take account of the background and requirements of black and minority ethnic service users

The DH 2003 guidance criterion fails to acknowledge the varied experiences and background of service users in the assessment process.

It is true that local authorities are reminded to take the views of black and minority ethnic service users into consideration when establishing direct payments schemes. They are also advised to monitor the quality of the service that black and minority ethnic service users receive.²¹ Nevertheless, the complex task of assessing the real needs of service users is left to care managers.

Will they be aware of the position of disabled people within many black and minority ethnic communities? Do they understand that the delivery of direct payments to service users might require complex negotiation and explanation to a range of interested parties? And that gender experiences may vary quite dramatically? Also, will they understand that the role of a paid carer can be complex and potentially disruptive?

The Joseph Rowntree Foundation research highlighted that many of the young people were known to social services departments and had had contact with social workers at some time during their lives. Yet few had contact with social services departments for their main care and support needs.²² This indicates that it is likely that care

managers would only have limited knowledge of the black and minority ethnic service users who they will assess.

3. Many service users do not have information on direct payments

One of the key findings of the Joseph Rowntree Foundation report was that many of the young people did not have any information on what services were available and/or whether or not they had a social worker. There was a lack of information regarding social care practices and policies. For example, practically no young person had any knowledge of direct payments and how these could enable them to live independently.²³

The DH 2003 guidance provides no clear ways in which to reach out to black and minority ethnic service users, beyond stating that local authorities should do so. Nor does it insist on monitoring the ethnicity of those who go on to direct payments and those who choose to remain in receipt of direct services.²⁴ This means we have no real way of knowing how successfully local authorities are advertising their direct payments schemes to black and minority ethnic communities in their regions.

4. There are difficulties in recruiting personal assistants who are able to meet the cultural, linguistic and religious requirements of service users

The Joseph Rowntree Foundation research revealed that most of its participants relied on informal support in their everyday lives. The family was especially important for physical care needs and emotional support. Having family nearby was a particular issue for those who lived in their own accommodation.²⁵

The assumption is often made that providing culturally compatible personal assistants who are from the same black and minority ethnic communities can meet the racial and cultural needs of the service user.²⁶ This would be ideal if such assistants were in abundance. It would also be ideal if social services departments really understood the difficulty of meeting the religious, linguistic and cultural requirements of, for example, older disabled people from black and minority ethnic communities. Will the personal assistant meet the appropriate gender requirements? Will personal assistants be of an appropriate social standing? Will they undermine family confidentiality?

These are a few of the questions that ought to be considered when thinking about recruiting personal assistants.

The difficulty of funding assistance of this kind may mean that other options within the direct payments scheme ought to be considered as well.

5. Local authorities fail to consider using direct payments in more innovative and creative ways

The DH 2003 guidance advises local authorities to suggest to service users that direct payments can be used in a variety of ways. For example, it can be used to pay

some costs that a carer might incur. They could also be used to purchase agency care, to provide for short-term care or to purchase short breaks for disabled children.²⁷

Despite this flexibility, many care managers might assume that the only option they can offer to black and minority ethnic service users is the use of family members as paid carers. This option is available to care managers if they believe that other options are not what the service user would consider. However, there is a great danger that the use of family members will be presented as the only option. In other words, black and minority ethnic communities might be less likely to be offered the same range of choices that other users enjoy.

6. There is a shortage of appropriate advocacy and support services

The absence of disability groups in the lives of disabled people from black and minority ethnic communities cannot be overemphasised. This is a critical issue for service users from these communities. The DH has placed great store in the role voluntary organisations play in supporting direct payments for service users, especially organisations run by disabled people.²⁸

Historically, the voluntary organisations that have worked with disabled people, including those run by disabled people, have neglected the views, opinions and requirements of disabled people from black and minority ethnic communities.²⁹ Similarly, organisations that are committed to black and minority ethnic causes have also neglected them. Finally, peer support groups are usually under-funded and overstretched, and are often poorly placed to bid for funding to become an effective support service. This has meant that service users from black and minority ethnic communities remain poorly served.

Research from the Joseph Rowntree Foundation also identified this gap in support. Existing disability groups did not cater for young people or for the concerns of black disabled people. Most of the young people wanted the opportunity to meet other young black disabled people – those who shared the same 'race', food and way of life – to learn about their culture, socialise and share experiences.³⁰

As a result of not having their views, opinions and requirements taken into consideration, it is likely that black and minority ethnic users of direct payments will receive less support, training, advice and help from the support services when compared to the majority of direct payments users.

7. There is a lack of resources for local schemes

The DH has promised to support voluntary sector initiatives via the Direct Payments Development Fund.³¹ However, there is no evidence that this commitment to increase funding will oblige local authorities to support those voluntary organisations that do make specific efforts to engage black and minority ethnic communities. This requires consistent commitment and high-quality training of employees, and will not be cheap. This additional cost may mean that local authorities might be less likely to support such initiatives.

8. There are varied levels of commitment to direct payments among local authorities

The Health and Social Care Act 2001 makes it mandatory for all care managers to offer direct payments to each eligible individual. As part of the care planning process, service users have the choice of having their needs for a relevant service met through direct payments rather than through direct services provided by the local authority. Local authorities are reminded that they must include the hard-to-reach groups, such as older people, people with learning disabilities and black and minority ethnic service users. Despite this expectation, local authorities will invariably establish commissioning and support services that best meet their obligations.

Local authority commitment to direct payments services for black and minority ethnic communities will vary. It is likely that inner-city local authorities in London, for example, will understand that their support services ought to be as accessible as possible to black and minority ethnic service users. This same appreciation will be absent in regions without a tradition of having sizeable black and minority ethnic communities, but this ought not to remove the need to consult and include service users from these communities. However, the commitment to ensuring their inclusion is likely to be far less.

9. There is the possibility for confusion over the relatives' rules

DH 2003 guidance discourages but does not totally forbid a service user purchasing direct payments services from a spouse (husband or wife), from a partner or from a close relative who lives in the same household.³²

The impact of this direction will be twofold:

- First, it will render such arrangements second class, as they will be seen as contrary to best practice in the eyes of care managers.
- Second, they will become 'ethnically specific' solutions. Care managers will be more likely to agree to this option when it is requested by black and minority ethnic service users but refuse the same request made by other service users. They will be likely to offer more innovative solutions to meet the other service users' needs and go for what might seem an easier option by agreeing to the employment of close relatives when working with black and minority ethnic service users.

The consequence of this inconsistency amounts to the worst of both worlds – it can only result in the creation of divisions among service users.

10. Lack of support for people to use the information available

The importance of publicising direct payments to hard-to-reach groups should be a priority for all local authorities. It is well understood that many people within black and minority ethnic communities do not use English as a first language. What is less recognised is that many are isolated and are unlikely to be reached through the usual advertising channels, especially black and minority ethnic parents with disabled children.³³ Furthermore, many disabled people from within black and

minority ethnic communities with either learning disabilities or a hearing impairment will be extremely difficult to include because their communication issues are rarely recognised.

Some local authorities will be reluctant to move beyond the tried and trusted methods of informing users. This will limit the innovation that is required to meet the challenge of informing all service users. This will inevitably slow down the take up of direct payments by service users and carers from within black and minority ethnic communities.

The questions

Many of the problems identified above could be mitigated by well-trained, informed, and connected community-based support services for black and minority ethnic service users of direct payments. However, few of the organisations that exist today could confidently claim that they provide this kind of service. The few that can claim this have usually achieved it in the face of local authority indifference. Therefore the questions in this section must relate to the way services might be better organised in general terms. It is not enough to just look at support services in isolation.

The purpose of these questions is to stimulate debate on the issues that have been raised above.

1. What should a support service for black and minority ethnic service users look like?

The advantages of informed and connected community-based support services are obvious. Workers will have the expertise to professionally engage with specific client groups, and this will create an inclusive service. But will it be easier to monitor?

What about areas with little tradition of working with black and minority ethnic communities? There is a danger that such work and the funding of it will be considered a low priority by the support service itself as well as by the local authority. Focusing resources on one organisation will stifle potentially innovative work by 'ethnically' specific organisations in the same region. Should support services be ethnically specific or part of a larger support organisation?

2. Care managers should ensure that the assessment process is fair and empowering for black and minority ethnic families. How might this impact on the support a community-based organisation can offer?

Both care managers and support services might share the ideals of independent living. However, how does the care manager ensure a truly service user-led assessment process? Each service user will approach giving consent differently. Will information on innovative direct payments options be provided despite assumptions about its likely acceptability? Who will undergo regular diversity training? How does one avoid the assumption that disabled people, older people, children and black and minority ethnic service users are members of mutually exclusive groups?

3. Are organisations led by disabled people the best way to deliver inclusive community-based support services to black and minority ethnic service users?

Service user-led organisations will be committed to giving choice and control to disabled people. They will help many black and minority ethnic service users move from direct services to direct payments. They will be able to explain service user rights coherently and act as advocates in the best interests of service users. They

can act as a training and information resource for service users, carers and care managers.

On the other hand, their commitment to independent living might alienate some black and minority ethnic service users and their families and their expertise in reaching out beyond their usual service user groups is limited. They will also require regular 'race' equality training as they might duplicate the functions of a peer support organisation.

4. How should black and minority ethnic women service users and mothers of disabled children be supported when using direct payments?

Gender differences can be significant within black and minority ethnic communities with more restrictions often placed on females.³⁴ Mothers from these communities raising disabled children also have the most needs and least access to information.³⁵

What kind of support services would benefit female service users and carers? Should advocacy and support services always be separate (which is a recommendation in the DH 2003 guidance)? How should advocates find and get in touch with the hard-to-reach female service users and carers?

5. Should the conditional restriction on allowing people to use direct payments to secure services from close relatives be retained?

Is this necessary to maintain the credibility of the service?

Will this rule create a racialised service?

What alternatives to using family members exist?

6. How should information on successful support services and expertise on supporting black and minority ethnic service users and carers be passed on to other local authorities?

Good practice will often be found in regions with a tradition of having large numbers of black and minority ethnic service users. Can sharing be achieved by making regular training compulsory? Should good practice be published? Should local authorities be penalised if they fail to engage with black and minority ethnic service users?

7. What kinds of figures should the DH publish about black and minority ethnic service user participation in direct payments services?

Should figures include take-up of direct payments and the number of service users who reject this option? Which options have been chosen? How many choose family members as paid personal assistants? What are the numbers of people who revert back to direct services after trying direct payments?

8. The biggest obstacles for many people within black and minority ethnic communities are probably linguistic barriers. How might they be overcome?

Should there be workshops and conferences for under-represented groups? Who should run them? Should smaller training sessions for black and minority ethnic people with, for example, learning disabilities, be held separately?

Would this be cost effective? Would service users in regions with no large black and minority ethnic communities miss out? Would the hard-to-reach groups (for example, women, older people) still miss out?

9. Appropriate personal assistance for black and minority ethnic service users is hard to obtain. How can this be remedied?

There must be extensive advertising in the black and minority ethnic media, and all communities should be educated about direct payments. There should also be better rates of pay for personal assistants.

Should the 'close relative' limitation be scrapped for all? Or is the problem overstated? Is the 'close relative' clause about right? Would resources be better spent elsewhere?

Conclusion

The new legislation has broadened the user base of direct payments. The updates to the equalities legislation, especially the duty under the Race Relations (Amendment) Act 2000 to promote 'race' equality, provide a way for local authorities to involve and improve direct payment services for black and minority ethnic communities. Local authorities have an opportunity to deliver innovative and flexible services to black and minority ethnic groups they have barely been able to assist in the past through direct service provision. There are going to be problems reaching some service users within this group, which has always been the case. However, the message is quite clear – direct payments can make a huge difference to the lives of service users and carers. Local authorities must engage with black and ethnic minority service users to work out the best way of ensuring that they get equal access to direct payments.

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Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers?

The direct payments scheme is seen as an important step towards achieving independent living. There is, however, growing evidence that black and minority ethnic service users will be under-represented in these schemes. This discussion paper explains the latest legislation on direct payments, summarises the evidence indicating that black and minority ethnic service users and carers are unable to fully embrace direct payments and poses questions that address ways in which direct payments can be effective for black and minority ethnic service users and carers.

This publication is available in an alternative format upon request.