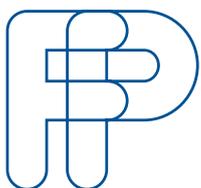


# Learning Difficulties and Ethnicity:

## Updating a Framework for Action

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foundation for  
people with  
learning disabilities



Department  
of Health

# Contents

Preface	3
Acknowledgements	4
Glossary	5
Introduction	7
Health	12
Employment	16
Housing	20
Being an active citizen	22
Appendix 1 - Useful references and websites	27
Appendix 2 - Giving us a Voice project	29
Appendix 3 - See 'Local Checklist For Action'	30

## Preface

**The Foundation for People with Learning Disabilities was commissioned by the Department of Health and the Office of the National Learning Disability Director, Anne Williams and Scott Watkins (co-Directors until 31st March 2011) to update the Framework for Action which was first published in 2004. This update highlights the continuing relevance of its message as well as those raised by Valuing People Now.**

Although the Office of The National Director for Learning Disabilities is no longer in operation the Framework for Action is still seen as a necessary tool in ensuring that people with learning disabilities and their families from different communities are engaged and supported by Health and Social Care.

People with learning difficulties and their families from BME communities have been highlighted as a priority group by Valuing People since 2001 and remain a priority for better access to health and social care support.

Although health and social care organisations have a statutory duty to ensure that there is equality of access and the uptake of services, sadly research suggests that very few successfully promote diversity.

In order to improve the access and inclusion of minority and seldom heard communities we need to know the local population and the best ways of engaging and supporting all communities. We also need to understand the needs and anxieties of people from BME communities as well as the gaps in current service provision.

It is hoped that this updated “Framework for Action” will provide some important ideas as to how this can be improved across both rural areas, (where there is still a need to identify the needs of newly arrived) and largely unknown communities and inner city areas where there may be higher concentrations of diverse communities and therefore some local expertise.

People with learning difficulties and their family carers from BME communities are everybody’s business and mainstream services, in partnership with local people and with the voluntary sector must work to ensure they are supported to be a part of their community, stay healthy, keep safe, choose where they live and access real employment opportunities.

# Acknowledgements

The updated “Framework for Action” was prepared by Richard Poxton from the Foundation for People with Learning Disabilities with the aid of a steering group whose input and assistance we are grateful for.

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We would like to thank the following organisations who kindly offered advice and feedback in developing the updated “Framework for Action”:

- Afiya Trust
- Crossroads Care
- Home Farm Trust
- Mencap
- The Princess Royal Trust for Carers

We would also like to thank the following staff members from MHF for their assistance in producing and editing this report and the accessible summary:

- **Christine Burke**, Senior Development Manager
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# Glossary

## **Culture**

The term culture has been used to mean a person's life experiences drawn from their family, their community, their disability, their sexuality, their gender and their personal history. Thus everybody has a culture that is unique to them.

## **Cultural competence**

Cultural competence occurs when people understand culture, are aware of its impact and act to ensure that the values of all people are respected.

## **Different needs**

The different requirements that people with protected characteristics may have which either must or should be met to provide equality, including equality of opportunity and access.

## **Discrimination**

Discrimination occurs when a person is treated differently from others because of their membership of a particular group, e.g. ethnicity, class, age, sexuality and disability.

## **Ethnicity**

A group of people who share certain background characteristics e.g. language, geographical origin, customs and history, which provide the group with a distinct identity as seen by themselves and others.

## **Harassment**

Unwanted behaviour that has the purpose or effect of violating a person's dignity or creates a degrading, humiliating, hostile, intimidating or offensive environment.

## **Indirect discrimination**

The use of an apparently neutral practice, provision or criterion which puts people with a particular protected characteristic at a disadvantage compared with others who do not share that characteristic, and applying the practice, provision or criterion cannot be objectively justified.

## **Learning Difficulty**

There are many words which people use to talk about learning difficulties or learning disabilities.

In this report we use the term 'Learning Difficulty'. This means people with specific learning difficulties (such as dyslexia) and people with learning disabilities (people with reduced ability to understand new or complex information, to learn new skills and a reduced ability to cope independently which starts before adulthood with lasting effects on development) as defined in Valuing People Now (2001).

## **Protected characteristic**

Everyone in Britain is protected by the Equality Act, 2010. The specified "protected characteristics" under the Act are (in alphabetical order): age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, sexual orientation.

**Public sector equality duty**

The duty on a public authority when carrying out its functions to have due regard to the need to eliminate unlawful discrimination and harassment, foster good relations and advance equality of opportunity.

**Race**

The protected characteristic of race: a group of people defined by their race, colour, nationality (including citizenship) ethnic or national origins.

**Racism**

The historical and institutional process which leads to minority ethnic people being treated less fairly because of their racial identity. This is attributed to those who have the power to turn prejudicial beliefs into acts of discrimination or unfair treatment at an individual or institutional level.

**Reasonable adjustments**

Where a disabled person is at a substantial disadvantage in comparison with people who are not disabled, there is a duty to take reasonable steps to remove that disadvantage by (i) changing provisions, criteria or practices, (ii) altering, removing or providing a reasonable alternative means of avoiding physical features and (iii) providing auxiliary aids.

## Introduction

**Learning Difficulties and Ethnicity – A Framework for Action was published in 2004. This update draws attention to the continuing relevance of its key messages together with information on the priority areas from Valuing People Now. There is a simplified action plan for action that should be taken locally and how to track progress.**

The update will be of interest to a wide range of local people and agencies involved in identifying and addressing the needs of people with learning difficulties from BME communities. However, it is of particular relevance for commissioners and providers in local authorities and other statutory agencies, as well as local providers, who all have duties to take certain actions. Learning Disability Partnership Boards, Local Involvement Networks and the new Health and Wellbeing Boards should also use the Framework to ensure progress is made locally and to hold the statutory bodies to account.

It seeks to influence local Joint Strategic Needs Assessments (JSNAs) and Commissioning Strategies; it refers particularly to the priorities stated in the national Valuing People Now programme: being in good health, having somewhere to live, being able to get a job, and being an active citizen.

It is also very much driven by the principles contained in the Vision for Adult Social Care, 2010: prevention, personalisation, partnership, plurality, protection, productivity and people. The accompanying 'Department of Health guidance Practical approaches to co-production, 2010' identified people from BME communities as one of the groups whose access to services would benefit from a different way of working that involved much greater emphasis on working with local communities.

Legislation defines rights and duties: it will be important to ensure that the Equality Act 2010 is implemented in respect of people with learning difficulties from BME communities, especially at a time when some people may feel less secure in their day to day lives.

Improvements have been made which benefit BME communities since Valuing People was introduced. But evidence and reports suggest that there is still much to be done and that this includes addressing remaining issues of discrimination and racism. People from newly arrived communities do not always feel welcomed. Some people with learning difficulties may be neglected within their own communities as issues of shame and stigma persist.

It is not always possible or appropriate to rely on statutory agencies to provide all the care and support that is needed. There are already examples of vibrant local BME community organisations working with and for people with learning difficulties: recently introduced ways of reciprocal working such as Time banking are a natural extension.

The Giving us a Voice project (GUAV) in 2010/11 enabled people with a learning difficulty, their families and carers from BME communities to inform local policy makers about what they need and expect from services. The project has produced a Charter for Inclusion that shows clearly what people and their families need to live happier and safer lives. Local statutory agencies, providers and families are encouraged to sign up to the Charter.

## What Valuing People Now said

Valuing People Now, 2009 said:

People with learning difficulties from black and minority ethnic groups and newly arrived communities and their families often face what is called “double discrimination”. They experience insufficient and inappropriate services. This may be caused by:

- Policy and services which are not always culturally sensitive
- Wrong assumptions about what certain ethnic groups value
- Language barriers
- Discrimination

Yet evidence shows that increasing numbers of children and young people from black and minority ethnic communities are being identified as having special educational needs and more profound disabilities.

The Race Relations (Amendment) Act (2000) requires all services to be compliant and public authorities must monitor their work for any adverse effect on race equality. This means that all actions and initiatives described in this strategy should be assessed for their impact on minority ethnic communities. However, 48% of partnership boards who responded to a survey in 2006/07 said that no race equality impact assessment had been undertaken – either for the board itself or as part of a wider equalities impact assessment. And a recent review of partnership boards indicated that only 17% of partnership boards involved families from black and minority ethnic communities.

In some rural areas there are small<sup>1</sup> numbers of people from black and minority ethnic groups and newly arrived communities and they can be less visible. This can mean that services do not meet people’s needs. Guidance on working with people from minority ethnic groups in rural areas can help local service planners and developers address this.

While the legislative framework to support equality of access to all services is in place, there is clearly much to be done for black and minority ethnic groups and newly arrived communities to be fully included. The National Directors, working with the Valuing People regional team and Deputy Regional Directors for Social Care and Partnerships led a programme of work:

- To raise the profile of this issue and ensure it is taken seriously by all agencies supporting people with learning difficulties and their families so that locally they will design and commission services to ensure genuine inclusion; and
- Including working with the National Advisory Group for People with Learning Disabilities and Ethnicity (NAGLDE) to develop and disseminate good practice to inform policy, in line with NAGLDE’s recommendations

## **The numbers of people with learning disabilities from black and minority ethnic communities**

Emerson et al (Improving Health and Lives: the Learning Disability Observatory) have estimated that in England in 2010 there were 900,000 adults and 288,000 children and young people under 18 years of age. These numbers are higher than those shown in earlier research for the Department of Health which estimated that in 2004 there were 828,000 adults with a learning disability in England. Although the numbers have to be treated carefully it is also estimated that in 2010 there were 191,000 people with learning disabilities known to learning disability services compared to 177,000 in 2004.

It is not known how many of the above numbers relate to people from BME communities. Nor is it easy to compare this data with overall population data that do record ethnic origin. But as a rough comparison the numbers of BME people in England according to Census and other official data rose from 4.4 million in 2001 to 6 million in 2007. So the basic expectation would be that numbers with a learning difficulty rose too.

It should also be noted that probably 20%-25% of young people currently in transition from children's to adult services are from BME communities: this means that there will be an increased proportion of people from BME communities as part of overall numbers of people with learning difficulties. Of this increase it is known that those with more profound and multiple difficulties are increasing more quickly.

In addition recent years have seen an important increase in the numbers of people from so called newly arrived communities – people who have not previously settled in the UK and who may have cultural and other needs that are unknown to statutory agencies. There is an increasing number of local areas with a very wide range of different BME groups, presenting a great challenge in engaging with local people and communities. Local work is beginning to show that there are people with learning difficulties in these newly arrived communities for whom local agencies should be in a position to offer support. Many urban areas will have important numbers of BME communities including newly arrived communities but this is also an issue for all other areas including rural ones where the smaller numbers involved may lead to particular problems associated with isolation.

### **Key points from the 2004 framework for action**

This update does not seek to repeat the more comprehensive 2004 Framework but it is worth noting some of the key general points.

All the policies and guidance produced as part of Valuing People and other Government programmes apply to all ethnic groups – additional barriers that are still faced by BME communities mean that specific, focused and determined action is required.

It is important not to make assumptions about both BME individuals and communities – the essence of a personalised approach is to get to know

the individual and their context and respond to that particular set of needs and aspirations.

In order to understand and appreciate different cultural and religious aspects it is important to engage effectively with individuals, their families and their advocates – including local community organisations.

Local services and other responses by statutory agencies and those working on their behalf must be accessible by people from all communities. Sometimes this may mean services specific to a particular ethnic or cultural group: this issue must be addressed in the light of local needs and preferences.

### **Local action plan**

It is vital that each local area led by the Local Authority is knowledgeable about how many people with learning difficulties from which BME communities are likely to be living there, for whom the statutory agencies therefore have some important responsibilities and duties to take action. A key starting point is to be aware of the basic numbers: population, people with learning difficulties in touch with “services”, BME population and people with learning difficulties from BME communities in touch with “services”.

A recent report (Culturally Responsive JSNAs, 2010)<sup>2</sup> commissioned by the Department of Health recommended that JSNAs should include improvements in culturally responsive practice (such as this action plan) within the overall context of broader work such as the local authority equality framework and equality impact assessment process.

A simplified version of the earlier audit tool is provided to help Local Authorities take the lead in this action, consult with local people and work with local community and other organisations, all for inclusion in the JSNA process.

### **Legislation**

The law is clear and forthright on local statutory responsibilities in respect of race and disability – people with learning difficulties from BME communities are clearly an important part of these responsibilities that fall to local statutory agencies.

The Equality Act 2010 came into force on 6 April 2011<sup>3</sup>. It simplifies and puts together previous laws to protect people from discrimination on grounds that include race, disability and gender.

<sup>2</sup> Available at the Race for Health website, see appendix 1.

<sup>3</sup> [www.equalities.gov.uk/equality\\_act\\_2010.aspx](http://www.equalities.gov.uk/equality_act_2010.aspx)

The “protected groups” to whom the Act makes particular reference include race and disability.

The Act places a general duty on public authorities:

- To eliminate unlawful discrimination, harassment and victimisation, and other prohibited conduct
- To advance equality of opportunities
- To foster good relations

The Act states that this should involve having due regard to the need to removing or minimising disadvantages suffered, taking steps to meet the needs where these are different, and encouraging participation in public life or in other activities. There are also specific duties, including:

- To publish information to demonstrate compliance with the general equality duty
- To prepare and publish equality objectives
- To provide details of engagement undertaken in pursuance of these duties

The Act makes it clearer that it is outside the law to treat somebody worse because they are a carer, including of course BME carers and those with learning difficulties themselves.

It is for public authorities to decide how they will comply with the Act, beyond preparing and publishing equality objectives and publishing information. The duties also apply to services that are contracted out.

Guidance produced by the government indicates that the published information should include performance information especially around: outcomes, access to services, satisfaction with services, and complaints.

This should include evidence of the effect of their policies and practices.

The guidance also expands on the general duty “to have due regard” stating that this calls for an evidence base to local decision making that may be obtained through local engagement with the “protected groups”. Public bodies are required to make reasonable adjustments for people with disabilities.

Public bodies can be brought to account before the courts if they do not comply with equality legislation. They are required under existing equality law to undertake assessments of how their policies will impact on disabled people, ethnic minorities and men and women, to ensure that existing or new policies do not unlawfully discriminate and also to look at how due regard might be had to the need promote equality of opportunity.

## Health

The 2004 Framework emphasised the importance of GPs and other Primary Care workers for ensuring the good health of people with learning difficulties from BME communities. Primary Care tended to have more contact with BME families than other professional groups doubtless because of its relatively easy accessibility. It is therefore vital that local health care workers are well informed about specific as well as general issues relating to the health of local BME communities. In particular, workers involved in Health Action Plans should be able to communicate effectively and should be knowledgeable about the incidence of health conditions including those that are culturally significant.

### Valuing People Now

Improving the health and health care of people with learning difficulties in general was one of the main priorities identified. Mainstream health services were all seen as needing to make improvements – including public health, primary care, acute health, community health and mental health provision. Many people were finding it hard to access services or were receiving poor treatment.

### Six lives progress report, Department of Health 2010

This report was concerned with making improvements in the health care of people with learning difficulties generally. However, the issues identified as being particularly important for making improvements may be seen to apply particularly well to people from BME communities where access to services is likely to be even more problematic:

- Good leadership is needed at all levels of decision making, from national and local strategic decisions to those taken by practitioners on day to day matters, so as to bring about change that is real and sustainable
- Involvement of people with learning difficulties and their families is very important: more effective engagement is required, especially by mainstream organisations e.g. NHS Foundation Trusts
- Annual health checks can be very effective in identifying and monitoring issues: more effort is required to promote take up and to ensure connection to health action planning
- Improving acute health care is making slow progress – where change is taking place acute liaison staff seem to be making a difference
- Better data and information are still required in respect of meeting the health needs of people with learning difficulties

- These data will enable reasonable adjustments to be made (as required by law) in all health settings – most progress to date has been in Primary Care
- Training is required for many health staff in mainstream settings especially in the basic understanding of learning difficulties
- Health commissioners should make specific reference to the health needs of people with learning difficulties when vetting contracts so that providers are aware of and able to meet their additional needs; health inequalities work should make particular reference; and joint working between the NHS and local authorities is essential for meeting the needs of people with learning difficulties

Issues continuing to cause concern that should also be noted were:

- More attention should be given to safeguarding and the development of best interest decision making
- Complaints procedures are often difficult to access
- Advocacy remains very important where capacity is an issue but also generally in order to secure good health outcomes

These points concern good practice in general affecting people with learning difficulties but it is considered that they are of particular importance to people from BME communities. They are often even more removed from the mainstream of general health care and may be ignorant of common illnesses such as cancer, and how to combat them. The major health charities may have a role to play in engaging people with learning difficulties. The website of Improving Health and Lives: the Learning Disability Observatory is a good source of information. It remains important that GPs are aware of the particular health needs of the different BME communities for whom they are responsible, including the importance of making relevant information easily available.

### **Race for Health – driving forward action on race equality and health**

Race for Health is a Department of Health funded programme that works with NHS Trusts on improvements in health for people from black and minority ethnic background. The programme reports that there is now ample evidence that people from BME communities have a poorer experience of health and social care as shown by health outcomes. The NHS and local authorities have duties in law to promote race equality and to tackle discrimination including discriminatory practices.

The programme has identified two key ways forward from its detailed work:

#### **1. Understand more about the people being served:**

- Listen and learn to trust

- Use local information and intelligence including from local organisations
  - Ensure accurate recording of ethnic origin as an absolute basic for commissioning of services
  - Engage with local BME communities, including to learn about different attitudes to health care (to which can be added attitudes about learning difficulty)
2. Focus upon obtaining better outcomes for people from BME communities, through:
- Robust and systematic equality impact assessments
  - Evaluation of services to ensure their relevance
  - Gathering patient views and experiences
  - Good leadership
  - Engaging with local communities

Towards Race Equality in Health - A Guide to Policy and Good Practice for Commissioning Services is a practical guide from Race for Health to incorporating race equality in PCT commissioning. It provides specific examples on how to close the health inequalities gap for people from BME communities including how to involve local communities.

Race Equality Foundation Better Health Briefing paper 20: Improving health and social care support for carers from BME communities, September 2010.

The main points identified in the Briefing also apply to people with learning difficulties from BME communities:

- The experience of BME carers (some of whom themselves have a learning difficulty) tends to be made worse by the low priority given by agencies to race equality
- Institutional barriers and culturally inappropriate support and services are often overlooked locally as reasons for the low take up of mainstream services
- There is a key role for local BME voluntary and community organisations to play in addressing needs but often these organisations are marginalised, poorly funded and not brought into local strategic decision making
- BME carers are generally not involved in local policy development work
- Diversity between and within local BME communities is often overlooked by local decision makers

## **Giving Us A Voice**

Giving us a Voice held a number of regional meetings to inform local policy makers about what people with learning difficulties, their families and carers need and expect from services. It was a systematic way of challenging local statutory bodies and providers to sign up to a Charter for Inclusion.

Included in this and the following sections are some of the main points rising from those regional meetings.

What people at the GUAV meetings said needed further action to improve the health of people with learning difficulties from BME communities:

- Improve cultural competence and awareness in hospitals and other health settings
- Steps should be taken to get over continuing language barriers including staff having better listening skills
- Mainstream health staff should know more about learning difficulties
- More attention should be given to making sure preventive services are relevant for people from BME communities
- Local agencies should make sure they know about the specific health needs of the BME communities in their area
- GPs should record ethnicity information as a matter of course
- Primary care workers should make sure health checks are suitable for individuals from BME communities
- Reasonable adjustments should be made, e.g. appointment times, interpreting services
- Local NHS Trusts and Primary Care should make more effort to build trust with different BME communities
- Local NHS Trusts and Primary Care should increase awareness and use of the personal health and hospital passport schemes

## Employment

The 2004 Framework indicated that in general people from most BME communities have higher rates of unemployment than white people and are more likely to be in low paid jobs. People with learning difficulties generally are significantly less likely to be in paid work. A person with a learning difficulty from a BME community is therefore likely to face double discrimination in finding a job.

The key issues identified were:

- Overcoming low expectations of employment
- Increasing awareness of possible work opportunities
- Implementing local strategies that work across agencies and with job seeking providers
- Working more effectively with local BME communities to promote work opportunities

### Valuing People Now

Key points made affecting people with learning difficulties generally were that it was still crucial to overcome fundamental misconceptions about individuals' capacity for work in paid jobs, including those with more complex needs. Schools and colleges as well as Social Care should address this issue through an individualised person centred approach with ongoing support to make sure the job is sustained.

### Valuing Employment Now

This policy was adopted in 2009 on the basis of some stark figures:

- 65% of people with learning difficulties would like a paid job;
- Only 10% of people with learning difficulties who receive adult social services have a paid job (the figure for people with physical disabilities is 48%);
- The aim is to have as many people with a learning difficulty as possible working 16 hours a week in paid work – when they will be financially better off and achieving greater social inclusion

For people with learning difficulties from BME and newly arrived groups, language barriers and culturally insensitive practices can mean “double discrimination” when seeking jobs: for example, there may be times when gender specific work opportunities are appropriate.

It is difficult for some communities to accept the idea of paid work for people with learning difficulties because of how learning difficulty is understood and perceived in certain cultures. This sort of stigmatisation can lead to

people being hidden away from the rest of society and the development of a worklessness outlook that requires addressing at an early age on a holistic basis: it is important to raise the aspirations of young people about the “world of work”.

Job Centre Plus and other job seeker advisers have to become properly aware of the challenges facing people with learning difficulties from BME communities, as well as the impact of the equalities legislation.

Valuing Employment Now calls for key changes all of which are especially relevant for people from BME communities:

- More effort to show that people with learning difficulties can hold down paid jobs
- Statutory, voluntary and private sector agencies should work together to develop clear employment pathways based upon individual (person centred) approaches
- Schools, colleges and adult learning should improve their job preparation content
- More use should be made of Personal Budgets
- High quality job coaching should be increased
- Self employment should be promoted
- Employers should be persuaded of the business case of employing people with learning difficulties
- Local transport to work arrangements should be improved
- The barriers to work for people in particular types of residence should be removed
- Particular attention should be paid to the support for people who are presently the most excluded from jobs
- There should be more emphasis on gathering better data and performance management for increasing employment opportunities
- People with learning difficulties and their families should be leading the way

In addition specific action was called for to collect data on the numbers of people in the most excluded groups (including people from BME communities); how many have paid jobs and the type of jobs. There should be local plans to develop job seeking expertise including local supported employment organisations and developing links with effective existing organisations.

## **An action plan for local employment**

People with learning difficulties from BME communities require focused practical support to get and then keep jobs but this may be tackled effectively as part of a local action plan – the key points below are taken from Northamptonshire's local action plan:

- Raise work awareness amongst both young people and adults with learning difficulties
- Offer support with job seeking including applications
- Work with employers to help create more accessible jobs
- Develop and promote local statutory agencies as good practice employers
- Set up a group (perhaps a sub group of the Partnership Board) to monitor
- Provide information on the different types of work available
- Arrange learning difficulty awareness training for employment finding and support staff
- Provide travel awareness training and support

## **Getting A Life: working across different agencies**

Getting A Life is a project working across several Government Departments for young people with severe learning difficulties. It is about raising aspirations, making changes to the system and creating a clear path to paid employment. It is doing this through finding and sharing new ways of working at different sites across the country so that young people with learning difficulties can leave school, get paid employment and have equal life opportunities. The project is exploring how to use person centred planning to bring together the assessment and funding streams from four different national and local policy areas. It will inform government about what local areas can achieve and what needs to change at a regional, national and/or policy level.

Advice on employment is particularly important for young people during their transition from children's services. ARC is producing a guide on supporting disabled young people from BME communities through transition to adulthood that will be available from the Transition Information Network at the Council for Disabled Children.

## **Giving Us A Voice**

What people at the GUAV meetings said needed further action to improve the employment opportunities of people with learning difficulties from BME communities:

- Improve local networking to help people get jobs through informal contacts
- Ensure that local BME communities are themselves involved in information about work and encouraging people with learning difficulties and their families to seek opportunities
- Help people from different BME communities understand how the job seeking system works
- Make sure that there is effective education from an early age about jobs and how to get them
- Be clear about the legislation affecting people with learning difficulties as well as those from BME communities
- Make contacts with local businesses including social enterprises

Support from family carers is often vital in finding and sustaining employment – as in other areas – for people with learning disabilities. The Coalition Government has shown how it will continue to support carers in a variety of ways: Recognised, valued and supported: next steps for the Carers Strategy, 2010.

## Housing

**The 2004 Framework indicated that people with learning difficulties from BME communities often have unmet housing needs – like many other people with learning difficulties they may find themselves living with their families for longer than they would wish. But it is important to note that individual wishes and circumstances may vary widely.**

Ageing parents are particularly concerned about future housing; some may be unaware of possible options or how to access them. “Independent living” may be a strange concept to some families – in practice none of us live totally independently. Local communities may have an important role to play in considering how best to proceed: “independence within the family” may be one option that it is appropriate to pursue.

There are specific questions that local statutory agencies should consider:

- How many people with learning difficulties from BME communities are in out of area placements?
- Are there any plans to develop relevant local services?
- Do these plans connect to overall local housing strategies?
- Do resettlement plans affect people from BME communities?
- Is information and advice readily available? Is it culturally sensitive?
- Are specialist and community based housing providers involved?

### **Valuing People Now**

Having an informed choice about where and with whom they lived was a major priority for people with learning difficulties, particularly options other than residential care and staying with their own families. Local statutory agencies should begin to address these options during transition planning from children’s to adult services, as part of having an informed choice.

Planners and commissioners should consider creative solutions using Supporting People and other housing related support programmes as well as local expertise. Joint Strategic Needs Assessments should identify housing needs to inform strategic planning. People with learning difficulties should be properly informed about the different housing models that might be available through person centred planning and individual budgets. The needs of people with learning difficulties including those from BME communities should be included in local authority housing strategies.

Planning and Commissioning Housing for People with Learning Disabilities Toolkit for Local Authorities has been produced to assist the planning and delivery of a wide range of housing options, all of which are relevant for BME communities (VPN website September 2010). Finding a Place to Live contains detailed practical guidance and is also to be found on the VPN website.

Housing needs are likely to continue to be more pronounced for BME communities: in August 2010 the Race Equality Foundation reported that overcrowding was a growing problem (especially in the private rented sector) and that BME households were more likely to be living in overcrowded conditions (Housing Briefing 16, August 2010).

The Housing Learning & Improvement Network (LIN) is the national network for promoting new ideas and supporting change in the delivery of housing, care and support services for older and vulnerable adults, including people with disabilities and long term conditions. Work undertaken on the needs of BME communities for extra care housing can also be seen as relevant when considering the housing needs of people with learning difficulties. The key points for commissioners of services were:

- Understanding potential local demand through good data and face to face consultations
- Understanding the extent to which current housing options are appropriate for the different local BME communities
- Explaining what the different housing options actually mean
- Working in partnership with local communities and their organisations and informal networks
- Being sensitive to different cultures without making assumptions
- Addressing the extent of demand for specialist standalone services compared to mainstream services that are flexible
- Involving BME organisations in the development and where appropriate the provision of services

It is important when considering housing (as well as other) support, not to make assumptions about how different BME families and communities behave: for example, it would be incorrect to assume that siblings would always be willing and able to offer accommodation; similarly some people from the same BME community might want to live together (or nearby) but others might well not.

### **Giving us a Voice (GUAV)**

What people at the GUAV meetings said needed further action to improve the housing opportunities of people with learning difficulties from BME communities:

- Better information on how the housing improvement system works especially for adaptations
- Accessible information e.g. on tenancies and independent living
- More referrals to housing providers
- Creating real choice in types of accommodation
- More understanding of what is meant by “culturally sensitive housing” including with appropriate support – independent living should not be outside people’s culture
- More emphasis on the importance of housing within communities
- More effort made to enhance “independence within the family home”
- Better practical support when moving home
- Being able to take adequate time to reach the right decision on the best housing option

# Being an active citizen

## The 2004 Framework:

**For many BME communities it was important to be aware that citizenship should be viewed as a collective, community focused issue as well as an individual one. It is therefore important to be aware of both family and local community implications when statutory agencies identify and seek to address needs.**

Effective advocacy is often crucial for people from BME communities getting access to appropriate services, but this is not always available. Some cultures are not always comfortable with the benefits of self advocacy. In addition the effects of racism and discrimination may have made some people with learning difficulties wary of putting themselves forward. Advocacy groups for and within local BME communities have been an important way forward in many cases.

Many people with learning difficulties from BME communities find friends and social activities through family and local community contacts. The particular requirements of different communities should be an important part of planning and publicising local day time opportunities.

## Valuing People Now

Key components of being an active citizen were seen as having access to advocacy when required, being able to use transport, having leisure opportunities and being safe both in the community and at home.

All people with learning difficulties should be able to speak up and be heard about what they want from their lives – both the big decisions and the everyday choices; and if they require support to do this, it should be available. Having the right information to make choices is crucial especially in order to understand and access health, social care and other systems.

People should be able to use public transport safely, easily and with confidence as this is essential for getting to work, college and school, and for meeting friends.

Leisure and recreation places need good information and access arrangements including staff with supportive and encouraging attitudes. As with other public services reasonable adjustments should be made to enable use by people with learning difficulties.

It is a basic right to live in a safe environment and have confidence in the criminal justice system to uphold this right. People from BME and newly arrived communities are particularly vulnerable to hate crime – both abuse and neglect. They should be able to report incidents easily and with confidence of action being taken. Local agencies should work together to ensure effective action is taken and guidance available.

## **Self advocacy**

The National Forum of People with Learning Difficulties has published (2011) *Staying Strong* – taking self advocacy into the future which emphasises the importance of self advocacy groups at a time of spending reductions. They help people with learning difficulties from different backgrounds to come together to give their views, learn new skills and support each other. They have a record of success at including people with complex needs and are in a good position to link with wider BME community groups. This aspect is particularly important when some people with learning difficulties are falling out of eligibility for services whilst still requiring some support to enable them to be active citizens and properly part of society.

## **Making good use of personal budgets through advocacy**

Grapevine (Coventry and Warwickshire) is running a project to help young people with learning disabilities from BME communities to understand and take up personal budgets in order to enable them to control how services are delivered and by whom. People with learning difficulties from BME communities are in general under-represented in take up of direct payments and personal budgets.

As the project continued some emerging messages were reported in December 2010. Local groups confirmed Grapevine's earlier findings that there was dissatisfaction amongst families at services offered leading to them providing care and support themselves; this was coupled with a general lack of awareness of rights, entitlements and available choices.

Some young people whose needs were assessed as insufficient for statutory support were at risk of "disappearing" within their family support when they leave school, with little if any outside social contact. Some local families lacked awareness of learning difficulties and needed support in coming to terms and coping.

Having a single consistent support worker seemed to make a difference in obtaining the necessary trust and confidence of the family so as to enable them to go on to consider various options for their son or daughter. The same worker may be called upon to provide a wide range of advice and support.

Face to face engagement with families tends to work best so that the worker understands the various family attitudes and wishes, and enables them to negotiate acceptable ways forward. Advocates have supported some families to explore female only groups where this is culturally required – they have encouraged families to allow their daughter to make her own choices.

More basically it is vital that personal planning works well for people with learning disabilities from BME communities – this is at the heart of identifying needs and ensuring effective responses.

### **Caring for all carers**

Overall it is reckoned that 60% of adults with learning difficulties live with their families and get most of their support and care from family members – the numbers may well be higher for BME families.

Pressures on carers continue to be great: carers from BME communities may find themselves caring for both ageing parents as well as a younger family member with a learning difficulty. There is a growing number of people with learning difficulties who are themselves carers. Mutual caring increases as carers get older and their son or daughter with a learning difficulty takes on some responsibilities for them. Siblings may be expected to look after their brother or sister with a learning difficulty. It is important that the needs of BME carers are considered within mainstream caring work including the notion of family focused assessments.

Commissioned by the Valuing People Now Family Carer programme the Princess Royal Trust for Carers and Crossroads Care undertook a survey of their services for carers of people with learning disabilities from BME and seldom heard communities in 2010, published under the title Caring for All Carers.

The main findings echo earlier ones for service provision generally. Local authority leadership, as commissioners, is an important local driver to ensuring equality and diversity from providers. Good practice relies upon being able to keep in touch with changes in local populations. Areas with the most experience of working with BME communities tend to place less reliance on translated materials. Rural areas with more scattered BME populations require particular support to ensure BME carers receive any sort of decent service.

Several good practice examples are worth noting:

- A carers centre adopting an informal strategy to employ BME workers in a number of different roles, making good links with the local Council for Voluntary Service who undertake equalities training, using the local media for publicising, producing own translated material
- Another centre having an emphasis on monitoring data by ethnicity
- Outworking with local communities, close working with the local Council
- Five centres across a large county contributing to meet the costs of a community outreach worker
- A centre who placed great importance on having a number of longstanding BME staff who had become a major trusted resource for local people and advice for other staff
- Another centre in an area with relatively few BME carers but who employed workers on merit in generic posts who with support from colleagues overcame suspicion from white carers

Also commissioned by the Family Carer Programme, the organisation 'hft' undertook work in a large, mainly rural county and found that BME carers faced similar barriers to their urban equivalents but with a greater sense of isolation and dislocation. Although numbers may be smaller than in other places they can still be significant – here the project identified 40 different languages being spoken. In rural areas there are less likely to be effective local networks of different BME communities – promoting information about services and systems as well as increasing learning difficulty awareness may require more effort. It is always useful to be clear that equalities legislation applies in rural areas as well as urban ones.

## **Giving Us A Voice**

What people at the GUAV meetings said needed further action to improve the citizenship opportunities of people with learning difficulties from BME communities:

- Supporting people with learning disabilities from BME communities to access independent advocacy groups, friendship groups and the local Partnership Board
- Listening to local BME communities and enabling them to speak up
- More people from BME communities need to be involved in local decision making
- Effective information giving and receiving
- Equalities legislation needs to be publicised locally, understood by all, acted upon and its progress reviewed
- Isolation of individuals needs to be identified and overcome, including being with friends
- Local systems and services need to be designed so they enable easy access by BME communities
- Diverse workforces need to be formed within statutory and other agencies
- Local transport needs to be cheap, easy to use and friendly
- Safety concerns need to be addressed

## Appendix 1 - Useful references and websites

**A Vision for Adult Social Care: Capable Communities and Active Citizens, Department of Health, 2010**

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_123203.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_123203.pdf)

**Caring for All Carers, The Princess Royal Trust for Carers and Crossroads Care, 2010**

[http://www.crossroads.org.uk/\\_downloads/\\_publications/Caring\\_for\\_all\\_carers\\_Nov\\_2010.pdf](http://www.crossroads.org.uk/_downloads/_publications/Caring_for_all_carers_Nov_2010.pdf)

**Equality Act 2010**

[http://www.equalities.gov.uk/equality\\_act\\_2010.aspx](http://www.equalities.gov.uk/equality_act_2010.aspx)

**Finding a Place to Live – Help with your Plans, 2010**

<http://www.valuingpeoplenow.dh.gov.uk/sites/dhvpnweb.rroom.net/files/webfm/CMS%20Videos/Housing%20Pages/Housing%20publication/Publication%20file%20228%20finding%20a%20place%20to%20live.pdf>

**Getting a Life Employment Project**

<http://www.gettingalife.org.uk/>

**Giving us a Voice Project**

<http://givingusavoice.org.uk/>

**hft**

<http://www.hft.org.uk/>

**Improving Health and Lives: the Learning Disability Observatory**

<http://www.improvinghealthandlives.org.uk/>

**Learning Difficulties and Ethnicity: A Framework for Action, Department of Health, 2004**

**Planning and Commissioning Housing for People with Learning Disabilities: A Toolkit for Local Authorities, 2010**

<http://www.valuingpeoplenow.dh.gov.uk/sites/dhvpnweb.rroom.net/files/webfm/CMS%20Videos/Housing%20Pages/NEW%20Housing%20Comissioning%20toolkit%20for%20Local%20Authorities.pdf>

**Race Equality Foundation**

<http://www.raceequalityfoundation.org.uk/>

**Race for Health**

<http://www.raceforhealth.org/>

**Recognised, Valued and Supported: Next Steps for the Carers Strategy, Department of Health. 2010**

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122077](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122077)

**Staying Strong, National Forum for People with Learning Disabilities, 2011**

[www.stayingstrongselfadvocacy.org.uk](http://www.stayingstrongselfadvocacy.org.uk)

**Timebanking**

<http://www.timebanking.org/index.htm>

**The Housing LIN (Learning and Improvement Network)**

<http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/>

**Valuing People Now, Department of Health, 2009**

<http://www.valuingpeoplenow.dh.gov.uk/sites/dhvpnweb.rroom.net/files/webfm/Valuing%20People%20Now%20Landing%20Page/Valuing%20People%20Now%20Strategy%20.pdf>

**Valuing People Now Summary Report, Department of Health, 2010**

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122385](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122385)

**Vision for Adult Social Care 2010, Practical Approaches to Co-Production**

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_121669.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121669.pdf)

## Appendix 2 - Giving us a Voice project

Giving us A Voice is a project funded by the Tackling Race Inequality Fund of the Department for Communities and Local Government and is run by ARC, Mencap and BILD – the first time that these important learning disability charities have worked together on a project.

The aim was “to make a plan for each region and a National Charter that shows clearly what people with learning disabilities and their families from ethnic minority communities need to live happier and safer lives”.

The project team from the three organisations talked to people with learning difficulties and family carers from BME communities, and to people who plan, pay for and run services. These groups were asked to think about what would be needed to make services better for people with learning disabilities from BME communities.

Nine big meetings (one in each region) were held for everyone to come and share their ideas about citizenship (getting a fair life), health, working and housing. Views were collected – good things and bad things – and regional plans and a National Charter for Inclusion were produced.

## APPENDIX 3

Learning Difficulties and Ethnicity: Updating 'A Framework for Action'

### LOCAL CHECKLIST FOR ACTION

This Local Checklist is only intended as a guide to enabling Learning Disability Partnership Boards and commissioners to know their population and understand what needs to happen for people with learning difficulties from Black and Minority Ethnic Communities in their localities.

<b>1. GETTING THE BASICS IN PLACE</b>			
	<b>YES/NO</b>	<b>IF NO, BY WHEN?</b>	<b>WHO IS RESPONSIBLE?</b>
1.1 Do you have clear and shared values and principles across your Local Authority/Partnership Board area to support your work with people with learning difficulties from BME communities and their families?			
1.2 Do you have a 3/5 years strategy for this work?			
1.3 Are you able to state your recent achievements and current priorities for action?			
1.4 Are you clear who is involved and who is leading this work?			

1.5 Do you know which agencies have responsibilities for the key decisions?			
1.6 Do you have a system for agreeing specific outcomes and for monitoring progress?			
<b>2. HAVING THE RIGHT INFORMATION ABOUT PEOPLE WITH LEARNING DISABILITIES FROM BME COMMUNITIES IN YOUR AREA</b>			
	<b>YES/NO</b>	<b>IF NO BY WHEN?</b>	<b>WHO IS RESPONSIBLE?</b>
<p>2.1 Do you know: How many people from BME communities with mild or moderate learning difficulties (people who need some support to be independent) there are in your area?</p> <p>How many are known to services or receive their own budgets?</p> <p>What proportion is this of the total numbers of people with mild to moderate learning difficulties?</p> <p>Is this proportion more or less than the overall figure?</p> <p>Is this information included in your Joint Strategic Needs Assessment?</p>			

<p>2.2 Do you know: How many people from BME communities with severe learning difficulties (people who need a lot of support, have complex needs) there are in your area?</p> <p>How many are known to services or receive their own budgets?</p> <p>What proportion is this of the total numbers of people with severe learning difficulties?</p> <p>Is this proportion more or less than the overall figure?</p> <p>Is this information included in your Joint Strategic Needs Assessment?</p>			
<p>2.3 Do you know: How many children and young people with mild or moderate learning difficulties (need some support) are there in your area?</p> <p>What services are they using?</p> <p>What proportion is this of the total numbers of children and young people with mild to moderate learning difficulties?</p> <p>Is this proportion more or less than the overall figure?</p>			

<p>Is this information included in your Joint Strategic Needs Assessment?</p>			
<p>2.4 Do you know: How many children and young people with severe learning difficulties (need a lot of support, have complex needs) there are in your area?</p> <p>What services are they using?</p> <p>What proportion is this of the total numbers of children and young people with severe learning difficulties?</p> <p>Is this proportion more or less than the overall figure?</p> <p>Is this information included in your Joint Strategic Needs Assessment?</p>			
<p>2.5 Do you have the breakdown by ethnic origin of the numbers recorded above, including those of recently arrived communities?</p>			
<p>2.6 Do people from local BME communities take part in needs identification work?</p>			

<b>3. HAVING AN EFFECTIVE PLAN IN PLACE FOR MEETING SPECIFIC NEEDS</b>			
	<b>YES/NO</b>	<b>IF NO BY WHEN</b>	<b>WHO IS RESPONSIBLE?</b>
<p>3.1 Do you have an action plan with clear priorities and outcomes, and arrangements in place to make it happen and for monitoring and review?</p> <p>Does the plan clearly identify responsibilities for action?</p>			
3.2 Does the plan include the different needs of different local BME communities?			
3.3 Has the plan been developed with the effective involvement of representatives of local BME communities including self advocates and family carers?			
3.4 Does the plan show how it will be funded?			
3.5 Does the plan properly reflect the importance of personalisation for people from BME communities? Is it included in the overall personalisation strategy?			

3.6 Is the plan embedded in local commissioning and other strategies (e.g. Equalities, Carers) including scope for feedback from users, families and local communities?			
3.7 Does the plan link to the Council's overall equalities work?			
3.8 Do you have a system for checking that providers' services are culturally sensitive?			
3.9 Do you check that children's and adult's services work together to ensure smooth transition?			
3.10 Does the plan include an effective training programme that includes cultural awareness?			
<b>4. PROMOTING RACE EQUALITY</b>			
	<b>YES/NO</b>	<b>IF NO BY WHEN?</b>	<b>WHO IS RESPONSIBLE?</b>
4.1 Have you decided what should be done to eliminate discrimination and harassment against people with learning difficulties from BME communities?			

<p>4.2 Do you ensure that people with learning difficulties from BME communities have fair access to services?</p> <p>Have you addressed the key points relating to Health, Employment, Housing and Citizenship that are shown in the Framework?</p>			
<p>4.3 Have all relevant policies been subject to Race Equality Impact Assessments?</p>			
<p>4.4 Have you decided what should be done to promote positive attitudes towards people with learning difficulties from BME communities?</p>			
<p>4.5 Have you decided what should be done to encourage participation by people with learning difficulties from BME communities in the work of the Local Authority, Partnership Boards and other decision making bodies?</p>			
<p>4.6 Have you signed up to the Charter for Inclusion that came from the Giving us a Voice project?</p>			

## **Foundation for People with Learning Disabilities**

The Foundation for People with Learning Disabilities promotes the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- Do research and develop projects that promote social inclusion and citizenship
- Support local communities and services to include people with learning disabilities
- Make practical improvements in services for people with learning disabilities
- Spread knowledge and information

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