

Self-directed support

Self-directed support and BME communities

Self-directed support is a new system. It's about people being in control of the support they need to live their life as they choose.

This fact sheet provides information about how self-directed support can be introduced to people from Black and Minority Ethnic (BME) communities.



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The basic facts

Definition of BME

For this fact sheet, the term 'BME' refers to communities whose ethnic origins lie in Africa, the Caribbean, Asia (e.g. India, Pakistan, Bangladesh, Sri Lanka), and China. It can be used to mean groups who would not define themselves as 'white'.

How might self-directed support be different for people from BME communities?

In most cases the basic needs of all individuals are the same, regardless of background or disability. For example, we all have the need for basic things such as:

- food
- water
- sleep
- security
- personal hygiene needs.

But we also need to have a sense of belonging and to feel part of a community through:

- family
- friendships
- and relationships with others.

Basic needs must be met, but when the disabled person has other needs and they have a different cultural background, the development of the support plan may require more thought and organisation. For example, the support plan may need to take into consideration language differences. It may also be necessary to provide a carer or a personal assistant who is from the same cultural background or the same gender as the disabled person.



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More information

Considering individual and cultural differences in a support plan

The support plan can be written by the disabled person and their family. It may also be written by a social worker, care manager, or an independent advocate but should be written in partnership with the disabled person. It is important that whoever writes the support plan has knowledge of the services within the community. They should know if these services or individuals involved in providing support are appropriate for the cultural needs of the disabled person.

Health and social care professionals do not always have a good understanding of the diversity and differences within BME communities; consequently many people from BME communities feel that the service provided in the community is not always appropriate to their needs. It is generally accepted that there are barriers which can prevent individuals from BME communities accessing or receiving appropriate self-directed support from health and social care services.

There are many barriers which can include:

Cultural differences

We all have a cultural background which we may not always be aware of until we mix with other people from different cultural backgrounds. For example we may go on holiday and realise that the food or the customs might be different. Everyone has a culture and a cultural identity. Culture can be seen as a set of attitudes, behaviour patterns and beliefs.

Consider a support plan which includes attending a day centre with a mixture of men and women: this may be unacceptable for some people from BME communities. For example some Muslim women may not mix socially with men.



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The differences in food are important: the preparation of meat (for example, Halal), or the type of meat (for example, pork) will be very important to many people from BME communities. When the support plan includes organising activities which provides food, these preferences and choices must be taken into consideration.

Language barriers

Many people from BME communities may not speak English as their first language. Using an interpreter is useful but if a family member is used to interpret, complicated words may need to be explained beforehand. Also some words or phrases may not be easy to translate and misunderstandings may arise. For example, in some cultures the term 'learning disability' is not easy to translate and the term may have a completely different meaning in other languages.

The support plan should be written in simple language that the disabled person and the family can read. If the disabled person and the family cannot read and understand the support plan it can be difficult for them to make informed choices.

Religious background

When organising a support plan or meeting with the disabled person and the family, religious periods or festivals may need to be taken into consideration. For example, the family may not be available to meet with health and social care professionals during certain religious periods.

The disabled person's religious needs may need to be taken into consideration, for example the disabled person may need to visit the mosque a few times per day and may need support to do this. A prayer room may need to be available for others.

Some religious practices include washing rituals, therefore additional wash room facilities may be required for some people from BME communities.



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More details

How can self-directed support meet the needs of people from BME communities?

When developing a support plan it may be helpful to consider doing the following.

Information gathering:

- Finding out which agencies have workers from BME communities
- Gaining knowledge of community groups who provide activities or services for BME people.

Partnership working:

- Work more closely with the family who may have local knowledge of community services available
- Link with religious or community leaders.

Cultural awareness for health and social care managers:

- Training for professionals, carers and personal assistants
- More information for professionals provided by people from BME communities.



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When things don't work - two examples:

Cultural Awareness

A community care worker was asked to speak with a group of Muslim women who are family carers. The women are a support group who meet together every week to discuss different issues. The group meet in the community centre which is attached to their mosque - the local religious leader co-ordinates the meetings.

The community care worker was asked to approach the local religious leader to arrange a meeting with the women to find out what their needs were.

The community worker was refused permission.

Why?

The Project Worker was male and it is not usual for the women to speak with men outside of their own family.

Religion

Maleek has a learning disability and is cared for at home by his family. The family are Muslim and English was not Maleek's first language.

Maleek's social worker had organised for him to attend a day centre which had a variety of activities and facilities. The family were happy with the day centre when they visited with Maleek.

At first, Maleek attended morning sessions and returned home for his meals. After a few visits Maleek and his family agreed to allow him to attend for a full day without his family and to have a meal with the other people who attended the centre.

After the first full day at the centre, the family were keen to find out how the day had gone.



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Although the family were happy with the facilities, they were unhappy with the meal choice and were reluctant to allow Maleek to attend another full day.

Why?

The family are Muslim and do not eat pork. Maleek was given pork sausages for his lunch.

Self-directed support – an example

Abdul

Abdul and his family live in the Midlands. Abdul's father had become quite frail over the last couple of years and was getting increasingly confused. Abdul went round up to four times a day to assist him and each week the visits became longer and he had to do more and more for his father. Abdul really didn't mind but it was impacting on his own family life and significantly, on his job. His boss had been flexible and considerate but it had started to reach a critical point where the level of support was starting to take over.

Abdul had enquired to social services before but had been put off pursuing it any further when people had told him about the inconsistency of staff and the difficulty in getting male carers. Abdul also knew his father would resist any type of help from people he didn't know, or who were not familiar with his cultural needs.

Abdul first heard about personal budgets when a work colleague described how well their family was coping through being able to choose a specialist agency which guaranteed consistent and same sex staff. After some research Abdul found that a personal budget would give him choice and flexibility for his father and that he didn't have to take the wider responsibility of managing staff and handling money. The Asian Elders group were able to help him with the support plan and together they decided on the best agency to guarantee same sex staff and which were very consistent; this was about 6 months ago.



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Abdul now describes his situation as completely different. He says "My father has really improved and I think that is because having the support has increased his opportunities, he is going out more and has reconnected with some people in his community. The confusion is still there and of course he is still frail but he is much more positive. We now have things to talk about when I visit and I certainly don't feel on edge and guilty all of the time when I'm at work or with my family. The agency have restored my confidence and keep in close contact with me, I know if anything happens to my father they will be in contact with me straight away. I can see personal budgets helping more and more people with diverse cultural needs."

There is a lot more information on the In Control website: www.in-control.org.uk

This fact sheet was written in collaboration with Sondra Butterworth, who has worked for BILD and MENCAP as a BME project worker. She has a background in general nursing, psychology and education. She has had many years experience of working with people with disabilities and their families. She works as an Equality and Diversity Co-ordinator and an independent advisor for community assessment (including moving and handling).

Her contact details are:

Tel: 07545 217 050
 Email: sondra@thephacsapproach.com
 Website: www.thephacsapproach.com

About the In Control and Me project

A three-year project to produce accessible information for everyone who wants to direct their own support, funded by the National Lottery through the BIG Lottery Fund. You can find out more at www.mencap.org.uk/incontrol or www.in-control.org.uk/icandme



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