



Creating an alternative future

What does it mean for Scotland's Black and Minority Ethnic communities?

Disability
Rights
Commission

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Terminology

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.’

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)

Cultural Competence: ‘A culturally competent service is defined as a service which recognises and meets 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.’

‘Cultural competence is the ability to maximise sensitivity and minimise insensitivity in the service of culturally diverse communities.’

Section One:

Methodology

Methodology

The purpose of this report is to examine the relevance of the key priorities outlined in the Disability Agenda – Creating an alternative future (Disability Rights Commission 2006) in relation to the experience and self-identified needs of Scotland’s Black and Minority Ethnic (BME) communities.

The evidence is drawn from a review of the 2001 census and other demographic data on ethnicity, a limited literature review of research into the health and health needs of BME communities in Scotland and a series of eight focus groups.

Three of the eight focus groups were disability-, illness-, or condition-specific in nature, cancer, learning disability and mental health. The learning disability group consisted exclusively of South Asian parent carers caring for a child or young adult with a learning disability (due to the remit of this organisation the term ‘learning disability’ includes conditions such as autism). The cancer focus group was the only mixed group consisting of both individuals diagnosed with cancer and family members providing emotional and/or practical support. This group was also exclusively drawn from the Chinese community reflecting the remit of this particular service initiative.

The remaining five focus groups consisted of: BME workers working in health- /social care-related projects in Scotland; informal carers from the Chinese and South Asian (Pakistani, Indian and Bangladeshi) communities respectively; and, those in receipt of informal care from these same communities.

It was considered important to specifically include the focus groups with carers for two main reasons: the negative health impact of caring is well documented and in many cases will lead to long-term health problems for the individual themselves and, secondly, the discussion also provided an opportunity for participants to ‘forward think’ their ‘wants’ should they become disabled or suffer from a long-term health condition in the future.

The inclusion of a focus group of BME workers was seen as providing a further means of obtaining information and intelligence on the impact of disability and long-term health conditions on the lives of BME individuals, their families and informal carers.

The majority of participants in all focus groups were drawn from Edinburgh and the Lothians with the exception of the cancer focus group where participants came from four health board areas: Lothian; Fife; Dumfries and Galloway, and also from the Scottish Borders.

The organisation of the focus groups reflected the availability of agencies working with individuals covered by the Disability Discrimination Act (DDA) and who could provide an informed input into the debate and its 10 priorities.

Concerted efforts were made by the authors of this report to widen participation but a number of factors mitigated against this. These included: time constraints imposed by the commissioning agency; the lack of a BME voluntary sector/community group infrastructure to facilitate wider engagement in large parts of Scotland; and a perceived lack of relevance of the subject matter amongst existing community groups which limited their involvement.

The report acknowledges these limitations and in particular the absence of a rural/semi-rural dimension to the discussion and a broader geographical spread more generally; the extent to which the experience of those affected by particular illnesses, disability or disabling conditions could be explored due to the lack of BME organisations addressing these needs; and the exclusion of non-visible Minority Ethnic groups such as the Polish community.

In addition to discussing each of the 10 priorities outlined in the Disability Agenda, all focus groups considered the question of 'identity' as this was seen as a crucial determining factor in their experience of disability.

Section Two:

Policy and legislation

Policy and legislation

The Disability Discrimination Act (DDA) 1995 makes discrimination on the grounds of disability in the fields of employment, access to goods, facilities, services and premises and education unlawful. Disability is defined as being a physical or mental impairment that has a substantial and long-term effect on a person's ability to carry out normal day-to-day activities. Long term is deemed as being at least one year. Discrimination can occur when a disabled person is treated less favourably than a non-disabled person has, or would be, treated, or when a service provider or employer fails to make a 'reasonable adjustment'. For example, the failure to remove physical features which bar access or to amend policies that prevent disabled people from using services, such as not allowing guide dogs in hotels.

The Act has, however, subsequently been amended to give protection to people who have been newly-diagnosed with cancer, multiple sclerosis or HIV in recognition of the discrimination that people can face even if their condition is not having a day-to-day impact on their health. Disability therefore has a broader meaning than that commonly ascribed to it – that of people with physical or sensory impairments – and can also include people with severe disfigurements, people who are incontinent or those with diabetes or epilepsy.

The Disability Discrimination Act (DDA) 2005 introduced the concept of a positive Disability Equality Duty – which came into force on 5 December 2006. This places new responsibilities on a wide range of public authorities, in future these bodies will need to demonstrate that they are taking steps to:

- promote equality of opportunity between disabled and non-disabled people
- eliminate discrimination that is unlawful
- eliminate harassment of disabled people
- promote positive attitudes towards disabled people
- encourage the participation of disabled people in public life; and

- take steps to take account of disabled people's disabilities even when this involves treating a disabled person more favourably than others.

This last duty is important as it stresses the difference between disability and other equality legislation. Unlike gender discrimination law where the object of legislation is to treat people the same, disability law recognises that disabled people may need additional assistance to achieve equal treatment. For example, a pupil with dyslexia may need additional time to sit an examination. The Act also requires employers and service providers to anticipate discriminatory outcomes from current practices before a person actually experiences or alleges discrimination.

Section Three:

The size, structure and location
of Scotland's Black and Minority
Ethnic communities

The size, structure and location of Scotland's Black and Minority Ethnic communities

The information contained in this report on Scotland's differing BME communities is drawn from the 2001 Census. A degree of caution is recommended in interpreting the data as it is believed that the figures not only significantly under-represent the size of Scotland's BME communities but also that the data does not capture or reflect the dynamic nature of Scotland's population. The figures are also six years old.

Population figures

The 2001 Census records the total BME population in Scotland as being 101,677 people or 2.01 per cent of the total population. This represents a growth of just under 1 per cent on the previously recorded figure/percentage in the 1991 Census. The largest single visible ethnic group recorded was the Pakistani community (31,793 or 0.63 per cent) followed by the Chinese (16,310 or 0.32 per cent) and Indian (15,037/0.30 per cent) communities. The three smallest BME communities recorded were the Bangladeshi (1,981 or 0.04 per cent), Caribbean (1,778 or 0.04 per cent) and Black Scottish (1,129 or 0.02 per cent). Over 55 per cent of Scotland's total Black and Minority Ethnic population described themselves as being Asian (Indian, Pakistani and Bangladeshi or Other South Asian).

Table 1: Scotland's Black and Minority Ethnic Population 2001 Census (Office of the Chief Statistician)

Ethnic Origin	% Total Population	% Minority Ethnic Population	Total
All	100.00	N/a	5,062,011
White Scottish	88.09	N/a	4,459,071
Other White British	7.38	N/a	373,685
White Irish	0.98	N/a	49,428
Other White	1.54	N/a	78,150
Indian	0.30	14.79	15,037

Pakistani	0.63	31.27	31,793
Bangladeshi	0.04	1.95	1,981
Other South Asian	0.12	6.09	6,196
Chinese	0.32	16.04	16,310
Caribbean	0.04	1.75	1,778
African	0.10	5.03	5,118
Black Scottish or any other Black background	0.02	1.11	1,129
Any Mixed background	0.25	12.55	12,764
Other background	0.19	9.41	9,571

Age structure

In stark contrast to the White majority population, Scotland's BME population has a significantly younger age profile with 56.1 per cent of the total BME population under the age of 30. This can be broken down by specific ethnic groups as follows: 52.8 per cent of the Indian community; 59.1 per cent of the Pakistani/Bangladeshi/Other South Asian communities; 53.6 per cent of the Chinese community; and 58.7 per cent of other non-White communities. This compares to 36.6 per cent of the White community.

In part this can be explained by higher birth rates within BME communities and particularly the South Asian communities. Migration patterns also contribute to this with a larger number of younger economic migrants entering and remaining in the country.

Conversely, population size decreases as age increases with 12,693 or 12.5 per cent of Scotland's total BME population being aged 50+ and of these, 6.4 per cent or 6,488 are aged 60 plus. The Pakistani and Other South Asian communities recorded the highest number of those aged 50+ at 36 per cent (4,570) followed by Other background, Indian and Chinese communities respectively at 26.2 per cent (3,335), 19.2 per cent (2,444) and 18.4 per cent (2,344). These same communities also recorded the highest number of individuals' aged 60 plus at 38 per cent (2,477), 24.5 per cent (1,593), 19.1 per cent (1,244) and 18.0 per cent (1,174) respectively. This compares with 21.3 per cent of the White community recorded as aged 60 plus.

In keeping with the geographical concentration of Scotland’s BME populations, Glasgow recorded the largest number of BME residents aged 60 plus at 2,056 followed by Edinburgh (976), Dundee (309) East Dunbartonshire (300) and East Renfrewshire (239).

Table 2: Persons by Age and Ethnic Origin

Age	Total	0-15	16–29	30–44	45–59	60–64	65+
Total	5,062,011	972,065	883,780	1,162,958	976,575	261,733	804,900
% White	98.0	19.0	17.2	22.9	19.5	5.2	16.1
White Population	4,906,334	942,658	855,081	1,137,616	964,834	259,407	800,738
% Indian	0.3	23.1	29.7	24.9	14.0	3.1	5.2
Indian Population	15,037	3,473	4,470	3,746	2,104	467	777
% South Asian	0.8	32.1	27.0	24.2	10.5	2.6	3.6
South Asian Population	39,970	12,827	10,777	9,963	4,196	1,021	1,456
% Chinese	0.3	21.6	32.0	25.3	13.9	2.4	4.8
Chinese Population	16,310	3,524	5,219	4,126	2,267	393	781
% Other	0.6	31.6	27.1	25.6	10.4	1.5	3.8
Other Population	30,360	9,583	8,233	7,777	3,174	445	1,148

Location

Although little documented work has been done to explain patterns of migration into Scotland, anecdotal evidence strongly suggests that a significant proportion of this is secondary migration from England. In common with England, settlement is highest in urban areas where business and employment opportunities operate as a significant ‘pull’ factor. In Scotland approximately 60 per cent of the total BME population can be located in four major cities/local authorities – Glasgow, Edinburgh, Dundee and East Renfrewshire. Conversely, the areas of lowest settlement correspond with areas at the periphery of Scotland – the Scottish Borders, Dumfries and Galloway and the

Highlands and Islands – where there are perceived to be less economic opportunities available.

However, patterns of migration are changing to the extent that small area data from the 2001 Census demonstrates that only 14 towns with a population of more than 500 residents recorded a zero Minority Ethnic population.

Table 3: Local Authority Area by Ethnic Origin

Local Authority	Local Authority Population	per cent White	White Population	per cent Minority Ethnic	Minority Ethnic Population
Aberdeen City	212,125	97.10	205,973	2.90	6,152
Aberdeenshire	226,871	99.29	225,260	0.71	1,611
Angus	108,400	99.21	107,544	0.79	856
Argyll and Bute	91,306	99.21	90,585	0.79	721
Clackmannanshire	48,077	99.16	47,673	0.84	404
Dumfries and Galloway	147,765	99.35	146,805	0.65	960
Dundee City	145,663	96.34	140,332	3.66	5,331
East Ayrshire	120,235	99.32	119,417	0.68	818
East Dunbartonshire	108,243	96.91	104,898	3.09	3,345
East Lothian	90,088	99.28	89,439	0.72	649
East Renfrewshire	89,311	96.15	85,873	3.85	3,438
Edinburgh	448,624	95.93	430,365	4.07	18,259
Eilean Starr	26,502	99.36	26,332	0.64	170
Falkirk	145,191	98.97	143,696	1.03	1,495
Fife	349,429	98.73	344,991	1.27	4,438
Glasgow City	577,869	94.54	546,317	5.46	31,552
Highlands	208,914	99.20	207,243	0.80	1,671
Inverclyde	84,203	99.11	83,454	0.89	749
Midlothian	80,941	99.09	80,204	0.91	737
Moray	86,940	99.13	86,184	0.87	756
North Ayrshire	135,817	99.32	134,893	0.68	924

North Lanarkshire	321,067	98.74	317,022	1.26	4,045
Orkney	19,245	99.56	19,160	0.44	85
Perth and Kinross	134,949	99.03	133,640	0.97	1,309
Renfrewshire	172,867	98.77	170,741	1.23	2,126
Scottish Borders	106,764	99.44	106,166	0.56	598
Shetland	21,988	98.94	21,755	1.06	233
South Ayrshire	112,097	99.32	111,335	0.68	762
South Lanarkshire	302,216	98.88	298,831	1.12	3,385
Stirling	86,212	98.51	84,927	1.49	1,285
West Dunbartonshire	93,378	99.29	92,715	0.71	663
West Lothian	158,714	98.67	156,603	1.33	2,111

More recent data published by the Scottish Executive (Office of the Chief Statistician 2005) on faith and religion in Scotland both reinforces and expands on information contained in the 2001 Census, particularly in relation to the inclusion of Jewish and Sikh communities, who were otherwise invisible in the ethnicity data.

Table 4: Faith Communities in Scotland

Faith	Population Size	%
Church of Scotland	2,146,293	42.40
Roman Catholic	803,847	15.88
Other Christian	344,723	6.81
Buddhist	6,581	0.13
Hindu	5,568	0.11
Muslim	42,521	0.84
Sikh	6,581	0.13
Jewish	6,581	0.13
Other	26,829	0.53
No Religion	1,394,584	27.55
Unanswered	277,904	5.49

Section Four

The health of Scotland's Black and Minority Ethnic population

The health of Scotland's Black and Minority Ethnic population

The 2001 census contains two sets of data that may provide some insight into the relative health of Scotland's BME communities. These are the number of BME individuals who identified themselves as suffering from a limiting long-term illness and those who identified themselves as informal carers.

Black and Minority Ethnic communities and limiting long-term illness

The 2001 Census recorded a total of 11,525 individuals or 12.4 per cent of the total BME population who defined themselves as having a limiting long-term illness (defined as a long-term illness, health problem or disability which limited daily activities or the work they could undertake). This compares with 20.5 per cent of the White majority population.

Within individual ethnic groups the highest percentage of limiting long-term illness was reported in the Black Scottish/Other Black category at 17.2 per cent. This was followed by the Pakistani community (16.8 per cent), the Afro-Caribbean community (14.2 per cent) and Other South Asian communities (13.1 per cent). The lowest percentage of limiting long-term illness was reported by the Other Ethnic groups (7.8 per cent), closely followed by the African (8.0 per cent) and the Chinese communities (9.1 per cent).

All ethnic groups recorded the highest percentages of limiting long-term illness in the 65 plus age category. The Pakistani community reported the highest levels of limiting long-term illness across all ethnic groups between the ages 35–65 plus whereas the Chinese community reported the lowest percentage in the 0–34 age range.

In terms of actual numbers, the Pakistani community recorded the highest number of individuals with a limiting long-term illness at 5,341 whilst the lowest was recorded by the 'Any Mixed Ethnic Background' category at 140.

The data remains problematic on two counts: the category of limiting long-term illness is self-defining and relies on individual interpretations of what constitutes a debilitating illness or condition; and secondly, no information is available about the nature of that illness or condition.

More limited data is provided by the Labour Force Survey (2005) suggests that at a national (Great Britain) level, 37 per cent of South Asians, 22 per cent of African and Afro-Caribbean individuals and 30 per cent of 'Other' aged 50–64 have a disability compared with 45 per cent of the White majority population.

Table 5: Limiting Long-term Illness by Ethnic Group (adapted from table S238 General Registrar's Office Scotland)

Ethnic Group	Population Size	per cent of Population	With Limiting Long-term Illness
White	4,960,334	20.5	1,016,868
Indian	15,037	12.7	1,910
Pakistani	31,793	16.8	5,341
Bangladeshi	1,981	11.9	236
Other South Asian	6,196	13.1	812
Chinese	16,310	9.1	1,484
Afro-Caribbean	1,778	14.2	252
African	5,118	8.0	409
Black Scottish/Other Black	1,129	17.2	194
Any Mixed Ethnic Background	12,764	12.1	140
Other Ethnic Group	9,571	7.8	747

Table 6: % of Limiting Long-term Illness by Age and Ethnicity (adapted from table S238 General Registrar's Office Scotland)

Ethnic Group/Age	0–15	16–24	25–34	35–59	60–64	65+
White	4.7	6.2	9.5	19.1	39.0	55.0
Indian	3.8	4.6	5.9	17.8	44.3	62.7
Pakistani	5.1	6.6	9.8	28.4	63.6	67.7
Bangladeshi	5.2	7.7	6.2	20.8	32.5	52.4
Other South Asian	4.9	4.9	9.8	19.1	47.0	55.1
Chinese	3.6	2.9	3.4	11.7	38.9	53.5
Afro-Caribbean	5.1	7.0	8.6	15.5	47.2	48.0
African	4.5	5.5	4.8	10.8	47.2	48.0
Black Scottish/Other Black	4.8	7.6	12.2	22.8	45.8	56.4
Any Mixed Ethnic Background	5.0	6.9	12.0	22.0	47.5	56.2
Other Ethnic Group	3.8	3.8	3.8	11.2	30.8	50.4

Black and Minority Ethnic communities and informal caring

The 2001 Census recorded a total of 6,815 informal carers within Scotland's BME communities.

Within individual ethnic groups the Pakistani community recorded the largest number of informal carers at 2,754. This is followed by the Indian community at 1,160 and Other South Asian at 766. However, when percentage levels are calculated the order changes with the Other South Asian category recording the highest levels at 12.6 per cent followed by the Pakistani community at 8.6 per cent and the Indian community at 7.6 per cent. This suggests that there are higher levels of informal caring within some ethnic groups relative to their population size.

The highest number of informal carers providing the most hours of care in a week fell within the Black Scottish or Other Black category.

The Afro-Caribbean community recorded the highest number of carers providing care of between 1–19 hours per week.

Data regarding the number of informal carers in Scotland’s BME population is limited in two key respects: there is significant anecdotal evidence to indicate that the language and concept of ‘informal caring’ is not readily understood within Minority Ethnic communities leading to problems with self-identification and accurate recording; and, the number of informal carers is not disaggregated by the nature of their caring situation so there is no information available on when caring commenced.

Table 7: Provision of Informal Care by Population Size (General Registrar’s Office Scotland)

Ethnic Group	Number of Informal Carers	Total Population
White Scottish	430,043	4,459,125
Other White British	34,194	373,576
White Irish	4,967	49,607
Other White	5,560	77,955
Indian	1,160	15,186
Pakistani	2,754	31,891
Bangladeshi	145	2,025
Chinese	388	16,198
Other South Asian	766	6,074
Afro-Caribbean	136	2,025
African	246	5,062
Black Scottish or Other Black	102	1,012
Any Mixed Ethnic Background	650	12,655
Other Ethnic Group	468	9,618
Total Population	481,579	5,062,011

Table 8: Provision of Informal Care by Ethnic Group and per cent

Ethnic group	Nil care provided	1–19 hours care per week	20–49 hours care per week	50 plus hours care per week
White Scottish	90.4	6.1	1.2	2.3
Other White British	90.8	6.0	0.9	2.2
White Irish	90.0	6.1	1.2	2.7
Other White	92.9	4.7	0.8	1.7
Indian	92.3	4.6	1.3	1.8
Pakistani	91.3	4.8	1.6	2.3
Bangladeshi	92.7	3.7	1.7	2.0
Chinese	93.7	3.3	1.1	1.9
Other South Asian	95.3	2.9	0.7	1.1
Afro-Caribbean	92.4	5.2	1.0	1.4
African	95.2	2.7	1.1	1.0
Black Scottish or other Black	91.0	3.8	1.9	3.4
Any Mixed Ethnic Background	94.9	3.3	0.6	1.2
Other Ethnic Group	95.1	2.7	1.0	1.2
Total Population	90.5	6.0	1.2	2.3

The following provides a summary of key findings relating to health conditions known to disproportionately affect BME individuals. Information on the prevalence of other disabilities or long-term health conditions has been included where available. Due to the lack of Scottish-specific data, English studies have been drawn upon. This is an approach supported by the Scottish Public Health Observatory who state, when discussing mortality, that:

‘... in the absence of Scottish data, estimates from England have been used as an approximate guide to likely causes and patterns ... in Scotland.’

Coronary heart disease (CHD) and stroke

Coronary heart disease has long been recognised as a major health issue for BME communities with higher levels recorded within the South Asian population in particular. Dietary choices were identified as a contributory factor but that this, in isolation, did not account for the higher rates of CHD present in the South Asian community.

Studies suggest that the higher incidence of CHD amongst South Asian people, particularly women, were more likely to result from a complex interaction of risk factors including insulin resistance, stress and wider socio-economic circumstances (Williams et al, 1994, cited in Netto et al, Scottish Executive 2001).

The 2004 Health Survey for England: The Health of Ethnic Minority Groups reports higher levels of angina amongst Minority Ethnic populations at 31 per cent compared with 9 per cent for the general population and a similar differential for heart attacks at 19 per cent for Pakistani men compared with 10 per cent of men within the general population.

Bangladeshi women and Afro-Caribbean men also reported approximately twice the number of strokes than the general population.

Diabetes

The same 2004 English study recorded that Afro-Caribbean men and women were more than two times more likely to experience diabetes at 10 per cent and 8 per cent respectively than the general population at 4 per cent and 3 per cent. Similarly, Indian, Pakistani and Bangladeshi men and women also experienced diabetes at more than twice the national average.

A recent survey in Glasgow (the National Resource Centre for Ethnic Minority Health 2004) of BME patients on the Glasgow Diabetes Register suggests that the:

‘... risk of being diagnosed with type 2 diabetes was eight, four and three times higher in the Pakistani, Indian and Chinese ethnic groups respectively, compared with the White majority population.’

Mental health

A review of community-based research conducted by Lothian NHS Board in 2000 noted that much of the data suggested higher levels of depression and anxiety amongst South Asian communities with social isolation and poverty as significant causal factors. This is borne out by the 2004 Health Survey for England.

Anecdotal evidence from community organisations suggest that Black and Minority Ethnic communities present at psychiatric services later than their White counterparts and more often in crisis when the illness has become more acute or when caring situations have broken down.

Learning disability

A study by Emerson et al (1997), cited by Sim, D. and Bowes, A. (2005) suggests that the incidence of learning disabilities within Minority Ethnic communities appears to be higher than that within the White majority population. This report, amongst others (Butt and Mirza (1996) and Mir et al (2001) identifies a number of possible contributory causes including the general effects of social, economic and educational deprivation, inequalities in maternity care and higher rates of genetic and environmental risk factors.

Hearing impairment

Information provided by the National Deaf Children's Society (NDCS) and cited by the Royal National Institute for the Deaf (RNID) identifies 3,000 moderately to profoundly deaf children and young people in Scotland.

Little Scottish research exists on the prevalence of hearing impairment amongst children and adults within Minority Ethnic communities. A 1996 English study (Naeem and Newton) found a higher prevalence rate for both mild to moderate and moderate to profound hearing loss amongst South Asian children. The same study also found that South Asian children had a markedly higher risk of incurring a hearing loss than White children.

Section Five:

Focus group findings

Focus group findings

A question of identity

An exploration of the issues surrounding identity was included so as to gain an understanding of, and an insight into, the following issues: how BME individuals affected by a disability or long-term health condition chose to identify or define themselves; to gauge participants' understanding of the term 'disability' and any subsequent positive or negative connotations associated with the use of the term; to determine any interplay of ethnicity and disability and whether this affected how BME individuals perceived themselves and their experience of daily life; and, to identify any sense of kinship or collective identity with other non-BME disabled people.

The discussion surrounding identity can be contextualised as part of a wider debate on multiple identities that recognises that disabled people cannot be seen as one homogenous or unitary group (Shakespeare 1996). Factors such as gender, class and socio-economic status, sexuality, age and race inevitably structure, influence and impact on their personal experience of disability. Equally, disabled people may differentiate themselves in terms of the nature of their disability such as physical, sensory or intellectual impairment. Research conducted by the Disability Rights Commission equally demonstrates that 52 per cent of those covered by disability legislation do not positively associate themselves with the term 'disabled' and within this, approximately 21 per cent find the label 'insulting'.

The subsequent discussion around identity within the focus groups confirmed that a wide range of factors needed to be taken into consideration in determining and attributing self-identity. Blanket terms such as 'Black and Minority Ethnic' were seen to be less useful as they obscured 'difference' both between and within ethnic groups. However, this was qualified to some extent by the sense of ethnic kinship expressed by participants as their predominant identity although this is again undergoing change for some ethnic groups. Current debates about 'Asian' identity suggest that Indian Hindu's

are increasingly rejecting the term 'Asian' due to the perceived negative associations with Islam.

Five of the focus groups (South Asian and Chinese carer's groups and those in receipt of informal care and the Chinese cancer group) stipulated that they would define themselves in terms of their ethnicity. Gender was seen as being self-evident and therefore not an issue in terms of identity. No links were drawn or differences identified between their experience as Minority Ethnic men and women as opposed to their gender identity as male or female.

The learning disability group was the only focus group where participants identified themselves as 'parent carers' first, followed by their ethnicity. Participants within the group ascribed this to the 'politicisation' they had undergone in fighting for services and therefore finding common ground with other parent carers of children and young adults with learning disabilities within the majority community. They also cited the stigma with which learning disabilities and disability more generally was seen within their own ethnic communities as being a major factor in contributing to this sense of shared identity although it was recognised that attitudes were changing amongst younger members of BME communities. At a more general level, participants felt that the majority community was more 'accepting' of difference and disability and therefore less likely to make a negative judgement.

Both the BME workers group and the men's mental health group stated that personal identity was more of a fluid concept that depended on a particular context or situation as to which element was paramount and therefore ascribed to, or ascribed by, themselves. Central to this was the notion of 'advantage' and in particular, the ability to access services. For example, any combination of ethnicity, gender and disability or illness may be crucial factors in determining their eligibility for a service such as a Black men's mental health project or a Chinese women's group. Additionally, the learning disabilities group felt that ascribing a disability to their children was useful in explaining challenging behaviour that was exhibited in public places particularly if the nature of their disability or health condition was not self-evident, for example, a child with autism.

Interestingly, two parents recounted how their children were adept at using the same argument to avoid any unwanted tasks asked of them:

‘I can’t do that because I’m disabled/have special needs.’

This group also recognised the ‘benefit’ in having a recognised medical condition as a passport to information.

The impact of other people’s views on how individuals perceived themselves was also recognised by participants within the men’s mental health group:

‘I would identify myself as a Scottish Chinese male. The Scottish tend to judge you more by your colour and now I identify myself more with the Chinese community.’ (Participant, men’s mental health focus group)

None of the participants in the focus groups saw disability or a long-term health condition as the primary factor in defining or describing themselves or those they provided informal care for.

All groups identified the stigma attached to the term ‘disability’ within BME communities as a key factor in this. In particular, some participants within the learning disabilities group stated that they felt other members of their communities judged them and attributed ‘bad karma’ and retribution for ‘wrongs’ in a previous life to explain the birth of a child with a disability. This view did not extend to disabilities acquired through illness or an accident in later life, as there were clearly external factors with which this could be attributed to. However, the reverse was true of the views expressed by some members of the BME workers group who felt that an acquired disability would be perceived within some BME communities as the outcome of ‘wrongs’ committed during the individual’s life. There was also a general view in the Chinese carers group that disability, illness or a long-term health condition was not something an individual had any control over but that it was due to ‘destiny’, fate or God’s will.

All groups cited a lack of information and awareness about disability as a major contributory factor in upholding and reinforcing stigma. Participants within the BME workers group cited examples of a fear within BME communities that certain conditions such as spina bifida

and dementia were infectious and to be avoided furthering contributing to the isolation experienced by those affected and their families.

The role of education, particularly into learning disabilities and other types of disability, illness or long-term health conditions which have significant levels of stigma attached to them, was stressed by focus group participants as the only way to challenge and raise awareness within their own communities.

‘We have to be out there ... there must be more exposure to different types of disability ... we must educate otherwise the (Black and Minority Ethnic) communities wont learn.’ (Participant, learning disabilities group)

There was consensus amongst all focus groups that the term ‘disability’ was too broad to be useful and that it did not capture or reflect an individual’s experience of their particular disability, illness or long-term health condition. It was also important to note that the term itself did not translate easily into different languages and that this would, in turn, influence how any disability, illness or long-term health condition was viewed both by the individual and their respective communities. The lack of a comparative term or concept also presented difficulties in enabling individuals to identify themselves as disabled or as having an illness or long-term health condition and therefore receive a timely diagnosis and access to services. It was also felt that this served to hide the true extent of disability within BME communities.

An important distinction was also made between visible and non-visible disabilities and the experiences that flowed from this. Participants within the learning disabilities group stated that they felt there was more understanding of physical disability as this could be seen whereas some forms of learning disability were not easily visible and therefore less well understood and tolerated.

There was a consensus amongst all focus groups that an individual’s own perception was a crucial determining factor in whether they considered themselves disabled or not. This appeared to be particularly strongly felt amongst the men’s mental health group:

‘I do not define myself as disabled and have come to accept my condition as part of me.’ (Participant, men’s mental health group)

‘I wouldn’t be me if I didn’t have a disability.’ (Participant, men’s mental health group)

‘Weakness is my strength. I have come to accept my disability.’ (Participant, men’s mental health group)

It was important to note that discrepancies may arise between an individual’s own view of their disability or long-term health condition and how the community at large viewed them. This clearly had important implications for the level and type of support offered and, in particular, whether individuals were ‘medicalised’ or not.

For the majority of participants being labelled as ‘disabled’ was seen as a means of excluding them from ‘mainstream’ society and curtailing life choices and opportunities. Participants in the men’s mental health group stated that they felt individuals with a disability or long-term health condition were adversely affected by mainstream or majority views of what constituted ‘normalcy’ and that this further served to disable individuals and ostracise them from mainstream society.

This was equally true of how they were viewed in their own communities. Participants within the learning disabilities group spoke of ‘marriage’ and ‘family’ being denied to young adults with any form of disability or disabling condition as a result of prejudice and a lack of understanding within their own ethnic groups. This view was echoed by the BME workers group who highlighted the cumulative effect on the family of having a disabled family member. The example given was the reluctance of other families wishing to marry into a family with a disabled family member for fear of being stigmatised by association. These views were seen to be particularly prevalent within South Asian communities. This wider impact also served to prevent or inhibit identification or self-identification of individuals within BME communities.

All groups tended to associate disability with easily recognisable and therefore visible conditions such as physical disabilities, severe

learning disabilities and visual impairments. The need for significant support in daily living was seen as a key indicator in determining whether someone was disabled or not. There was much less awareness that the definition provided in the Disability Discrimination Act covered illnesses and conditions such as cancer, mental health problems, diabetes, arthritis, Alzheimer's and HIV/AIDS.

Links were also made between participants' experiences of racism and disability. The BME workers group identified a feeling amongst their service users of 'having to be better' and 'try harder' because of what they perceived to be a dual disadvantage imposed on them by mainstream service providers and the wider community. One participant within the learning disabilities group echoed this feeling:

'People make assumptions. A nurse asked me 'can you understand this?' They just look at your clothes and skin colour and make assumptions about you, that you can't understand what they are saying and that you don't speak English even though you may be second or third generation Asian.'

The impact of class or socio-economic status was also raised by the BME workers group as a consideration in determining or contributing towards an individual's quality of life. It was surmised that high levels of educational attainment, wealth and status would enable some families to effectively 'buy' their way out of any/some restrictions that a disability may impose on a family member and family life.

There was very little sense of collective identity expressed by focus group participants with the wider disabled community. Notably, participants within the men's mental health focus group highlighted the existence of a 'hierarchy' within the 'disabled' community where a 'ranking' order of ability served to further disadvantage particular groups and individuals.

The only exception to this was the attachment felt by members of the learning disabilities group to parent carers of children and young people with learning disabilities within the majority community.

The BME workers group was the only group to recognise that some disabled people, such as those with a significant hearing impairment,

had a definite and identifiable culture of their own which was largely exclusive.

Overall, there was a general consensus that 'disability' was used to distil individual experiences into a common 'melting pot' based on the assumption that 'everyone had the same problems'. However, the limitations of this argument were also recognised:

'There is a tendency for some groups who suffer discrimination to see the differences and not to see the things they have in common and to claim common ground with other people.' (Participant, men's mental health group)

The Disability Agenda priorities:

Increasing democratic participation and active citizenship

The ability to actively participate as a full member of society was seen as both desirable and essential to an individual's quality of life. However, there was a recognition that the ability to participate depended on a range of external factors that would, in themselves, influence the extent to which participation became a reality. Additionally, participants stated that there was not one universal 'standard' of participation but rather that it would depend upon the ability, desire and willingness of each individual to engage. Individual parameters also meant that one person's involvement might be seen as 'tokenistic' by another individual.

A common theme linking the focus group discussions was the need to ensure an accessible 'environment' that would enable and actively foster participation. This was not confined solely to the 'built environment' but extended to all areas of an individual's life where support was required in order to participate.

For the majority of older participants within the focus groups, the lack of accessible information was a fundamental barrier to participation. Very often, this, in itself, was the primary means of exclusion from a wide range of activities and opportunities. Participants argued that there was a need for information to be provided in a format and

languages that were suitable and most importantly, that it should be disseminated in places that are utilised by BME communities:

‘I do not know how to get access to activities in the community because I do not read or speak English. It would help if information materials are written in Chinese and distributed in places where we normally go such as Chinese supermarkets, Chinese restaurants and other community groups. It would be helpful if the Chinese broadcasting channels are used to disperse information to the Chinese community.’ (Participant, Chinese focus group)

All focus groups expressed a desire to become more involved in community and public life, even going so far as to state ‘... that you should be loyal to the country (UK) and contribute towards society.’ (Participant, Asian focus group).

Meaningful involvement in democratic processes was seen as an essential part of contributing towards society, both within their immediate community networks and more widely. Two examples of participation were identified as being particularly problematic: user involvement; and, voting in local and national elections.

One participant within the men’s mental health focus group recounted how he, as part of a wider group, had been invited to express opinions on the services provided by a particular agency. When his response was not entirely favourable, the response of the service providers was to retaliate with ‘you people are always so critical’.

He felt very strongly that ‘... we have the experience and knowledge and we need to have a say in planning services. We need accountability.’

Whilst, in theory, there appeared to be a commitment towards user involvement, both this group and the BME workers group stated that practice varied considerably from organisation to organisation. Central to this was a reluctance on the part of institutions and individuals to give up or share ‘power’.

At an even more fundamental level, participants within the Chinese carers focus group felt that they were being excluded from the

political process and completely disenfranchised by the lack of recognition of, and adjustment made for, their specific needs:

‘All of us (including those they provided informal care for) would like to take part in voting but we don’t know where and when voting takes place and even the voting forms are in English. We do not know who our local MP or councillor is and what they can do to help us fight for our rights.’

Volunteering was also recognised as another means of contributing to the wider life of the community but was not an option that was pursued by the majority of participants within the focus groups for a variety of reasons. Concerns were expressed about the ability of mainstream organisations to effectively recruit and support Minority Ethnic volunteers due to a lack of skills, capacity and resources. For these reasons, it was easier and a more attractive option to volunteer with community organisations that are already geared towards meeting the specific needs of BME volunteers.

Increasing the number of BME volunteers was also seen as the most pragmatic solution to enabling people with a range of disabilities to participate more in community activities, both within their own ethnic specific community and the wider community. This would be a significant step towards ensuring that the cultural and linguistic needs of individuals were met. This feeling of needing to be reassured of ‘cultural compliance’ was articulated most strongly by parent carers within the learning disabilities group:

‘... my worst nightmare is that he will be stuck in a home in front of the telly and doped up on sedatives with no-one to stimulate him or take him out because they cannot speak his language or understand our culture.’

Participants in this group and the Asian carers focus group also suggested that enabling Minority Ethnic people with disabilities to employ family members as paid carers or personal assistants would make a very real difference to the quality of life experienced.

The fear, or an actual experience of, racism was also identified by participants within the men’s mental health focus group as being a significant barrier towards increasing participation:

‘Not all participants are racist but it only takes one or two to put you off attending or participating.’

Structural issues in the physical built environment were also identified as major barriers to participation. The lack of accessible transport and buildings were consistently identified as the two major stumbling blocks:

‘It is very difficult to get into a coach because the door is too narrow and the steps are too high for me.’

‘I almost had a fall in the train because of the gap between the train and the platform.’

Whilst the introduction of ‘priority’ seating for older people and people with mobility problems in buses was welcomed, problems were still identified due to the lack of awareness of the general public or an unwillingness on the part of bus drivers to enforce their correct use:

‘The seats were taken by people for their luggage and shopping. I asked them to give me the seat but they refused. I had to get off the bus because I could not manage to stand for the journey.’

‘The priority seats in the bus are very often taken by young people and children. The introduction of priority seats is good, however, this should be reinforced so that older people and disabled people can benefit from it.’

Personal safety and being subjected to racism and harassment were also concerns expressed by older participants within the focus groups particularly in relation to using public transport:

‘I told the bus driver that we had to get off at the next stop and my husband would need plenty of time to get off the bus due to his mobility problem. The bus driver was very good, however there were some teenagers on the bus teasing us. We felt angry about it but what could we do and it has made us hesitate to use public transport.’
(Participant, Chinese cancer focus group)

‘We were discouraged in using public transport because of discrimination by the public. We felt we were discriminated against because we are Chinese.’ (Participant, Chinese cancer focus group)

Bullying and harassment were also singled out as being regular occurrences for children with disabilities:

‘If you are disabled you are a target for bullying from others. Your child gets a lot of harassment from other children.’ (Participant, learning disabilities focus group)

Participants within the men’s mental health group also identified negative attitudes of individuals using community provision such as adult education classes as being a disincentive:

‘I went to ‘Welcoming Project’ run by ALP (Adult Learning Project) but they were not very welcoming. I did not feel accepted and understood. I did not go back.’

In addition to very often experiencing a hostile ‘social’ environment, problems were also identified with the ‘built’ environment that made it difficult to maintain outside interests and involvement in the community:

‘I used to go to a restaurant for meals but now I have to go to another one because my mobility has deteriorated over the years and I cannot manage to climb the stairs going into the restaurant.’ (Participant, Chinese cancer focus group)

‘I used to go swimming with my husband every single day. However, since my husband’s mobility problem has deteriorated I stopped going for a swim because the pool is not safe for my husband. The floors are too slippery and there are no adaptations, for example, handrails in the pool area so my husband can hold on for some support in walking to the pool.’ (Participant, Chinese cancer focus group)

‘I went for a sauna this morning in the swimming pool. I slipped and fell onto the floor because it was slippery. It would be better if there were handrails installed so that I can hold onto them for support.’ (Participant, Chinese focus group for people with disabilities, illness or limiting long-term condition)

The poor quality of premises having to be utilised by BME groups working with people with a range of disabilities, illnesses and limiting

long-term conditions also came in for criticism. Buildings were often in a poor state of repair and inaccessible to individuals with mobility problems. A lack of funding and value being attached to the work were cited as the main reasons for this. However, it was felt very strongly that the role of BME organisations should be acknowledged as in most cases these were the only agencies offering both practical and emotional support to individuals.

Three of the focus groups (BME workers group, men's mental health group and the learning disabilities group) all expressed the opinion that BME communities suffered from a culture of 'low expectations' and that collective action through forging alliances with a range of 'like-minded' organisations and groups was the only way forward:

'We need to make people aware of their rights and how to claim them. People need information and support to make participation more of a reality. If we get together, we have collective power' (Participant, men's mental health group)

Ending poverty and widening employment opportunity

There was a consensus across all focus groups that disabled people and those with long-term health conditions should have the same right to work as non-disabled people. The ability to earn a 'decent' living wage and to support oneself was not just equated with financial return but rather a sense of self-respect and being able to 'contribute' to society.

'Everybody should be encouraged to work in order to contribute to society and their local community. It gives you self respect and a meaning.' (Participant, Asian carers focus group)

There was universal recognition of the impact of 'dual' or double discrimination faced by BME individuals in respect of race and disability or long-term health condition.

For non-disabled BME individuals, the range and availability of job or career opportunities were already perceived to be limited due to the impact of discrimination in the employment market. Participants in all of the focus groups were able to describe examples where they felt

family members, friends or acquaintances had been unfairly treated on the basis of their race or ethnicity.

When disability or a long-term health condition was factored in, there was a consensus that those individuals would be at even more of a disadvantage. One participant within the men's mental health group described his experience of working with a voluntary sector organisation:

'No-one could understand why my performance was falling as I had been so articulate and enthusiastic at the job interview. But after four months, my mental health problems surfaced and I was struggling to do my job competently. My manager did not ask me what was wrong and I was given no support or help. I felt that I was being bullied and harassed. I spoke to my trade union who told me that I could either resign or face being sacked. In the end I felt I had no option but to resign as I think I would have been sacked anyway.'

A participant within the Asian focus group for people with disabilities and long-term health conditions also had experience of a family member being sacked from their job due to mental health problems and the subsequent lack of support and awareness shown by his employer.

The nature of employment within the BME business sector was also seen to create additional problems with its large numbers of small to medium scale retail or catering enterprises. It was recognised that the jobs available demanded long hours and physical fitness due to the strenuous nature of many of the tasks and that this, in itself, posed particular difficulties.

'It is very difficult in Chinese catering business. I used to have a worker suffering from diabetes and I could only employ him part time because restaurant work is strenuous. He understood this and knew very well that I could not offer him a full time contract.' (Participant, Chinese focus group for people with disabilities and long-term health conditions)

Similarly:

‘A worker would often feel tired and restless due to his diabetes problem. The manager would often talk to the staff and would hint that he would be better off if he would quit his job and stay at home to rest.’ (Participant, Chinese carers focus group)

‘When people came to me for jobs in my restaurant, if they are still on medical treatment I would ask them to be fully recovered before starting to work. I could not afford to pay for sickness in my business.’ (Participant, Chinese cancer focus group and restaurant owner)

More generally, it was acknowledged that even meeting the minimum legal requirements for an employer was difficult:

‘The employer found it difficult to provide long-term benefits such as in long-term sickness benefit because financially it would be impossible for a takeaway to provide this kind of benefit. It would be easier for the worker to apply for a state benefit. (Participant, Chinese cancer focus group and retired takeaway owner)

‘In the past employers did not pay for the national insurance contributions for the employees and we did not know how it would affect us in applying for state benefits. Only when we became ill then we knew the significance of it.’ (Participant, Chinese cancer focus group and retired restaurant worker)

The need to increase awareness of an employer’s obligations to make a reasonable adjustment under the Disability Discrimination Act was raised in relation to the BME business sector by the BME workers group. Participants stated that they felt employees would be unfairly penalised if they needed to take time off for treatment and recuperation and that this would affect their longer term employability if they were to gain the reputation of being ‘lazy’ and always absent from work. The focus group also felt that the attitude of the employer and any colleagues would be influenced by the extent to which the disability or long-term health condition was visible or not. There was also recognition that employees might be wary of disclosing any health problem that was not immediately ‘visible’ due to the insularity of the BME business sector and concerns around

confidentiality. The fear of dismissal was particularly acute for those with a long-term health condition that had a high degree of stigma attached to it such as HIV/AIDS or a mental health problem.

Recourse to the law was not seen as a viable option for BME individuals who had been discriminated against on the basis of their disability or long-term health condition, particularly if their employer was from the same ethnic group or community, as it could mean making yourself 'vulnerable' in the longer term.

The BME workers group also expressed a concern that disabled employees and those with long-term health conditions would either be forced into 'menial' low paying jobs because they felt this was the only opportunity left open to them or become reliant on the welfare benefit system and the so-called 'benefits trap'.

All of the focus groups expressed the opinion that more needed to be done to enable BME individuals with a disability or long-term health condition to gain, or return to, worthwhile employment. Suggestions included promoting existing 'access to work' schemes amongst BME communities, increasing the amount of career guidance available to adults, providing counselling support to disabled people who had been long-term unemployed, increasing the range and availability of vocational training opportunities and increasing the number of supported employment schemes. The need to ensure cultural competency was a fundamental requirement if such initiatives were to have any measure of success within the communities.

'The Government should provide training to Chinese restaurant workers to move into some other sector if they cannot continue to work in Chinese catering business due to illness.' (Participant, Chinese cancer focus group)

'I have been exploring the opportunity to learn IT skills in Chinese for three years but I still have not found anything. It would be very useful to have IT skills as I could get another job.' (Participant, Chinese cancer focus group)

At a more general level, focus group participants felt that relatively small changes could be implemented by employers that would have a

beneficial effect on the ability of disabled individuals to remain in, or undertake, employment, such as regular rest breaks not just being available but being widely accepted as part of the organisational culture.

Again, there was a consensus amongst the focus groups that if an individual was unable to work due to disability or a long-term health condition, then a sufficient level of income should be provided by the Government to ensure a reasonable standard of living. Aside from the men's mental health group who suggested the introduction of a 'disability tax credit' similar to the pension credit, no other concrete actions were identified by any of the groups in relation to welfare reform.

Developing a social care system fit for the future

All focus groups participants expressed the opinion that they would prefer to continue living in their own homes for as long as possible. This was a view shared by the two carer focus groups in respect of wanting those family members that they were providing informal care for also to be able to continue living in their own home. This was in spite of the recognition that in the current environment of inaccessible and inappropriate services, this would mean very little support being provided to assist them.

'A person was born with a disability and has been looked after by family ever since. The family has many burdens because they have to work and care for this person all the time. They did not get help from social work service and I do not know why. The family does not speak English and find it difficult to get help and support.' (Participant, Chinese cancer focus group)

The reasons given for this overwhelming preference included significant concerns about the availability of culturally appropriate care (see definition of cultural competence) within residential care establishments, the fear of racism, bullying and harassment from staff and other residents, not being able or supported to maintain family, kinship and community networks and a fear of negative judgements being made within the community.

‘It is our culture. We prefer to look after our elderly at home. There is more compassion within your own family as no-one can care for you like your own.’ (Participant, South Asian carers focus group)

The desire for older people to remain in their own homes for as long as their health permits is a view shared by the White majority population. Focus group participants identified feelings of familiarity, security, confidence, freedom and proximity to family as being the key reasons for this overwhelming preference.

‘If there is enough support from the families then the person should not be forced to live in a care home. However, if the person is not able to look after themselves and there are no family members able to help, it would be better for the person to live in a home. If that person continues to struggle by themselves it would not do them any good.’ (Participant, Chinese cancer focus group)

However, it was acknowledged that when an individual’s health had deteriorated to the extent where personal safety became a real concern, that residential care might be the most appropriate option. This was qualified by the need for reassurance that any residential care facility would have to be able to meet the cultural and linguistic needs of a Minority Ethnic individual before any such living arrangement would be considered. The fear of racism was also a factor in dissuading participants that this was not the most appropriate or desirable option open to them.

The appropriateness of some residential care placements was also questioned by the BME workers group who felt that individuals may be placed in a care home on the basis of whether they share a common disability with other residents rather than looking at the age appropriateness of such a placement.

Overall, there was a shared feeling and concern that BME communities have to ‘fit’ into services rather than services being designed around their particular needs. There was a sense that little had changed for people on the ground despite the enactment of recent equalities legislation and protestations of good intent.

There was a universal and strongly-held agreement that disabled people should have the right to choose how and where they live and that adequate resources should be provided by the Government to make this a reality. Underpinning this was the belief that every individual had the unequivocal right to autonomy and self-determination in every aspect of their lives. The only qualification placed on this was the need to ensure that the right to live without interference did not threaten the safety of the individuals themselves or put others at undue risk.

Within this context, independent living was understood to be the right to acquire, or remain within, one's own home with the necessary support to live a full and independent life. This extended to both the practicalities of running a home such as shopping and housework to the ability to actively participate in the recreational and social activities of your choice.

There was a consensus that this had not been achieved for the overwhelming majority of BME individuals with a disability or long-term health condition. Both societal and structural issues were identified as contributing to this.

All of the focus groups, with the exception of the men's mental health group, identified a reliance on informal or unpaid care as a means of hiding the true extent of service deprivation experienced by Minority Ethnic individuals with a disability or long-term health condition. One participant from the South Asian focus group for people with disabilities and long-term health conditions summarised a general experience as:

'...don't feel independent and don't have much control over anything due to health conditions. We always have to depend on somebody to help us with shopping, meeting friends or attending hospital appointments. If they can't do it, we can't.'

Dissatisfaction was also expressed by both of the carer focus groups who felt 'taken for granted' with little or no recognition of their own individual support needs such as short breaks or respite services. This over-reliance on the part of service providers and more widely, Government, was also seen to impact on their own ability to lead

independent lives yet, crucially, any dissatisfaction had to be weighed against a major lack of confidence in current services and whether they or those they were providing care for were willing to accept a 'less than satisfactory' service. For participants in both of the carer focus groups, the answer was a categoric 'no'.

Both the BME workers group and the Learning Disabilities group identified direct payments as a possible solution to both sets of needs. The difficulty in securing direct payments across all eligible groups was acknowledged but it was felt that BME groups suffered an additional disadvantage. The current criteria which precluded the employment of a close family member as a personal assistant or support worker was seen to be a major barrier to achieving independent living for BME individuals with a disability or long-term health condition. Participants in both groups stated that the current regulations did not take into account the relatively small external pool of labour that BME families and individuals could recruit from without allowing recourse to family members or close relatives as part of that 'pool'.

Changing the regulations to reflect the reality of family and community structures would address not only the availability of labour but also concerns about cultural observance and language support needs.

Parent carers within the learning disabilities group also raised an additional concern regarding perceived and actual differences in cultural norms between minority and majority cultures. Participants felt that very often their involvement in their son or daughter's life was misconstrued as 'over-protectiveness' or interference by mainstream organisations especially when there was disagreement between the approach taken by the organisation and the wishes of the parents. This was particularly the case where sons or daughters had reached the age of 18 and were being encouraged to make what their parents perceived to be life-changing decisions such as their preferences for living arrangements. Participants felt that there was very little understanding about what constitutes 'the coming of age' in minority cultures particularly in relation to young women and how this differs from the majority culture.

The parent carers within this group clearly stated that they wanted their sons and daughters to lead independent and self-sufficient lives. However, this was qualified by wanting to have any independent or supported accommodation within reasonable proximity of the family home so familial and community links could be maintained and additional support provided when asked for. Concerns were also raised about their sons or daughters being subjected to both racism and harassment due to their disability within the community where they were going to live.

Additional barriers to independent living that were identified by all focus groups included poor public transport, poor housing and inadequate aids and adaptations. At a service provision level, both the BME workers group and the learning disabilities group felt that more input on life skills and preparing young BME people with disabilities for living independently should be available.

Building stronger, safer communities

All of the focus group participants agreed that they were more likely to, or had had experience of, bullying and harassment on the basis of their ethnicity rather than disability or a long-term health condition, although this did not exclude experiences of ‘double’ victimisation:

‘Being Chinese and suffering from a disability is very difficult. We are discriminated against because of our ethnic background and the disability.’ (Participant, Chinese cancer focus group)

The men’s mental health group felt that ‘visibility’ in terms of ‘difference’ was a contributory factor in whether an individual experienced harassment. Some disabilities or long-term health conditions, such as mental illness, were not immediately apparent and therefore not picked up on.

However, the BME workers group felt that in some instances an individual’s vulnerability increased in relation to the nature of their disability or long-term health condition rather than its ‘visibility’. One worker who supported a Minority Ethnic individual with HIV described how they had been forced to move from their home due to the harassment they had suffered once their health status had become widely known. There was agreement that the stigma and fear

attached to some long-term health conditions were so prevalent that individuals were subjected to persistent and often escalating levels of harassment.

All of the focus groups agreed that the victimisation of disabled people and those with long-term health conditions should be treated as hate crimes. There was also a consensus that legislation should be enacted to provide them with the same protection as those victimised on the basis of their race or ethnicity.

Bullying was of particular concern to the parent carers within the learning disabilities focus group. Whilst they were reasonably confident that their children were not subjected to bullying at school, they were able to recount several instances where their children had been victimised within their local communities by other children and young adults.

The group felt very strongly that the parents of such children should be held accountable for their behaviour. One option suggested was to introduce legislation similar to that used to counteract persistent truancy by levying financial penalties or custodial sentences on the parents or guardians of children who refuse to take responsibility for their behaviour.

Ensuring personal safety was also a major issue for other focus group participants. All of the focus groups, with the exception of the learning disabilities group, stated that they would not use public transport after dark as they felt this was when they were most visible and therefore vulnerable to either verbal or physical attack. The men's mental health group also stated that there were certain areas within the city that they would not venture into again after dark for the same reasons. Whilst most participants felt reasonably safe within their own immediate locality, this was not always the case. One participant described how he had lived in the same area for a number of years but still did not feel safe after dark.

The BME workers group felt that the 'fear' extended both ways and that White communities and individuals were growing increasingly fearful of BME people due to recent developments both within the UK and worldwide.

This was a view shared by the South Asian focus group for people with disabilities and long-term health conditions:

‘The media gives the wrong impression about Ethnic Minorities to the wider community which results in harassment and discrimination.’

Measures identified by the focus groups to both protect and reassure vulnerable individuals included more CCTV cameras and street lighting and increasing police presence on the streets, particularly after dark.

Meeting the future housing challenge in Scotland

Affordable, accessible and quality housing were identified by all focus groups as a fundamental requirement if disabled people and those with long-term health conditions were to achieve independence and autonomy in their lives. All groups shared the perception that current housing stock fell far short of this, with participants identifying gaps specifically in relation to the lack of adapted housing for disabled people, ground floor apartments for people with mobility or ambulatory problems and barrier free or SMART technology housing.

Focus group participants had also experienced problems and delays in being assessed for, and acquiring, aids and adaptations. These problems were compounded for those in private rented accommodation where the permission of the owner had to be sought before any major adaptations could be made. As this was not always forthcoming, some participants continued to live in housing that was totally unsuitable to their needs and, in some cases, had contributed to their health condition worsening. Overcrowding was also identified as a cause for concern by participants in the South Asian and Chinese carers focus group.

All focus group participants identified financial constraints as a limiting factor in their ability to exercise choice. This was felt particularly acutely by those in low paid employment or who were reliant on welfare benefits, to the extent that they felt completely disempowered:

‘There is nothing I can do. It all depends on welfare benefits and the social security system. I would like to move but I cannot afford it.’
(Participant, Chinese cancer focus group)

It was also felt that the external built environment needed to be more accessible with the lack of parking spaces for disabled people and the height of pavements relative to roadsides being singled out as a cause for concern. One participant stated that both of these problems presented real difficulties in enabling him to get into his home.

Whilst there was a strongly-held consensus that disabled people should be able to exercise choice in their living arrangements, there were mixed opinions about the desirability of housing developments built solely for people with disabilities. One parent carer within the learning disabilities group described such developments as ‘ghettos’ and felt it did nothing to increase the integration of, and exposure to, disabled people within the wider community.

‘We must not hide our children away. We are guilty of keeping them within the home. We should expose our communities to disability. It is everybody’s responsibility not just ours.’ (Participant, learning disabilities focus group)

Other participants felt that such developments offered a degree of ‘security’ and provided a focus for the long-term care of their sons or daughters. More concerns were expressed that when ‘race’ was factored in to reflect the wishes of some of the parent carers that their sons or daughters live either in small-scale ‘group homes’ or flats in a small development with other individuals from the same ethnic group, they would become a target for racism and harassment.

All focus groups with the exception of the men’s mental health group and the BME workers group reiterated their preference for housing to be provided near other family members. Proximity to local amenities was also a key consideration in enabling people with disabilities and long-term health conditions to be more independent. Participants within both the Chinese and South Asian focus groups for people with disabilities and long-term health conditions stated that they did not wish to rely on their families or carers to take their places as this reduced their feeling of independence. The need for practical support

to enable them to remain in their own homes for as long as possible was also key to retaining their independence.

Retaining their independence was the reason participants within both of the Chinese focus groups cited for their decision to move into a sheltered housing complex for Chinese older people. However, recent changes to the service, which meant that the onsite warden was no longer available, had left many residents feeling more vulnerable and concerned that their independence would suffer as a result of this.

Looking to the future was an issue that was raised by participants within the South Asian carers focus group. There was an awareness within this group that the social structure of their community was changing due to economic and social pressures and that housing provision would need to reflect this. One participant felt that younger people now had different expectations from their generation and that this would mean more elderly parents living on their own as their sons and daughters moved away to pursue education or employment.

Bringing an end to child poverty

As the majority of focus group participants were either adults, or caring for someone, with a disability or long-term health condition, it was difficult for them to comment in any great depth about this priority. However, all focus groups agreed that no child or young person should have to live in poverty or have their life chances curtailed due to disability or a long-term health condition.

It was recognised that having a disability, ill health or caring responsibilities contributed significantly to low incomes for individuals and families. Both of the carer focus groups spoke specifically of the ‘cost’ of caring in terms of additional heating, laundry and food bills with little financial help available. Poverty was also seen to extend beyond material well-being with all of the focus groups, with the exception of the men’s mental health group, identifying ‘social’ poverty as a direct outcome of having little disposable income. The inability to socialise with one’s peers affected adults, children and young people alike and was seen to isolate them

even further. There was a strong acknowledgement, however, that this would disproportionately impact on children, as socialising with your own age group was one of the ways in which social skills were learnt.

The parent carers of children and young people with learning disabilities described how important it was to them that their child enjoyed the same opportunities and upbringing as their brothers or sisters. Yet all of the parents described ‘battles’ where they had had to fight to achieve this:

‘You will move heaven and earth to help your child achieve what is possible.’

‘I had to teach my son the Koran. It took six months for the Mosque to get someone to teach him.’

Another parent spoke about the ‘dreams’ her son had for his future:

‘All children have dreams. He dreams of being a fireman just like any other little boy.’

She described the dilemma she faced in both encouraging him to reach his potential but tempering it at the same time with reality.

Securing adequate learning support for children and young people with learning disabilities was also an issue identified by participants within the BME workers group. It was felt that this would not only affect their immediate educational attainment but that it would disadvantage them in the longer term also and lead to a ‘lifelong’ reliance on welfare benefits. These same workers also felt that the local authority education department did not listen to parental views about their preferences for their child’s education, citing examples of the ‘pressure’ exerted on parents to send their children to ‘special’ schools. It was felt very strongly that this was driven by ‘protectionism’ and the view that ‘special’ schools were the best place for children with ‘special needs’. This view ran contrary to what parents wanted and they felt it only served to isolate their children even more from wider society.

Whilst it was difficult for the focus groups to suggest ways in which child poverty might be addressed, a number of suggestions were made about tackling poverty amongst people with disabilities, long-term health conditions and carers generally. These included more information for parents on the opportunities available to children and young people with disabilities to enable informed decisions and choices to be made, better careers guidance for children and young people with disabilities, more support for disabled people to get into work, greater availability of specialist equipment to support disabled people in the workplace, grants to enable small employers to provide specialist equipment and therefore recruit from a much wider pool of potential employees, more flexible working patterns, the introduction of ‘carer friendly’ policies in the workplace and support to help carers get back into work once their caring role had ceased.

Increasing life chances through learning and skills

Two of the focus groups, the South Asian carers group and the group for people with disabilities and long-term health conditions, felt unable to comment on this priority as they felt that they were ‘too old’ to consider gaining new vocational or personal skills.

The remaining groups all identified language barriers and the lack of suitable ICT training provision as the major barriers to gaining new vocational skills and therefore employment;

‘In order to increase our vocational and personal skills, government should help us to improve our English skills first. I am literate in Chinese but I could not find any Chinese IT tutor and all the computers use English package and not Chinese’ (Participant, Chinese focus group for people with disabilities and long-term health conditions)

‘We have to overcome language barrier first before we can have further vocational training.’ (Participant, Chinese cancer focus group)

‘Chinese restaurant workers have no other skills at all and we would like to have training to improve our skills so that we can work in other areas.’ (Participant, Chinese cancer focus group)

The Chinese carers group suggested that more flexible educational opportunities should be available to adults with a disability or long-term health condition. The example of home tutoring was suggested as it was felt that much provision was currently inaccessible to individuals with language and other support needs. Participants also suggested that government grants should be provided to enable individuals to purchase computers for use at home as part of any educational or vocational package.

The men's mental health group also wanted to see the emphasis removed from paid employment and more of a recognition of the benefits of volunteering for disabled people and those with a long-term health condition. It was felt that volunteering had a valuable role to play not only in enabling individuals to gain new, or enhance existing, skills but that it provided wider social benefits such as building confidence, increasing social contact and providing a 'stepping stone' to other opportunities. Group participants also suggested that counselling and other forms of support should be available to the long-term unemployed as part of any strategy to get individuals into employment.

The need for additional support was a view echoed by participants within the Chinese cancer focus group:

'I cannot work in Chinese catering business any more after recovering from my cancer illness. I went for interviews as a cleaner and as a post office worker in sorting the mail. I was not successful in the interview and was told that my English was not good enough to communicate with other workers which would make me unsuitable for the job. I felt they were only using this as an excuse to put me off, my English is not very good but I am managing ok. What is the guideline of 'communicating with other workers?' I have been studying English to improve my language skills, it would be nice if the job centre can arrange work placement for me. I would like to get a job but it is not easy at all.'

This example also illustrated the view of some participants with the Chinese cancer focus group that individuals were discriminated against on the basis of race as well as ability.

The BME workers group acknowledged that providing additional support to improve the vocational and personal skills of disabled people would have significant resource implications but stressed that a long-term view had to be taken. It was felt very strongly that current provision was based on ‘short-termism’ with no recognition that increasing the vocational skills of disabled people would have considerable economic and social advantages.

Tackling health inequalities

For the majority of participants, the inability to communicate effectively with health professionals was cited as a major barrier in accessing a range of healthcare services. Participants identified two main issues: a lack of confidence in interacting and challenging health professionals, particularly general practitioners, and a lack of proficiency in speaking English. Participants within the BME workers group described the attitude of some of their users as feeling ‘they were too old and did not want to ask too many questions as the doctor knew best’.

For some participants, these difficulties were compounded by an unsympathetic response or, in some cases, behaviour perceived as racist, by their GPs:

‘Some doctors felt that using an interpreter or asking someone to help out on the phone was bothering him. It made me feel uncomfortable and unwelcome.’ (Participant, Chinese cancer focus group)

‘I found it difficult to communicate with the doctor because of language barrier. Some doctors made me feel uncomfortable because I could not communicate in English. It took a long time to arrange an interpreter and I could not be seen on the first available appointment. I had to wait for another two or three days in order to arrange an interpreter.’ (Participant, Chinese focus group for people with disabilities and long-term health conditions)

‘We felt we were racially discriminated by a GP in the practice. Every time I accompanied my husband for an appointment we were kept waiting in the practice and were seen at the last. After his retirement we were seen according to our appointment time. We strongly felt he did this on purpose.’ (Participant, Chinese cancer focus group)

Emergency appointments and attending hospital accident and emergency departments were identified as being particularly problematic due to the delays in arranging language support.

A more generalised difficulty in accessing information on, or the value of, health services was also identified as a barrier in seeking advice. The example given concerned the prevalence of misconceptions about the need for preventative measures such as cervical screening or smear tests within Minority Ethnic communities. Workers within the BME group cited examples of parents not taking young female family members to appointments because they understood such tests to be necessary only if an individual was sexually active or married.

The learning disabilities group suggested that health professionals undertake specific training, both as part of the curriculum and through post-qualifying professional development to remedy this. There was also a general consensus that GPs needed to allocate more consultation time to build relationships and foster better communication with Minority Ethnic patients.

‘GPs should spend more time to understand their patient’s needs and should take a pro-active role to identify their needs and point out the right direction for their patients.’ (Participant, Chinese carers focus group)

One participant with mental health problems within the South Asian focus group felt it would be useful if the practice could remind patients of appointments, particularly if there is a history of missed appointments as it may be down to their health condition, as in his case, rather than assuming individuals could ‘not be bothered’ to attend.

Participants also cited late presentation to health services and a subsequent delay in treatment as repercussions from what they perceived to be, or experienced as, a less than satisfactory health service. The BME workers group raised the issue of poorer medical outcomes and possible long-term health problems as a consequence of this.

The prevalence of certain illnesses in Minority Ethnic communities was raised by the BME workers group yet there was a consensus within

the group that GPs had done little to familiarise themselves with causation and treatment. Instead they felt that GPs tended to pathologise BME communities, blaming lifestyle factors and a lack of personal responsibility as a major contributory factor for increased levels of poorer health.

Difficulties also arose in terms of the willingness of GPs to share information regarding the condition of individual patients with their spouse, carer or family. The BME workers group felt that there needed to be more recognition that disability or long-term health conditions may also be a family issue and that there was a need to balance the rights of the individual to privacy with the family's need for information and support. Too often it was assumed that no information should be shared without discussing the extent of family involvement with the individual patient. This was a view echoed by a participant within the South Asian carers focus group and the learning disabilities group:

'The GP did not tell me about my husband's illness or treatment because I was not the patient but I am the one who cares for him all the time.' (Participant, South Asian carers focus group)

'GPs should speak to the parents as they know their child and they know what is wrong.' (Participant, learning disabilities focus group)

Utilising informal carers to improve the health of family members with a disability or long-term health condition through health promotion activities was suggested by the BME workers group as one way in which to promote more active involvement in the healthcare of individual patients. However, it was recognised that this could result in further disempowering disabled people.

Whilst the learning disabilities group felt that having support to encourage a healthy lifestyle for their child would be beneficial, there were societal barriers that limited their ability to participate in a wide range of activities. Parent carers described the difficulties they had encountered in trying to secure places for their child to participate in mainstream youth clubs, sports activities and after school provision as the perception was that any aspect of 'challenging behaviour' was too problematic and time-consuming to address. Parents were also

unwilling to let their child play outdoors as they were subjected to racist bullying by other children in the neighbourhood. The availability of 'specialist' provision for children with learning disabilities such as Scotland Yard was limited and subject to long waiting lists. This led to concerns that their children were not only missing out on opportunities to socialise but that it would cause longer term problems in terms of childhood and adult obesity.

The BME workers group identified the potential of independent health advocates as a means of redressing the imbalance in what the health service strived to deliver and what was actually experienced on the ground. One area that was singled out for action was supporting individual patients to exercise choice in their healthcare, particularly in relation to supplementing prescribed medical regimes with traditional and complementary forms of treatment which are particularly valued in Minority Ethnic communities. Participants also felt there was a tendency for GPs to view all health problems as arising from an individual's disability rather than seeing it as a separate health issue.

Promoting a culture of equality and human rights

All of the focus groups found it difficult to comment in any depth on this priority. Only two of the focus groups, the men's mental health group and the BME workers group, had heard of one or more of the existing Commissions but had little knowledge or understanding about their role. None of the groups were aware of the new single equality body, the Commission for Equality and Human Rights (CEHR) and its remit.

Following a brief explanation on the new arrangements, the men's mental health group commented that it was important that the CEHR recognised that people did not fit 'into boxes'. The new organisation would need to ensure that one equality strand did not take precedence over another and that arrangements were in place for individuals affected by two or more of the equality strands such as BME disabled people.

At a more general level, five of the focus groups commented on the role of BME organisations in informing individuals and communities

of their rights and entitlements and that more could be done to train BME workers so they were able to assist more effectively. Participants also found that focus groups and discussions, such as the one they were currently engaged in, useful for raising their own awareness.

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Advocacy and carer support is available to residents in Edinburgh and the Lothians.

Our respite service is available within Edinburgh.

Our resource library and training service is available to anyone in Scotland.

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