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Briefing Sheet 05

Self Directed Support and Scotland's Black and Minority Ethnic Communities

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It is widely acknowledged that mainstream services have failed to meet the care and support needs of Scotland's Black and Minority Ethnic (BME) communities. Problems of access and the inappropriateness of much of what is currently available continue to present major challenges for individuals requiring community care services. Research strongly suggests that BME communities will struggle to receive individually tailored support from traditional services[1].

The development and implementation of self-directed support (SDS), with its focus on choice and control, on the face of it provides BME communities with an opportunity to acquire the support they need.

This paper explores the challenges that will have to be addressed if this is to become a reality. The development of SDS and the experience of direct payments are drawn on initially to provide context.

What is Self Directed Support

The Scottish Government, in its 10 year Strategy 'Self Directed Support: A National Strategy for Scotland (2010) defines SDS as:

"…the support individuals and families have after making an informed choice on how their individual budget is used to meet the outcomes they have agreed. SDS means giving people choice and control."[2]

The Strategy sets out a clear vision for the future delivery of social care services in Scotland and the core values, principles, processes and mechanisms necessary as well as the cultural shift required to successfully achieve self-directed support:

"The lives of people who require support are enriched through greater independence, control, and choice that leads to improved or sustained health and wellbeing, and the best outcomes possible. Self-directed support should become the mainstream approach to the delivery of personal support. Building on the success of direct payments, every person eligible for statutory services should be able to make a genuinely informed choice and have a clear and transparent allocation of resources allowing them to decide how best to meet their needs. The choice should be available to all but imposed on no-one."[3]

The Strategy also widens the concept of self-directed support beyond direct payments although they remain an integral part of SDS.

Self-directed support itself sits within the wider context of the personalisation of care with its emphasis on individual outcomes and the co-production of services.

[1] http://www.mecopp.org.uk/files/documents/research/mecopp_briefing_sheet_03.pdf
[2] Scottish Government (2012) *Self Directed Support: A National Strategy for Scotland*
[3] Scottish Government ibid

A recent publication by the Social Care Institute for Excellence (SCIE)[4] describes personalisation as:

- tailoring support to people's individual needs whatever the care and support setting;
- ensuring that people have access to information, advocacy and advice, including peer support and mentoring, to make informed decisions about their care and support, or personal budget management;
- finding new collaborative ways of working (sometimes known as 'co-production') that support people to actively engage in the design, delivery and evaluation of services;
- developing local partnerships to co-produce a range of services for people to choose from and opportunities for social inclusion and community development;
- developing the right leadership and management, supportive learning environments and organisational systems to enable staff to work in emotionally intelligent, creative, person-centred ways;
- embedding early intervention, reablement and prevention so that people are supported early on and in a way that's right for them;
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities; and,
- ensuring all citizens have access to universal community services and resources – a 'total system response'

Cumulatively, SDS, personalisation and co-production seek to shift the 'balance of power' moving individuals from passive recipients of services to active citizens who are fully involved in selecting and shaping the support and services they receive. The relationship between practitioners and service users is redefined as of one 'mutuality and reciprocity'.

Self-directed support was given a legislative basis with the passing of the Social Care (Self Directed Support) (Scotland) Act (2013) in November 2012. The Act requires local authorities to offer individuals four choices on how their social care needs can be met:

- **Option 1** – the local authority makes a direct payment to the supported person for them to arrange their support (this can include the purchase of support);
- **Option 2** – the supported person chooses their support and the local authority makes arrangements for the support on the person's behalf;
- **Option 3** – the local authority selects the appropriate support and arranges support on behalf of the supported person; and
- **Option 4** – a mix of options 1, 2 and 3 for specific aspects of a person's support

Each option provides the individual with varying degrees of ongoing control and responsibility for the purchase and management of their support arrangements. It is important to note that individuals can move from one option to another if they decide their original choice is not suitable or no longer meets their needs.

The Act also contained a range of additional duties and powers including a power for local authorities to support unpaid carers and a duty to provide information to enable the individual to make an informed choice.

[4] Social Care Institute for Excellence (2012) *Personalisation: A Rough Guide*

Direct Payments

Chronologically, direct payments (DP's) predate both the National Strategy and the Social Care (Self Directed Support) (Scotland) Act (2012). In practical terms, much of the impetus behind the development of individual or personal budgets (a component of SDS) draws on the experience of direct payments. The Scottish Government itself acknowledges that direct payments can be described as 'the first step on the road to personalisation'.[5] Payne[6] goes further and argues that, until recently, self-directed support in Scotland had become synonymous with direct payments. Manthorpe[7] similarly argues that whilst there have been some initiatives to widen the understanding of SDS beyond direct payments, much of the information and analysis currently available relates to direct payments.

It is in this context that the use of direct payments is explored both generically and in relation to BME communities.

Statistics on the take-up of direct payments have been available since 2001. The following data is taken from the Scottish Government's latest Statistical Bulletin[8] on self-directed support (direct payments).

- The number of people in receipt of SDS (Direct Payments) has increased by 15% from 4392 in 2011 to 5049 in the year to 31 March 2012;
- The number of individuals using direct payments to purchase care and support has increased each year while the number of people receiving home care services provided or purchased by local authorities has fallen over the last 5 years. The number of people using Direct Payments is still small when compared with the 63,500 people receiving home care services at March 2011;
- 37% of people receiving Self-directed Support (Direct Payments) had a physical disability and 24 per cent had a learning disability. A further 4 per cent had both a physical and a learning disability;
- The value of direct payments has increased each year from £2.1 million in 2011 to £59.4 million in 2012;
- Over the last year, the value of direct payments increased by 18 per cent, from £50.2 million in 2011 to £59.4 million in 2012;
- The age profile of Self-directed Support (Direct Payment) clients has changed since 2011, with a greater proportion of recipients now aged 65 or over. In 2001 only 7 per cent of recipients were in this age group, compared to a third of clients in 2012;
- In the year to 31 March 2012, 1,663 people aged over 65 received payments (33 per cent of the total);
- Overall there were slightly more females than males in receipt of Self-directed Support (Direct Payments) in 2012, 53 per cent compared to 47 per cent; and,
- The age profile varies by age group. In the under 35 age groups there were more males than females using Direct Payments while in the 65 and over age group, there were nearly twice as many females than males.

[5] Cited in Payne, J., (2012) SPICe Briefing *Social Care (Self Directed Support) (Scotland)* Bill Scottish Parliament

[6] Payne, J., ibid

[7] Manthorpe, J., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Hunter, S., Little S., & Gray, B., (2011) *Self Directed Support: A Review of the Barriers and Facilitators* Scottish Government

[8] Scottish Government (2012) *Self-directed Support (Direct Payments) Scotland 2012* A National Statistics Publication for Scotland

Age and gender of clients received Self Directed Support (Direct Payments) packages 2012[9]

Age	0 – 17	18 – 34	35 – 49	50 – 64	65 +	Total
Male	448	678	328	386	556	2,396
Female	249	421	422	454	1,107	2,653
Total	**697**	**1,099**	**750**	**840**	**1,663**	**5,049**

Direct Payments and BME Communities

Information on the number of direct payment recipients by ethnicity has been provided to the Scottish Government since 2010 (for the reporting period 1 April 2010 – 31 March 2011). Comparison of figures over the two year period for which ethnic data is available shows an increase of 31.6% in the number of BME recipients (mixed or multiple ethnic groups, Asian, African, Caribbean or Black or other ethnic group) compared with 11.5% for the White ethnic group although overall figures for BME communities remain very small.

The figures also highlight the need for more robust ethnic monitoring by local authorities.

Ethnicity of clients receiving Self Directed Support (Direct Payments) 2011[10] & 2012[11]

Ethnicity	Number of Clients	
	2010/11	2011/12
White	3,588	4,001
Mixed or multiple ethnic groups	7	14
Asian	40	50
African, Caribbean or Black	11	12
Other ethnic background	21	28
Not disclosed	92	85
Not known	633	859
All	3,667	5,049

Draft policy and practice guidance published by the Scottish Government (2006) recognised that assumptions made by practitioners regarding the provision of informal care within BME communities may be incorrect:

"It is starting to be recognised by some local authorities that the assumption that minority ethnic families have continued a tradition of looking after their own members may not be the case. Direct payments could be a key way of ensuring minority ethnic individuals and families have better access to community care services generally."[12]

[9] Scottish Government (2012) *Self-directed Support (Direct Payments) Scotland 2012* A National Statistics Publication for Scotland
[10] Scottish Government (2011) *Self-directed Support (Direct Payments) Scotland 2011* A National Statistics Publication for Scotland
[11] Scottish Government (2012) *Self-directed Support (Direct Payments) Scotland 2012* A National Statistics Publication for Scotland
[12] Scottish Government (2006) *Direct Payments for Self Directed Care: Draft Policy and Practice Guidance*

The draft guidance identified a number of actions for local authorities to consider in ensuring that direct payments were routinely available to BME communities[13]:

- Promote direct payments for minority ethnic users. There is a very low knowledge base within some communities.
- Awareness of locally funded direct payments support needs to reach the whole community through, for example, outreach programmes, since many people may only hear of direct payments through word of mouth, may not be sure if they are eligible, or may not be aware of it at all, particularly if English is not their first language.
- Provide specialist support targeted to minority ethnic users' needs if needed, for example, a translator, advocate or support worker with specialist skills.
- Ensure minority ethnic users and potential users have access to information targeted to their needs.
- Train minority ethnic users on pre-assessment, care planning and care management via local support organisations.
- Train local authority care managements on race equality issues, and encourage a culture of open and honest dialogue to enable more minority ethnic people to take up direct payments if it best meets their needs.

It is reasonable to assume that the actions have been developed in response to the challenges facing local authorities in mainstreaming direct payments for all sections of the population.

There is little Scottish based research on the experience of BME communities and the use of direct payments and SDS. However, English research on the potential of direct payments and self-directed support to transform the provision of community care services to BME communities **and** the direct experience of current BME direct payments recipients reinforce the challenges ahead. This information has been supplemented by Scottish based research where available.

Studies undertaken by the Social Care Institute for Excellence[14] and Carers UK[15] as well as individual researchers[16] [17] identify the following key issues:

- Confusion over the meaning of 'independent living';
- Eurocentric assessment processes;
- Low levels of access to appropriate and accessible information;
- Lack of support to use available information resources;
- Difficulties in recruiting staff who can meet the cultural, linguistic and religious requirements of BME service users;
- Shortage of appropriate advocacy and support agencies; and,
- Possible confusion over the 'relatives rule'.

[13] Scottish Government ibid

[14] Stuart, O (2006) *Will community based support services make direct payments a viable option for Black and Minority Ethnic service users and carers?* Stakeholder Participation Race Equality Discussion Paper 1 Social Care Institute for Excellence SCIE

[15] Carers UK (2011) *BAME Families and Personalisation A Person Centred Approach: Making personalisation successful for Black Asian Minority Ethnic (BAME) families and communities* Policy Briefing

[16] Terashima, S (2011) *Personalisation of care for people from South Asian communities* Learning Disability Practice March 2011 Volume 14 Number 2

[17] Pearson, C (2004) *The Implementation of Direct Payments: issues for user-led organisations in Scotland* in Barnes, C and Mercer G. (eds) 2004: *Disability Policy and Practice: Applying the Social Model*, Leeds: The Disability Press, 130 14 3)

The research also identifies a range of concerns at local authority level which have the potential to impact on BME communities:

- Failure to consider using direct payments in more innovative and creative ways;
- Lack of resources for local authorities; and,
- Variable levels of commitment to direct payments amongst local authorities.

Stuart[18] argues that the highly 'politicised' nature of direct payments, particularly in relation to independent living, influences the language used which may, in turn, cause fear and confusion for BME communities. He cites research conducted by the Joseph Rowntree Foundation[19] which found 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 own lives with taking an active role in their families and helping out family members."

Stuart[20] also argues that the concept of independent living is based on Eurocentric norms without reference to differing cultural norms within BME communities leading to concerns that direct payments may impose an autonomous lifestyle on BME service users whether they want it or not.

The failure to recognise and accommodate different cultural norms and expectations also extends to the assessment process. BME communities tend to have less engagement with community care services which may mean that community care practitioners have limited knowledge and experience of the specific needs of BME service users and carers. Stuart[21] raises the question as to whether practitioners will be aware of the lived experience of BME disabled people and how care may be organised within the family unit. SDS and direct payments as an option may require negotiation with an extended family rather than the individual making a lone decision.

The language of self-directed support and direct payments also present challenges for BME communities[22]. Research conducted by MECOPP to explore BME carers and service users' understanding of the new terminology found little, if no understanding of terms now in common usage. Concerns were expressed about the complexity of the language used, lack of consistency when information is translated or interpreted and a failure to take into account lower levels of literacy, particularly amongst BME older people.

Participants also highlighted the need for additional support to understand and respond to changes in the delivery of care citing a strong preference for BME specific organisations where they had an existing relationship. Underpinning this was a lack of confidence in mainstream support agencies who have little, if any, knowledge and experience of BME service users and carers. The cultural shift from passive recipients of services to 'active agents' was also highlighted as a major concern requiring time and investment to overcome.

[18] Stuart, O ibid

[19] Hussain, Y., Atkin, K., & Ahmed, W. (2002) South Asian disabled young people and their families, Bristol/York: The Policy Press/Joseph Rowntree Foundation in Stuart, O. ibid

[20] Stuart, O ibid

[21] Stuart, O ibid

[22] Pearson, C (2004) *The Implementation of Direct Payments: issues for user-led organisations in Scotland* in Barnes, C and Mercer G. (eds) 2004: *Disability Policy and Practice: Applying the Social Model*, Leeds: The Disability Press, 130 14 3)

Stuart[23] also identifies difficulties in recruiting employees who are able to meet the cultural, linguistic and religious requirements of service users as a barrier to the uptake of direct payments by BME communities. In towns and cities where the BME population is relatively small, the potential labour pool is even smaller. The concept of PA's (personal assistants) is also less well developed within BME communities, perhaps as a consequence of the relatively lower level of 'politicisation' of disability and independent living when compared with disabled people in the majority population.

The employment of close family members to fill the employment gap is one option that may be utilised by BME and other communities, eg. rural and remote, where there are fewer opportunities to recruit. Prior to the passing of the Social Care (Self Directed Support) (Scotland) Act (2013), local authorities had a discretionary power to allow the employment of close family members in exceptional circumstances. New Guidance and Regulations underpinning the Act now allow for this in **appropriate** circumstances providing more leeway. However, the employment of close family members, particularly in the same household, raises a number of important questions.

The research undertaken by MECOPP indicates that this would be a popular option for BME communities. However, changing familial relationships to one of employer/employee raises concerns about the distribution and exercise of 'power' within the family unit. Local authorities may be reluctant to pursue this option as it may not be seen as best practice thereby contributing to the development of a 'second class' system. Stuart[24] argues that such an approach may also become ethnically specific stifling more creative and innovative solutions offered to non BME individuals.

There is also a wider concern that SDS and direct payments may become the default position of local authorities who cannot meet the needs of BME communities within mainstream provision. Ultimately, it is argued, this would diminish the need for mainstream services to adapt and change to meet the needs of BME service users and carers.

Conclusion

The potential of self directed support to transform the provision and delivery of services to BME communities is, as yet, untested. Many of the issues that inhibited the uptake of direct payments by BME communities remain unresolved. Feedback from the evaluation of the Scottish Government test sites (City of Glasgow, Dumfries and Galloway and Highlands) to increase the uptake of SDS found that investment did little to increase take-up amongst BME communities[25]. The actions set out in the Scottish Government Guidance (2006) remain pertinent and provide a useful 'road map' if BME communities are to truly benefit from self directed support.

[23] Stuart, O ibid
[24] Stuart, O ibid
[25] Ridley, J., Spandler,H., Rosengard, A,. Little, S., Cornes, M., Manthorpe, J., Hunter, S., Kinder, T., & Gray, B., (2011) *Evaluation of Self Directed Support Test Sites in Scotland* Social Research Health and Community Care Research Findings 109/2011 Scottish Government