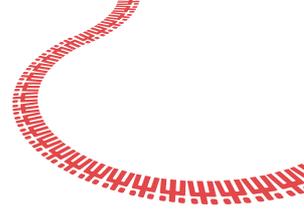


# Lost in Translation

Making Self-directed Support  
work for BME Communities







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# SECTION ONE: Introduction

This toolkit has been developed by MECOPP (Minority Ethnic Carers of People Project) as a guide to support the health and social care sector in Scotland to understand the importance of a culturally competent approach for people from Black and Minority Ethnic (BME) communities when engaging with Self-directed Support (SDS).

## Who is this Toolkit for and how can it Help you?

This toolkit is aimed at anyone supporting people from BME communities who may be assessed as eligible for social care support from their local authority. The toolkit will explain what impact SDS has on BME communities and why it is different to the way in which social care and support has been delivered previously. The exercises in the toolkit have been developed to increase knowledge of the specific issues affecting BME carers and service users.

The toolkit is suitable for both individual self-directed learning or within a group setting.

## About MECOPP

MECOPP is Scotland's only dedicated Minority Ethnic carer's organisation. We provide a wide range of services from our Carers Centre in Edinburgh which include: multi-lingual advice and information; advocacy and casework support; education, training and learning opportunities; individual and group support; recreational, social and therapeutic services and practical support in the home through our domiciliary care at home service. We also deliver specific projects supporting Gypsy/Traveller carers. We provide complimentary services to our statutory partners through policy, service and workforce development.

## The Self-directed Support (SDS) Development Project

The purpose of the SDS Development Project was to ensure people from BME communities with long term health conditions and disabilities assessed as eligible for support receive equal access to and benefit from the opportunities presented under SDS. The objectives of the project were to: raise awareness of SDS amongst South Asian and Gypsy/Traveller communities; promote uptake of SDS within the target communities, support the capacity of partner organisations to meet the needs of BME SDS recipients more appropriately; and, to ensure that local and national policy recognises and reflects the needs of diverse communities. This project was funded by the Scottish Government. More information on the project and the resources it has produced is available on our website at [www.mecopp.org.uk](http://www.mecopp.org.uk)

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Making Self-directed Support work for BME Communities

# SECTION TWO: Scotland's BME Communities

## **A bit of fun! Understanding BME Communities and SDS**

1. According to the 2011 Census, what is the total Minority Ethnic population of Scotland (to the nearest '000)?  
a. 50,000    b. 100,000    c. 150,000    d. 200,000
2. According to Social Care Scotland 2015 how many people are in receipt of Direct Payments?  
a. 645    b. 6,450    c. 16,450    d. 160,450
3. According to Social Care Scotland 2015 what percentage of the Minority Ethnic population are currently social care clients?  
a. 1%    b. 5%    c. 10%    d. 15%
4. According to the 2011 Census, how many towns in Scotland reported a zero Minority Ethnic population?  
a. 0    b. 1-5    c. 5-10    d. 10-15
5. What is identified as the main reason for people from BME communities not accessing social care support?  
a. Lack of accessible communication  
b. BME communities 'look after their own'  
c. They are not aware of the support available

## **Answers in Section Eleven**

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## Making Self-directed Support work for BME Communities

### BME Census Information

The 2011 Census <sup>(1)</sup> recorded a total BME population of 210,996 which represents approximately 4% of Scotland's total population. This compares with the 2001 Census figures of 101,677 or 2.01% of the population. These figures demonstrate that Scotland's BME population has doubled in the last decade and with current migration rates will continue to rise. Glasgow has the largest BME population (12%) followed by Edinburgh and Aberdeen City (8%) and Dundee (6%). Every local authority has seen significant growth in its BME population, and in line with this there has also been an increase in the number of BME carers. The South Asian (Indian, Pakistani and Bangladeshi) population is the largest minority ethnic group with 3% of the BME population.

### Carers in Scotland

A publication released by the Scottish Government; Official Statistics Publication for Scotland <sup>(2)</sup> (March 2015) on Scotland's carers stated that 17% (759,000) of the Scottish population (over 16 years) identified themselves as carers. 171,000 carers reported that they provided over 35 hours of care each week. 96% (164,160) were of White ethnicity and 4% (6,840) from other ethnicities. The carers were predominantly women. Of those interviewed for this publication many didn't identify themselves as carers, but recognise the support they provide as part of their role as a spouse, partner, family member, a friend or neighbour.

### Health Status of BME Communities in Scotland

BME communities tend to have a higher rate of poor health; these statistics vary significantly between each community. Over 29% of the South Asian communities and 9% of the Chinese communities are recorded as living with limiting long term illness in Scotland (Census, 2011). The over 65 year age group has the highest percentage of limiting long term illness, with the Pakistani community reported as having the highest levels of limiting long term illness across all ethnic groups between the ages 35-65 plus <sup>(3)</sup> (Scottish Government, 2011). It was reported that poor health was more prominent in those born in the UK, than those from first generation migrants <sup>(4)</sup> (Parliament UK, 2007) <sup>(5)</sup> (Better Health, 2008).

South Asian people are reported to be six times more likely to develop type 2 diabetes; with a higher risk of developing other long term diabetic related health conditions such as glaucoma, amputation of legs and kidney disease. It is recorded that 20% of the South Asian community have Type 2 diabetes, in comparison to 3% of the general population. They also tend to develop Type 2 diabetes earlier (around 25 years) than their White counterparts (around 40 years) <sup>(6)</sup> (Oxford Journals, 2005), <sup>(7)</sup> (Diabetes UK).

Research has also shown that people from the South Asian communities living in Scotland are 60-70% more likely to develop heart related issues and have a stroke. As a result 50% are more likely to die prematurely. Heart disease is more prominent in Indian and Pakistani men. The Chinese communities have a low rate of heart and stroke related incidents <sup>(8)</sup> (NCIB, 2003), <sup>(9)</sup> (Hindawi, 2013), <sup>(10)</sup> (Better Health, 2010), <sup>(11)</sup> (MECOPP).

Despite having a higher rate of conditions such as heart disease, stroke and diabetes, the South Asian and Chinese community have a 20%-60% lower risk of getting certain cancers. They are less likely to develop breast, prostate, lung and colorectal cancers, however, are at greater risk of developing liver (in both men and women), mouth and cervical cancers for women in the over 65 age category <sup>(12)</sup> (MacMillan, 2015).

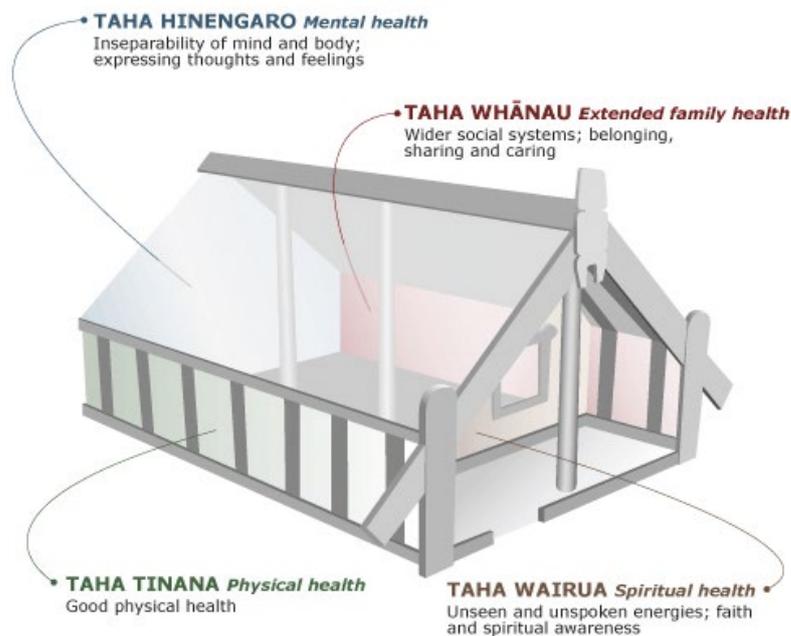
Statistics in relation to BME communities and mental health at this time is only anecdotal. It is suggested that depression and anxiety amongst South Asian communities is much higher than any other ethnicity, but due to stigma attached to mental health within some of the BME communities, people only tend to access mental health services once they have gone into crisis. The suicide rate of Indian women is nearly double that of other ethnicities and there continues to be a marked increase in suicides amongst women in the over 65 age category from the South Asian community (13) (MHPPF, 2015), (14) (SAMH), (15) (Mind, 2013).

It has been suggested that the types of health issues faced by BME communities are caused by socio-economic pressures such as lower educational attainment in some BME communities, lower employment, lifestyle choices, limited finances, poor (sometimes overcrowded) housing conditions, as well as other factors. Other factors include; stigma from their own community and discrimination from other communities, poorer access to health and social care services and limited knowledge about the services on offer, not accessing services for early intervention and lack of accessible information to highlight the risks of certain conditions (4) (Parliament UK, 2007).

People from BME communities are also dying younger than their White counterparts. In Scotland the average life expectancy of a White male is 75 years, this is in comparison to 62 years for a male of Pakistani origin and 58 years for an Indian male. A White female living in Scotland has a life expectancy of 79 years, in comparison to 65 years for a female of Pakistani origin (11) (MECOPP, 2010).

## Different Perspectives of Health, Ageing and Disability

Religious beliefs and cultural norms may influence how recipients, carers, family members and the community respond to illness, disability and other limiting or long-term conditions. Different ways in which BME communities may see health and well-being is identified by some within BME communities as a physical, social, spiritual and cognitive balance and takes a four pillar approach. It is recognised that a weakness in one area of health, can cause other areas (pillars) of health to become weak and collapse. For that reason it is important to assess, 'treat' and support the individual holistically.



(16) (Based on Mason, D. Te whare tapu wha model)

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## Making Self-directed Support work for BME Communities

A holistic approach needs to take into account the importance of a traditional western approach combined with alternative therapies. This includes therapies such as massage, acupuncture, homeopathy, and tai chi if physical and emotional health and well-being is going to be brought into alignment – body, mind and spirit. It requires an open-minded practitioner to move away from the use of a medical model approach to physical and cognitive conditions.

Different generations of the same family may have a different understanding and/or expectations of Western social care provision and some may be fearful of accessing these services. Older (+65) first generation immigrants may see certain health concerns and disabilities as a result of chakras being disturbed; possession of the body by evil spirits or as punishment. As a result they may want treatment and support more in keeping with the traditional methods of their place of origin. Whereas, their children and grandchildren may take a more Western view of health and disability and be more accepting of using Western approaches to treatment alongside more traditional methods. <sup>(17)</sup> (Dimension of Culture, Carteret, 2010).

# SECTION THREE:

## What is Self-directed Support?

### Explanation of Self-directed Support (SDS)

“Self-directed support (SDS) allows people to choose how their support is provided to them by giving them as much ongoing control as they want over the individual budget spent on their support” (18) (SDS Audit, 2014).

SDS is personalisation. It is about having personal choice, independence, control and flexibility to choose the type of services the recipient feels is required to increase their quality of life, and provide a ‘good life’.

A useful analogy to the historic provision of social care may be to think of it as going into a restaurant which has no menu and where the meal is chosen by the Chef with little or no consideration given to specific needs. Essentially, a ‘take it or leave it’ approach. SDS is like ‘the menu’. It gives choice and allows people to get something that they think they will like and will meet their requirements.

A Social Care Institute for Excellence (19) (SCIE, 2012) publication, Personalisation: A Rough Guide 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, re-ablement 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 services users is redefined as of one ‘mutuality and reciprocity’.

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## Making Self-directed Support work for BME Communities

### Social Care (Self-directed Support) (Scotland) Act 2013 – Summary

The Social Care (Self-directed Support) (Scotland) Act was enacted in 2013 to ensure people (both children and adults) with long term health conditions and/or disabilities and assessed as eligible for support have access to the same rights, opportunities and experiences as anyone else in society. It allows the social care recipient to have more control over their life and gives them the opportunities to make choices and decisions about how they would like their support services provided.

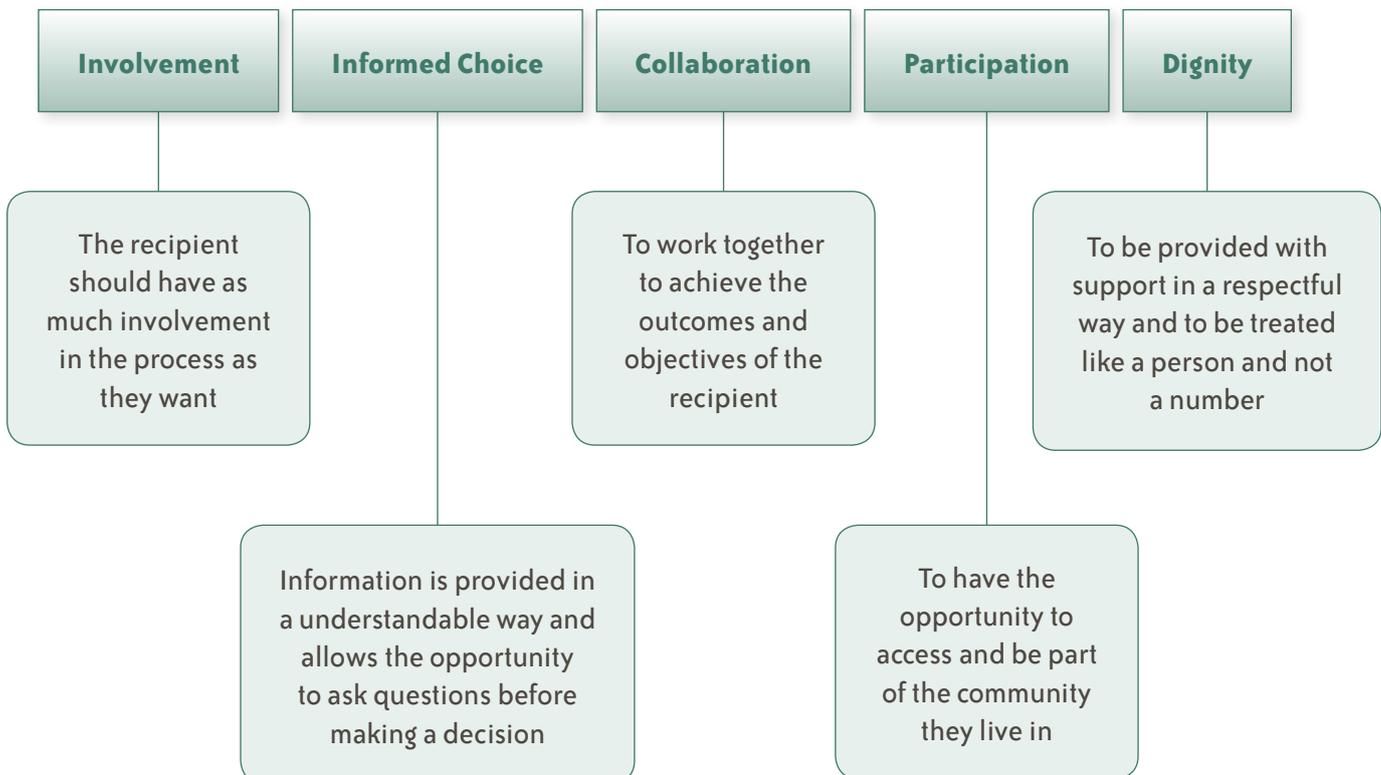
Currently the Act gives local authorities the power to support carers with SDS, but this is not a Duty. However, with the commencement of the Carer’s Act anticipated in 2018, carer’s will have a legal right to access SDS.

The legislation sets out the principles in which all local authorities should adhere too when going through the SDS process. This includes; involvement, information and choice, collaboration, dignity and the right to participate in their community.

Under Section 12 of the Social Work (Scotland) Act 1968, the local authority is required to complete an assessment to establish eligibility and provide sufficient information and adequate choices to allow the recipient to make decisions that will best meet their personal outcomes, whether they are eligible for local authority funded support or not. (20) (Self- directed Support Scotland).

### Principles of Self-directed Support

(21) (In-control)



## Explanation of Personal Outcomes

Personal Outcomes are built on three core components: engaging, recording, and using information. It is about practitioners, recipients and others working together to achieve the best results for the recipient in need of social care support.

Engaging with the recipient is essential when using a personal outcomes approach, as it recognises the recipient as being the only person that understands what they need to give them a 'good life'. This component helps the practitioner to support the recipient to:

- ▶ explore what outcomes (goals) they [recipient] want to achieve;
- ▶ understand why these specific outcomes are important to them [recipient];
- ▶ look at how they [recipient] can work towards achieving their own outcomes;
- ▶ determine any potential risks and hurdles which need to be mitigated;
- ▶ consider who they want to support them to achieve the outcomes; and
- ▶ set an achievable timeframe to achieve the outcome.

Recording the information ensures that the outcomes set out by the recipient, the timeframes and those responsible to support the recipient with the outcomes are properly documented. This makes it easier to review and audit. Using this information helps the recipient, practitioners and others involved have a clear pathway to achieve outcomes (22) (JIT – Cook & Miller, 2012).

## The Self-directed Support (SDS) Options

SDS is a selection of choices offered to people who are eligible for social care services and support (23) (SDS Scotland).

**OPTION ONE:** The local authority pays the money that can be spent on their support directly into the recipient's bank account, so they can choose and pay for the support they feel best meets their support needs and outcomes. This is known as a Direct Payment'.

**OPTION TWO:** The local authority decides how much money can be spent on the recipient's support, the recipient chooses how they want their support to be provided and the local authority arranges this on their behalf. External agencies can be nominated to manage the budget on an individual's behalf.

**OPTION THREE:** The local authority arranges the services or support in collaboration with the recipient.

**OPTION FOUR:** The recipient can mix any of these options to meet the different support needs and outcomes they have. For example the recipient may have a direct payment (Option one) to fund acupuncture sessions to support them with pain management. They may also choose a provider for home support and ask the local authority to pay for it (Option two).

## The Self-directed Support Process

It is the responsibility of the local authority to facilitate the process with people – this includes:

**STAGE ONE:** The practitioner introducing themselves and their role to the person and gaining consent from the supported person to proceed with the process. This is an opportunity for the practitioner to set expectations of each stage of the process, including assessment, eligibility and support exploration and planning.

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## Making Self-directed Support work for BME Communities

**STAGE TWO:** Completing a full assessment to help determine the person's support needs and personal objectives/outcomes.

**STAGE THREE:** Determining eligibility for support and informing the person if they meet the eligibility criteria, and if not, why not?

**STAGE FOUR:** A financial assessment determines how much; if anything, the recipient will contribute to the cost of their care and support.

**STAGE FIVE:** Providing assistance to the recipient to explore the natural and community assets, as well as the Self-directed Support options available and the benefits and risks of each option – this should include advising them of the estimated available budget for each option.

**STAGE SIX:** A support plan is developed, bringing together the services and supports that the recipient has identified in stage five. This stage will also include completing reviews when required.

It is the local authority's responsibility to "take reasonable steps" to ensure the principles of SDS are adhered to, and that the recipient receives the most appropriate support option, which allows them to make decisions about support and services that will best meet their support needs <sup>(24)</sup> (IRISS, 2012).

There are currently over 5,700 people in Scotland who are in receipt of SDS Direct Payments, and this continues to rise whereas services provided or purchased by the local authorities continues to fall. A great number of those in receipt of SDS have a physical disability and are over the age of 65. This may be as the result of strokes and diabetes <sup>(4)</sup> Parliament UK, 2007).

## Models of Working with SDS – Brokerage

Brokerage is about supporting the recipient to identify the barriers and any gaps in service which prevents them [the recipient] from meeting their personal outcomes. It is needed to ensure the recipient is seen and heard, and a plan is developed to represent the recipient as a whole and not just their disability or health issues. It is about providing the recipient with the confidence to express what will genuinely provide them with a 'happy life' and enhance their quality of life before fully exploring how this can be achieved.

## Benefits of Brokerage

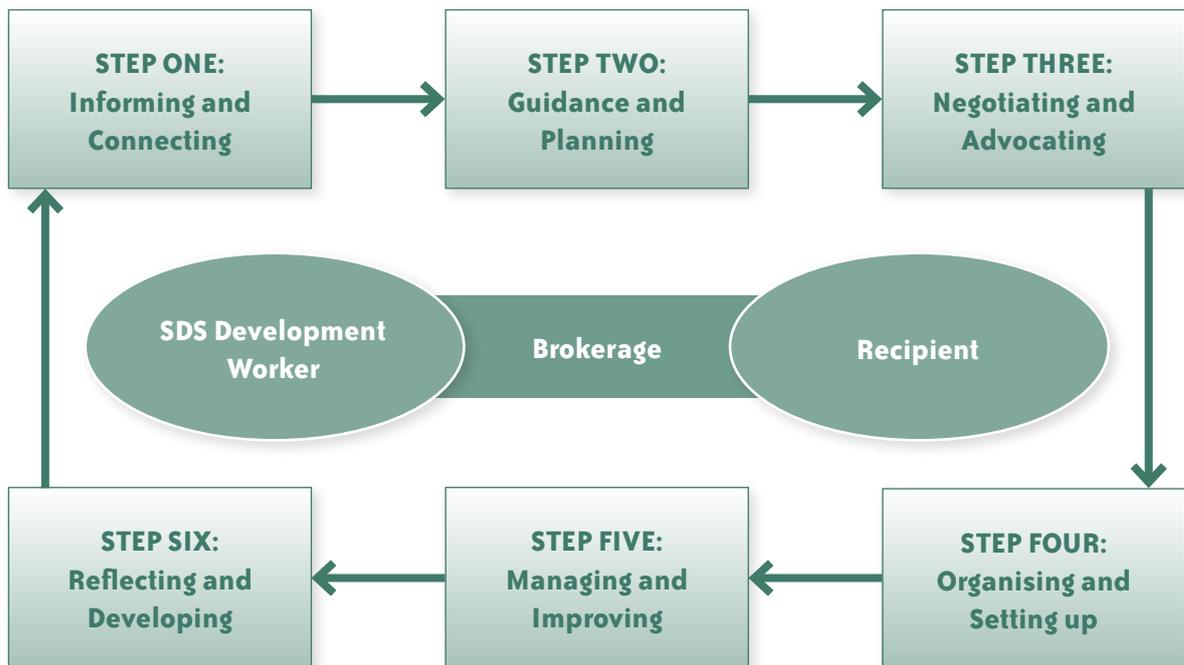
Some of the benefits of using a Broker include:

- ▶ having the time and resources to be creative and 'think outside the box'
- ▶ having the time to identify and mitigate risk
- ▶ being able to build up and develop a more long term trusting relationship
- ▶ the Broker does not have a vested interest (if they are an independent broker)
- ▶ the recipient feels more in control of the situation
- ▶ the recipient has the time to make choices and informed decisions
- ▶ if part or all of the support package does not work, the recipient is more likely to contact the Broker and ask for help to explore other avenues.

The Broker doesn't have to necessarily be someone from a Brokerage agency. It could be a recipient's family member, friend, neighbour or any other person who had the best interests of the recipient at heart and will support them to have a 'good life' <sup>(25)</sup> (Imagineer – Leach, 2015).

## Brokerage: Working together with the supported person

(26) (Centre for welfare – S. Duffy & K. Fulton, 2010)



### Brokerage Process

**STEP ONE:** Informing and Connecting – Broker provides information, advice and support in a way that is accessible to the recipient.

**STEP TWO:** Guidance and Planning – Broker supports the recipient to explore creative solutions to have a support need met.

**STEP THREE:** Negotiating and Advocating – Broker supports the recipient to ask questions and collect knowledge before making an informed decision about support services. The broker is responsible for ensuring the recipient is listened to and the right supports are provided to meet the desired outcomes and support needs.

**STEP FOUR:** Organising and Setting up – Broker supports the recipient to identify the right services or support for them and helps them to make contact with support providers and services that will meet desired outcomes and support needs. The Broker ensures the recipient mitigates any risks identified with any decisions they have made.

**STEP FIVE:** Managing and Improving – Broker supports the recipient to manage their services and supports.

**STEP SIX:** Reflecting and Developing – Broker supports the recipient to review their support plan, services and supports, and explore what is working well and what could be improved on. The Broker supports the recipient to look at further options that may be able to meet their support needs and help them achieve their desired outcomes.

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Making Self-directed Support work for BME Communities

# SECTION FOUR: Cultural Competence and SDS

## What is Cultural Competency?

The effective implementation of SDS for BME communities benefits from an understanding of, and ability to, adopt a culturally competent approach.

Cultural competency has emerged as a key driver in the formulation of policy and the delivery of services to BME communities over the last two decades. Cultural competency is about working with an open mind and not letting our own thoughts, values, beliefs and behaviours shape our views. It is about accepting and valuing the differences of each individual, their culture and religion, without prejudice and about recognising the hurdles faced by minority communities to achieve their desired outcomes.

It is important to note that there is not one universally accepted definition of cultural competency. In this instance we will define cultural competency from the perspective of health and social care...

*“recognising and meeting the diverse needs of people of different cultural backgrounds. This applies to every individual with a healthcare need. It includes, but is not limited to, making provision for religious and cultural beliefs such as worship, diet and hygiene requirements, catering for communication and language diversity and involving users in service development. A key part of cultural competence is ensuring that discrimination on the basis of culture, belief, race, nationality or colour has no role in the delivery of services” (27) (MECOPP publication, extracted from Scottish Executive, 2002).*

## Models of Cultural Competency

There are several models which enable practitioners and organisations to self-assess where they are on the cultural competence continuum.

### Cultural Competency Model

Unconscious incompetence	Conscious competence
Conscious incompetence	Unconscious competence

**Unconscious incompetence:** you lack awareness that something needs to change, so nothing changes.

**Conscious incompetence:** you have awareness that you need to change, but don't know how to do it.

**Conscious competence:** you have the awareness of what you need to do, you have made the changes, but you have to work hard to make sure you maintain this.

**Unconscious competence:** you have full awareness of what needs to be done and you don't have to think about it. It has become embedded in your practice.

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## Making Self-directed Support work for BME Communities

### CONSIDER

- ▶ Which one do you recognise within your practice?
- ▶ What one best describes your place of work?

### Why is it Important to Achieve a Culturally Competent Approach?

As the 2011 census has identified, Scotland is becoming an increasingly ethnically diverse country and as BME communities increase and age, increasing demands will be made on health and social care services.



### Understanding the Impact of Culture and Stereotypes in Cultural Competency

Stereotyping creates labels which can be harmful. It can cause a person to lose the essence of who they are and can cause opportunities to be missed. Stereotyping can have an adverse effect on the delivery of service provision and can lead to people not wanting to access certain services if they feel they will be judged and treated unfairly. (28) (Mather Lifeways – Lehman, Fenza, Hollinger-Smith, 2012) (29) (NHS Scotland).

### Group task – Three things in Common

Reference Icebreaker: (30) Unusual Things in common Dave “Gonzo” Kelly

- ▶ Ask three participants from the group to leave the room and identify three things they have in common (e.g. they have blonde hair, they own a cat). Then ask them to identify something that is unique to each of them (e.g. I lived in Canada, I was on TV).
- ▶ Ask the three participants to go back into the room and one presents to the rest of the group the three things they had in common and then each of the unique things without saying who they belong to.

- ▶ Ask the group to guess who each unique thing belongs to; and why they have guessed in that way.
- ▶ Discuss the judgements and assumptions made in their guesses. Discuss how we can challenge conscious or unconscious stereotypes.

## Understanding Visible and Invisible Culture

An analogy that is regularly used to describe the components that make up culture is the Iceberg Model. The Iceberg Model shows a two tier structure with visible elements sitting above the water and invisible elements below. Visible culture is easy to recognise and it is easy to see, for example – the clothes people wear, the food they eat, the music they listen to. Invisible culture is not so easily recognisable and you have to dig deeper to identify people’s beliefs, morals and views (31) (Aboriginal Construction).

### The Iceberg Concept of Culture

**Like an iceberg, the majority of culture is below the surface.**

#### Surface Culture

##### Above sea level

Emotional load: relatively low

food · dress · music · visual arts  
drama · crafts · dance · literature  
language · celebrations · games

#### Deep Culture

##### Unspoken Rules

Partially below sea level  
Emotional load: very high

##### Unconscious Rules

Completely below sea level  
Emotional load: intense

courtesy · contextual conversational patterns · concept of time  
personal space · rules of conduct · facial expressions  
non verbal communication · body language · touching · eye contact  
patterns of handling emotions · notions of honesty · concept of beauty  
courtship practices · relationships to animals · notions of leadership  
tempo of work · concepts of food · ideals of childrearing  
theory of disease · social interaction rate · nature of friendships  
tone of voice · attitudes towards elders · concept of cleanliness  
notions of adolescence · patterns of group decision making  
definition of insanity · preference for competition or cooperation  
tolerance of physical pain · concept of ‘self’ · concept of past and future  
definition of obscenity · attitudes towards dependents  
problem-solving · roles in relation to age, sex, class,  
occupation, kinship, and so forth...

To appreciate the culture of others, it is important to recognise and appreciate their [recipient] values, attitudes and beliefs. Before we can understand other people’s culture, we need to be mindful of what elements build up our own visible and invisible cultural structure (32) (Constant Foreigner, 2010. Model developed by E. Hall, 1976)



## Understanding Personal Culture

Personal culture is about having a deeper knowledge and understanding of our own culture to allow us to recognise where our own feelings, views, assumptions and prejudices come from. By recognising our own culture will help practitioners recognise and respect the cultural diversity of other people (33) (Age UK, 2015), (34) (Bridging the gap, 2015), (35) (Futurist Publication – Hiemstra, 2000).

### EXERCISE: My Culture – How I see Myself

<b>My name is...</b>	
<b>The origin of my name is...</b>	
<b>I was born in...</b>	
<b>The ethnicities of my parents are...</b>	
<b>The ethnicities of my grandparents are...</b>	
<b>I would describe my ethnicity as...</b>	
<b>What do I know about my ancestors?</b>	
<b>The family traditions we have are...</b>	
<b>The languages I speak are...</b>	
<b>The religion I practiced when growing up was...</b>	<input type="checkbox"/> None <input type="checkbox"/> Christianity <input type="checkbox"/> Islam <input type="checkbox"/> Hinduism <input type="checkbox"/> Buddhism <input type="checkbox"/> Sikhism <input type="checkbox"/> Judaism <input type="checkbox"/> Atheism <input type="checkbox"/> Jainism <input type="checkbox"/> Jehovah Witness <input type="checkbox"/> Mormonism <input type="checkbox"/> Taoism <input type="checkbox"/> Unitarianism (open minded about all religion) Other.....
<b>The religion I now practice is...</b>	<input type="checkbox"/> None <input type="checkbox"/> Christianity <input type="checkbox"/> Islam <input type="checkbox"/> Hinduism <input type="checkbox"/> Buddhism <input type="checkbox"/> Sikhism <input type="checkbox"/> Judaism <input type="checkbox"/> Atheism <input type="checkbox"/> Jainism <input type="checkbox"/> Jehovah Witness <input type="checkbox"/> Mormonism <input type="checkbox"/> Taoism <input type="checkbox"/> Unitarianism (open minded about all religion) Other.....

# Lost in Translation

## Making Self-directed Support work for BME Communities

<p><b>The values I learned from my family are...</b></p>	<p> <input type="checkbox"/> Education <input type="checkbox"/> Faith <input type="checkbox"/> Friendship <input type="checkbox"/> Health  <input type="checkbox"/> Aggressiveness <input type="checkbox"/> Decisiveness <input type="checkbox"/> Practicality  <input type="checkbox"/> Non-conformity <input type="checkbox"/> Structure <input type="checkbox"/> Obedience <input type="checkbox"/> Making a difference  <input type="checkbox"/> Originality <input type="checkbox"/> Frugality <input type="checkbox"/> Generosity <input type="checkbox"/> Unity  <input type="checkbox"/> Passion <input type="checkbox"/> Beauty <input type="checkbox"/> Being the best <input type="checkbox"/> Control <input type="checkbox"/> Creativity  <input type="checkbox"/> Gratitude <input type="checkbox"/> Discipline <input type="checkbox"/> Dominance <input type="checkbox"/> Integrity  <input type="checkbox"/> Fairness <input type="checkbox"/> Intuitiveness <input type="checkbox"/> Duty <input type="checkbox"/> Loyalty <input type="checkbox"/> Commitment  <input type="checkbox"/> Honesty <input type="checkbox"/> Motivation <input type="checkbox"/> Privacy <input type="checkbox"/> Professionalism  <input type="checkbox"/> Accountability <input type="checkbox"/> Reflection <input type="checkbox"/> Assertiveness <input type="checkbox"/> Respect  <input type="checkbox"/> Love <input type="checkbox"/> Ambition <input type="checkbox"/> Belonging <input type="checkbox"/> Approachability            Others.....         </p>
<p><b>My eye colour is...</b></p>	<p>(If you use coloured contact lenses, why do you change your eye colour?)</p>
<p><b>My hair colour is...</b></p>	<p>(If you dye your hair, why?)</p>
<p><b>My skin colour is....</b></p>	
<p><b>The disability/health conditions I have are...</b></p>	<p>For Example: I have Rheumatoid Arthritis. It caused me to be physically impaired and the pain can cause me to become mentally unwell at times. I have to take time of work when it becomes inflamed.</p>
<p><b>When I grew up I lived in a...</b></p>	<p> <input type="checkbox"/> Manor house <input type="checkbox"/> Detached house <input type="checkbox"/> Semi-detached house  <input type="checkbox"/> Terraced house <input type="checkbox"/> Cottage <input type="checkbox"/> Bungalow <input type="checkbox"/> Flat  <input type="checkbox"/> Caravan <input type="checkbox"/> Cabin <input type="checkbox"/> Tent <input type="checkbox"/> I am homeless            Other.....   <input type="checkbox"/> Privately rented <input type="checkbox"/> Rented from Local Authority  <input type="checkbox"/> Mortgaged <input type="checkbox"/> Owned outright <input type="checkbox"/> Leasehold <input type="checkbox"/> Freehold            Other.....         </p>
<p><b>I now live in a...</b></p>	<p> <input type="checkbox"/> Manor house <input type="checkbox"/> Detached house <input type="checkbox"/> Semi-detached house  <input type="checkbox"/> Terraced house <input type="checkbox"/> Cottage <input type="checkbox"/> Bungalow <input type="checkbox"/> Flat  <input type="checkbox"/> Caravan <input type="checkbox"/> Cabin <input type="checkbox"/> Tent <input type="checkbox"/> I am homeless            Other.....   <input type="checkbox"/> Privately rented <input type="checkbox"/> Rented from Local Authority  <input type="checkbox"/> Mortgaged <input type="checkbox"/> Owned outright <input type="checkbox"/> Leasehold <input type="checkbox"/> Freehold            Other.....         </p>
<p><b>The community I grew up in was...</b></p>	<p> <input type="checkbox"/> Local Authority housing estate <input type="checkbox"/> Urban City <input type="checkbox"/> City Suburbs  <input type="checkbox"/> Town Villages <input type="checkbox"/> Rural Woodland <input type="checkbox"/> Caravan Park  <input type="checkbox"/> Gated Community <input type="checkbox"/> Historic districts <input type="checkbox"/> Commercial/Red light districts  <input type="checkbox"/> Kibbutz <input type="checkbox"/> Private Estate <input type="checkbox"/> Refugee Facility            Other.....         </p>

<b>The community I now live in is...</b>	<input type="checkbox"/> Local Authority housing estate <input type="checkbox"/> Urban City <input type="checkbox"/> City Suburbs <input type="checkbox"/> Town Villages <input type="checkbox"/> Rural Woodland <input type="checkbox"/> Caravan Park <input type="checkbox"/> Gated Community <input type="checkbox"/> Historic districts <input type="checkbox"/> Commercial/Red light districts <input type="checkbox"/> Kibbutz <input type="checkbox"/> Private Estate <input type="checkbox"/> Refugee Facility Other.....
<b>If I was to attach 'status' to describe myself it would be...</b>	<input type="checkbox"/> Precariat <input type="checkbox"/> Traditional Working Class <input type="checkbox"/> Emergent Service Workers <input type="checkbox"/> Technical Middle Class <input type="checkbox"/> New Affluent Workers <input type="checkbox"/> Established Middle Class <input type="checkbox"/> Elite Other.....
<b>I would describe my childhood as...</b>	
<b>The type of school I went to was...</b>	<input type="checkbox"/> Urban State School <input type="checkbox"/> Mixed Sex <input type="checkbox"/> Boys Only <input type="checkbox"/> Girls Only <input type="checkbox"/> Catholic <input type="checkbox"/> Village State School <input type="checkbox"/> Independent <input type="checkbox"/> Boarding <input type="checkbox"/> Home Schooled Other.....
<b>The level of education I achieved was...</b>	<input type="checkbox"/> Secondary School qualification – Standard Grade, Highers <input type="checkbox"/> College – HNC, HND etc. <input type="checkbox"/> University – Master, Bachelor, PhD <input type="checkbox"/> Employment Study Other.....
<b>The types of work I have done are...</b>	
<b>The work I now do is...</b>	
<b>The types of clothes I wear are...</b>	
<b>I recognise good personal care as...</b>	
<b>The foods I eat are...</b>	
<b>The festivals I celebrate are...</b>	<input type="checkbox"/> Nirvana Day <input type="checkbox"/> Wesak <input type="checkbox"/> Lent <input type="checkbox"/> Christmas <input type="checkbox"/> Holi <input type="checkbox"/> Diwali <input type="checkbox"/> Ramadan <input type="checkbox"/> Eid <input type="checkbox"/> Rosh Hashanah <input type="checkbox"/> Yom Kippur <input type="checkbox"/> Vaisakhi <input type="checkbox"/> Guru Nanak <input type="checkbox"/> Halloween <input type="checkbox"/> St Andrews Day <input type="checkbox"/> Burns Day
<b>The things I like to do socially are...</b>	
<b>The types of music I like listening to are...</b>	<input type="checkbox"/> Dance <input type="checkbox"/> Rock <input type="checkbox"/> Punk <input type="checkbox"/> Easy Listening <input type="checkbox"/> Blues <input type="checkbox"/> Rap <input type="checkbox"/> Indie <input type="checkbox"/> Gospel <input type="checkbox"/> Jazz <input type="checkbox"/> Latin <input type="checkbox"/> Classical <input type="checkbox"/> Country <input type="checkbox"/> Opera <input type="checkbox"/> Soul <input type="checkbox"/> Reggae <input type="checkbox"/> World Other.....

# Lost in Translation

## Making Self-directed Support work for BME Communities

The countries I have travelled to are...	
The things I have learned when travelling are...	

### CONSIDER

- ▶ Reflect on the things you have identified. What drives your behaviour?
- ▶ Can you see how it has built you as a person?

*Why do I practice this religion?*

*Why do I speak these languages?*

*Why do I have these values and traditions?*

*Why do I eat these foods?*

*Why do I celebrate these festivals, especially if I do not practice the religion they are linked too?*

*Why did I choose to go to these countries?*

*Did these values and traditions influence my choice of study and employment?*

*Why have I chosen to live in that type of accommodation/ community*

*Why do I identify myself as that particular class?*

*Why do I wear these clothes?*

## SECTION FOUR: Cultural Competence and SDS

We all hold conscious or unconscious views, beliefs and assumptions about many things in society – age, gender, sexual orientation, status, religion, ethnicity and culture. A professional who is conscious of these views and assumptions will demonstrate cultural self-awareness and will be able to go through a SDS process without bias.

A good way to achieve cultural competency within practice is by keeping a reflective journal. By keeping a journal you can observe, identify and reflect on your own behaviours and influences which may impact on your role. Try keeping a professional journal for a week and see what you observe in that time.

### EXERCISE: Journal Template

<b>Date:</b>	
<b>List today's tasks:</b>	
<b>My views, assumptions and feelings on this task were:</b>	
<b>Why did I have these views, assumptions and feelings on this task:</b>	
<b>Today I learned:</b>	
<b>This is how I will do it differently in the future:</b>	

Keeping a journal – (36) (Inc – Stillman)

# Lost in Translation

## Making Self-directed Support work for BME Communities

### EXERCISE: Personal Case Study

Choose a service user from a BME community you are currently working with or have previously worked with and consider:

Based on the information given:

- ▶ What were my views and assumptions about the service user, their family, home environment and health situation, before I met with them?
- ▶ Why did I think that?
- ▶ Did my views and assumptions change when I met them? If so, why?
- ▶ Did my views and assumptions change the way I would normally behave?
- ▶ Why did it change my behaviour?
- ▶ Did this change after spending some time with them?
- ▶ Did it affect how I would normally conduct an assessment/meeting?
- ▶ Did it affect what supports and services were offered or put in place?

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### NOW CONSIDER:

- ▶ Where did my views and assumptions come from? – Was it my parents, friends, the community, working with previous services users with the same ethnicity, religion, social networking, media?
- ▶ Were my views caused by lack of knowledge and understanding, fear or uncertainty?
- ▶ How could I work on changing my views, assumptions and prejudices?
- ▶ When working with this person where would I have placed myself on the cultural competency model?

### EXERCISE: Learning Plan

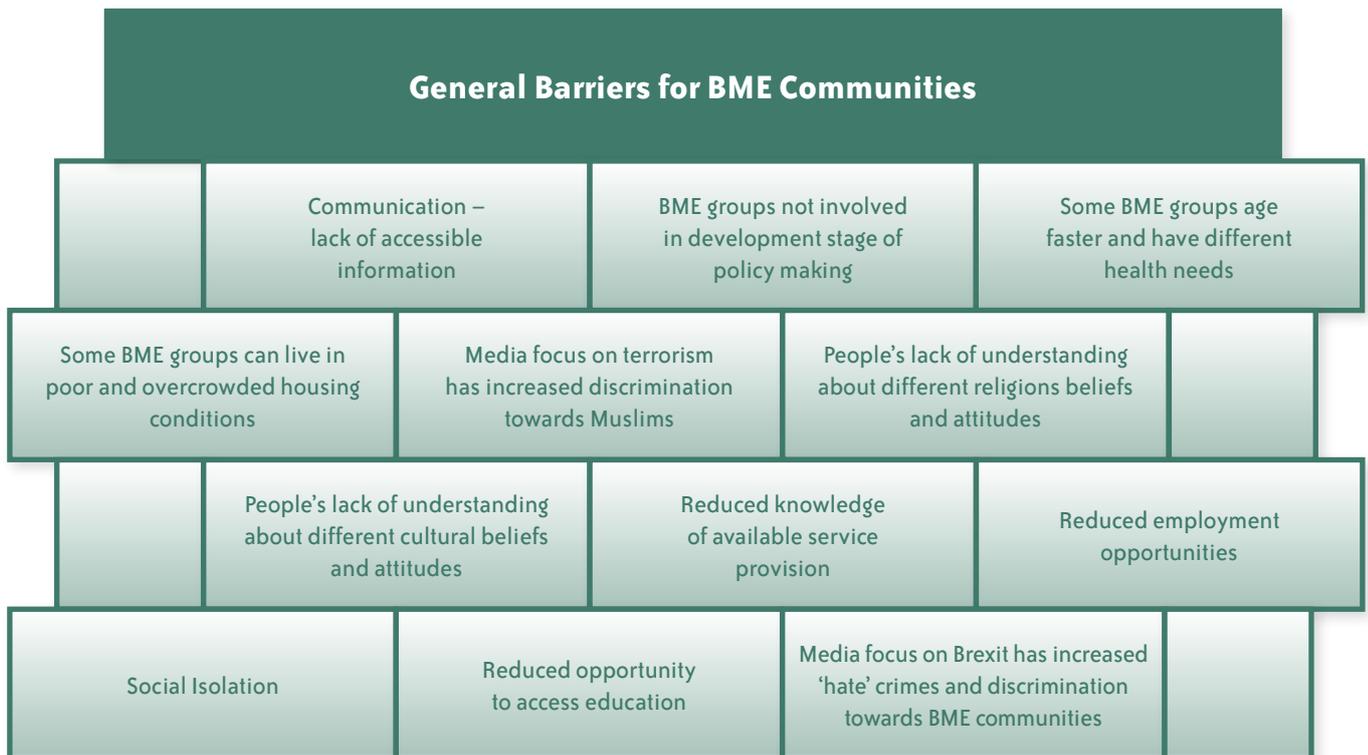
From what you have identified in the previous exercises develop a personal learning plan to improve your cultural awareness.

My action point	My achievement Date	The resources I need to achieve it are...	How will I know when it's been achieved?
e.g. keep a reflective journal	On-going	Diary	When I start identifying changes I need to make

How to develop a learning plan – (37) (dlsweb, 2006)

# SECTION FIVE: Cultural Competency and BME Communities

## General Barriers for BME Communities



(38) (Better Health), (39) (Engage)

## Institutional and Structural Barriers

### Institutional Barriers

Legislation is inclusive and does not discriminate against ethnicity and other minority groups. It is used as the basis and reference point of all social care organisational policies whether statutory, private or voluntary-sector run. Unfortunately, evidence has shown, this at times does not filter down into practice.

Capturing equalities data about the differing ethnicities accessing social care services is essential if people from BME communities are to receive the same opportunity to access services and treatment, delivered in a culturally appropriate way. If data around ethnicity is not documented, there is nothing to evidence that appropriate cultural, linguistic, and spiritual services are required. This causes people to go without support and services that are needed to meet their personal outcomes, improve their quality of life and give them a 'good life'.

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**CONSIDER:** What are the values, principles, guidelines and policies of your organisation which promote inclusiveness when working with BME communities?

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# Lost in Translation

## Making Self-directed Support work for BME Communities

### Structural Barriers

Service design which is based on meeting the needs of the majority community can disadvantage minority communities. For example, services only being provided on days of the week which clash with religious observance or services being located in areas which are not easily accessible to minority communities.

A lack of culturally specific services is not the only barrier faced by BME communities requiring social care support. Research has identified that a lack of accessible information together with limited use of interpreters is apparent not just in social care but other areas of Government funded activity such as housing and welfare benefits. Access to information that meets the linguistic needs of its readers, will give people a better understanding of what services and supports they may be eligible for. It will give them the knowledge needed to make decisions that could improve their quality of life, and give them the opportunity to self-manage their own situation and maintain autonomy and self-determination.

At a time of austerity social care organisations find themselves having to make careful choices and compromises regarding their budget. Restricted funding and resources can make it difficult for social care organisations to access interpreters or advocates to assist with assessments and support planning. It can also prevent organisational information being translated into the community languages of their recipients. Interpreters, advocates and accessible information may be seen as a luxury rather than a necessity. Unfortunately, until social care organisations start providing recipients with verbal and written information in a format suitable for them to gain knowledge and have understanding, there will continue to be structural barriers <sup>(40)</sup> (brighter futures) <sup>(41)</sup> (Ida Scotland), <sup>(42)</sup> (Iriss).

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**CONSIDER:** What resources does your organisation have and use to ensure cultural competency?

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### EXERCISE: Mapping Community Resources – Ethnicities, Languages and Religions in your Workplace

Think about your place of work. Note the different ethnicities, languages and religions in your organisation.

Ethnicity	Language	Religion

<sup>(43)</sup> (SCIE)

## Cultural Barriers

Cultural barriers can be as a result of institutional and structural barriers. Without accurate data, sufficient funding and resources there may be reduced attention to cultural competence within social care organisations. To ensure good practice and a culturally competent approach, practitioners require a proficient knowledge and understanding of BME communities, their different cultures, beliefs, norms and expectations. Inaccurate knowledge and personal views can lead to personal barriers (44) (Community Care – Carson, 2011)

### **EXERCISE: Mapping Community Resources – Ethnicities, Languages and Religions in your Community**

Now, think about the community you work in. Note the different ethnicities, languages and religions in your community.

<b>Ethnicities:</b>	
<b>Languages:</b>	
<b>Religions:</b>	

# Lost in Translation

## Making Self-directed Support work for BME Communities

**EXERCISE:** Before moving on to discuss personal barriers, please consider whether you think these statements are **True** or **False**

Statement	True	False
It is the role of the women in the household to look after the 'sick and needy' as a natural support		
White British/Europeans are 6 times more likely to develop diabetes than people from South Asian countries		
White British/Europeans are twice as likely to develop heart disease than people from South Asian countries		
White British/Europeans eat Asian food, so Asian people can eat a Western diet		
Every practising Muslim is expected to fast during Ramadan		
We just need to treat everyone the same, it doesn't matter where they are from		
BME communities prefer to look after their own		
BME communities tend to identify health and well-being as a balance between mind, spirit and body requiring a more holistic approach to treatment and support		
Islam is the most practiced religion in South Asian countries		
Hindi, Punjabi and Urdu are the only languages spoken in South Asian countries		
Disability and some health conditions are identified as punishment and/or possessed by evil spirits by some in BME communities		
<b>Your thoughts to consider</b>		
People from BME communities should be literate in English if they are going to live in the UK		
People from BME communities should follow UK customs if they are going to live here		

## Personal Barriers

A lack of knowledge and understanding about BME communities can lead to unconscious preconceptions about the beliefs, customs and norms of BME communities. Personal opinions which can work to the detriment of BME communities may include the following:

### **‘They can just eat the same as us’**

Many of the South Asian religions follow a vegetarian diet or have restrictions in which meat they can consume. Hinduism for instance forbids the consumption of beef, but recognises dairy products as an important part of the diet to ensure the balance of body, mind and spirit. Whereas, Chinese people don’t tend to use a lot, if any, dairy as their digestive system can find it difficult to break down lactose. Some of the Chinese cultures recognise the importance of a balance between yin (cooling foods) and yang (warming foods) to ensure the body, mind and spirit remain balanced and encourage good health. When talking about cooling and warming foods this is not ice cream versus hot apple pie, but foods that cause the body to become internally wet and dry – Yin/Yang <sup>(47)</sup> (Path to perfect health).

Some cultures and religions have times in which fasting is practiced <sup>(45)</sup> (Opposing Views) . This is particularly common in the Muslim culture where fasting can be practiced regularly. Within the Muslim culture fasting can be practiced for 6 days over Shawwal and over the month of Ramadan. Fasting is between 1.5 hours before sunrise and sunset over these days. People with health conditions such as diabetes are exempt from fasting should they choose <sup>(46)</sup> (Today’s Dietician – El-Zibdeh, 2009).

### **‘We just need to treat all people from BME communities the same’**

Everyone is different, with individual beliefs, customs and priorities, even if they come from the same part of the world. For example, South Asia has eight culturally diverse countries, with more than eight religions – Hinduism being the most practiced, then Islam, and Buddhism; all with different traditions, customs, beliefs and values <sup>(48)</sup> (Say Lord, 2012), <sup>(49)</sup> (niu – Klienmeyer, 2004). There are also more than four languages spoken, including Hindi, Punjabi and Urdu all with different dialects and variations dependent on the tribe and region <sup>(50)</sup> (Matador Network – Carreiro, 2010).

An understanding of different cultural and religious practices, traditions, beliefs and values is essential to ensure people from BME communities are not all treated the same. Treating everyone the same is seen as discrimination, as specific needs may not be met. It is therefore essential for the practitioner to concentrate on the individual needs of the person <sup>(51)</sup> (Guardian – Stafford, 2015).

### **‘We shouldn’t have to provide information in ‘their’ language; if they come to the UK they should be literate in English’**

Research has shown that due to the lack of childhood educational opportunities, particularly for women in South Asian countries, there are lower literacy levels in an individual’s own language. Education in South Asian countries can be recognised by some cultures as a privilege and dependent on caste and gender. This is particularly true for the older generations (first generation immigrants). However, young people (particularly women), often still leave school with only basic literacy and numeracy skills. English has been recognised as one of the most difficult languages to learn; without adequate funding and resources, accessing classes to learn English is difficult <sup>(52)</sup> (Archivis Online, 2015), <sup>(53)</sup> (MECOPP), <sup>(54)</sup> (UNESCO), <sup>(55)</sup> (Oxford Royale, 2014).

# Lost in Translation

## Making Self-directed Support work for BME Communities

### The community 'look after their own'

We now live in a society where there are on-going environmental, social and personal changes for people from any culture. It is a myth that the White majority community don't care about their relatives, friends and neighbours that have additional care needs, just as it is a myth that all BME communities 'look after their own'. In any culture as their situations change so will their ability to provide support. It may appear more likely that BME communities 'look after their own' if the person for whatever reason is reluctant to access external support services. For example family may choose to care for a family member with dementia or a mental health condition without external support as they may fear the implications of their community finding out.

It would be unfair to suggest that barriers are only caused by practitioners and organisations. Barriers can also be a result of the cultural norms and beliefs of some in BME communities itself. Some cultures suggest it is unacceptable to ask or accept support from external sources. Because of this support provision is kept within the family home, but this can lead to preconceived ideas that the family 'look after their own'. It is up to the practitioners and organisations to support the recipient to work around these views to ensure the recipient has a full understanding of their options to enable them to make an informed decision (44) (Community Care – Carson, 2011).

Structural, institutional, cultural and personal barriers can lead to reduced SDS options for people from BME communities. With lack of sufficient data to evidence the increase in BME communities using or requiring social care provision, service providers are not adapting their current practices or services to meet the needs of BME communities. It also makes it difficult for new services to be established as the data on potential demand and uptake isn't available. Accurate data will show how many people from different ethnic groups are accessing social care services and prove demand for culturally appropriate service provision. Until then, SDS options two, three and four will not fully provide a service that is culturally, linguistically and spiritually appropriate and be 'fit for purpose' to allow people to have choices in the provision of support.

Now you have completed section four and five, reflect again on the cultural competence continuum.

- ▶ Unconscious incompetence: you lack awareness that something needs to change, so nothing changes.
- ▶ Conscious incompetence: you have awareness that you need to change, but don't know how to do it.
- ▶ Conscious competence: you have the awareness of what you need to do, you have made the changes, but you have to work hard to make sure you maintain this.
- ▶ Unconscious competence: you have full awareness of what needs to be done and you don't have to think about it. It has become embedded in your practice.

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### CONSIDER

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- ▶ Which one do you recognise within your practice? How could you make changes?
- ▶ What one best describes your place of work? How could your organisation make changes?

**EXERCISE:** Try completing the True/False exercise again.  
Have any of your answers changed?

Statement	True	False
It is the role of the women in the household to look after the 'sick and needy' as a natural support		
White British/Europeans are 6 times more likely to develop diabetes than people from South Asian countries		
White British/Europeans are twice as likely to develop heart disease than people from South Asian countries		
White British/Europeans eat Asian food, so Asian people can eat a Western diet		
Every practising Muslim is expected to fast during Ramadan		
We just need to treat everyone the same, it doesn't matter where they are from		
BME communities prefer to look after their own		
BME communities tend to identify health and well-being as a balance between mind, spirit and body requiring a more holistic approach to treatment and support		
Islam is the most practiced religion in South Asian countries		
Hindi, Punjabi and Urdu are the only languages spoken in South Asian countries		
Disability and some health conditions are identified as punishment and/or possessed by evil spirits by some in BME communities		
<b>Your thoughts to consider</b>		
People from BME communities should be literate in English if they are going to live in the UK		
People from BME communities should follow UK customs if they are going to live here		

# Lost in Translation

Making Self-directed Support work for BME Communities

# SECTION SIX: SDS and BME Communities

## How can SDS support BME Communities?

Choice, control and autonomy over how an individual's support needs are met are equally important and applicable to BME communities. SDS has the potential to transform services to a wide range of diverse communities in a more flexible and creative manner and to mitigate barriers which continue to exist in mainstream services.

### **EXERCISE:** Before continuing, what do you think some of the benefits and barriers of SDS for BME communities are?

**CONSIDER:** The benefits of and barriers to SDS for the BME community

Benefits of Self-directed Support	Barriers to Self-directed Support
<p>It gives the recipient control and choice in what services and support they want to engage with.</p> <p>It gives the recipient flexibility in when they want to have their service and support provided.</p> <p>It gives the recipient the opportunity to be creative with their package.</p> <p>It gives the recipient the opportunity to develop a support package in a way they feel best meets their support needs and outcomes.</p> <p>It gives the recipient the opportunity to engage with more culturally accessible services.</p> <p>It gives the recipient the opportunity to have independence.</p> <p>It gives the recipient the opportunity to remain in the home environment longer than they may have previously.</p>	<p>Lack of accessible information – spoken and written in the community languages.</p> <p>Lack of cultural and linguistic appropriate assessment tools.</p> <p>BME community may not be aware or have no understanding of the traditional western support services available.</p> <p>Lack of cultural appropriate advisory and support services to support the BME community.</p> <p>Different generations from the South Asian community have a different understanding and expectation of social care provision.</p> <p>Some may be fearful of accessing services</p> <p>Lack of cultural competency within the support service professionals – stereotypes, personal prejudices.</p>

# Lost in Translation

## Making Self-directed Support work for BME Communities

### Why BME Communities may not Access SDS

- ▶ They don't know that the service is available due to lack of accessible information.
- ▶ The assessment process is not culturally appropriate.
- ▶ Professionals lack understanding about culture, religion and language.
- ▶ Lack of culturally specific services to choose from.
- ▶ Lack of culturally specific advocacy services to support with support planning or brokerage.
- ▶ Concerns about losing services or benefits.
- ▶ Concerns about having their financial affairs looked at.
- ▶ Concerns about confidentiality within the community due to potential stigma.
- ▶ Recruitment issues – unable to employ someone that can speak the same language or has an understanding of their culture and religion.
- ▶ Professionals not supporting recipients to look at how funding could be used in imaginative and innovative ways.
- ▶ In some cultures it is not seen as appropriate to accept support.
- ▶ There is a lack of consistency between local authorities and practitioners about the assessment process, support planning, the funding available to meet needs and what support and services are available to meet the needs. This causes confusion.
- ▶ Social care jargon can confuse people and cause them some level of fear about accessing SDS.

Barriers to inclusive support services			
Lack of accessible information: people are unaware of services		Providers limited knowledge on culture, spirituality, linguistic needs – we just treat everyone the same	Lack of knowledge about rights and entitlements
	Communication: recipients limited opportunity to make views and needs known	Not having diversity within own support team	
Support staff/providers own views, attitudes and assumptions of what cultural competency is		Support provider unable to provide a support worker with the same cultural background	
	Support provider unable to provide a support worker that can speak the same language	Support provider unable to be flexible with support hours. Unable to work around religious observance	

### Case Study

Mrs X is a 48 year old female and has a diagnosis of chronic spondylitis and ankyloses causing pain in her spine and pelvis, breathing difficulties and problems with her heart. She lives with her husband, who has his own health concerns and her daughter who has two part-time jobs. Mrs X is originally from Pakistan and speaks fluent Urdu, and is unable to read or write in this language. She speaks little English and relies on her 25 year old daughter to translate for her. Due to her high levels of pain and fatigue, her daughter helps with her with personal care and household management tasks and supports her to get out into the community and keep physically active. This is difficult for her daughter. She works more than 40 hours per week and has a lengthy commute. Although brought up in a Muslim household, Mrs X no longer strictly practices her religion, but her husband does.

The assessment was scheduled for the day before Eid-al-fitr (last day of Ramadan). On the day of the assessment the assessor arrived 30 minutes late and informed the daughter she got held up at another meeting. She walked into the house without removing her shoes. The assessment was conducted in the recipient's bedroom, as she was unable to get out of bed due to her pain and fatigue on that day. The assessor did not introduce herself to the recipient and only talked to the daughter during the assessment. The daughter was there as an interpreter, but was not given the opportunity to translate the information to her mother during the assessment process. The assessment took 30 minutes to complete. The questions asked were focussed on how long tasks take and no in depth detail was gathered. No questions were asked about what was important to Mrs X in relation to cultural, linguistic or spiritual needs. Mrs X was never asked what her ethnicity was and was recorded as 'Asian, undefined' on her assessment document. 20 minutes into the assessment the assessor give a leaflet about Direct Payment written in English to the daughter and told her that this was the only option to meet her mother's cultural, linguistic and religious needs and the Direct Payment could be used to bring someone in from her community to provide the care. The assessor was asked if they were going to document information about what was important to Mrs X from a linguistic, spiritual or culturally perspective to evidence their decision to provide Direct Payment, they were informed that they treated 'everyone the same'. MECOPP provided the information about the principles of SDS and the four options in an accessible way to the recipient and her daughter.

**QUESTION:** Can you identify the institutional, structural, cultural and personal barriers faced by the recipient and her daughter during the assessment process?

#### Feedback from the recipient's daughter

She walked through my house and into my bedroom with her shoes on

The reason my mum needs support from an Urdu speaking worker is due to her limited English, but she [assessor] gives us information in English!

How can she treat everyone the same? Mum doesn't have the same needs as others!

# Lost in Translation

Making Self-directed Support work for BME Communities

# SECTION SEVEN: First Contact – Accessible Information

## What is Accessible Information and why is it Important?

### Effective Communication + Information = Informed Choice and Consent

Accessible information is using the most suitable method of communication to support a recipient to understand the information required to make a decision and give consent. Informed choice and consent is an important element if the SDS principles are to be adhered to. Effective communication and accessible information gives the recipient control and the opportunity to self-manage their own situation.

Accessible information is important. It gives the recipient help to negotiate their way through the social care process, from the assessment, eligibility and the exploration of support options and developing a support plan. It gives them [recipient] the opportunity to ask questions and gain essential knowledge and understanding about each stage and choices and decisions about their level of involvement and what support and services they feel would best meet their desired outcomes.

It supports recipients to move past the traditional social care model of ‘one size fits all’ and move towards the five founding principles of SDS – involvement, informed choice, collaboration, participation and dignity and ensures the recipient has autonomy and empowerment in tailor making a support package.

# Lost in Translation

## Making Self-directed Support work for BME Communities

### Different forms of Communication

Verbal Communication	Non-Verbal Communication	Visual Communication
Face-to-Face	Head Movement	Signs
Phone	Eye Movement	Pictures
Video – Skype, Facetime	Facial Expression	Animation
Letters	Touch	
Emails	Posture	
Text Message	Gestures	
Posters	Body Language	
Brochures	Physical Presentation	
Leaflets	Active Listening	
Instant Messenger		
Social Media		
Websites		
British Sign Language		
Lip Reading		
Braille		
Large Print		

Communication is a two-way process, so it is essential that different methods of communication are used to ensure that everyone involved (including the support person and the practitioner) understands. Effective communication is especially important to those that may have English as a second language.

If done well and in a culturally competent and accessible way; verbal, non-verbal and visual communication is hugely beneficial. It can produce good working relationships, develop trust, show care, empathy and compassion and help the process to be successful and achieve outcomes. It is also important to listen. Listening to a recipient and giving them the time to talk is essential if mistakes and errors are going to be mitigated. To ensure the recipient is aware you are listening it is a good idea to mirror communication, whether you copy the recipient's body language or reflect and repeat the words they have used. This reassures the recipient that you have listened and understood what they are telling you.

Verbal communication completed face-to-face is identified as the best method of communication. It ensures everyone is given the opportunity to ask questions to clarify aspects and fully understand what is being explained to them. Face-to-face contact integrates with non-verbal communication. This helps convey the message. However, to ensure successful verbal and written communication for people with English as a second language it is essential to use accessible resources such as translators, interpreters, and audio and written information in the most commonly spoken languages.

Written methods of communication such as letters, text message, emails and brochures are an effective way of giving information, and a communication resource that the reader can go back to as a point of reference. Written information can be used to back-up what was said during face-to-face contact.

Visual communication such as photos, pictures and signs are a very simple way of conveying a message and is understood whatever language you speak.

Before communicating with others from a different cultural background to our own we should be aware that what may be culturally appropriate to ourselves may be offensive or have a different meaning to others.

As each cultural group has different characteristics when it comes to verbal and non-verbal communication, we cannot possibly provide a definitive list of what you should and shouldn't do. But we can provide some points to consider and we encourage you to do a little research before meeting with a recipient <sup>(56)</sup> (Bright Hub – Nayab & Scudder, 2015), <sup>(57)</sup> (Skills you need), <sup>(58)</sup> (Tutorials Point)

### **Verbal Communication:**

It is important to remember that humour and sarcasm that may be found as funny in your own culture; may not translate well and may cause offence or misunderstanding. All cultures verbally communicate with different dialects, volumes, tones and speed. Some can come across as fast, loud and abrupt which could be wrongly interpreted as hostile and confrontational. If taken as a personal attack this can cause people to become defensive and change the way they behave and communicate back.

### **Non-verbal Communication:**

**Eye contact** – in some cultures, particularly in Western countries, it is important to maintain eye contact as it can communicate to someone you are engaged, interested, and listening to what is being discussed. However, with other cultures eye contact or staring may be seen as rude, confrontational, and intimidating. Eye contact between males and females may be discouraged as it may be seen as inappropriate. It is suggested that the practitioners take the lead from the participant and if someone is not providing eye contact, consider why? You may need to change the seating position to ensure direct eye contact is not made and does not make the recipient feel uncomfortable.

**Touch** – a handshake in most Western cultures is seen as an important form of communication to open proceedings and demonstrate mutual respect. However, in other cultures it could be recognised as being inappropriate for a woman to shake hands with a man. We also need to take into consideration that some cultures recognise the importance of shaking hands with the right hand only. The left hand may be for personal care tasks and therefore seen as 'unclean', so would be offensive to present it for someone to shake. It is suggested that the practitioner does not shake hands unless the recipient offers.

# Lost in Translation

## Making Self-directed Support work for BME Communities

**Gestures** – head nodding in Western cultures can communicate ‘yes’, ‘understand’, ‘I agree’, etc. However, in some of the Indian cultures a head nod in agreement may be a side-to-side tilt. In Western cultures this type of head movement might suggest they have not understood or are confused. The Western sign for are you okay (forefinger on top of thumb to make an ‘O’ shape and pointed in the direction of the recipient) may be perceived as an evil eye and seen as being offensive.

**Posture** – in Western cultures it can be a sign of being relaxed or trying to be dignified for someone to cross their legs, however, showing the soles of your feet to some other cultures may be offensive. It may be interpreted that they are beneath you and not worthy.

**Personal space** – In Western cultures it is important to maintain a good level of personal space to ensure the person feels comfortable. However, in other cultures it may be seen as rude to move or lean away or inappropriate to stand too close. Always take the lead from the recipient.

**Appearance** – In Western cultures people tend to dress for the weather and in the summer may wear clothing that shows the knees and shoulders. This could be recognised by other cultures as undignified and offensive, particularly if it is a woman. When attending a recipient’s home it is important to consider wearing appropriate clothing which cover these areas, so as not to offend (59) (Bright Hub – Stoy & Richter, 2015)

### Visual Communication:

When using visual aids it is important to be aware of what is in the picture and consider whether it may be seen as offensive before using. An image containing male and females sitting close to one another, a person not adequately clothed, or all images with just White people could be seen as inappropriate.

## Language and Literacy in BME Communities

The 2011 census (1) suggested that 4.5% (over 238,000) of the population in Scotland spoke another language other than English in their household. Urdu is the fourth most commonly used language in Scotland (23,394 speakers), with Punjabi (23,150 speakers), and Cantonese/Mandarin (16,830 speakers) follow fifth and sixth respectively. However, these figures are only based on those who responded to the Census and may not accurately reflect the actual number. Even though every household is required to complete the census, some may not have carried out this duty due to the accessibility of the document, despite there being a translation helpline.

Research has shown that particularly within the older generations of BME communities there is lower literacy levels in their own language due to reduced childhood educational opportunities. Therefore, written methods of SDS information even in community languages would be of little or no value. With a continuing increase of South Asian people over the age of 65 years living in Scotland, accessible information is essential if people are going to receive the right support.

## Accessible Information and BME Communities

Information is everywhere yet it is not equally accessible to all sections of the population. It is widely acknowledged that some communities find it more difficult to access information than others. This is particularly true of BME communities where the lack of accessible information directly affects their ability to use a wide range of supports and services which would assist them in their daily living.

Regardless of language or literacy skills, use of ‘professional jargon’ when talking about services can be difficult for anyone who is unfamiliar with the systems. This is particularly challenging when translating ‘jargon’ to languages without comparable terms or where concepts are unfamiliar. For example, in cultures where children are expected to look after ageing relatives as a matter of course the concept of an unpaid, informal carer is not understood, and thus there is no word for ‘carer’ in the community language. Similarly English speakers with no previous experience of the social care system can struggle to understand the language practitioners use to describe services and processes. This underpins the need not only to consider language and literacy when producing information, but also the complexity of the content and vocabulary used <sup>(53)</sup> (MECOPP, 2014).

### Accessible Information, SDS and BME Communities

The language of SDS and direct payments presented as a challenge for BME communities. Research conducted by MECOPP to explore BME carers and services 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 around BME older people. For further reading on how MECOPP produced accessible information for BME communities, please read **appendix one**.

In 2014 MECOPP produced two key resources about SDS: a translation guide and an animated video. The translation guide takes 22 terms related to SDS and puts them into context, translating both the term and the definition into Punjabi, Urdu, Bengali and Chinese. The SDS resources can be found on [www.mecopp.org.uk](http://www.mecopp.org.uk).

# Lost in Translation

## Making Self-directed Support work for BME Communities

### Accessible Information Checklist

Task	How will we do this?	What resources do we need?
Create a focus group/s to help you determine what information is actually needed and in which formats		
What other support is required –translators for community languages and BSL, facilitators, community organisations and local authority input		
Use a focus group/s to provide feedback throughout the process		
Ensure the information is in the correct format for group – community languages, braille, audio, BSL		
Put the information in a logical order		
Separate each piece of information into different sections		
Use headings for each section		
Use colour to separate each section		

Task	How will we do this?	What resources do we need?
Make sentence structure short and to the point		
Do not use jargon, use everyday words – make the information clear and simple		
Cut out any information that is not needed		
Use pictures and photos		
Be aware of font size and type used		
Determine your budget to fund the production of the accessible information		
Determine where you are going to get the funding from for example, grants, loans, private funding, organisational funding. Make applications		
Determine what production company you are going to use		

### Using a Translator or Interpreter

The use of a translator/interpreter is an important resource to ensure verbal and written communication gets the appropriate message across. It is a very effective method of accessible communication and allows accurate information to be passed from one participant to another and reduces the likelihood of misunderstandings and mistakes. A translator/interpreter can also take the lead and support the practitioner to work in a culturally competent way and produce a culturally appropriate assessment. This can lead to an effective support plan, support provision and services which maybe successful to meet the needs of the recipient.

When arranging a translator/interpreter it is important to take into consideration several things:

1. The translator/interpreter may be from the same community and may have a connection to the recipient, their family, community and place of worship. This may cause the recipient concern regarding confidentiality, particularly if there is stigma attached to the health conditions.
2. The translator/interpreter may speak the same language, but in a different dialect, which can make it difficult for the recipient to understand.
3. The translator/interpreter may speak the same language, but have a different culture which may cause conflict. For example, the interpreter and recipient may both speak Urdu and come from Pakistan. But one might be a Sunni Muslim and the other a Shia Muslim.
4. It may be inappropriate to have a male translator/interpreter if the recipient is female. There may be some intimate information around activities such as personal care, which would be unsuitable for a female to discuss in front of a male.
5. It is also important to allow more time for an assessment where a translator/interpreter is being used. The process of translation between three people can be lengthy and cannot be rushed if accurate information is going to be collected.

All these factors could impact on the assessment and support planning processes and SDS, as it can potentially reduce the information that is needed to do a comprehensive assessment. If the assessment does not capture the appropriate information about a recipient's needs, objectives and culture, then the most suitable type of support and choice of SDS option cannot be explored and put in place. This can then affect the quality of life of the recipient and their family (60) (Euromed), (61) (Modern Healthcare).

### Principles to consider when working with a translator/interpreter

1. Ask a family member to make the recipient aware that there will have to be a briefing between the practitioner and translator/interpreter prior to the meeting. Reassure them about confidentiality.
2. Ask a family member to ask the recipient if they are happy to have the translator/interpreter come along.
3. Meet with the translator/interpreter prior to meeting the recipient to discuss any terminology (e.g. Self-directed Support) which may be problematic to translate. Find ways around how you can get the recipient to understand the information. If you are concerned that there may be questions that may cause offence or not be appropriate to ask the recipient, ask the translator/interpreter to clarify.
4. When meeting the recipient you should explain to them about the role of the translator/interpreter and reassure them again about confidentiality.

## SECTION SEVEN: First Contact – Accessible Information

5. When meeting with the recipient sit in a position where you can fully engage with the recipient. You should always maintain eye contact (if appropriate) with the recipient and your full attention should be on them, not the translator/interpreter. You need to forget the translator/interpreter is there when communicating with the recipient. The translator/interpreter is only the voice; it is you and the recipient saying the words.
6. You should only ever use short, simple sentences during the meeting and never use jargon. It is important to remember that there may not be an exact translation for the words and terminology you use, so it may take the translator/interpreter time to explain it to the recipient.
7. You should never interrupt the translator/interpreter whilst they are speaking and you should never change the topic suddenly.
8. You should never ask too many questions at once.

Limited budgets and resources can cause natural supports to act as interpreters during the assessment and supporting planning stages. There have been many identified risks attached to this, including:

- ▶ The practitioner cannot be sure that the discussion between the recipient and the person translating is an accurate account.
- ▶ The person translating may potentially withhold information if they feel it will cause the recipient distress or give information in a way that is to their benefit and not that of the recipient.
- ▶ The practice can potentially disempower a recipient and therefore is not in line with the fundamental principles of SDS including control, choice, independence and self-determination.

### Team Task – Accessible Information Activity

This task aims to show you the importance of communicating all relevant information to someone in a way they understand, which will allow them to make an informed decision.

Tell your team they have a day off work and they can choose to go to any one of the following events – a movie, a concert and a political conference.

Allocate three areas in the room for each event and ask the participants to stand in the part of the room next to the event they want to go to.

Now tell them:

- ▶ To get to the movie you will be going by limo to Newcastle
- ▶ To get to the concert you will be flying first class to Sydney
- ▶ To get to the political conference you will be going to Cardiff by Megabus

Ask the participants: based on the new information do they want to change their event. Ask them to move to the event they now want to go on.

Now tell them:

- ▶ At the movie you will get free refreshments and movie memorabilia
- ▶ At the concert you will get free concert merchandise
- ▶ At the political show you will get £2,000 to go on a shopping trip

Ask the participants: based on the new information do they want to change their event. Ask them to move to the event they now want to go on.

# Lost in Translation

## Making Self-directed Support work for BME Communities

Now tell them:

- ▶ When you go to the movie in Newcastle you will be staying overnight in a Travelodge
- ▶ When you go to the concert you will be staying in a youth hostel
- ▶ When you go to the political show you will be staying in a spa hotel with free treatments for guests.

Ask the participants: based on the new information do they want to change their event.

Ask them to move to the event they now want to go on.

Now tell them:

- ▶ The movie is a black and white, silent Charlie Chaplin film
- ▶ The concert is Justin Bieber
- ▶ The political show is a Ricky Gervais comedy saltire about politics

Ask the participants: based on the new information do they want to change their event.

Ask them to move to the event they now want to go on.

Discuss learnings from the task:

- ▶ How did they feel?
- ▶ What barriers and difficulties did they experience?
- ▶ What will the participants take away from this task?

# SECTION EIGHT:

## Assessment and Eligibility

### Preparing for an Assessment

Pre-planning is essential before carrying out a culturally appropriate assessment. It allows the practitioner involved to gain the knowledge they require to ensure they respect and understand the cultural aspects of the person they are going to assess. This can make the assessment process easier for the practitioner, but also make the recipient feel more comfortable and confident in the practitioner's abilities. It provides the recipient with reassurance that the practitioner is aware of their cultural differences and is therefore more likely to support them to identify more individualised services.

1. Use information already provided about the recipient to research possible cultural, spiritual and linguistic aspects, which may come up before or during the assessment...
  - ▶ taking shoes off before entering the house,
  - ▶ whether handshakes are appropriate,
  - ▶ how to pronounce the recipient's name correctly,
  - ▶ is there a 'greeting' that could be used,
  - ▶ is eye contact respectful within that culture or seen as confrontational,
  - ▶ would it be rude to decline a drink or food if offered.
2. Determine what days and times will be appropriate to do assessments. Make sure they don't clash with days that are identified as sacred, or fall during festivals, or are at a time that would conflict with prayer. Also, will the recipient have support there at the time? If you arrive and discover the assessment will clash with prayer time, either reschedule or offer to leave the house whilst the pray takes place.
3. Consider what questions may or may not be appropriate to ask someone of that specific gender, age or culture.
4. Research if there is accessible information in that specific community language about social care services.
5. If the assessment document needs to be translated for the recipient, how can this be done?
6. Organise the resources required to do the task, e.g. an independent interpreter (if required) and remember to put aside sufficient time for an assessment to be completed, e.g. you haven't planned other things that may cause you to arrive late or leave early.

Research should only be used as a guideline. It should not be used to make generalisations or assumptions that 'all' people from that specific BME community are the same.

### The Importance of Culturally Competent Assessments and the things to Consider

Social care assessments tend to be very systematic. It requires a creative assessor that is able to communicate effectively, to hold a meaningful conversation about someone's needs and outcomes and to take a standard assessment recording tool and turn it into something that is appropriate for people from BME communities. It is important to remain flexible, non-judgemental, open-minded and respectful throughout the process and to listen to the person.

It is important to ensure the assessment, the support planning and service and support provision are all identified as very individual parts of the process with different roles that should not impede on each other. For example; current support provision from natural supports and agencies should not be the main focus during the assessment process.

It is essential that an assessor has confidence to ask the recipient about their culture. Asking questions will be the only way to gain a greater understanding of what is important to the recipient about their culture and faith.

At the beginning of the assessment process it is beneficial to ask the recipient if there is anything from a cultural and/or spiritual perspective that is important to them that you [the assessor] should be aware of before starting the process. This opens the gate for the recipient to talk about their cultural and spiritual beliefs and customs. If a recipient feels safe to talk about their culture and spiritual beliefs and customs they will provide more information, and the assessor will have increased confidence to ask more questions. This will be of value when getting to the support planning stage.

Giving someone the opportunity to openly and safely discuss these elements of their life can allow a more trusting relationship to develop. This can see more beneficial results, not only with the outcome of the support plan, but also with the collection of data around ethnicity. As already discussed, data is essential if we are to evidence the need for more culturally appropriate services.

Areas in the assessment could be modified to include cultural, spiritual and linguistic questions. This toolkit is not about listing what culturally competent questions to ask in an assessment, as the list would be exhaustive. It intends to be a resource to provide some points to consider when you are amending an assessment document to meet the needs of BME communities.

**Spirituality:** By allowing someone to start the process with a prayer or a moment of silence; if they wish, can allow them to relax into the process. It also allows them to see that they are respected as an individual with different customs and beliefs. Talking about spirituality allows the assessor to identify if the recipient practices their religion and how much of their activities of daily living revolve around their religion. For example, those following the Islamic faith and pray five times a day, may require some level of support with ablutions – washing of hands, forearms and face before and after prayer. Some may identify prayer as a form of exercise as it keeps the spirit healthy.

**Personal care:** It is essential for the assessor to be aware whether there are any cultural or religious restrictions attached to personal care tasks. Different cultures see modesty and privacy as different things, so it is important to know how a support worker could maintain a recipient's modesty and privacy during personal care tasks. It is also important to know what protocols there are around ablutions for religious practices and also around cultural practices, such as how does the recipient eat their meals, is it with their hands or with utensils? If they use their hands, do they need support to wash their hands before and after meals?

Foot hygiene and care may be important to someone from the Chinese communities. Pain and disease may be identified by some Chinese people as an imbalance between the body and earth. To bring the body and earth closer together walking in bare feet is essential to allow the body to be grounded.

When discussing dressing tasks with a recipient, it is important to remember that some cultures may wear a turban, hijab or other form of headscarf or cultural dress. Some may need their hair pinned back in a certain way to accommodate headwear. These aspects of personal care all take time and may take longer than someone who wears western dress.

**Medical needs:** By asking someone to explain to you what they currently do to improve or maintain their health and well-being, you are opening the assessment up for them to talk about how they see their condition – is it a punishment from a past life? Their medication – is it western based medication or more traditional, such as Chinese herbs they are using? Their treatment – are they using western treatments such as physiotherapy or are they using more traditional (to their specific culture) treatments such as acupuncture?

**Household support:** Looking at the cultural role the recipient had in the household before deterioration in their health condition and/or disability is important. Was this person responsible for cooking, cleaning, buying the groceries? It is essential to look at the effects on the recipient of being unable to participate in these tasks, particularly if the role met cultural expectations. Experience has shown that social care recipients would prefer to cook, clean and do grocery shopping independently with support as it allows them to maintain their role in the household. If this role is taken on by another party, it can detract from their sense of independence and autonomy both within the family and also their community.

**Nutrition:** If funding does not cover fresh meals to be prepared every day it is important to acknowledge that the recipients still have nutritional needs. By gathering information about the recipients nutritional needs, more creative options can be explored to meet the support need. It is important to look at the recipients dietary requirements:

- ▶ What can the recipient eat and not eat either for health, cultural or religious reasons?
- ▶ How does the recipient eat their meals, is it by sitting on the floor or using hands?
- ▶ Does the recipient fast, if so, when, for how long and how can fasting impact on their health?

Ignoring the recipients' nutritional needs can leave them with no other option but to eat food they don't like, are not used to, or which can cause them to become malnourished and sick.

**Cognition:** It is important to remember that this subject may be difficult for recipients and their carers to discuss, due to the fear of being ostracised by their peers and community resulting in social isolation. This section should be treated with care and compassion.

**Family support:** It is important not to assume that family are able to provide support to meet the needs of the recipient, because people from BME communities 'look after their own' or because they live in the same household. During the assessment process it is important to look at the family commitments, whether it's work, their family, or their own health conditions and do they need to visit family members overseas. It is essential to determine how the recipient's condition impacts on the family, whether they are able to provide suitable support, and if so, what? It is important to remember that in some cultures women have their own area in the house and it is prohibited for a man to enter it.

**Confidentiality:** Confidentiality is really important to BME groups as they may not want their community being aware of their illness or disability for fear of judgement. It is important to reassure the recipient about the confidentiality policy of your organisation.

# Lost in Translation

## Making Self-directed Support work for BME Communities

**Socialisation and access to the community:** To reduce social isolation it is important to identify what the recipient was doing before their health condition or disability made it difficult for them to access the community – Were they working? If so, what were they doing? How did this make them feel? Did they attend any social/community groups, if so, were they culturally specific or were they mixed ethnicity? What makes it difficult for them to now do this?

**End of life care:** If a recipient is requiring end of life support, it is important to remember that all cultures and religions have their own protocols and rituals when it comes to death and dying. Hindus for example will lay a person on the floor just before death so they can be closer to Mother Earth and rituals will happen around them. For the soul to leave easily the person's head will point North. For a practicing Muslim it may be important to be facing Mecca. To mitigate the risk of offending a family at an already stressful time, it is essential to be aware of these types of protocols.

Without asking cultural and spiritual questions, there will never be a full understanding of the recipient as an individual with individual needs, making it difficult to produce a support plan and provide services that are suitable and beneficial. Once information is gathered you can support the recipient to identify their support needs and where support will be required to achieve desired outcomes.

(62) (Hackney Govt), (63) (al-islam), (64) Beliefnet, 2001), (65) (HSJ)

## Cultural considerations for the assessment process

**EXERCISE:** Looking at the individual needs of BME communities what cultural considerations do you think have to be made during the assessment process?

**What do you need to take into consideration before carrying out a culturally appropriate assessment?**

**What resources would you need before carrying out a culturally appropriate assessment?**

**How would you access these resources?**

# Lost in Translation

## Making Self-directed Support work for BME Communities

### Designing a culturally appropriate support plan

**EXERCISE:** What questions or conversation would you have in an assessment to get the information you need to design a culturally appropriate support plan?

Assessment Section	The questions or conversation
Background – Cultural/faith issues. Can be referenced in all below	
Meeting personal needs and looking after myself (Includes health, personal care, wellbeing)	
Staying safe (Includes risk enablement/falls/going out)	
Making decisions and organising my life (Includes making own choices and decisions, choosing where to live and how to spend your money; choosing who supports you)	
Complex needs and risks (Includes how your actions/actions of others affect you and others; cognitive issues; vulnerability)	
Social relationships and community activities (Includes faith and belief issues)	
Running and maintaining the household I'm living in	
Personal development and learning/employability and volunteering	

**QUESTION:** Returning to the case study on page 34 how would you prepare for this assessment and what questions would you ask to make it culturally respectful?

**Feedback from the recipient – Mrs X**

*The assessor was in and out in ½ hour. How could she have got all the information she needed?*

*She [assessor] had already decided our only option was Direct Payment... she didn't want to listen to my story*

*If she [assessor] doesn't have the information, how can she decide what is the best option for me?*

### Informed Choice and Participation

During the SDS process the recipient should always be included even if there is a Power of Attorney <sup>(66)</sup> (Age Scotland). In Scotland a Welfare POA does not automatically give people authorisation to make decisions about the recipient's welfare if the recipient still has some level of capacity to understand. It is the responsibility of the practitioner involved to communicate the information to the recipient in a way that they will understand and for the recipient to be able to give some level of consent. If there is no legal documentation in place to stipulate that a recipient does not have the capacity to understand, then it should be assumed that they do have some level of capacity and should be encouraged to participate in the process. This can be particularly difficult when working with the parents of a person who has just turned 18 years old. Legally, their 'child' is now an adult and different laws apply. Parents may have been used to making the decisions and advocating on behalf of their child/ren. However, once their 'child' has turned 18 years, the parent (Carer) will have to go through a legal process and have legal powers to make choices and decisions and speak on behalf of their 'child'.

There will be times when a full, or part assessment will be done in the absence of the recipient, and an assessor will talk directly to a carer, guardian or POA. This will only be on occasions where there is a risk the assessment process will cause some level of distress to the recipient. It may also be deemed necessary when the carer is requesting support, but the supported person will not engage in the process causing a potential risk to physical and/or mental well-being of the carer. Legislation promotes that intervention should be the 'least restrictive' as possible.

### Signing off an Assessment

It would always be advised that a social care recipient not sign off an assessment document until they were 100% happy with its contents. This can be time consuming particularly if the recipient has English as a second language. In a situation where the recipient has English as a second language the following suggestions would be made:

1. If an interpreter/translator has been involved you could ask them to read through the contents of the assessment to the recipient. At this point changes, additions and clarifications can be made before sign off.
2. Determine if your organisation has access to someone that could translate the document into the recipient's community language – either written or recorded. Send the translated copy to them and give them the opportunity to make changes before sign off.

# Lost in Translation

## Making Self-directed Support work for BME Communities

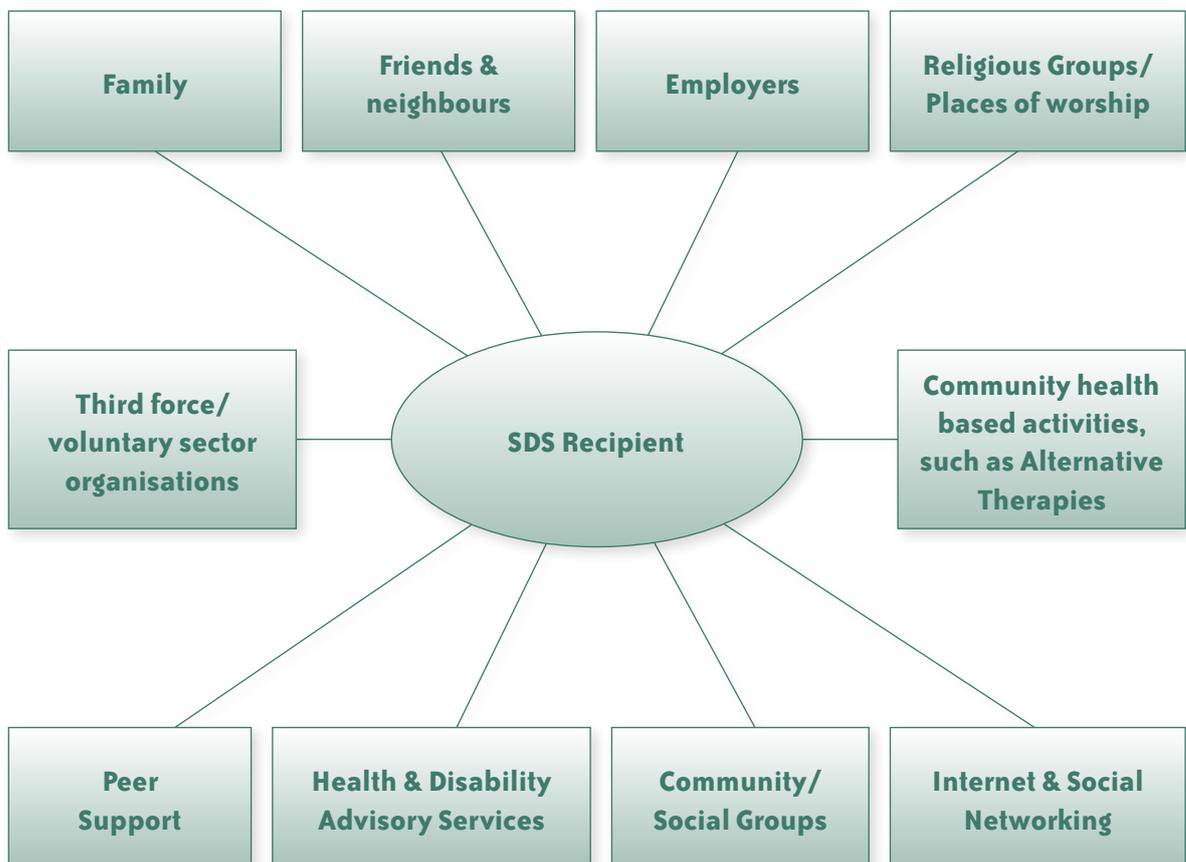
3. Leave the assessment document with a family member to go through it with the recipient at a time suitable for them. Remember to leave a way of the recipient being able to send the assessment back, either by post (stamped addressed envelope) or by email where they can scan and email it.

If the recipient makes the decision to keep the document to read with family or requests that it's translated into their community language, make them aware that eligibility or exploration of support options will not be able to go ahead until a signed copy of the assessment is received. This allows the recipient to have ownership of the assessment; control over what information is put in the document and meets with all five principles of SDS. If for safety reasons (there is significant risk of harm to a recipient or carer), other ways to complete the process in an efficient way have to be looked at.

Time constraints and pressure put on practitioners to meet deadlines can cause assessments to be signed off without the recipient having a full awareness of its contents. This could be potentially detrimental to the support planning phase and any appeal that the recipient may want to lodge.

# SECTION NINE: Exploring the SDS Options – The Need to be Culturally Competent and Creative with Support Planning

## Natural, Informal and Community Based Supports



# Lost in Translation

## Making Self-directed Support work for BME Communities

### Looking at Support Options

To increase creativity and personalisation when supporting someone to develop an individualised support plan exploring every avenue before using the SDS budget can be really effective. It is a good way of getting the recipient 'more bang for their buck'. Other areas of support provision that could be explored:

**Natural Support:** Support provided by someone free from payment. Usually someone you have a day-to-day relationship with – family member, friend, neighbour, colleague, and acquaintance. Natural supports can be developed by accessing and engaging with informal supports <sup>(67)</sup> (bmehf), <sup>(68)</sup> (Power 2 U).

**Community/Informal Support:** Support provided by a community or social network. Usually someone you have regular contact with – place of worship, lunch club, sport clubs, library, online groups.

**Self-Funded support:** The recipient paying for services privately.

**Other Government funded support:** Support provided by the government that isn't related to social care funding – Pensions and Benefits, Housing, NHS services, Education.

**Local Authority provided social care support:** SDS – Option One: Direct Payment. Options Two and Three: Care at Home Support providers, Day activities and Centres, short breaks from caring and so on. Option Four – a mixture of the above.

### Brokerage and BME Communities

Social care services continue to reflect the needs of the majority population often to the detriment of minority groups. Services are not necessarily tailored to meet the needs of BME communities and there is often an absence of cultural competency amongst social care providers, leading to a lack of knowledge and understanding about the needs of minority ethnic groups. BME recipients of social care report that it is difficult to find a service that recruits and provides staff that speak their language, or share similar cultural values. They report that they feel they have to neglect their religious practice because home care visits don't allow for time for prayer between bathing and eating. Brokerage services can be a very effective way of overcoming these difficulties'. A Brokerage service can support recipients from BME communities to explore their options to have their social care outcomes met in a cultural, spiritual and linguistic appropriate way. Brokerage can bring people together (the recipient, family, community and local business owners) to work together to develop services to fill identified gaps.

Brokerage is about knowing your community; who lives in it, what is available for its populations and considering how services can be provided in a unique and creative way to meet the needs and personal outcomes of its recipients. Brokerage supports recipients to explore natural, informal, and other government supports, establish 'Circle of Support' groups, as well as supporting them [recipient] to develop a SDS package that will ensure their personal outcomes are achieved.

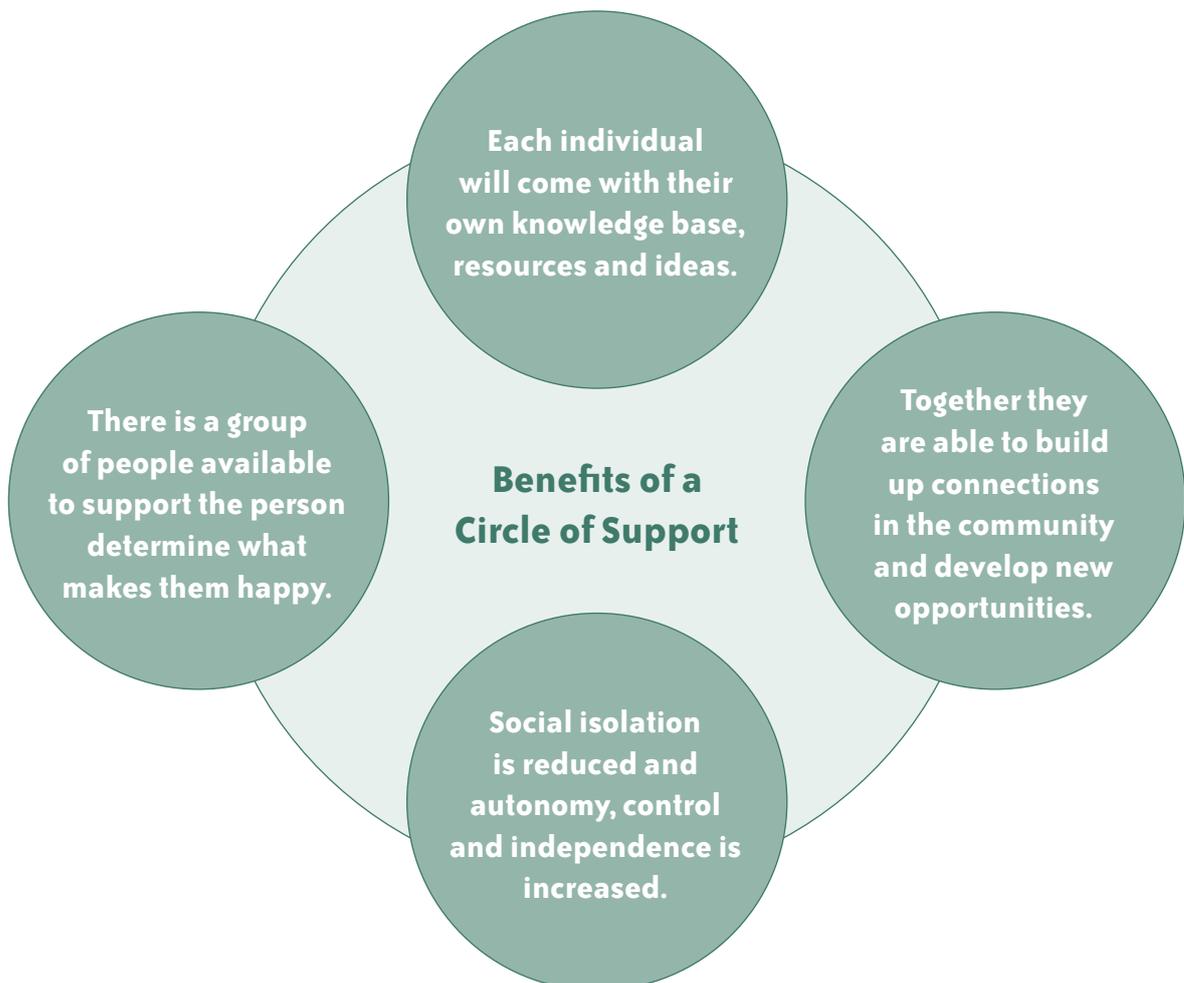
## Circles of Support

A circle of support is a small group of people who meet together on a regular basis (every six to eight weeks), bringing with them countless knowledge, skills and creativity to help the recipient to recognise their personal outcomes and support them to achieve these outcomes.

The people that participate in this support group do not tend to get paid, but take part because they want to. These people tend to fall into five categories:

- ▶ Those we trust and could not do without. You can always depend on them.
- ▶ Someone you seen now and again, but you can still trust them when needed.
- ▶ Acquaintances from a community, social or spiritual group.
- ▶ An individual that may be paid to provide support include – support providers, social workers, care workers and other practitioners.
- ▶ An individual you don't know, but would like to volunteer their services as they have a good knowledge of community based assets.

The recipient should always take control of the meetings, but can delegate the facilitation to someone else if they wish. The sign of a successful circle of support is when the recipient has autonomy and has the ability to be independent and in control. This type of support should never cause dependency. There are many benefits to creating a circle of support including:



(69) (imagine act and succeed)

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## Making Self-directed Support work for BME Communities

### Employing a Family Member

Employing a family member as a personal assistant is not necessarily for everyone. Like anything, there are benefits and also things to consider whatever ethnicity you are. With a limited amount of culturally appropriate services available, employing a family member to be a personal assistant can sometimes be the only option to get a service that is suitable to meet the recipient's cultural, spiritual and linguistic needs.

#### What the Law says:

The Self-directed Support (Direct Payments) (Scotland) Regulations 2014 state that the local authority can agree to someone in need of support employing a close relative or family member in "appropriate circumstances". 'Appropriate circumstances' meets the founding principles of Self-directed Support to allow people to have an opportunity to develop their own support package; in a way that they feel best meet their needs. There will be times when despite an individual's preference to employ a family member, the local authority may not be in agreement. There is no legal right to employ a family member, it is just one of many options which should be explored.

#### Who is a family member?

**Under the Direct Payment Regulations 2014, a family member is the direct payment users:**

- ▶ Spouse or civil partner of the direct payment user or a person who lives with the direct payment user as if their spouse or civil partner
- ▶ Parent, child, brother or sister
- ▶ Aunt or uncle, nephew or niece, cousin
- ▶ Grandparent, grandchild,
- ▶ The spouse or civil partner of any of the above

**Before you employ a family member as a personal assistant, the local authority must determine:**

- ▶ Whether you and your family member are in agreement about the support being provided in this way.
- ▶ Whether your family member is capable of meeting your support needs.
- ▶ Whether your family member is your welfare guardian or Power of Attorney (POA). Your welfare guardian or POA cannot be paid to provide your support. It would be identified as a conflict of interest. If someone has both welfare and financial POA they cannot be employed by the recipient as a Personal Assistant, as in effect they would be employing themselves and paying themselves.

**The local authority must also determine what "appropriate circumstances" apply:**

- ▶ There is a limited choice of providers who could provide the support
- ▶ The supported person has specific communication needs which make it difficult for another provider to provide the support
- ▶ The family member will be available to provide support at times when other providers would not reasonably be available
- ▶ The intimate nature of the support makes it preferable to the supported person that the support is provided by the family member
- ▶ The supported person has religious or cultural beliefs that make the provision of support by a family member preferable to the supported person

- ▶ The supported person requires palliative care
- ▶ The supported person has an emergency or short-term necessity for the support – (this could refer to instances where the employment of a family member would constitute a bridging solution until another care and support solution is found.)

**The benefits of having a family member as your Personal Assistant:**

- ▶ You get to have flexibility, choice and control with how you develop your support plan to meet your daily support needs.
- ▶ You already know your support person and have a good trusting relationship with them, which may lead to better provision of support and care.
- ▶ You are not tied to a provider schedule and have to fit in with their service hours and expectations. This may reduce your anxiety levels about whether or not your support will turn up.
- ▶ You will receive a service which meets your identified support needs in a culturally appropriate way and takes your spiritual needs into account.
- ▶ There may be reduced levels of guilt and stress about your family member providing the support if they are being paid.

**The benefits for the family member providing the care to you:**

- ▶ They already know your support needs, which will allow them to provide a good level of support and care.
- ▶ They don't have the stress and time constraints of 'training' an agency worker around the support needs.
- ▶ Their stress levels and anxiety may be reduced by knowing sufficient support is being provided in a timely manner.
- ▶ The stress caused by the financial impact of being a caregiver may be reduced and coming off a benefit and starting to contribute to tax and national insurance may raise self-esteem and self-worth.
- ▶ Their role as a caregiver is recognised, which may increase self-worth and social status. All the benefits when using Direct Payments to employ a family member may increase the quality of life for the family as a whole and should be strongly considered by workers– “the promotion of dignity and respect for the person is apparent”. However, there are also factors that the supported person and their family carer need to take into consideration.

**Factors that the supported person needs to consider:**

- ▶ If they are paying their family to provide the support, would their expectations of them change?
- ▶ Would it dramatically change their relationship with the family member? For example, would the recipient really be in control (as the policies intends), or would it be the family member in control?
- ▶ How would it affect their relationship if they had to reduce their Personal Assistants hours, make them redundant or sack them?
- ▶ What would their contingency plan be if their Personal Assistant was unable to work?
- ▶ How would they manage being in the role of the employer? Would they be able to deal with the legal responsibilities of being an employer? Examples of such responsibilities are disciplinary action, taxation, holiday entitlement, sick pay, ensuring the environment is a safe to work in and working time directive.

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## Making Self-directed Support work for BME Communities

### What family member needs to consider:

- ▶ Are they healthy and physically and mentally able to provide the level of support required?
- ▶ What would happen if they fell ill and were unable to meet the job specifications?
- ▶ How will it affect their quality of life, health, relationships, financial and social situation?
- ▶ Would they be able to differentiate between being a Personal Assistant and a family member?
- ▶ Would they be able to cope with having the supported person as their employer?

### Risk mitigation versus being risk adverse

Despite risks, all explored support options should include the possibility of a family member in 'appropriate' circumstances' being employed by Direct Payment. Risk is a necessity to ensure the recipient has independence, opportunities, and experiences, and has the ability to make their own life choices <sup>(70)</sup> (NHS, 2010).

Risk is also a way for the recipient to achieve their goals and objectives. Unfortunately, due to the threat of legal implications should something go wrong, workers are adverse to allowing people with health conditions and disabilities to take risks if they feel it compromises 'duty of care'. To ensure this is done correctly and successfully workers need to be competent in risk analysis. They must have the ability to identify actual and potential risks and be able to support a recipient, carer and their employer to look at how these risks could be mitigated to allow the support to be successful. This requires a comprehensive assessment to be completed so all potential risks are identified. It also requires the local authority to invest in appropriate training to provide their social care team with the confidence to take appropriate risks <sup>(71)</sup> (Wisdom in practice), <sup>(72)</sup> (Iriss).

### Case Study

Mrs K is a 59 year old Indian woman, with a diagnosis of diabetes, and end stage renal failure which causes her fatigue and pain, and reduces her ability to carry out her activities of daily living. An assessment was completed by the local authority and Mrs K was identified as requiring support. When exploring the SDS options Mrs K was given misleading information about Direct Payments from the local authority. The information consisted of social care jargon and was filled with potential barriers. Mrs K was left feeling concerned about being an 'employer' with employer responsibilities and her understanding was that she would be left to do this alone. This caused Mrs K to accept option two. As a result Mrs K received a service that did not meet all her desired outcomes and support needs. This service quickly failed and Mrs K was left without support.

When MECOPP become involved they supported Mrs K to review her desired outcomes and support needs. They helped her identify how she felt these outcomes and needs could be best supported. Once this was done MECOPP provided Mrs K with information in a format that helped her understand the SDS options. With this additional support Mrs K made the decision to choose SDS option one – Direct Payment. Mrs K now uses her Direct Payment to pay a support worker that tends to her personal care needs, on the days and times suitable for her and in line with her spiritual, cultural and linguistic needs. The support worker was employed using a recruitment agency. Her Direct Payment also funds a leisure pass that allows her to attend woman only swimming sessions to help her maintain her weight, and acupuncture sessions help her maintain her pain threshold.

# SECTION TEN: The Need for Providers to be Flexible and Creative

## The Benefits of SDS for BME Communities

Self-directed Support (SDS) provides an exciting alternative for people from BME communities, with long term care and support needs (either through ill health or disability) to have choice, flexibility and control over their care and support services. It can help people live full and independent lives in their own home and remain in their community. SDS plays a pivotal role ensuring that everyone can have the same level of opportunity and access to culturally and linguistically appropriate and faith-based supports; which meet their individual needs and basic human rights. Traditional western social care services are often not appropriate for BME communities, as they do not recognise the importance of language, culture and religion and the use of a holistic approach. Elements of life identified as significant by BME communities are that physical, social, spiritual and cognitive health is well balanced and maintained. SDS gives social care recipients the opportunity to be innovative when creating a support plan and package. It allows the recipient to access a combination of traditional western support and alternative services to tailor-make a support package that can meet their cultural, linguistic and spiritual requirements. To provide a service that meets the recipient's needs requires the provider to recognise people as individuals, with differing needs.

By ignoring cultural and spiritual needs and 'treating everyone the same', support agencies will be unable to provide an individualised service and our BME communities will continue to have very limited choice when it comes to social care provision. Dr. Obasogie, a professor at the University of California's Hastings College of Law suggests that such 'colour-blindness' causes issues not to be acknowledged, and therefore nothing is done to try and resolve it (Guardian, 2015). The best way to ensure social care recipients receive equal access and opportunities to support services; is by treating them like the unique individuals they are.

## Developing Good Practice

The following example demonstrates what can be achieved when organisations work together to achieve a common aim.

MECOPP partnered with Diversity Matters to create case-studies within BME communities which illustrated the potential of Self-directed Support to meet a variety of social care needs in a creative and flexible way. Under the banner of 'Everyone Together', workshops were delivered to members of the South Asian, Chinese and Gypsy/Traveller communities respectively. Individuals were provided with accessible information on SDS, asked to identify personal outcomes and subsequently provided with a small budget to achieve their outcomes. In delivering the workshops, the following good practice was developed:

- ▶ An informal approach was used due to the importance of ensuring everyone was comfortable with the format of the day. It was observed that participants benefited and engaged more with 'discussion' rather than formal presentations where they felt they were being 'talked at'. This required a more flexible approach and a willingness to deviate from planned proceedings, adapting content, style and delivery to suit the 'mood' in the room.

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- ▶ The schedule was adapted to suit people's caring commitments and prayer rituals.
- ▶ To address literacy issues, information materials were made accessible by cutting down on text and translating slides into Urdu and Chinese. Audio visual materials were also used and individuals from the respective communities with experience of SDS actively contributed to presenting and facilitating on the day. Additional language support was provided by professional interpreters.
- ▶ Through a combination of exercises, video's and group discussions, participants were supported to identify personal outcomes and what (small) changes would make a big difference to their quality of life. Follow-up support was provided to assist individuals to agree actions to meet personal outcomes and to arrange for these to be implemented.

Examples of what was achieved are set out in the following case studies:

### Case Study: Computer lesson

The South Asian workshops were split over two days, a week apart. On the first day we asked everyone to think about their outcomes and actions for feedback the following week. On the second day, a week later, we asked people to feedback what they had come up with; some people had no ideas, while others came with a long list! One older gentleman, handed over a piece of paper on which he had written that he would like "to be able to learn computer skills i.e. the internet and to be able to use smartphones, but would like to do this one to one, in Urdu or Punjabi. Would be a new world open for me and would help me achieve a happier life". It was clear that computer tuition would meet a whole range of outcomes for him, so we allocated £100 for 10 hours of lessons and helped him to find someone to teach him in Urdu or Punjabi. After a few false starts the gentleman suggested asking a young man he knew from when he was working in the local petrol station. The young man was happy to help and they have arranged the lessons between themselves. This is a much more natural arrangement than our initial ideas of finding a qualified teacher or getting support from a computer literacy charity, and is benefitting both parties. The older gentleman's daughter told us he is growing in confidence since starting the lessons and he's excited to learn more!

### Case Study: Meal delivery

When working with the Chinese group it became clear that there were some common needs, many elderly people were struggling with cleaning and cooking in particular. Those in receipt of home care services often found the care workers did not have time or were not allowed to help with housework and meal preparation. Existing meals on wheels or frozen food delivery services do not provide authentic Chinese food. This is a big problem for a lot of people. Our initial idea was to pay someone to cook with people in their own homes, invite others to join them for the meal, or hand out individual portions to people living nearby. This could have helped not only with cooking, but also with the isolation some of the participants told us they were feeling. However, we couldn't find anyone who was willing and able to do this and there were some concerns about the practical arrangements. We then thought of asking a Chinese lunch club currently operating 3 days a week if we could pay them to deliver meals; they couldn't do this due to their contractual funding arrangements. Finally – and getting desperate – we asked a local Chinese caterer if they could provide a meals on wheels service once a week, delivering several meals at once, and they agreed! This cost £8 per person per week, and they received 3 meals with rice each week. Considering a popular frozen meal service charges £3-5 per main meal, this is pretty good value for money! One of the participants explained to us that due to operations on her hands she is unable to carry shopping or cook for herself, and due to changes to previous support services she was dependent on family for help with this. As she put it, “The meal delivery service is what I have always needed.” As this was an experiment we were only able to provide the service for 5 weeks and it is already being missed.

Since the ‘Everyone Together’ events we have had an increase in people either wanting to apply for support, or wanting to change their existing support. This is encouraging as we were aiming to inspire and empower people from these communities to take more control. As our stories have shown, a little money can go a long way when people have flexibility and freedom to be creative and we think we all need to work together to conquer this particular mountain!

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Making Self-directed Support work for BME Communities

# SECTION ELEVEN

## Glossary of Terms

For the purposes of this report the following definitions have been adopted.

### **Black and Minority Ethnic (BME):**

'...refers to communities whose origins lie mainly in South Asia (eg. Indian, Pakistan and Bangladesh), Africa, the Caribbean (originally Africa) and China. It can be used to mean groups who would not define themselves as White (the term 'Black' may also be used in this case).'

### **Minority Ethnic:**

'... refers to ethnic groups who are in the minority. In Scotland the term 'Minority Ethnic' could also include people from English, Irish, Polish and Italian communities as well as groups covered under the term 'Black and Minority Ethnic'. The term would also include refugees, asylum seekers and (Scottish) Gypsy Travellers. Distinctions are often made between 'visible' Black and Minority Ethnic communities and 'invisible' Minority Ethnic communities based on skin colour.'

### **South Asian communities:**

People who recognise their ethnic origins as being from Afghanistan, Bangladesh, Bhutan, Maldives, Nepal, India, Pakistan, and Sri Lanka.

### **Disability:**

The Disability Discrimination Act (DDA) sets out the circumstances in which a person is disabled. You are disabled if you have:

- ▶ a mental or physical impairment
- ▶ this has an adverse effect on your ability to carry out normal day-to-day activities
- ▶ the adverse effect is substantial
- ▶ the adverse effect is long-term (meaning it has lasted for 12 months or is likely to last for more than 12 months or for the rest of your life).

(Source: Disability Rights Commission website)

### **Toolkit:**

A set of activities and resources to help a person develop knowledge and understanding of a specific topic.

### **Recipient:**

The person in receipt of social care support.

### **Practitioner:**

The person working on behalf of the local authority to determine the social care needs of a person in need of support.

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## Making Self-directed Support work for BME Communities

### Appendices

**Appendix one:** Producing Accessible Information for BME Communities

[http://www.mecopp.org.uk/files/documents/MECOPP%20publications/producing\\_accessible\\_information\\_briefing\\_sheet\\_08.pdf](http://www.mecopp.org.uk/files/documents/MECOPP%20publications/producing_accessible_information_briefing_sheet_08.pdf)

**Appendix two:** People from minority ethnic groups directing their own support – Communities of identity and Self-directed Support, 2015.

[http://www.mecopp.org.uk/files/documents/misc/raising\\_awareness\\_self\\_directed\\_support\\_and\\_minority\\_ethnic\\_communities.pdf](http://www.mecopp.org.uk/files/documents/misc/raising_awareness_self_directed_support_and_minority_ethnic_communities.pdf)

### A bit of fun! The Answers

1. According to the 2011 Census, what is the total Minority Ethnic population of Scotland (to the nearest ,000)?
  - a. 150,000 (141,000 people from Minority Ethnic groups)
2. According to Social Care Scotland 2015 how many people are in receipt of Direct Payments?
  - a. 6,450 (“The number of people choosing a Direct Payment to purchase the services they require continues to increase, with an estimated 6,450 clients and £86.1 million spent during the 2014-15 financial year”) Source: Scottish Government Social Care Survey 2015  
<http://www.gov.scot/Resource/0048/00488746.pdf>
3. According to Social Care Scotland 2015 what percentage of the Minority Ethnic population were social care clients?
  - a. 1% (Ethnicity of all 2015 Social Care clients for whom ethnicity information was known – White 144,000 99% Other ethnicity 1,680 1% Ethnicity information was unavailable for 59,740 clients) Source: Scottish Government Social Care Survey 2015  
<http://www.gov.scot/Resource/0048/00488746.pdf>
4. According to the 2011 Census, how many towns in Scotland reported a zero Minority Ethnic population?
  - a. 0
5. What is identified as the main reason for people from BME communities not accessing social care support?
  - a. Lack of accessible information and c. They are not aware of the support available

### Related Legislation

There are many pieces of legislation related to the provision of social services and SDS in Scotland. Here are a few of the Acts.

#### **Social Care (Self-directed Support) (Scotland) Act 2013:**

*“The Act gives people a range of options for how their social care is delivered, beyond just direct payments, empowering people to decide how much ongoing control and responsibility they want over their own support arrangements. The Act places a duty on council’s to offer people four choices as to how they receive their social care support”.*

You can read more at: <http://www.selfdirectedsupportscotland.org.uk>

**Community Care and Health (Scotland) Act 2002:**

*“The Community Care and Health (Scotland) Act introduced 2 new changes:*

- ▶ the introduction of free personal care for older people, regardless of income or whether they live at home or in residential care*
- ▶ the creation of rights for informal or unpaid carers, with the intention of providing adequate support services to ensure the continuation of care-giving in the community*

*The Act created the right to a separate carer’s assessment’ and the responsibility of health boards to produce ‘carer information strategies’ which must be submitted free of charge to carers”.*

Read more at: <http://www.careinfoscotland.scot>

**Human Rights Act 1998**

*“It means that you can defend your rights in the UK courts and that public organisations (including the Government, the Police and local councils) must treat everyone equally, with fairness, dignity and respect...*

*... Human Rights Act protects all of us – young and old, rich and poor. The Government wants to replace our Human Rights Act with their “British Bill of Rights and Responsibilities”. This would weaken everyone’s rights – leaving politicians to decide when our fundamental freedoms should apply”.*

Read more at: <http://www.liberty-human-rights.org.uk>

**Carers (Scotland) Bill – Carers (Scotland) Act 2016 now in place. Anticipated commencement date 1 April 2018.**

*“to make provision about carers, including the identification of carers’ needs for support through adult carer support plans and young carer statements; the provision of support to carers; the enabling of carer involvement in certain services; the preparation of local carer strategies; the establishment of information and advice services for carers; and for connected purposes”*

This Scottish Government Bill was introduced by Shona Robison MSP, Cabinet Secretary for Health, Wellbeing and Sport on 9 March 2015 and was passed by the Parliament on 4 February 2016.

You can read more at: <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/86987.aspx#sthash.ykmX57qj.dpuf>

**Race Relations Act 1976**

*“The Race Relations Act (RRA) 1976 amended 2000 makes it unlawful to treat a person less favourably than another on racial grounds. These cover grounds of race, colour, nationality (including citizenship), and national or ethnic origin. The RRA (Amendment) act outlawed discrimination (direct and indirect) and victimisation in all public authority functions not previously limited exceptions. It also placed a general duty on specified public authorities to promote race equality and good race relations. There are also specific duties for listed organisations including the production of Race Equality Schemes (RES)”.*

Read more at: <http://www.universities-scotland.ac.uk/raceequalitytoolkit/legislation.htm>

**Adults with Incapacity (Scotland) Act 2000**

*“The Act introduced a system for safeguarding the welfare and managing the finances and property of adults (age 16 and over) who lack capacity to act or make some or all decisions for themselves because of mental disorder or inability to communicate due to a physical condition. It allows other people to make decisions on behalf of these adults, subject to safeguards. The main groups to benefit include people with dementia, people with a learning disability, people with an acquired brain injury or severe and chronic mental illness, and people with a severe sensory impairment”.*

Read more at: <http://www.gov.scot/Resource/Doc/217194/0058194.pdf>

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## Making Self-directed Support work for BME Communities

### Feedback form: Tell us what you think of this toolkit

	Strongly Disagree ► Strongly Agree				
	1	2	3	4	5
Did you find this toolkit beneficial?					
Did you find this toolkit interesting?					
Did you find this toolkit informative?					
Did you find this toolkit easy to navigate?					
Did you find the exercises and case studies useful?					
Was there a good variety of exercises and case studies?					
Will you take any learning's from the toolkit and put them into practice?					
Do you now have more of an understanding about your own culture, values, views and possible prejudices?					
Did the toolkit help you understand some of the barriers and challenges faced by the BME communities when trying to engage with social care services and SDS?					
Did the toolkit help you understand the importance of accessible information?					
Will you communicate differently with services users from BME communities as a result of this toolkit?					
Do you have a better understanding of cultural competency?					
Do you have a better understanding of the importance of a cultural approach to the process and exploring the SDS options?					
Did the toolkit help you understand what planning and resources are required to make social care and the SDS process more accessible to BME communities?					
Has this toolkit encouraged you to change the way you facilitate the assessment process to make it more culturally appropriate?					
Has this toolkit encouraged you to be more creative when meeting people's support needs?					

#### Further feedback:

Please send your feedback to Michelle Coup – Self-directed Support Development Officer:

[michelle.c@mecopp.org.uk](mailto:michelle.c@mecopp.org.uk)

#### With Thanks

MECOPP would like to sincerely thank those that took the time out of their own busy schedules to support us in the creation of this toolkit with their insightful contribution. We are incredibly grateful.

## DISCLAIMER

MECOPP has made every effort to ensure the information contained in this toolkit is accurate, but we understand that sometimes mistakes can be made. If you see any errors in our toolkit, please make contact with MECOPP and we will be happy to discuss and will do everything possible to amend it.

This toolkit has been produced to support you in your practice when working with BME communities, but MECOPP would always advise discussing any concerns or queries you have about working with the BME community with your line manager or supervisor.

## Further MECOPP publications referenced in Toolkit

- ▶ Health of Scotland's BME communities briefing sheet 2.pdf
- ▶ Informal Caring briefing sheet 3.pdf
- ▶ Policy and Legislation briefing sheet 4.pdf
- ▶ SDS briefing sheet 5.pdf
- ▶ On the Margins Audit Tool R.pdf
- ▶ Cultural competence briefing sheet 6.pdf
- ▶ Producing accessible information briefing sheet 08.pdf
- ▶ Creating an alternative future: What does it mean for Scotland's Black and Minority Ethnic communities? DRC-MECOPP.pdf
- ▶ Manifesto for unpaid carers in Scotland
- ▶ The Scottish Parliament Health and Sport Committee Stage 1 Report on the Carers (Scotland) Bill
- ▶ A national scoping study about minority ethnic enterprises in Scotland.
- ▶ Over-looked Communities, Over-due Change: how services can better support BME disabled people.
- ▶ The Case for Care Leave: Families, work and the ageing population
- ▶ Self-directed Support, Regulation and Inspection Research Report
- ▶ Analysis of Equality Results from the 2011 Census, including Ethnicity, Gypsy/Travellers, Religion, Disability and BSL results from 2011 census.pdf
- ▶ People from minority ethnic groups directing their own support – Communities of identity and Self-directed Support, 2015.
- ▶ MECOPP SDS Stories
- ▶ MECOPP SDS DVD
- ▶ MECOPP Translation Guide

All the above publications can be found at [www.mecopp.org.uk](http://www.mecopp.org.uk)

### The following sources were also used in the making of this Toolkit

- 1 2011 Census results  
<http://www.scotlandscensus.gov.uk>
- 2 Scottish Government Document: Scotland's Carers – Chapter 3: Carers' Employment, Health and Finance  
<http://www.gov.scot/Publications/2015/03/1081/4>
- 3 An official statistics publication for Scotland: Equality, poverty and social security  
<http://www.gov.scot/Resource/0048/00484303.pdf>
- 4 Parliament UK, January 2007 Issue Number 276 – Ethnicity and Health  
<http://www.parliament.uk/documents/post/postpn276.pdf>
- 5 A Race Equality Foundation Briefing Paper: Long-term ill health, poverty and ethnicity (Race Equality Foundation) Long-term ill health, poverty and ethnicity, K. Harriss and S. Salway, 2008  
<http://www.better-health.org.uk/sites/default/files/briefings/downloads/health-brief8.pdf>
- 6 HEALTH EDUCATION RESEARCH Vol.21 no.1 2006 Theory & Practice Pages 43–54 Advance Access publication 13 June 2005. 'I can't do any serious exercise': barriers to physical activity amongst people of Pakistani and Indian origin with Type 2 diabetes, J. Lawton, N. Ahmad, L. Hanna, M. Douglas and N. Hallowell.  
<http://her.oxfordjournals.org/content/21/1/43.full.pdf+html>
- 7 Young South Asian people at higher risk of diabetes and associated heart disease  
[https://www.diabetes.org.uk/About\\_us/News/Young-South-Asian-people-at-higher-risk-of-diabetes-and-associated-heart-disease/?print=1](https://www.diabetes.org.uk/About_us/News/Young-South-Asian-people-at-higher-risk-of-diabetes-and-associated-heart-disease/?print=1)
- 8 ETHNIC DIFFERENCES IN CARDIOVASCULAR DISEASE – Journal, 2003 Jun; 89(6): 681–686.  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1767706/>
- 9 Health Beliefs of UK South Asians Related to Lifestyle Diseases: A Review of Qualitative Literature  
<http://www.hindawi.com/journals/job/2013/827674/>
- 10 Better Health Briefing 16 – Ethnicity and coronary health disease: Making sense of risk and improving care. A Race Equality Foundation Briefing Paper, Feb 2010, F. Astin and K. Atkin  
<http://www.better-health.org.uk/sites/default/files/briefings/downloads/health-brief16.pdf>
- 11 MECOPP: Health of Scotland's BME communities briefing sheet 2.pdf
- 12 The Rich Picture: People with cancer from BME Groups  
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