Diversity matters

Good practice in services for disabled children and their families from black and other minority ethnic communities

Justin Simon

Council for
Disabled
Children

national
children's
bureau

department for
education and skills

About the National Children's Bureau (NCB)

NCB is an umbrella organisation in England and Northern Ireland. It promotes the voices, interests and well-being of all children and young people across every aspect of their lives. NCB provides essential information on policy, research and best practice for members and other partners and its aims are to:

- challenge disadvantage in childhood
- work with children and young people to ensure they are involved in all matters that affect their lives
- promote multidisciplinary cross-agency partnerships and good practice
- influence government policy through policy development and advocacy
- undertake high-quality research and work from an evidence-based perspective
- disseminate information to all those working with children and young people, and to children and young people themselves.

NCB (England and Northern Ireland) works in partnership with Children in Scotland (www.childreninscotland.org.uk) and Children in Wales (www.childreninwales.org.uk).

About the Council for Disabled Children (CDC)

The Council for Disabled Children operates under the aegis of the National Children's Bureau. The Council for Disabled Children provides a national forum for the discussion and development of a wide range of policy and practice issues relating to service provision and support for disabled children and young people and those with special educational needs.

Our membership is drawn from a wide range of professional, voluntary and statutory organisations, including parent representatives and representatives of disabled people. This ensures we have a good balance of interests and expertise.

Our broad based membership and extensive network of contacts gives us a unique overview of current issues. It also helps us promote collaborative and partnership working among organisations, and develop quality support for disabled children and their families.

For more information on CDC please see our website at www.ncb.org.uk/cdc

Council for Disabled Children
8 Wakley Street
London
EC1V 7QE

telephone 020 7843 1900
email cdc@ncb.org.uk

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The content does not necessarily reflect the views of the DfES or Council for Disabled Children.
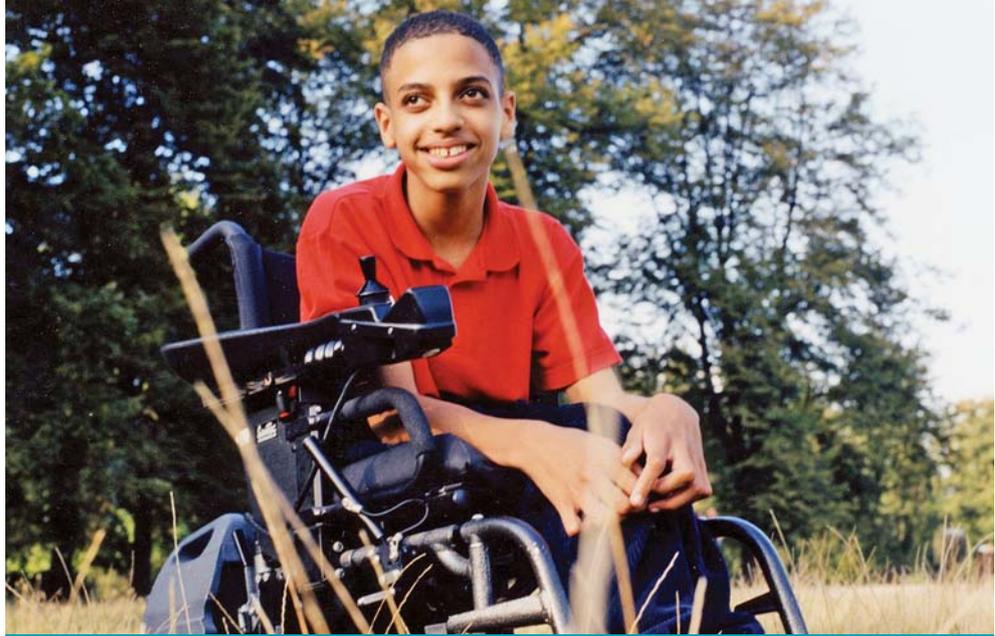
Contents

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1 Introduction

'Good practice starts with acknowledging, recognising and responding appropriately to the diversity of people's backgrounds. It should seek to counteract discriminatory attitudes and procedures in a manner that becomes a routine aspect of how an organisation works.

For many organisations working mainly on race-related issues, this means recognising and understanding how disablism and all its forms affect their work. Equally for organisations working mainly on disability issues, this means examining their values and practice for racism in all its forms.'

(Disability Rights Commission 2004, p11)

Disabled children from black and other minority ethnic communities face difficulties and challenges in accessing and receiving services, and often those they receive are not sensitive to their culture and language or relevant to their needs. They face the double discrimination of being disabled and being from a minority ethnic group. Baxter and others (1990) identified this in *Double discrimination* and Shah addressed it in *The silent minority* (1992, revised 1995), in which she focused on disabled children from Asian families (from Pakistan, Bangladesh and India).

Many publications since then have identified the shortcomings of services (Butt and others 2005; Chahal and Ullah 2004; Chamba and others 1999; Hatton and others 2004), yet there has been little recognition of those organisations that have succeeded in providing culturally appropriate and targeted services.

The aims of this guide

Many agencies and projects have had resounding successes in providing services to minority ethnic disabled children but their work has not been publicised. In order to fill the gap in knowledge about services for disabled children from black and other minority ethnic communities, the Council for Disabled Children received funding from the Department for Education and Skills to help identify successful projects, highlight good practice and disseminate key messages.

The aims of this guide are to:
- help to improve access to social care services for black and other minority ethnic disabled children
- identify how services have successfully targeted black and other minority ethnic disabled children, young people and their families
- provide tips and recommendations for service providers to help them ensure their services are accessible and relevant to all.

What is in this guide

This guide includes:
- examples of successful projects (Appendix 2)
- tips on what to look for when setting up and delivering a service
- possible challenges
- common experiences that have led to success
- practical suggestions
- summaries of key legislation and policy with implications for practice (Appendix 1)
- a list of useful resources and references (Appedix 3 and 4).

The guide draws on practice, research and publications that address the needs of minority ethnic disabled children and their families. It identifies lessons that can be learned from working with children, with disabled children, with children from black and other minority ethnic communities, and with disabled adults.

In addition, practice can be informed by the experiences of disabled people from black and other minority ethnic communities in wider contexts, such as in schools, in health care, in their transition to adulthood, in gaining employment and in gaining adequate housing. Learning from these disciplines has been incorporated.

definitions

Black and other minority ethnic communities

In this guide, we use the term 'black and other minority ethnic communities' which includes:

- people of African and African-Caribbean heritage
- people of South Asian heritage including Pakistan, India, Bangladesh and Sri Lanka
- people of Latin American, Chinese, Korean heritage
- people from white minority ethnic communities, such as those of Irish heritage
- people from Eastern European countries such as Bosnia and Kosovo
- Gypsy and Traveller children
- asylum seekers and refugees
- some religious groups.

To avoid too many repetitions in the text, the term 'black and other minority ethnic communities' is sometimes shortened to 'minority ethnic groups' or 'minority ethnic disabled children'.

Disability

A broad definition of disability has been used in this guide. It includes people who identify their children as disabled, irrespective of clinical diagnosis. This means that the focus is on the needs of the child and their family, rather than on categorisation of the child's impairment.

Disablism

Prejudice or discrimination based on a person's impairment.

Children and carers

The age range of children covered in this guide is birth to 18 years. The term 'children' is sometimes used to refer to children and young people, and the term 'parents' can include other people with a caring role.

Background

Services were identified using established networks within the Council for Disabled Children (CDC) and the National Children's Bureau (NCB). In addition, emails were sent via both networks, and a dedicated email bulletin provided regular updates to over 250 interested individuals. Publicity material was distributed at conferences and on the internet.

Identifying projects was a slow process. On several occasions, projects that were contacted as a result of reading about them in research, or in an article in a magazine no longer existed.

While some local authorities have a relatively high proportion of minority ethnic families, it does not always follow that they

provide the best services for these families. Where a local authority has a predominantly white population, it will be important to check if there is a significant white minority ethnic population (such as Gypsies and Travellers), and/or if there is a significant refugee/asylum-seeking population. Disabled children in these communities may not be officially noted in census statistics so unless efforts are made to target them, they risk remaining without services.

The majority of projects identified for their good practice are in the social care sector. Reference is also made to education and health service initiatives to support children from black and other minority ethnic communities. For example, the Ethnic Minority Achievement Grant funded by the Department for Education and Skills (DfES) helps local authorities to meet the needs of pupils for whom English is an additional language, and to raise standards of achievement for those minority ethnic groups who are particularly at risk of underachieving. Primary care trusts have a responsibility to take the lead on race equality, to ensure that the Race Equality Impact Assessment is carried out.

Respecting values and culture

Work with black and other minority ethnic disabled children brings together services for people from minority ethnic communities and services for disabled children. Many professionals will feel experienced in one of these areas, but far fewer will feel experienced in both.

Working with disabled children and their families requires an understanding of how disablism occurs, just as working with children and families from black and other minority ethnic communities requires an understanding of racism. Therefore, both forms of discrimination need to be understood and challenged in order to work effectively with minority ethnic disabled children (see Chapter 2).

Barriers

This guide addresses the barriers which face disabled children and their families from black and other minority ethnic communities, rather than focusing on the children's impairments. This comes from thinking that if the barriers are removed, people are no longer 'disabled'.

For example, one of the barriers that prevents disabled minority ethnic children from taking up services is that their cultural and religious practices are not always understood or respected. If an

event is planned on a fast day, such as Ramadan for Muslims, or Yom Kippur for Jewish people, then some of these families may not send their children. If this happens, these families may be less likely to send their children to other events, fearing that similar cultural practices will not be respected, such as regulations related to diet. In this example, the problem is not the religion of the family, but the fact that services have not taken a community's culture or religion into account, thus creating a barrier to the provision.

Similarly, if a leisure activity is set up in a local adventure playground that does not have facilities for disabled children, then these children will not attend. The barrier to their participation is not that they have an impairment, but that the park facilities do not enable all children to take part.

Barriers are often invisible and can become part of everyday practices that are taken for granted, such as the way assessments are carried out. Therefore, if organisations are committed to overcoming barriers to service take-up, they must be equally committed to identifying those barriers.

Disabled children and young people face numerous barriers, but it is the responsibility of service providers to work out what those barriers are, else they risk excluding these children in the long term. It can take considerable courage to attend a leisure activity when you are the only disabled young person, especially if you don't know whether the venue really will be accessible. In his column for *Community Care* (11–17 August 2005), Simon Heng, a disabled adult, wrote:

> 'I once turned up to a hotel after being reassured that there was level access to all rooms. They forgot to mention the flight of 12 steps to the front door.'

This experience is common, as many people do not foresee how the venues they choose for conferences and meetings may pose challenges for disabled people. Another example of this was a manager who said that their hotel was fully accessible, but the car park was made of gravel and it would have been very hard for a wheelchair user to reach the hotel entrance.

What is important is that services for disabled children from black and other minority ethnic communities, whether they are provided by the voluntary or statutory sector, do not unintentionally create barriers which put people off from using services. This is why it is so important to include disabled people in all aspects of planning and delivering facilities, so that they can take a full part in helping to shape services and the way they are delivered.

Barrier-free services

These are suggestions, adapted from the Alliance for Inclusive Education, to help make a school inclusive:

- you get the help you need without having to fight for it
- everybody is able to make a contribution
- there are systems to help children and young people when they don't know what to do
- children are valued equally and not ranked or compared to each other
- children are taught skills such as mediation, peer mentoring and tutoring, which help to keep their school a friendly and helpful place
- everyone's first language is considered of equal value, including sign language
- children are treated with respect

Summary

- Professionals may sometimes feel that they lack the skills to work with disabled children, or with children from black and other minority ethnic communities, or with either group.
- The barriers faced are often invisible so lead managers in organisations will have to work hard to identify local barriers and how to eradicate them.
- Being clear that no form of discrimination will be accepted in any part of the service will send an important message to providers and service users.
- It is essential to involve disabled children and their families at all levels of planning, developing and monitoring services.

2 Discrimination

Black and other minority ethnic disabled children face discrimination in many aspects of their daily lives. There are three recognised forms of discrimination, as follows:

Discrimination on an individual level

Treating everyone the same is discriminatory because we are not all the same, and it risks ignoring all the ways in which we are different from each other, for example through religion, age, gender, socioeconomic status, ethnicity or impairment.

Discrimination on an organisational level

Baxter and others (1990) reported that South Asian parents appeared to receive a later diagnosis of their child's impairment, partly because their concerns were not taken seriously enough by practitioners.

Institutional discrimination

Flynn (2002) describes how discrimination on a whole-system level would operate:

'An institutionally racist approach to service delivery would locate the responsibility for finding out about and accessing services with families themselves.'

Discrimination may be based on:

- impairment, such as negative attitudes and low expectations
- ethnicity, such as the belief that all people of a certain ethnicity are inferior
- gender, such as stereotypical views of what lifestyle a girl from a Pakistani background can expect
- age, such as younger children not seen as being worth listening to
- immigration status, such as children who are refugees or asylum seekers
- religious or faith background.

Discrimination is particularly difficult to challenge for children who have a communication impairment, and their views are often not heard. Many disabled children do not express their views because:

● they are not asked for their views, because some professionals say they don't have the skills nor extra time required
● they lack confidence
● they do not want to criticise anything they receive, in case it is withdrawn
● their non-verbal communication systems may only have the vocabulary to state what they want on a day-to-day basis, and may not enable them to state an opinion.

Therefore, it may feel much harder to complain about being discriminated against unless something concrete has happened as a result of the discrimination.

Each of these forms of discrimination has their own terminology – disablism, based on a person's impairment, and racism based on a person's skin colour, ethnicity or nationality. Professionals need to understand the way in which discrimination is acted out in order to challenge it and improve services for minority ethnic disabled children and their families.

It can be very hard for people to understand the impact of discrimination if they themselves do not experience it, and so there is a danger of it being minimised. For disabled children who are refugees or asylum seekers, their experience can be even worse because they have minimal rights, their views are not known, and their very presence in this country may be is hard to pinpoint. Consequently, it is very hard to meet their needs on more than an ad hoc basis. They may also live in predominantly white areas, where there are fewer support networks.

The pervasive effect of racism and disablism must not be underestimated. Legislation in the form of the Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005 now provides a tool for tackling racism and disablism. The combined effect of these laws is that public services must have both a race equality scheme and a disability equality scheme, which together should help to tackle the discrimination faced by minority ethnic disabled children.

3 Culturally competent services

An awareness of the ways in which disabled children from black and other minority ethnic communities encounter discrimination provides a foundation on which respecting a person's culture can be built. It is important to understand what is meant by the term 'culture', and to recognise that it applies to everyone, regardless of their ethnicity.

Culture is about the way people live their lives; it is not static but changes over time. An individual's culture will be determined and influenced by a number of factors, such as beliefs, customs, values, religion, disability, ethnicity, gender, parenting, socio-economic status and schooling. Culture may be hard to identify, because it is based on many aspects of our identity. Often, the best way to find out about a person's culture is to ask them about it.

Understanding an individual's culture can enable a more positive relationship to develop.

Religious awareness

Knowledge of a person's religion will mean that certain days will be avoided for appointments because they are religious holidays. In this country, it would be unlikely for a local authority, primary care trust or national charity to arrange a consultation event on Good Friday because it is recognised as a Christian holiday. However, it is common for conferences and consultations to be organised on holidays of other religions because of a general lack of awareness. However, since the implementation of the Employment Equality (Religion and Beliefs) Regulations in December 2003, services should have a framework for providing basic understanding of

diverse faith backgrounds, and this framework should make it easier to respond to people's individual needs.

An organisation which visibly respects and acknowledges cultural differences will be seen as much more welcoming. Cultural understanding means being sensitive not only to religion but to other influences on the way people in communities live and what is important to them.

Assumptions should not be made about a child's culture so time needs to be taken to discuss it with them and their family. Some young people may identify with being disabled and may want to attend leisure activities with other disabled young people. Others may identify with being disabled and from a minority ethnic community and want to attend leisure activities with others like them. Sometimes it is parents who make choices for their children, and sometimes brothers and sisters may do so.

Tips

- Identify what makes up your cultural identity before asking this of a child or family.
- Check a multi-faith calendar before suggesting or arranging an appointment with a family from a minority ethnic group, but do not assume they practise any religion without checking with them.
- Depending on the local population, check a multi-faith calendar before organising conferences, consultation events, and parents and children's forums.
- There are websites that provide free religious festivals calendars, for example:
  – www.diversiton.com/downloads/downloads.asp
  – www.EEFaithsCouncil.org.uk
  – www.interfaithcalendar.org/2006.htm

Language issues

Another way to demonstrate cultural sensitivity is to offer translation and interpreting.

Translations

Leaflets and publications in languages other than English are important for enabling greater access to services. However, there must also be a dissemination strategy to ensure that information reaches the target audience. Furthermore, written information cannot replace the importance of a sympathetic, knowledgeable person who can offer advice on the range of services available.

There is some debate about the value of translating materials. One reason is that some people to whom the translation is aimed may not be able to read and may prefer someone to translate an English leaflet. Cost is also an issue for smaller projects.

Tips on translating materials

- Ask local parents, families and children what they want. Community development workers, health advocates, childcare workers and community-based social care schemes are good places to start.
- Ask the views of local community leaders.
- Identify the languages spoken locally. Many families are multilingual and can read information in English.
- Make sure that you can deliver on the offer to translate written materials.
- In addition to translating leaflets, consider whether your organisation can visit families to explain about the services offered, or whether you could commission another service to do this.
- It can be useful for translated materials to be translated back into English by a different translator, because it is very common for words to be mistranslated and for the meaning to become confused. If there are terms that do not translate, they need to be described in other ways to ensure the meaning is understood.
- The cost of translations (and interpreting) should be included in funding bids.
- Organisations could consider sharing the language skills of their staff to reduce costs.
- If a child or parent turns down an offer of translation, this should not be viewed as final, and the same offer should be made at future opportunities.
- Try to pilot a draft version of a translated leaflet or publication before paying for a large print run.

Interpreting services

There are some questions about the appropriateness of using interpreters, particularly if a child or parent seems able to speak and understand English. However, the ability to take part in a conversation is not the same as understanding complex information. It is always important to check with the child or parents about their need for an interpreter.

Working with interpreters is a skill that needs to be acquired in order to get the most benefit from it. Good preparation and an understanding of the process are essential for it to work well. It is well worth talking it through with a colleague who has used an interpreter to gain first-hand tips.

Tips on working with interpreters

- Interpreters need to be briefed about the subject matter before meeting the child or parent to ensure they understand the context of the discussion.
- If they have not worked with disabled children before, they will need to be told in advance about the way the child communicates.
- Allow more time for the visit.
- If there is any confusion about the meaning, then it is the worker's responsibility to clarify it.
- Some words (eg learning difficulty) are not easily translated, so it is important to ensure that you have a shared understanding of what is meant.
- Use non-verbal communication and observation to complement your conversation, in the same way that it is used without interpretation.
- Maintain eye contact with the child or parent rather than with the interpreter.
- Three-way interpreted telephone calls can be very helpful because you can answer questions directly rather than the interpreter speaking to you after having a conversation with the family.
- Do not use a child as an interpreter for their parent. Always use a professional.
- For consistency, always try to use the same interpreter.
- Keep in mind that for cultural and religious reasons, some parents and children may prefer to communicate with an interpreter who is the same gender as themselves. Check this and use female or male interpreters, as appropriate.
- Do not make assumptions about what people need – always ask them.

More tips will be available in *A process for change* by Kaushal and Nawaz, to be published later in 2006 by the Shared Care Network. Also see Alexander and others (2004).

4 Refugees and asylum seekers

Disabled children who are refugees or asylum seekers can be hard to identify and appropriately support. Many of them arrive in the UK unaccompanied by any adult who has responsibility for them. The literature that describes their circumstances is sparse, so the difficulties they face tend to be addressed on a case-by-case basis.

Many children who come into the UK seeking asylum have fled wars, conflicts and countries where human rights abuses have taken place (Save the Children 2003). There are many accounts of children who have been caught up in conflicts, who have been tortured, raped, beaten, forced to take part in military action or who have witnessed murder or other violent acts. These experiences can have a very negative impact on a child's physical, emotional and psychological well-being.

Research suggests there are potential mental health implications of traumatic events and experiences, including the flight into exile and the experience of living in exile. However, there is little recognition of the impairments that can be caused by these experiences.

Kidane (2001) suggests that some refugee children may have physical difficulties such as:

- bullet wounds, mutilated limbs from landmines or other forms of violence
- physical difficulties as a result of torture, inadequate healthcare, or lack of immunisations
- undiagnosed or misdiagnosed impairments or health conditions.

It is likely, therefore, that some asylum seekers or refugees may not be identified as disabled but would benefit from support from children's disability services. There may also be some whose impairment is not visible, and therefore not known about, by the professionals supporting them.

In addition, it may be difficult to identify the children affected in this way because:

- the immediate priority will be to clarify the child's immigration status, which secures their right to be in the UK
- some children who are unaccompanied asylum seekers or refugees may not want to be identified as being disabled, out of fear that this would affect their claim.

definitions

The 1951 United Nations Convention defines a refugee as someone outside his or her country 'owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion'. (Article 1A (2))

An asylum seeker is defined as 'someone who has left their country and is seeking refugee status' (Social Services Inspectorate/Department of Health 1995).

Children who are unaccompanied are also known as 'separated children'.

'Separated children are children under the age of 18 years old who are outside their country of origin and separated from both parents, or their previous legal/customary primary caregiver.' (from the Statement of Good Practice from the Separated Children in Europe programme 2004)

Research

Roberts and Harris (2002) carried out research into the circumstances of disabled adults who are refugees and asylum seekers. Roberts and Harris found that:

- 'Unmet personal care and domestic assistance needs (eg washing, dressing, making meals) were common, and few people were aware that social services might be able to assist with such tasks. These problems were often exacerbated by problems with inadequate housing and a lack of aids and adaptations.'
- Lack of knowledge of entitlements was one of the greatest barriers, and service providers frequently lacked this knowledge, thus making it doubly hard for the right information to be passed on.
- There were instances of extreme isolation – some disabled

people reported rarely leaving their home, and having very few visitors

- Uncertainty about which agency is responsible delays service provision for this group, who are already extremely vulnerable.

Although this research was about the lives of disabled adults, it highlights some important issues that need to be addressed for children:

- The impact of poor housing, and housing that does not meet needs can limit the life-chances of a disabled young person.
- The cost of supplying aids and adaptations to a family can be far less than the cost of intervening due to an injury caused by lack of appropriate aids or adaptations.
- Disabled children are just as likely to become severely isolated, particularly if the host country seems to be unresponsive to individual needs.
- If agencies are unclear about who should take responsibility, these children may 'fall through the net'.

While some of the issues may be resolved if the disabled child is with their parents, the difficulties are exacerbated if the child is an unaccompanied minor.

case study

An inner-city social services department described a young person they were supporting, an unaccompanied 15-year-old from Eritrea who was disabled as a result of a bomb. Not only did the boy have to come to terms with being away from home, but he was also newly disabled, as he had had to have his hand and arm amputated.

The social worker appointed to support this young man had never worked with disabled people. She sought assistance initially from the social services team for disabled children and then contacted occupational therapists who assessed the boy for aids and adaptations.

Initially, this young man was placed with Eritrean foster carers, but very soon they began to take over his life, and he was at risk of becoming dependent on them at a time when he was almost ready to live independently. It is not surprising that the foster carer wanted to help him, given his experiences, but this period of vulnerability needed to be kept short, rather than maintained in any way.

Fortunately, his social worker was also from Eritrea and was able to gain his trust, speak to him in his own language, and ensure that his needs were fully and appropriately addressed. The young man moved into a flat, and social services helped with more than just the basics. They undertook an assessment of his needs, including those arising from his impairment, and they bought him additional equipment to assist him, such as a liquidiser, as he only had the use of one hand. They also employed someone to help him on a short-term basis with budgeting and cooking.

This case study demonstrates how complex this area of work is, and how important it was to keep in touch with the young person after placement, rather than leaving the foster carers to meet all this young person's needs. Interventions are most effective when they empower a young person to live their own life. They can do this while living at home or with friends, as long as they are enabled to make choices and decisions for themselves.

In the case study, the social worker identified the following challenges:
- the young man had no extended family, so he had no informal support
- the trauma of being an unaccompanied minor had been exacerbated by his disability
- he did not understand how 'the system' works in the UK.

Because the social worker spoke the same language, misunderstandings were avoided. The social worker had a shared cultural understanding because she was also from Eritrea and there were no barriers to communication, so this young man was able to open up and ask questions.

Summary

More research is needed in this area, and it is likely that once local and national research identifies the number of refugee children and young people who are disabled, services will develop to meet their needs. In the meantime, services will be improved if:
- staff training includes information about asylum-seeking or refugee children who are disabled, addressing the impact this may have on their lives and the support available
- medical staff who undertake Looked After Children medical examinations remain vigilant for disabled children who may require support.

Tips for working with disabled children who are asylum seekers or refugees

Ensure that you and your colleagues know:

- the services and benefits a disabled child is entitled to
- the child's immigration status
- if the child would prefer support from someone who is the same gender
- the language, ethnic and cultural group to which the child belongs
- if there is a staff member who has the same language or cultural heritage, and if not, where you might find such a person or gain the appropriate support – if the child is in agreemnt with this
- that training is available that covers the context of where asylum seekers and refugees come from, what their needs are, and issues affecting disabled children
- whether the children and young people on your caseload have any 'hidden' disability, such as a hearing or visual impairment. Medical intervention is costly in some countries, and some children may hide impairments through fear of being different or adversely affecting their immigration status.
- if a disabled child has a communication impairment, then ensure that specific communication assistance is used if necessary.

Resources

The Children's Legal Centre has a factsheet on their website about the support that the disabled child of an asylum seeker is entitled to (see www.childrenslegalcentre.com).

The National Information Forum (see Appendix 3) guide *How to access disability services* is specifically about entitlement for disabled refugees and asylum seekers, with information about services for both children and adults.

The Refugee Council website provides general information about children who are asylum seekers and refugees (www.refugeecouncil.org.uk).

5 Barriers and how to overcome them

Many publications over the last 20 years have drawn attention to the scarcity of appropriate services for black and other minority ethnic disabled children and their families, and the barriers they face. This chapter will draw on the findings and recommendations from several of these publications including Shah 1995; Chamba and others 1999; Mir and others 2001; Flynn 2002; Audit Commission 2003; Disability Rights Commission 2004; Chahal and Ullah 2004.

Tips are included which have been gathered from the research literature and from the projects that were contacted for this guide.

In *All our children belong* (Broomfield 2004) a parent was asked about her experiences; her response is indicative of the barriers faced:

> '*In what ways do you feel that black and minority ethnic people, and parents of disabled children, could be better served by education, health and other statutory services?*
> They need to raise their profile more within the black Asian and other ethnic minority communities. They should target our communities, especially where English is a second language. I know of many black and Asian people who are not aware of some of the services they are entitled to, or aware of the help they can access from certain services. I think it is important that everyone is made aware of the services out there to support them.'

Barriers to finding out about services

- Unfriendly or ill-informed reception staff, who act as the gateway to many services
- Ineffective communication systems that may prevent black and other minority ethnic families from understanding the services to which they are entitled and how to access them – eg families who want short break services but are unaware of the services available
- Lack of translation and interpreting services
- Physical barriers, such as buildings, restaurants, houses, transport, and meeting rooms being inaccessible to wheelchair users or people with a mobility impairment
- Lack of induction loops (a technical system which amplifies sound for individuals who have a hearing aid)
- Use of small print in publications, posters, presentations and handouts
- An assessment itself can be a barrier, because the child and family may have to wait for it to happen, and they are less likely than white majority families to know about other support or benefits that are available
- Previous bad experience of service provision or professionals
- More reliance on public transport
- Not speaking English was identified as a barrier to accessing social and welfare entitlements

Tips for overcoming barriers

- Make arrangements with local translation and interpreting services.
- Use a variety of means to disseminate information, such as audiotapes, large print, video/DVD/CD-ROM and Braille.
- Provide training for reception staff about the importance of effective signposting.
- Subscribe to a national interpreting service – eg Language Line, which operates a 24-hour telephone interpreting service (tel: 020 7520 1430) or EITI interpreting and translation services (tel: 0800 731 7878).
- Provide specific assistance to children and families – eg Hopscotch (Camden London), Contact a Family (Lambeth London), Bright Eyes (Luton) and Pukar (Preston).
- Organisations that provide a keyworker system have been able to empower families more easily to gain support – eg Alafia (Reading).
- Improve dissemination of information to target health, social care and education services, as well as faith groups and businesses
- Ensure that transport is provided to enable black and other minority ethnic families to attend. Some organisations contacted

for this study have done this – eg Birmingham Children's Centre, Parvaaz (Slough).

- Direct Payments from social services departments can provide a way for disabled children and their parents to manage and commission their own support services.

Barriers due to the lack of information about, and analysis of, local minority ethnic disabled children

- The lack of accurate local data about black and other minority ethnic disabled children leads to the inability of services to make appropriate plans for delivery and improvement, as well as an inability to monitor service uptake.
- Low numbers of minority ethnic people in the local population may be cited as a reason for inattention to meeting the rights and requirements of these groups of parents and children.

Tips for overcoming barriers

- Find out about the ethnicity and religion of the population in each local authority, which is available from the Census 2001 website: www.statistics.gov.uk/notices/Census_25Jun03.asp.
- Ensure that information about ethnicity and disability is recorded in all registers and assessments – eg Disabled Children register, registration for people who are blind or visually impaired, child protection registration, child development centre assessments, school admissions, referral forms.

  Some services have been established as a result of a local research project which identified lack of provision and made recommendations to resolve it, so it may be worth contacting them to find out how this was achieved – eg Naseby Centre (Birmingham), Apne Bachay Project (Dewsbury), APASENTH (Tower Hamlets), Include Me Too (Wolverhampton).

  Authorities with a relatively low number of disabled minority ethnic children will need to take targeted action to ensure that they do not remain marginalised.
- Bayley (2005) has put together some questions for Race Equality Officers which after a slight adaptation may be helpful as an audit tool for services for disabled children.
  It would be beneficial if all managers could answer these basic questions:
  – What is the ethnicity and age profile of your area? How many disabled children from black and other minority ethnic communities are there in your area?

- How many have a learning disability?
- How many have a physical impairment?
- How many have a sensory impairment?
- What is the current uptake of services by these groups of people?
- What is the projected uptake of services?
- Are you consulting with disabled children from black and other minority ethnic communities when planning and establishing services?
- What provisions are in place to ensure that services are accessible for minority ethnic disabled children?
- What do your answers tell you about your information base?
- What do they tell you about how inclusive your race equality work is?
- How can you use your existing skills to include disabled children and their parents/carers? Think about:
  - communication
  - involvement in decision making
  - working across service areas.
- What are your own support needs in the above areas of work?

In any discussion about people from black and other minority ethnic communities, it needs to be recognised that these are not homogenous groups, and their needs cannot necessarily be met in the same way. Assessments need to be individualised, and consultation work cannot rely on what a similar group of people said in another part of the country, as people's experiences will be different, as will the way services are delivered in different areas.

Data from the 2001 Census provides information about people from 'other white' minority ethnic groups. However, except for a category of Irish, there is no breakdown of these groups. For example, in Cambridgeshire, the Census 2001 shows there are 22,386 people in the category of 'other white', which represents 4 per cent of the total population. However, the detail of who these people are is not available, so that even where data is known, it is not always helpful, and it will need to be supplemented by local knowledge. This means that the white minority ethnic population may be hidden, and is likely to be larger than estimated.

Barriers due to discrimination and prejudice

- Lack of anti-discriminatory training for staff, including management
- Assumption that black and other minority ethnic families 'look after their own' and have extended family network for support
- Ignorance of the Race Relations (Amendment) Act 2000
- Insensitivity to a family's culture and religion
- Assumption that minority ethnic communities make up a homogenous group, leading to an over-generalisation and over-simplification of individual's social welfare needs
- Duty to take account of the child's racial origin, ethnic and linguistic background (section 22 of the Children Act 1989) not always carried out
- If a child is prevented from making a choice or taking part in an activity, it must be clear why this decision has been taken, to ensure that it is not as a result of any form of discrimination.
- Assumptions made about what communities want because local parents and children are not consulted.

Children and parents will naturally prefer to use a service that meets their needs effortlessly. It is important to let service users know what to expect, eg making it clear that professionals in a service respect the rights of black and other minority ethnic disabled people and will demonstrate zero tolerance of racism and disablism.

Example

Ehsas Carers (Dudley) leaflet states the following aims:
- **to identify and assist carers, particularly if they cannot speak English, by publicising services in Urdu and Mirpuri**
- **to provide families of children or adults with disabilities with a culturally sensitive support group that offers emotional and social support, and time out to engage in community and leisure activities.**

Tips for overcoming barriers

- Identify local minority ethnic communities and build links with community organisations that support them.
- Ensure staff are familiar with the statutory requirements of the Race Relations (Amendment) Act 2000 (see Appendix 1).
- Ensure that adequate attention is paid to children's racial origin, ethnic and linguistic background, by finding out what these mean to them and what they mean to the children's parents (Children Act 1989).
- Ensure that a child's impairment does not take over from all other aspects of their identity in an assessment.

Barriers caused by lack of staff diversity

- Lack of targeted job advertising in minority ethnic press
- Few bilingual staff recruited
- Little targeted recruitment of black and other minority ethnic carers for short- and long-term fostering
- Insufficient effort made to increase the number of minority ethnic workers if they are underrepresented within the services

Tips for overcoming barriers

- Develop an organisational strategy for the recruitment, training, career development and retention of staff from black and other minority ethnic communities.
- Use informal networks and email groups to supplement other advertising.
- Ensure that ethnic monitoring is carried out by employers. Does the workforce reflect the ethnicity of the area it serves?
- Promote your organisation as a fair and supportive place for minority ethnic people to work.
- Contact an organisation that has recruited minority ethnic staff – eg Bristol Social Services Family Link, Buckinghamshire Social Services Take a Break, Parvaaz (Slough) and Scotland Ethnic Enable have recruited bilingual volunteers.

Barriers to services being established and sustained

- The lack of long-term funding for small community organisations
- Good work is not being identified, evaluated and embedded into mainstream practice

Tips for overcoming barriers

- Some organisations could employ or share fundraisers.
- Ensure services are evaluated and the recommendations are disseminated to the local authority, councillors, MPs, primary care trusts and others with authority to make changes happen.
- Absorption of successful projects into mainstream services.

Barriers to participation by disabled children and their parents

- Many professionals feel they do not have the skills to find out the views of disabled children, and cannot therefore maintain a dialogue with them.

- The views of parents are often not given as much credence as the views of children.
- Children and parents may lack confidence to express any dissatisfaction, and they may think that support will be reduced as a consequence.

Tips for overcoming barriers

- Contact projects that have already sought the views of minority ethnic disabled children and their parents, eg The Children's Society (London) and Include Me Too (Wolverhampton).
- Several projects have consulted with parents and reported their findings – eg Include Me Too (Wolverhampton), Parents for Inclusion
- Find out about the consultations with disabled children which have been undertaken and written up (Marchant 1999; Marchant and Jones 2003).
- Obtain the two guides about facilitating parent participation that have been published by the Council for Disabled Children and Contact a Family for parents and professionals (McBride 2004; Shelley and Winters 2004).

In the same way that parents' forums are set up to find out the views of parents and carers, it may be necessary to set up children's forums. The building blocks for these may already exist in schools, such as circle time or school councils, and residential homes for children (both short term and long term) often have house meetings. There may be other activities organised by statutory and voluntary organisations where groups of disabled children meet, as well as groups of disabled and non-disabled children, such as youth services and holiday activities organised by a charity.

More recently, there has been an increase in the amount of time and funding provided to ensure that children's views are sought and acted upon. This may be a reflection of the increased attention that this area of work has received, with the emphasis in the Special Educational Needs Code of Practice 2001 on the importance of pupil participation for children with special educational needs, the NHS guidance on seeking consent from children for medical interventions, the Children Act 2004 emphasis on finding out the wishes and feelings of all children, and the appointment of a Children's Commissioner for England.

The difficulty of finding out about local services is a very commonly reported barrier

If a parent or child does not know that a service exists, they will not request information about, and if they do not understand about entitlement to services, they will not ask for them. To complicate this difficulty further, although there may be several organisations providing services for disabled children and young people from black and other minority ethnic communities, it can be hard to find them, and particularly hard to know who in a local authority should be the first point of contact.

If it is hard for the project worker with over 20 years of experience of working with disabled children, how much harder is it for children or parents to find information, especially if English is their second language? To illustrate this, the project worker completed three 'mystery shopper' enquiries.

case study Mystery shopper

The mystery shopper telephoned the main switchboard of three local authorities and asked about support services for black and other minority ethnic disabled children.

Local authority 1 The worker was put through to adult services, and twice connected to Childline. On the fourth attempt, the worker was put through to the social services duty officer, who was very helpful and rang back within 24 hours with additional information.

Local authority 2 The worker was put through to the Equalities and Diversity division, and from there to the social care and health division of the equalities directorate. The manager was off sick and no one could help for ten days. The worker rang again and asked for services for disabled children, and was given a number which was on answerphone. The message was passed from the disability register office to the social services team working with disabled children. A duty social worker rang back the next day, referring the enquiry back to the disabled children's register office.

Local authority 3 The worker was put through to the housing department.

Tip

- It would be very difficult for someone to find the right person to speak to if they did not know how a local authority works and who does what.
- Ringing the main council switchboard may seem to be the obvious first choice, but as the examples above demonstrate, it is very easy to end up nowhere near the right source of information. As all councils have a Children's Information Service (CIS), this could be a first port of call. One way to find the local CIS is to contact the National Association for Children's Information Services (NACIS), tel: 020 7515 9000, email: info@nacis.org.uk, website: www.nacis.org.uk

EXAMPLE

The Liverpool Children's Information Service has started to train their front-line staff to ensure that the people who are the first point of contact for members of the public are informed about the wide range of services provided, and about the barriers that prevent easy access to them.

who to ring for information about support services

Children's Information Service (CIS)
Social services team for disabled children
Parent Partnership Service
Child Development Centre
Council for Voluntary Services (CVS)
Children's Centre
Carers organisation
Local council play services
Local council youth services
Voluntary organisation – eg Contact a Family

Websites
Every local authority has a website, and these are listed in alphabetical order on the website: www.direct.gov.uk under the heading of 'Directories'. Some local authority websites have a wealth of information, but it can take time to identify the right information.

6 What works well

This chapter illustrates the variety of ways in which statutory authorities and voluntary organisations meet the needs of disabled children from black and other minority ethnic communities services.

Starting places

Apart from parent-led groups, a starting point for other organisations must be to determine local need in the area. Among local authorities and voluntary organisations:

- some have not identified the number of black and other minority ethnic disabled children in their area
- some have done so, but not taken any action
- some have taken action with limited success
- some have taken action with success.

For those authorities or organisations that have not identified the number of black and other minority ethnic disabled children in their area

- Does anyone in the authority/organisation have this information? For example, some information may be on the disabled children register, or held by the education department, or be known to youth services, or known to local voluntary sector organisations.
- Of the total estimated number of minority ethnic disabled children, how many are receiving services?
- How does that number compare with the number of white majority disabled children receiving services? Should this comparison be further investigated?

- What stops minority ethnic disabled children from being a priority group that needs to be targeted?
- Who would take the lead on this?
- Is there any forum in which interested stakeholders can meet?
- Are there any support groups for minority ethnic parents of disabled children?

EXAMPLE

Telford and Wrekin Borough Council (population: 158,000, largest ethnic population: Indian 2,600 or 1.6%) has a relatively low number of black and other minority ethnic families. The Joint Commissioning Team believes this may mean that families are even more isolated. They have established a Disabled Children's Commissioning Group which has commissioned research to find out from disabled children and their families what services would meet their needs. The strategy document dated July 2005 states:

> **'One of the priorities of the Telford and Wrekin *Disabled Children and Young People's Strategy* is, in partnership with disabled children and their families from black and ethnic minorities, to identify the prevalence and specific needs of disabled children from black and other minority ethnic communities and review and develop services accordingly.'**

The joint commissioner, Lindsay Richardson, commented that the process of gathering the material was useful in itself. It has heightened awareness, among a range of service providers, of the needs of disabled children. One of the benefits of having a commissioning group was that a number of links were made between, and sometimes within services, which proved to be very helpful and acted as a catalyst for action.

For those authorities or organisations that have identified numbers, but have not taken any action
- Who has this information?
- What needs to happen next to make progress?
- Who will do it?
- Is there any forum in which interested stakeholders can meet together to formulate plans and action?

For those authorities or organisations that have identified numbers and have taken action, but with limited success
- Has the service been evaluated?
- What needs to happen next?
- Who will take the lead?
- How will it be prioritised?
- Is there anyone locally or nationally who could take on an advisory role?

For those authorities or organisations that have taken action with success

- Has the service been evaluated?
- How will it remain a priority area of work?
- Who has the lead?
- Is there sufficient ongoing funding to maintain the service and develop it further?
- How can good practice be shared?

Inclusive services

Many organisations operate services which are deemed to be 'open to all'. This means they do not have any specific strategy or separate groups or activities for disabled children from black and other minority ethnic communities because they are welcome to join in with the activities that are already organised. If minority ethnic children do not attend these groups, assumptions may be made that they do not need these services.

However, an inclusive strategy means more than advertising services as 'open to all'. Specific targeting of local underrepresented groups is needed, so that the service:

- makes minority ethnic disabled children feel welcome, by taking their culture and religious practices into account
- addresses the barriers that prevent the participation of minority ethnic children
- is proactive in seeking out new people to be involved in its activities
- ensures that people from black and other minority ethnic communities know about the activities and where to find out information about them
- ensures that publicity materials are printed in relevant languages.

Authorities with a large minority ethnic population vary in the number of services they provide. There may be a number of services targeted at minority ethnic groups, but there may also be many gaps in the support services, partly because minority ethnic communities do not form a homogenous group and do not live in just one part of an authority's catchment.

Gaps in services are often plugged by national and local voluntary organisations. Gaps are also plugged by parent support groups set up to meet the needs of local parents but which then broaden their scope to include child-oriented activities, such as playschemes or holiday activities. This is one of the reasons it is always important to consult parents and carers about plans to

develop services if there is an intention to consult children and young people.

There are many examples of practice where inclusive policies work and where underrepresented groups have been targeted.

EXAMPLE

Volunteers for Parents' Voices (Nottingham)

The project manager of this organisation found that they had a shortage of minority ethnic volunteers, so they decided to undertake some targeted advertising. They now have three bilingual volunteers who work very closely with their local parent partnership service, and ensure that parents are referred on to them for any specific education advice. One or two people are volunteers for Volunteers for Parents' Voices and for the local parent partnership service, and where this person is advising on separate issues, the organisations have agreed to enable just one volunteer to remain with the family, rather than re-allocating to a second volunteer.

EXAMPLE

APASENTH is a parent-led organisation in the London Borough of Tower Hamlets (population: 196,000; largest minority ethnic group: Bangladeshi – 65,500, 33.5%). APASENTH has become the main provider of services for disabled children and young people with learning difficulties in the borough.

EXAMPLE

In Birmingham, over 80 different groups support Somali families, and yet none were supporting parents of disabled children. In 2004/05, the regional office of Contact a Family (Birmingham) helped a group of Somali parents to establish a support group, develop training for Somali volunteers and launch an inclusive playscheme.

EXAMPLE

In the London Borough of Ealing, there are approximately 50,000 people whose ethnic origin is Indian out of a total population of 300,000 – ie 16 per cent. There are several voluntary organisations in Ealing that are supporting disabled children from black and other minority ethnic communities, including Mencap, the Physical Activities Club in Ealing (PACE) and Contact a Family.

Tips

A good service will:

- identify the number of black and other minority ethnic disabled children who are live in the area and ensure that the Disability Register reflects this number
- identify existing statutory and non-statutory groups that provide support for minority ethnic parents and their children, and publicise this information, identifying which groups are inclusive and which are specialist
- share knowledge about the funding available to assist small organisations, such as funding from social services, education departments, Connexions and other local and national government initiatives.

Challenges

- Funding provided on a short-term basis
- No internal or interagency strategy underpinning the development of a project or post
- Disability register data held on database that cannot easily collate different types of information

Models of service delivery

There is a wide range of services provided for minority ethnic disabled children and their families, and they have been developed and are run in different ways. Services can be separated into five models of delivery, and examples of each type of service follows:

- parent-led services
- community-led services
- local authority-led services
- charity-led services
- spot purchasing of services.

Parent-led services

APASENTH (Tower Hamlets), Khaas (Bristol), Ehsas Carers (Dudley), Parents for Inclusion (London), Asian Families Support Service (Sandwell)

These organisations were set up initially by parents and for parents. However, many widened their remit once the organisation became more established and funding streams were secured.

APASENTH (Asian Parents' Association for Special Educational Needs in Tower Hamlets, London)

One of the founders of Apasenth explained:

'In 1984 my son, who had severe learning disabilities, attended a local special school. I became very dissatisfied with his lack of progress. He could not speak, could not dress himself, lacked most basic skills. I decided to try to get together with a few other parents with disabled children at the same local school. Four or five parents began to meet on a regular basis to discuss our difficulties and try to plan how best to help our children learn.'

Education was the core focus originally, and parents met weekly to:
- **share experiences**
- **give each other advice and support**
- **decide what services were needed**
- **promote the children's learning and happiness.**

After some time, Tower Hamlets social services allocated the group a social worker, who offered support and provided information about the toy library. Other professionals were invited to speak to the group and seminars were arranged so that parents could learn new information and skills.

Initially, funding was from small subscriptions to pay for a meeting room. This was later provided in a community centre by the local authority. Eventually, funding was identified through the local authority and a number of charitable trusts. A number of services were set up, and these have continued to expand.

(Source: http://www.eenet.org.uk/parents/stories/apasenth.shtml)

Community-led services

Apne Bachay (Dewsbury), ABCD (Wales), Alafia (Reading), Apna Sahara (Lincolnshire), Parvaaz (Slough), Hopscotch (Camden, London), Pukar (Preston)

These are projects staffed by professionals, and set up once a gap in services was identified. Some were established as community centres and have widened their remit to include services specifically for disabled children (eg Hopscotch). Others were established specifically to support disabled children and their families – eg Alafia and Apne Bachay.

Alafia

Alafia was established in 1995 in Reading to provide family support for parents from black and other minority ethnic communities and their disabled children. It offers outreach and individual support.

The project worker found that it was not enough to signpost families to services. For example, telling a family they were entitled to Disability Living Allowance was not enough; parents needed to know how to get the form and how to fill it in. Once the project worker began to visit the families more often, she realised that some could not read or write, and some did not understand about benefits or about the assessment process for a statement of special educational needs. As a result, a keyworking model was developed, which enabled the worker to go with parents to family reviews, help with letters and ensure an interpreter attended if necessary.

The importance of using interpreters was clear from early on, but some conflicts arose because:
- **it could be very difficult for a family to complain about services if the interpreter is employed by the local authority**
- **although many families have a reasonable amount of 'social English' and can get by, expressing opinions and emotions may be more difficult.**

Although there was a very good response from Asian families, Reading has a sizeable African-Caribbean population which was not represented in service take-up. The project worker wondered if it would have made a difference to have an African-Caribbean manager.

The project began to run a playscheme during term time, as social services only ran one in the holidays. However, lack of funding meant the playscheme had to cease.

Local authority-led service

Naseby Centre (Birmingham), Cheviots (Enfield, London), Bristol Family Link, Buckinghamshire Social Services Take a Break, Dudley Learning Disability Services, Liverpool Parent Partnership

This is where a service is set up, funded and developed by a local authority, usually following a local analysis of need – eg the Naseby Centre in Birmingham, although sometimes it can emerge from the interest and experience of a worker who has an interest in a certain area of work.

Liverpool Parent Partnership Service

The post of Ethnic Minority Community Parent Links Officer was established within the parent partnership service in association with the Ethnic Minority and Travellers Achievement Service, and it arose from the Stephen Lawrence Inquiry report. The parent partnership manager found that the service had not reached black and other minority ethnic parents sufficiently, and those that did use the service came to it later on in the process of having their child assessed for special educational needs.

The focus of the post is on children with special educational needs and disability, on raising the profile of support services to minority ethnic parents, and explaining the parent partnership role to teachers and community leaders. In addition, the parent partnership team received training to enhance their understanding of the cultural issues around disability.

Three elements to the work were identified:
- **individual work with families**
- **bridge between school and parent for black and other minority ethnic parents**
- **link with community groups – eg meeting arranged between schools and representatives from the Somali community.**

An important aspect of the post was that the worker reported directly to the chief executive, thus giving the work a higher profile.

Charity-led services

Locally: Birmingham Children's Centre, The Children's Society (London), Contact a Family (Birmingham and Lambeth), Barnardo's (Waltham Forest, London), York Traveller Trust, Project Smile (Manchester Jewish Fed)

Nationally: National Autistic Society, Mencap Sunna project, Shared Care Network, Deafblind UK

Many charities are currently addressing the needs of minority ethnic disabled children. Nationally, some have found that disabled minority ethnic children are underrepresented in their services and consequently have employed a specific worker to redress this situation. On a local level, some have developed services based on the needs in a particular area – eg The Children's Society, Manchester Jewish Fed.

EXAMPLE

York Travellers Trust

A Traveller family with two disabled children was helped by the trust. The hospital was reluctant to carry out an operation on one of the children because the family lived in unsuitable accommodation, and the operation would have meant that the child would have to become a wheelchair user. The only solution was a static caravan, but no one was willing to take responsibility for this, and the family could not afford it. The local authority housing department offered a house, which the family did not want for cultural reasons – their family and support systems were all based on living within the Traveller community, and not in a house. Yet the housing department had discharged their duty by offering a house.

The York Travellers Trust wrote to the chief executive of the local authority and explained the cultural reasons why a static caravan would meet the child's needs, as well as the family's housing needs. As a result of the support and legal advice that was offered, a static caravan was provided.

Spot purchasing

The London boroughs of Camden and Hammersmith & Fulham, The Children's Society Disability Advocacy Project (London), Somali Carers Project (London)

If a local authority does not have the resources to provide a service itself, but accept that there is a need for the service, they may decide to purchase it from a local service provider. This is called 'spot purchasing'. The authority may also set up a tendering process to actively seek a provider who will meet a local need.

EXAMPLE

The Children's Society Disability Advocacy Project in London provides a service for disabled children living in residential accommodation away from home. Several London authorities purchase services from the project. An advocate with the project explains how the project assisted a young disabled person.

'Ali is a 15-year-old Asian boy with autism. He lives in a school placement far from home in a predominantly white, rural area.

'Ali is a Muslim and when I first began working with him I discovered that the school provided a bus every Sunday morning to take children to the local church. They did not, however, have any provisions for taking any of their Muslim children to a mosque. I asked Ali if he was

interested in attending the local mosque. He immediately replied 'Yes'. I approached Ali's keyworker, who said he would like to help, so I asked him to find out more.

'When I returned a month later, Ali told me about the trip to the mosque with his keyworker. Unfortunately, the keyworker had not known what time to go, and they had missed prayer times. I soon realised that despite the genuine attempt made by the keyworker, he needed more support from the school, and that going to the mosque should not be a special treat. The school had many children from diverse cultural backgrounds and it should be better equipped to address their individual needs. Additionally, I was concerned about the lack of diversity among the staff.

'In my report for Ali's upcoming review I challenged the school for not providing equal access to religion for all the residents. I also expressed a wish that the culture and ethnicity of staff should reflect that of the young people they work with. Soon after my report, Ali informed me that he had gone to the mosque during prayer time with a new employee who was also a Muslim.

'What I did was convey what Ali wanted and encouraged the school to address it. Instead of ignoring or defending the situation, the school demonstrated that it was open for change and improvement. This is one of the reasons this is still one of my favourite schools to visit.'

Challenges

Not all projects are immediately successful. It is often through identifying gaps in services that lessons can be learned and services improved.

EXAMPLE

A national charity set up a local project to help young people with learning difficulties to access leisure facilities. They did this in partnership with a minority ethnic organisation, from whom they received their referrals. The plan was to match support workers with young people so the workers could get to know the young people, find out what they liked doing, and identify leisure activities for them, whether mainstream or specialist activities – eg going to the cinema or joining Riding for the Disabled.

This project found that it was not possible to recruit support workers with experience of working with disabled young people, so the project plan had to be revised.

A local authority short break service employed a minority ethnic worker to identify more black and other minority ethnic carers for disabled children. This worker found that she was in a difficult position when a child protection issue arose, as the family lived in her neighbourhood, and was part of her religious community. Because some communities are very small, this made it very difficult for the worker, and she left as a result.

People who work in a small minority community where they also live, may hold themselves back from applying for a job which may put them in conflict with their community. This potential conflict needs to be recognised by potential employers, with ways built in to support the worker. For example, providing regular supervision for staff is one way to enable a worker to overcome this difficulty, as this will provide an outlet to discuss and resolve any apparent conflicts that arise.

Summary

- Organisations may start from different places in their delivery of services, but there are always opportunities to improve
- Having a service which is 'open to all' does not go far enough. Specific targeting of local under-represented groups is needed, so that children and families are not solely responsible for finding out information about services
- There are different models of delivery, each with their own strengths and challenges.

7 Critical success factors

The following factors are critical in enabling providers to successfully deliver services to disabled children from black and other minority ethnic communities.

Understanding the needs of the local community

- Liaising and linking with local associations, and holding regular meetings
- Targeting black and other minority ethnic disabled children and their parents
- Having a steering group made up of statutory and voluntary agencies, and including disabled people and parents – eg Apne Bachay (Dewsbury, Kirklees)
- Being situated close to the community being served – Birmingham Children's Centre, Apne Bachay, Naseby Centre (Birmingham), Alafia (Reading), Include Me Too (Wolverhampton)

EXAMPLE

Naseby Centre

In order to determine what service was going to be provided to disabled children in the Washwood Heath area of Birmingham, a short research project was undertaken by the Naseby Centre to identify the local needs of parents and professionals. The centre then organised an event in Carers' Week and parents and children were invited, and a celebratory lunch was organised. As a result of meeting at this day, a small group of parents and carers met regularly for mutual support. In addition, key professionals were invited to the group to gain their interest and support.

Disability support workers were subsequently employed to help families overcome the barriers that prevented them from taking up services and benefits to which they were entitled.

Working in partnership

- Working in partnership with community organisations – eg Early Years Play Services (Bradford) works closely with the Asian Disability Network
- Consulting children and their families
- Including disabled children in mainstream activities from an early age

EXAMPLE

The Include Me Too project in Wolverhampton identified four partners with whom they wanted to work in order to identify and support black and other minority ethnic disabled children. These partners were:

- children and their parents
- faith communities – by contacting the local leaders of 11 religious groups
- businesses – by contacting a range of local people, from travel agents and grocers, to corporate organisations
- statutory agencies.

The project sent questionnaires to families and organised a consultation event for children and young people. Creative arts were used to help gain children's views – these included dance, Dru Yoga, Islamic art and drumming. Preparation was carried out in association with six local special schools, and the artists all attended an induction day to ensure they could get the most from the children. Brothers and sisters of disabled children were invited to the day and their views were recorded. Pupils from two mainstream schools agreed to take part in the consultation. The aim of this was to increase their awareness of their disabled peers from the special schools.

The project wrote a Children's Charter setting out the rights of the local minority ethnic disabled children, produced a children's music CD about being included and created a gallery of positive images of minority ethnic disabled children from which photographs can be bought for use in publications.

The project plans to have the charter endorsed nationally so that all black and other minority ethnic disabled children can find out about their rights and work out ways in which those rights will be respected.

Cultural sensitivity

- Improving the cultural awareness of all workers
- Ensuring workforce diversity
- Providing interpreting and translation services
- Employing a minority ethnic development worker – eg Dudley Learning Disability Services, Liverpool Parent Partnership, London CLIC Sargent
- Providing training on all forms of discrimination – eg ethnicity, religion, disability and gender
- Liaising with local minority ethnic communities to foster trust

EXAMPLE

The project worker at Contact a Family in Birmingham was contacted by a health visitor to assist a local Somali parent support group to become more established. The worker met the group two or three times, and they talked about the difficulties facing Somali disabled children, adults, the elderly and their families and how their group was trying to help. The group had identified the following issues that needed to be addressed:

- Families were finding it very difficult to access information and services because many did not speak much English or understand the system or their rights.
- Families who had managed to get an assessment of needs had inappropriate services put in place – eg an Asian care worker would be sent to a family who only spoke Somali and a little English, and the care worker did not know anything about Somali culture.
- Families did not understand the adult or child's disability.
- Many children were not attending school regularly.
- Families did not understand the education system or how they could help their children.

It was important for the project worker to visit the community in an open-minded way, and although it may have been hard to believe how little information families had about support available, this is commonly the case. A significant amount of cultural understanding is required to gain the trust of a family, especially for people who do not share the same ethnic heritage. In this example, the project worker was white and knew that it was essential to find out what mattered to the group in order to work respectfully with them and to represent them effectively other agencies.

The Project worker was able to link up the Somali group with a local Crossroads Service. Crossroads then worked with the group to recruit and train local Somali care workers.

(See Chapter 3 for more information on cultural sensitivity.)

Accessible, flexible and responsive

- Non-stigmatising services
- Information available in relevant languages, in Braille and large print, and in non-written forms – eg CD-ROMs, tapes
- Range of services provided
- Services are adapted as needed by local people
- Referrals are dealt with quickly
- Targeted publicity
- Identifying local barriers and ways of overcoming them
- Running holiday schemes for the whole family, not just the disabled child
- Providing one-to-one support for families through a keyworker

EXAMPLE

Pukar

A disabled Asian woman established Pukar in Preston in 1998. It offers a range of services for parents and carers so that they can learn together, socialise, be supported and support one another. It also acts as a signpost to other agencies and provides services for children, such as weekend and evening activities.

Project keyworkers visit families and discuss any current plans for their disabled children and the challenges families are facing. Language is the biggest barrier that parents experience, which is compounded if they do not understand the role of the statutory services. Parents have said that they value the personal contact offered by a keyworker, who can explain how the statutory and voluntary sector can provide support.

Training

Training about working with black and other minority ethnic disabled children should include the following topics:

- The Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005, which set out the requirements for race equality and disability equality schemes (see Appendix 1 for details).
- The impact of attitudes and assumptions that are made about black and other minority ethnic disabled children, how this informs people's values and the outcomes for this group of children.
- The importance of building relationships with people from different religions and different minority ethnic communities. This is important, whether or not staff routinely provide any services for people from minority ethnic communities. People who have less contact may be less aware of the issues and more

likely to lack confidence, which is why opportunities to gain knowledge are important, and should not be restricted to the occasional training day.

To enable staff to understand the significance of the value base from which they work, it is essential that they attend regular training. If they work in teams they should attend with colleagues, including colleagues from other agencies. The risk of not doing this is that professionals themselves become a barrier that disabled children and their parents face when trying to access services.

Sustainable funding

- Work that is funded from core budgets rather than being short term and project based
- Skilled assistance with fundraising

EXAMPLE

Cheviots Children's Disability Team (Enfield, London)

Cheviots Children's Centre provides a service for families with disabled children aged from birth to 18 years. The Centre provides and coordinates care packages that can include home care, play schemes, family-based respite care and weekday/weekend activity groups.

The centre was established following the closure of the local residential home which provided short breaks for disabled children. Instead of overnight packages of support being provided, the council moved to providing outreach support in people's own homes. Funding for these support services is now covered by social services.

Cheviots has recently established a consortium of organisations that work locally, and the centre now holds and distributes the grants available. This was arranged because it was thought that the organisation would have good, up-to-date information about the services available, and would therefore be able to ensure that the grants were paid to the most appropriate organisations

8 Conclusion and recommendations

First of all, it is important to acknowledge that there are a wealth of projects across England that are providing innovative and successful services for disabled children and their families who are from black and other minority ethnic communities. Those mentioned in this guide are by no means all that exist, but they are the ones that have been identified in the short life of this project.

Successes

The projects have been set up in a variety of ways. Some have been created as a result of local parents identifying a gap in services, and seeking to fill the gap themselves. Some have been created as a result of a local professional identifying a gap. Some have been created as a result of a strategic decision by a statutory or voluntary organisation to research the take-up of services by black and other minority ethnic communities.

The most successful projects are those that are led from within the minority ethnic voluntary sector. These projects do not report difficulties in attracting minority ethnic staff. They recognise the importance of understanding and respecting cultural issues rather than seeing them as barriers to be overcome, and project workers often speak several languages.

But these projects can have difficulty in reaching all the minority ethnic groups in their area – eg projects employing Asian staff tend to attract Asian families, just as projects employing black staff tend to attract black families. This works well in areas where these are the targeted groups, but on the whole, projects need

staff and volunteers who reflect the diversity of their local population.

Some projects are very successfully run by white workers, when these workers are aware of the barriers and discrimination that black and other minority ethnic families face.

Funding was one of the difficulties that was repeatedly raised. Organisations find it is increasingly hard to get sustainable funding so that short-term projects can carry on. Most of these projects do not have the staff or skills to undertake fundraising, and so their services, or the specific schemes they organise, are often under threat of closure.

Having a project with one or two workers employed on a short-term basis is only enough to begin to tackle the endemic problems that face minority ethnic disabled children and their families. As inroads are made into the local community, and a relationship develops, so there is likely to be a gradual increase in the take-up of services. It takes time to build the trust on which these services can be based, and often there is not enough investment, where quick outcomes are needed in an ever-changing political landscape.

It appears that a national network for professionals who work with black and other minority ethnic disabled children and families would be able to provide a link to share experiences, and find out about local and national developments. There is currently a network for people working with black and other minority ethnic children and adults with learning disability: the Association for Real Change (ARC) has created a UK-wide network called the National Learning Disability and Ethnicity Network. It publishes a quarterly newsletter and has over 1,000 members. The primary purpose of the network is to give advice about where to find the right information. However, this network was set up with short-term funding which ends in 2006.

The interest and use of both ARC and CDC networks demonstrates how important it is to know other professionals who are struggling with similar dilemmas, and that help and advice is available. In a professional world that can otherwise feel very isolating, these established networks can reach far wider than their nominal membership would suggest.

Success factors

There is no obvious factor that determines which projects will last. Several of the parent-led projects have been running for

several years, while others remain very small, surviving on the goodwill of committed volunteers. Those that rely on one or two committed individuals, whether they are paid or voluntary, are likely to be the most vulnerable, because they risk closure when a worker leaves.

There is a lot of competition for scarce public resources and for funding. Initiatives that work closely with parents and other local partners and have a long-term strategy based on evidence and research may be more likely to gain funding. This is also true of projects set up by national charities (see Appendix 2). The majority of projects set up by national charities are established on a short-term project basis, where there is no guarantee that the funding will continue. The danger with this is that contacts with individuals and progress that has been made may be lost.

It is very important that organisations look not only outwards at the communities with whom they work, and the services they provide, but they must also look inwards to ensure that their staff, councillors, trustees and volunteers reflect the diversity of the communities they serve. Furthermore, they need to check that all policies and development plans take account of the needs of the whole community, and specifically include disabled children from black and other minority ethnic communities.

The importance of cultural sensitivity cannot be over emphasised. Project workers need to have an understanding of the discrimination that children and their families face as a result of their ethnicity, religion and disability. The combined impact of the statutory requirements arising from the Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005 should be that every worker is aware of how disabled children from black and other minority ethnic communities may face discrimination in their lives, and what they can do to challenge and overcome it.

Although most of the projects described in this guide are specifically for black and other minority ethnic disabled children and their parents, there are examples of inclusive services, many of which also work with the brothers and sisters of disabled children. In the process of contacting a larger number of organisations than those listed, most of those who said they were inclusive did nothing to ensure that their service users reflected the make-up of the communities they served. Being inclusive has to be recognised as an active rather than passive process.

Recommendations

Commissioners of services need to accept that short-term funding will not deliver the sustainable objectives that everyone hopes for. They need to accept that cost-effective services can only be delivered if funding strategies are clearer and if black and other minority ethnic work is integrated into mainstream provision.

It is often through parent-to-parent contact that information about local resources is passed on. Services therefore need to acknowledge the valuable contribution that parent-led organisations make and assist them in their development so that they can flourish.

National charities undertaking work with black and other minority ethnic communities need to look at sustainability from the outset of project planning.

Some community groups need support in order to provide cost-effective essential services for minority ethnic disabled children and their families. They would benefit from help in identifying funding sources, preferably from fundraising professionals paid for by the local council, primary care trust or the Children's Trust, depending on what the group wants to offer.

The Children Act 1989, the Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005 provide the bedrock on which services for black and other minority ethnic disabled children should be based.

In the Audit Commission report, Let Me Be Me (2003) the author states about the Race Relations (Amendment) Act 2000 that:

> 'this legislation is designed to ensure that everyone has access to the same quality of service, regardless of race or disability'.

It will be important to ensure that subsequent policy and practice reflect these aims.

Training on the Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005 should be prioritised for *all* staff working with disabled children and with children from black and other minority ethnic communities. This training must cover the individual and combined issues of racism, discrimination, prejudice and disablism within a diversity framework.

Research is needed into the lives of disabled children who are refugees and asylum seekers.

Further work is needed to ensure that the views of disabled children from black and other minority ethnic communities are heard.

Lack of trust has been found to be one of the greatest barriers for services to overcome. Parents and carers have reported how badly they have been treated by statutory services, how they do not feel supported, and overall that their experience is one of not being listened to. Stronger partnerships between minority ethnic communities and education, health, social services and other government departments may help to resolve this.

All organisations need to ensure they can monitor the take-up of services by disabled children from black and other minority ethnic communities in order to better plan how to target services and best meet their needs.

In order to adequately represent the communities they serve, agencies need to ensure a workforce that reflects these communities. This includes representation at leadership level, through to management and front line staff.

It is crucial that all services:
- carry out research into the numbers and circumstances of disabled children from black and other minority ethnic communities in their locality
- consult with these children and their families about what works best and what services they would use
- set up and facilitate ongoing forums for children and parents
- work in partnership with other organisations
- ensure that cultural sensitivity is built into their policies and practices
- fund specific projects for at least three years, and embed plans so that they may continue to be funded after that period.

Legislation and policy

This appendix contains key points in primary legislation and government policy documents which determine the way in which services are delivered. The implications for practice are summarised to assist service providers in ensuring that all families have equal access to services for disabled children.

Primary legislation
Children Act 1989 and 2004

Key points

Disabled child is by definition a 'child in need'.

Definition of disability is same as in National Assistance Act 1948 i.e.

> 'A child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially or permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.'

There is a requirement to ascertain the wishes and feelings of the child (as amended by Children Act 2004).

Section 17 was amended by the Health and Social Care Act 2001 to enable disabled parents, parents of disabled children and disabled 16 and 17 year olds to receive direct payments in lieu of services following an assessment. The Council for Disabled Children has published *Direct Experience: A Guide for Councils on the Implementation of Direct Payments in Children's Services*.

Section 22: This specifies the requirement to have regard to children's cultural and religious needs.

Implications for practice

Most social services departments have eligibility criteria for services. For example, to be on the disabled children's register does not mean that a child is considered disabled under the National Assistance Act 1948. Access to social services remains dependent on an assessment of need, usually carried out by a social worker.

Although ascertaining the wishes and feelings of the child is central to the Children Act, the research into how this is achieved with disabled children shows that it is not always successful, rather than it being the norm (Morris 1995, 1998). If children communicate non-verbally, this challenge services, and more so if their first language is not English.

In *Safeguarding Children* (Commission for Social Care Inspection 2005), the issue of recognising a child's needs arising from their ethnicity is specifically addressed:

> 'Agencies recognise that they should pay attention to a child's ethnic, cultural, religious and language needs. In practice, they are still not taken sufficiently into account across all settings. Councils usually have a range of policies and generally try to take account of diversity issues. However, only one-third of councils believe that they consistently communicate effectively with children whose preferred language is not English or who use non-verbal forms of communication.'

The duty in the Children Act to ascertain the wishes and feelings of disabled children is frequently overlooked in respect of disabled children, and the child's impairment is often identified as their primary need, and services are sought that address this rather than any other part of

their identity. However, ask a young person how they identify themselves, and it may not be in terms of their impairment. For example, the Aasha project run by SKILL (National Bureau for Students with Disabilities) interviewed young people from black and other minority ethnic communities who had left school, to find out about their lives, and many talked about their families and religion as a way of defining who they were, rather than talking about their impairment.

Disability Discrimination Act (DDA) 1995

Key points

The DDA definition of disability, which includes children, differs from the Children Act 1989 definition.

The DDA defines a disabled person as someone with 'a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'. This differs from the Children Act definition, yet does apply to children.

Part 3 of the DDA covers access to goods, facilities, services and premises and makes it unlawful for a service provider to discriminate against a disabled person by:
- refusing to provide (or deliberately not providing) any service which it offers or provides to members of the public or
- providing a service of a lower standard or in a worse manner or
- providing a service on worse terms or
- failing to comply with a duty to make reasonable adjustments if that failure has the effect of making it impossible or unreasonably difficult for the disabled person to make use of any such service.

Disability Discrimination Act 2005

Key points

From December 2006, public organisations will be under a duty to promote equality of opportunity for disabled children and adults.

There is a general duty which applies to all public authorities.

The basic requirement for a public authority is to have due regard to do the following:
- promote equality of opportunity between disabled people and other people
- eliminate discrimination that is unlawful under the Disability Discrimination Act
- eliminate harassment of disabled people that is related to their disability
- promote positive attitudes towards disabled people
- encourage participation by disabled people in public life
- take steps to meet disabled peoples needs, even if this requires more favourable treatment.

Implications for practice

One of the key requirements of this Act is that disabled people must be involved in the drawing up of the disability equality scheme. This means that an opportunity will be created for black and other minority ethnic disabled adults and children to give their views about their experiences, and how their lives could be improved.

Race Relations (Amendment) Act 2000

Key points

This makes it unlawful to treat someone less favourably on grounds of colour, race, nationality, or ethnic or national origin.

The Act came about as a result of the Stephen Lawrence Inquiry, and its main aims are to:
- outlaw all forms of racial discrimination
- place a duty on local authorities to promote race equality
- require public authorities   to take account of racial equality in the day-to-day working of policy-making, service delivery, employment practice and other functions.

The general duty of the Act means that public authorities will need to ensure that they:

- consult minority ethnic representatives
- take account of the potential impact of policies on minority ethnic communities
- monitor the actual impact of policies and services and take remedial action when necessary to address any unexpected or unwarranted disparities
- monitor their workforce and employment practices to ensure that the procedures and practices are fair.

Implications for practice

One of the strengths of this Act is that it can be used to tackle the way organisations and institutions discriminate against people from black and other minority ethnic communities. This includes local authority services such as social services and education departments. In addition, if a public service commissions work from the independent, private or voluntary sector, then they have to comply with the duties.

Employment Equality (Religion and Beliefs) Regulations in December 2003

These Regulations prohibit discrimination on the grounds of religion and belief, and allow employees or prospective employees to bring claims before the Employment Tribunal alleging discrimination. Religion or belief is defined as any religion, religious belief or similar philosophical belief, but excludes political beliefs.

Code of practice

Special Educational Needs (SEN) Code of Practice 2001

The SEN Code of Practice provides procedures for identifying, assessing and making provision for children's special educational needs. It legally defines children with SEN as children who have a considerably greater difficulty in learning than others of the same age. It also includes children who, because of their disability, cannot use the educational facilities which other children of a similar age use. There is a

chapter on pupil participation which says that children should, where possible, take part in all the decision-making processes that take place in education. A separate chapter on parent partnership sets out the support provided to parents.

Key policy documents

1989 United Nations Convention on the Rights of the Child

Key points

There is a specific article about services for disabled children (article 23), but it is important that all articles are applied to disabled children, especially article 12 which addresses the importance of enabling children to express themselves.

Valuing People White Paper 2001

Key points

Although this focuses primarily on services for adults with learning disability, it also applies to children, and there is a chapter in it specifically about children's services. In addition, the Valuing People pack included a separate report, *Learning difficulties and ethnicity* (Mir and others 2001) which addresses the discrimination and barriers encountered by black and other minority ethnic adults with learning difficulties.

Implications for practice

At a time when services are becoming more specialised and separate, it is a helpful reminder that services for disabled children and adults have much to learn from each other. As black and other minority ethnic disabled children move towards adulthood, it is important that planning for them takes a long-term perspective.

Every Child Matters

Key points

The Every Child Matters: Change for Children programme aims to put in place a national framework to support the joining

up of services so that every child can achieve the five Every Child Matters outcomes:
- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being.

The ten key elements of the national framework are:
1 the duty to cooperate to promote the well-being of children and young people
2 the duty to make arrangements to safeguard and promote the welfare of children and young people
3 the development of statutory local safeguarding children boards to replace non-statutory Area Child Protection Committees
4 the appointment of local directors of children services
5 the National Service Framework for Children, Young People and Maternity Services
6 the Outcomes Framework
7 the development of an integrated inspection framework
8 the appointment of a Children's Commissioner
9 the development of a Common Assessment Framework
10 workforce reform to help develop skills and ensure staffing levels.

Implications for practice

Although black and other minority ethnic disabled children are often not highlighted as a specific group who will gain from the changes in the national framework, it is important to ensure that their profile is raised within all aspects of the wider agenda for children. For example, now that there is a Children's Commissioner, it is important to ensure that the concerns of black and other minority ethnic disabled children are raised not only with government ministers, but with the Children's Commissioner.

The National Service Framework for Children, Young People and Maternity Services 2004

Key points

The National Service Framework describes what effective health and social care services look like in practice.

Although Standard 8 is the one that specifically addresses disabled children, the other standards are of equal relevance:
- Standard 1: promoting health and well-being, identifying needs and intervening early
- Standard 2: supporting parenting
- Standard 3: child, young person and family-centred services
- Standard 4: growing up into adulthood
- Standard 5: safeguarding and promoting the welfare and children and young people
- Standard 6: children and young people who are ill
- Standard 7: hospital standard
- Standard 8: disabled children and young people and those with complex health needs
- Standard 9: the mental health and psychological well-being of children and young people
- Standard 10: medicines for children and young people
- Standard 11: maternity services

In Standard 8, acknowledgement is made of the importance of:
- being culturally sensitive
- working in partnership with children and their parents
- enabling access to information
- targeted outreach
- providing information in appropriate formats and language.

Implications for practice

Many of the barriers to accessing services which have been identified in the past have been reproduced here. Now that they are detailed in the national strategy for children's services, it will be important to keep them on the agenda, in addition to the ways to overcome them.

The Prime Minister's Strategy Unit Report *Improving the Life Chances of Disabled People* (2005)

This report contains several key points in relation to minority ethnic disabled children.

- Black and other minority ethnic groups are more likely to experience poor outcomes if they are disabled.
- Families from black and other minority ethnic communities with disabled children have a lower take-up of services, and often feel less informed or able to access the system.
- A high proportion of the black and other minority ethnic population live in deprived areas and fall into disadvantaged groups, where a higher incidence of impairment would be expected.
- There are additional barriers for families from black and other minority ethnic groups, as some service providers assume that they will provide more assistance than white families.
- The overall take-up of short breaks by minority ethnic families has not been improving. There is significant unmet need and a disproportionate number of families using institutional rather than family-based provision compared with white majority families. This is despite the fact that home-based services – such as sitting and befriending – are popular with black and other minority ethnic families.
- A particularly good source of knowledge for disabled young people can be others with personal experience of encountering and overcoming disabling barriers. This can have added significance for young people from black and other minority ethnic communities, who are more likely to experience isolation from others with similar experiences.

Implications for practice

Improving the Life Chances of Disabled People highlights the disproportionate way in which disabled children and adults from black and other minority ethnic communities are disadvantaged. It is a long-term strategy, and although it has raised these concerns, a concerted effort will be needed to ensure that they are not lost.

Services

This Appendix lists the main projects and organisations contacted in the course of this study.

Birmingham City Council

Naseby Centre

Contact Shamaila Parveen
Telephone 01212 464 5054
Email smila_p@hotmail.com

The Naseby Centre in Birmingham is a youth and community centre where the disability project is based. Findings from local research highlighted the need for extra provision for disabled children and young people in the Washwood Heath Ward, and focused on the lack of provision and take-up of youth services by disabled young people aged 11–25. A report in 2000 also showed that disabled children face barriers to local leisure facilities, including playgrounds. The project was established to identify the specific needs of disabled young people and their families. The following were identified as central issues to consider when providing services: cultural and religious factors; independence; language barriers; other factors which limit access, such as lack of public transport. The project worker, employed by Birmingham City Council Youth Service, has direct contact with children and families. Families are now provided with emotional and practical support, and the project has increased the take-up of welfare benefits.

Contact a Family

Contact Sarah Chandler
Telephone 0121 415 4624
Email sarah.chandler@cafamily.org.uk

Contact a Family assisted a group of Somali parents to establish themselves as a parent support group. With this assistance, they were able to find premises, run support groups for parents of disabled children, and latterly a playscheme.

Birmingham Children's Centre

Partner agencies: NCH, Social Services, South Birmingham PCT
Contact Susan North, NCH
Telephone 0121 507 9500
Email wmmatthewd@mail.nch.org.uk

The centre provides a range of services for children and families, and particularly disabled children. The Child Development Centre is based here, and the building has two playrooms, a sensory room, outdoor play facilities and a sensory garden. A family room exists for parents and there are several clinic and therapy rooms. All of these are on the ground floor. Staff have been employed who speak a range of Asian languages, because there is a large population who live locally from Pakistani, Punjabi, and Bangladeshi communities. Transport is provided to attend appointments and activities.

Bradford Metropolitan District Council

Early Years Play Services

Contact Andy Parkin, Special Needs Development Officer, Bradford Early Years
Telephone 01274 437566
Email andy.parkin@bradford.gov.uk

The Play Service works closely with the Asian Disability Network (Tariq Ahmed 01535 214 422) who may join them on their first visit to a family, and who provide interpretation and background cultural information. Andy Parkin works with early years play settings before introducing children to them, as this leads to the highest success rate of placements. Leaflets have been produced in community languages about the services they offer, but these have not been as useful as the direct contact that joint visits has allowed.

Bristol City Council

Khaas
Contact Gurda Shan
Telephone 0117 955 4070
Email khaas_bristol@yahoo.co.uk

Khaas (meaning 'special') is a parent-led organisation that provides assistance to South Asian families who have a disabled child. They provide: holidays; Saturday club; assistance for young carers; older carers come to regular meetings on Mondays and Wednesdays; help with housing and benefits. They have 50 users, 1 full time manager, 2 part time development officers and 12 part time support staff. Most of the workers speak the languages used by the users i.e. Urdu, Punjabi and Hindi. The project started in 1987, based at the community centre.

Family Link Short Breaks Bristol Social Services
Contact Jonathan Hughes
Telephone 0117 954 8506
Email jonathan_hughes@bristol-city.gov.uk

This project started in 2000, influenced by Bradford Social Services who had recruited Asian carers in 1997. They initially tried to identify families through advertising, on the radio etc, but this was not successful. As a result, they appointed an Asian worker specifically to recruit families, and to work with the local community group Khaas, and attend other community events. They have been working with Shared Care Network who have produced a toolkit (A Process for Change) about finding families for disabled children from black and other minority ethnic communities. Through this partnership, the Link scheme has been able to expand as a result of attracting more black African-Caribbean carers.

Buckinghamshire County Council

Buckinghamshire Social Services Department, Take a Break
Contact Janet Vale
Telephone 01494 475 061
Email jvale@buckscc.gov.uk

The team recruits, assesses, trains and links carers and befrienders to disabled children. Care can be in the carer's home, in the child's own home or in the community. The Aylesbury team employed a part time Ethnic Minority Worker who identified 5 link carers from the local community. When this worker left, two part time Ethnic Minority Workers were subsequently employed, in order to avoid the feeling of isolation that their previous worker had felt.

Kirklees Metropolitan Council

Apne Bachay Project
Contact Samina Zafir
Telephone 01924 457 545
Email samina.zafir@virgin.net

Apne Bachay Project in Dewsbury was set up in 2003 with funding from the Kirklees Children's Fund, as a result of a local consultation. Apne Bachay means 'our choice' in Hindi/Urdu. Savile Town is an area of Dewsbury in a ward that has a 98% minority ethnic population, and it was found that families with disabled children from minority ethnic communities were not using services. Many of the aims of the project have been achieved as follows: 47 disabled children supported (21 of whom have complex health needs); information and signposting provided about services to which they are entitled; volunteers recruited; multi-sensory room and toy library established; holiday playscheme provided; Direct Payments initiated with 14 families; Disability Awareness day held, which provided information to local people and professionals.

Dudley Metropolitan Borough Council

Ehsas Carers

Telephone 01384 212 600

Ehsas Carers (Ehsas means empathy or understanding in Urdu) was originally set up in 2002 by Muslim parents to provide a culturally sensitive support group. It now offers support to parent-carers and families who have children with special needs or adults with learning disabilities. A minority ethnic Family Support Worker is based at the Ehsas carers office at Dudley Muslim Association. Support is offered to families to attend school and medical appointments, and with completing forms.

Dudley Learning Disability Services

Contact Ali Mohammed

Telephone 01384 813 348

Email ali.mohammed@dudley.gov.uk

This is a specialist social worker post to support people with learning disabilities from black and other minority ethnic communities. As a result of this post being created, the local authority is now supporting the Apna self advocacy group for people from ethnic minorities who have a learning disability, and the Ehsas Carers group.

Leeds City Council

Umeed

Telephone 0113 247 0411

Email info@peopleinaction.org.uk

Website www.peopleinaction.org.uk

Umeed means 'hope' in Punjabi, Gujerati, Hindi and Urdu, and this is a group for parents or carers of children and adults with learning disabilities from Asian communities. Volunteers are linked with families to provide one-to-one assistance, and support for the project is provided by People in Action.

Liverpool City Council

Liverpool Parent Partnership

Contact Pierre Ngendakumana, Ethnic Minority Community Parent Links Officer, Parent Partnership Service

Telephone 0151 233 2947

Email pierre.ngendakumana@liverpool.gov.uk

The overall aim of this project is to support black and other minority ethnic parents who have a child with special educational needs through their educational assessment. Liverpool has several white minority ethnic communities, such as Irish and Traveller, and this specialist post was created in association with EMTAS – the Ethnic Minority and Travellers Achievement Service.

Building Bridges

Contact Suzanne Hughes

Telephone 0151 252 5967

This project provides a service to support the emotional and psychological well-being of black and other minority ethnic families, through working with existing multi-agency services and developing services. They have two bi-lingual workers who speak Chinese and Hindi. They support parents of children who have a physical and/or learning difficulty, by attending appointments with them and offering information and advice on welfare benefits.

London

London-wide

The Children's Society

Disability Advocacy Project

Contact Parul Begum

Telephone 020 7613 2886

Email parul.begum@childrenssociety.org.uk

This project provides advocacy support to disabled children who are in care, most of whom live in placements outside of London. The project receives referrals from inner-London local authorities. A high proportion of the children and young people who are referred are from black and other minority ethnic communities. Once the advocate has got

to know the young person, they may liaise with the family, school and social worker, and visit the young person in their placement. They have produced a DVD about advocacy with disabled children and young people.

Mencap Sunna Project (Sunna means to listen)
Contact Isabella Bedi
Telephone 020 8765 8400
Email Isabella.Bedi@mencap.org.uk
This project is addressing the barriers facing young people from black and other minority ethnic communities who have a learning disability, when accessing leisure services. The University of Bradford will develop pilot projects. This will involve training young people with a learning disability to assist with delivering focus groups as well as participating in face to face meetings with service providers. Young people with severe learning disability will also be involved using multi-media profiling. One of the project's aims is to produce a group of young people with learning disability who will be consulted in the decision-making processes and whose views will be used when planning services.

National Autistic Society
Contact Prithvi Perepa
Telephone 020 7704 3806
Email Prithvi.Perepa@nas.org.uk
Website www.nas.org.uk/nas/jsp/polopoly.jsp?d=660&a=8858
The aim of this project is to increase awareness of autism within black and other minority ethnic communities across London, and to encourage more black and other minority ethnic groups to use the services of the National Autistic Society. The project organised conferences about black and other minority ethnic issues through out the country which generated considerable media interest. An Asian radio station arranged a phone-in programme which was very popular with families. As part of raising awareness, the project has stalls at various community events, and a monthly drop-in service in Lewisham has been organised in the local library.

Somali Carers Project
Telephone 020 8854 8665
Website www.somalicarersproject.com
The Somali Carers Project was founded in 1998 to provide domiciliary care to Somali families – including older people, disabled adults, and children. More recently, the charity has broadened its scope and supports families from a wide range of black and other minority ethnic communities across London. A number of local authorities use this charity to support black and other minority ethnic families, as they are able to meet families' cultural needs.

Camden London Borough Council

Hopscotch Asian Women's Centre
Contact Lakhy Khan or Sufia Ahmed
Telephone 020 7388 6200
Email lakhy.khan@hopscotchawc.org.uk
Website www.hopscotchawc.org.uk
Hopscotch provides a support service to disabled and non-disabled children and their families, as well as to adults. The support for disabled children and their families includes: residential holiday breaks, a Fun day in February, social outings, home visits, support regarding health, education, social and leisure activities, support for children with special educational needs at school, and supporting families with advocacy and relevant information regarding both statutory and voluntary services. The other service include: parents and carer support, a Family Link and fostering and adoption service, and children and families assessment work.

Ealing London Borough Council

Physical Activities Club in Ealing (PACE)
Contact Krishna Birdy
Email krishna_birdy@yahoo.com
This is a fortnightly club run by volunteers for young disabled people from 13–25 years old, their friends and siblings. The emphasis is on sports that can be adapted to include everyone, such as volleyball, basketball and lacrosse.

Enfield London Borough Council

Cheviots Children's Disability Team
Contact Janet Leach
Telephone 020 8363 4047
Email cheviots@enfield.gov.uk
   This team provides and co-ordinates care packages for families with a disabled child/young person in Enfield. They have established a group for Asian carers which provides a sitting service and activities for families.

Haringey London Borough Council

Haringey Council
Website www.haringey.gov.uk
   Haringey have a directory of support groups which is available on their website. This means that they are relatively easy to find out about, compared to some support groups (see: www.haringey.gov.uk/index/children_and_families/childrensdirectory.htm). Several specific groups are listed, including:
   • African/Caribbean Community Parent/Carers Support group
   • Asian Carers Support Group
   • Black and Ethnic Minority Carers Support Service
   • Greek Cypriot Special Needs Support Group

Lambeth London Borough Council

Contact a Family
Contact Sharon Kitson
Telephone 020 8671 7665
Email sharon.kitson@cafamily.org.uk
   In the London Borough of Lambeth, Contact a Family has a high take-up from the black African/Caribbean community. Many activities are organised for both children and their families, and they publish a quarterly newsletter.

Tower Hamlets London Borough Council

APASENTH
Contact Mahmud Hasan
Email info@apasenth.org.uk.
   APASENTH started as a parent-led group as a result of a group of parents identifying the lack of local resources for their children. Now it is a thriving charity that is the main provider of services to black and other minority ethnic children and young people with learning disability in Tower Hamlets. They provide short breaks, day care, home care, training and employment, advice on welfare rights, and they have an local authority parent adviser based with them to provide a service for children with special educational needs.

Waltham Forest London Borough

Barnardo's Hamara
Contact Ruth Watson, Children's Service Manager
Telephone 020 8503 7270
Email hamara.walthamstow@barnardos.org.uk
Website www.barnardos.org.uk/hamarafamily
   This project (hamara means 'our' in Hindi and Urdu) is based in an area where a high percentage of families are from black and other minority ethnic communities. The project was established in 1990 and now offers a range of non-residential services to disabled children and young people. Support includes care in the children's own home, play, leisure and holiday activities, support for parents/carers and brothers and sisters, and support for children to take part in mainstream activities. The sitting service supports over 150 children and young people, and employs up to 100 staff from different backgrounds. More recently, it was recognised that there was a Turkish population whom they were not reaching. A Turkish parent was employed to work alongside a social worker visiting families. This included visits to families who had been visited before, but who did not then take up the service. This worker supported families to attend reviews, complete

application forms and take up services. She has also helped at the time of diagnosis. Funding for this post was identified for three months originally, but this increased to 18 months when the need for the work was confirmed. They are adopting a similar model for work with Portuguese-speaking families.

Luton Borough Council

Bright Eyes
Contact Mrs Yousef
Telephone 01582 755377

This is a small charity that has been running for about ten years. It provides leisure activities for Asian disabled children on Saturdays and after school on Tuesday evenings. They work closely with social services through a social worker who provides a direct link.

Manchester City Council

Project Smile Manchester Jewish Fed
Contact Carol Moffatt
Telephone 0161 795 0024
Email info@thefed.org.uk

Project Smile has a team of trained Family Support Workers who are specially matched to families, paying attention to their cultural and religious needs. The service currently supports around 90 families, and over 200 children. They also run a fortnightly play group for children with special needs in the Orthodox Jewish Community.

North Lincolnshire Council

Apna Sahara
Telephone 01724 330 073
Email apna.sahara@btconnect.com

Apna Sahara, meaning 'our support' in Urdu, is a charity that aims to improve access to and the availability of public services for people from black and other minority ethnic communities, and to increase the understanding of different cultures and religions by providing training. They provide the following services: Signposting; assessments or joint

visits; attendance at case conferences and reviews as interpreters; advice on cultural barriers, work on community development, assistance at hospital appointments (funded by health); training on religious and cultural awareness of the religions of the local South East Asian Community.

Nottingham City Coumcil

Volunteers For Parents' Voices
Contact Nicola Upton
Telephone 0115 934 8476
Email nicola.upton@fwaprojects.org.uk

Volunteers for Parents' Voices is a Family Welfare Association Project that offers support to parents and carers of disabled children and children with special needs. Parents are supported by trained volunteers and a small staff team. They have identified three bilingual volunteers after recognising that they had a shortage of black and other minority ethnic communities volunteers.

Preston City Council

Pukar
Contact Nisha Patel
Telephone 01772 822 700
Email pukar@ukonline.co.uk

Pukar, which means 'voice' in Gujerati, is a charity providing direct services to Asian disabled children and their families, including activities after school, at weekends and in the evenings, fun days, outreach, support to parents and carers, signposting, a translation service, language classes and computer skills training.

Reading Borough Council

Alafia – Health and Disability

Contact Nina Sethi
Telephone 0118 986 8755
Email nina@rcre.co.uk
Website www.rcre.org.uk/alafia

Alafia is a voluntary sector service which is based in Reading Council for Racial Equality. It was established in 1995 to provide family support, signposting, advice, guidance and assistance, and identify gaps in services for parents from black and other minority ethnic communities with disabled children. Alafia offers outreach and individual support which has enabled many black and other minority ethnic families to access a variety of services for their children.

Sandwell Metropolitan Borough Council

Asian Family Support Service

Telephone 0121 558 2198
Email safss@btconnect.com

This project provides care and support services for children and young adults (aged 0–30) from South Asian communities with a disability or life threatening condition. Care is provided at home, in an after-school club, in a group for young adults with disabilities and as support for parents and carers.

Sheffield City Council

Jeevan

Contact Sara Nawaz
Telephone 0114 282 3228
Email jeevanproject@lycos.co.uk

This is a project whose aim is specifically to support young Asian women (12–25 years) with learning disabilities who live in Sheffield. They provide advice and guidance, social activities, short courses, volunteering opportunities and signposting to other agencies.

MILAAP

Contact Misbah Hassan
Telephone 0114 255 0595

This project provides counselling and guidance for parents of disabled children. They run three support groups across the city at Rushey Meadows, Darnall and Firth Park. Asian parents of children with disabilities are welcome to attend these local support groups.

Slough Borough Council

Parvaaz

Contact Bharaj Burewal
Telephone 020 8538 7701

Parvaaz project provides a specialist and culturally sensitive support services for young Asians with disabilities in Slough. It has its own accessible transport. It aims to address the social exclusion, inequality and lack of culturally appropriate services for young disabled Asians. The project recruits and trains volunteers and advocates from within the Asian communities to provide practical support and mentoring to users. In addition, a three-hour session is arranged every week which provides young Asians with disabilities with social, leisure, recreational activities, and classes in literacy, numeracy and IT skills.

Telford & Wrekin Borough Council

Telford & Wrekin Borough Council

Contact Lindsay Richardson
Telephone 01952 217 355

The council has identified that there are particular challenges in ensuring services are sensitive and relevant to the needs of disabled children from black and other minority ethnic communities and those of their families. As a result, the authority is undertaking local research to identify the prevalence and specific needs of minority ethnic disabled children, with the aim of reviewing and developing services accordingly.

Wolverhampton City Council

Include Me Too
Contact Parmi Dheensa
Telephone 01902 773 761/2 (ask for option 3)
Email pdheensa@wolverhamptonvsc.org.uk
This project was set up because Wolverhampton Voluntary Sector Council's Health and Social Care Project recognised the lack of provision and take up of services by black and other minority ethnic disabled children and their families, and their under-representation in influencing service delivery. Two pieces of research have been undertaken locally to find out the views and experiences of the families, and also of the children and young people themselves.

York City Council

Travellers Trust
Contact Christine Shepherd
Telephone 01904 630 526
Email travellerstrustyork@yahoo.co.uk
This Trust offers a wide range of services for Travellers in York, including advocacy, benefits advice, computer access, a mediation service and debt advice. York's largest ethnic minority are Travellers, and the city currently maintains three official sites for them.

Wales

Access for Black and Minority Ethnic Children and Young People with Disabilities (ABCD)
Contact Wahida Shah Kent
Telephone 01686 611705
Email w.shah@ntlbusiness.com
This project was established in 1992, and provides direct services to local black and other minority ethnic disabled children and their families. They also give advice and provide training to organisations on how to open up services to be fully inclusive.

Scotland

Ethnic Enable
Telephone 0141 334 2277
Email info@ethnicenable.com
Website www.ethnicenable.com
This organisation has been working with minority ethnic disabled children and their families since 2000. They provide direct support which includes advising parents and carers on how to access appropriate support services. They also provide bilingual volunteers, transcription services, Arabic Braille, leisure services, and liaison with minority ethnic community organisations to ensure that events are accessible. They have established a Cultural Education Course for children and young adults with learning and physical disabilities, to give them the opportunity to gain knowledge of their culture whilst socialising in a group. This course is also run for people who are deaf or have a hearing impairment and who communicate using British Sign Language.

National organisations

Association for Real Change (ARC)

National Ethnicity and Learning Disability Network
Contact Bridget Fisher
Telephone 01246 555 043
Email bridget.fisher@arcuk.org.uk
Website www.arcuk.org.uk
This is a short-term project set up in August 2003 to run a good practice / information sharing network on all initiatives concerned with learning disability and ethnicity. The project publishes four newsletters a year, hosts an annual conference and facilitates networks and information-sharing.

CLIC Sargent

Contact Pilar Gonzalez-Doupe
Telephone 020 8752 2953
Email pilar.gonzalez-doupe@clicsargent.org.uk

CLIC Sargent offers advice, financial and emotional support, and practical care to families where a child has been diagnosed with cancer or leukaemia. They have created two family support worker posts to work specifically with children and their families from black and other minority ethnic communities in east London.

Deafblind UK

Contact Raihanna Hirji
Telephone 01733 358100
Email raihanna.hirji@deafblind.org.uk

This charity have employed a Black & Minority Ethnic Coordinator to target the communities who are under-represented in the take up of their services. Current work includes: Working with existing deafblind people from a black and other minority ethnic background in delivering a culturally appropriate service; improving cultural sensitivity of staff at all levels; increasing black and other minority ethnic representation within the head office and with field worker staff; working in partnership with key workers from minority communities to raise awareness of dual sensory loss.

Family Fund

Telephone 0845 130 4542
Email info@familyfund.org.uk
Website www.familyfund.org.uk

The Family Fund established a project to raise the profile of the services they provide for black and ethnic minority families who have children and young people with severe disabilities and serious illness. Uptake of services increased as a result.

Parents for Inclusion

Telephone 0845 4500 411
Helpline 0800 652 3145
Email info@parentsforinclusion.org
Website www.parentsforinclusion.org/pihomepage.htm

Parents for Inclusion is a national organisation of parents of disabled children, which aims to help disabled children to be included in their schools and local communities. It runs a telephone helpline, inclusion groups in schools and training workshops for parents and professionals. Their report *All Our Children Belong* describes the experiences faced by black and other minority ethnic families with disabled children in Britain. It contains interviews with parents and disabled children and recommendations.

Royal National Institute for the Blind (RNIB)

Contact Younus Khan
Telephone/Fax 01772 821 714
Email younus.khan@rnib.org.uk

A national post of Diversity Development Coordinator has been created to enable better access for people from black and other minority ethnic communities to their services. Examples of good practice have been identified, and a report has been written that summarises the issues emerging from research and reports on the needs and experiences of people from black and other minority ethnic communities with sight loss.

Shared Care Network

Contact Candy Smith
Telephone 0117 955 0226
Email c.smith@bristol.ac.uk
Website www.sharedcarenetwork.org.uk/scn/dynamic/scn80.shtml

Shared Care Network is a national organisation which promotes family-based short breaks for disabled children. They have published a guide called *A Process for Change: A guide to improving access to services for black and minority ethnic disabled children and their families*. This guide was the result of an 18-month development project looking at the process of making short break services more inclusive of black and other minority ethnic communities, based on the recommendations from the Flynn (2002) report.

Values Into Action (VIA)
Contact Mark Brookes
Telephone 020 7729 5436
Email mark.brookes@viauk.org

VIA works to support and promote the right of people with learning difficulties to enjoy their lives, and to be treated with the same respect due to all citizens. This specific post has been created to open up self-advocacy for minority ethnic people with learning difficulties.

Whizz-Kidz
Contact Jan Morrison
Telephone 020 7798 6109
Email J.Morrison@Whizz-Kidz.org.uk
Website www.whizz-kidz.org.uk

Whizz-Kidz provides customised wheelchairs, tricycles and other specialised mobility equipment, wheelchair training, information and advice to change the lives of disabled children across the UK. They are seeking funding to employ a black and minority ethnic outreach worker in one city to ensure that families with disabled children from black and other minority ethnic communities can access the services available to them, both from the NHS and from Whizz-Kidz.

Useful resources and organisations

Resources

DVD/videos/CD-ROMs

ARC *Services for all Training video for staff Chesterfield*
This is to help staff understand how the services they provide should support the culture and heritage of the person using these services

ARC *Services for all A video of opportunities for people with learning disabilities from minority communities*
This was produced to help people with learning disabilities decide on their best choices as they become adults. Available in five community languages.
Telephone 01246 555 043
Fax 01246 555 045
Email contact.us@arcuk.org.uk

Change Picture Bank
This organisation produces pictures on CD-ROMs to make information easier to understand.
Telephone 0113 243 0202
Website www.changepeople.co.uk/default.aspx

Disability Advocacy Project (2005)
I can tell you what I want (DVD)
The Children's Society London
Telephone 020 7613 2886

Reading Council For Racial Equality
(1997) *Mad, bad or naughty Attitudes to Disability and the Asian Community* (video)
Telephone 0118 986 8755

Triangle (2001) *Two Way Street: Communicating with disabled children and young people. Training video and Communication handbook. Hove.*
This aims to improve practice in communicating with children and young people who have communication impairments, and it was developed in consultation with a group of disabled children and young people.
Telephone 01273 413 141
Website www.triangle-services.co.uk

Organisations

Black and other minority ethnic organisations

Afiya Trust
Telephone 020 7582 0400
Website www.afiyatrust.org.uk

Black Information Link
Website www.blink.org.uk

Commission for Racial Equality
Telephone 020 7939 0000
Website www.cre.gov.uk/index.html
This website provides very helpful information about the Race Relations (Amendment) Act 2000

Council for Ethnic Minority Voluntary Sector Organisations (CEMVO)
Website www.emf-cemvo.co.uk

Institute for Race Relations
Telephone 020 7837 0041
Website www.irr.org.uk

Refugee Council
Telephone 020 7346 6700
Website www.refugeecouncil.org.uk

Organisations which provide information about disabled children from black and other minority ethnic communities

ARC
Telephone 01246 555 043
Website www.arcuk.org.uk
www.movingonup.info
This website is especially for young people with a learning disability from ethnic minority communities and their supporters and families to find out about transition.

BME Spark
Telephone 020 8348 8263
Website www.bmespark.org.uk

Children's Legal Centre
Telephone 0845 456 6811
Website www.childrenslegalcentre.com

Disability Rights Commission
Telephone 08457 622 633
Website www.drc-gb.org

Early Years Equality (EYE)
Telephone 01244 310 569
Website www.earlyyearsequality.org/pages
earlyyearsequality/1_1.html

Health for asylum seekers and refugees portal (HARP)
Email Pauline.Lane@nhs.net
Website www.harpweb.org.uk/index.php

Joseph Rowntree Foundation
Telephone 01904 629 241
Website www.jrf.org.uk

London Ethnic Minority Deaf Association (LEMDA)
Telephone 020 8522 1842
Website www.lemda.org.uk

Multikulti
Website www.multikulti.org.uk
This provides translated information on welfare law, debt, employment, health, housing, immigration and welfare benefits. There is also a substantial database of organisations under the heading of 'local agencies'. The information site only applies to England.

National Information Forum
Telephone 020 7402 6681
Fax 020 7402 1259
Email info@nif.org.uk
Website nif.org.uk
This is a voluntary organisation which is committed to encouraging the provision of accessible information for disabled people, asylum seekers, refugees and anyone else disadvantaged in gaining access to information.

Northern Ireland Southern Area Children and Young People's Committee
Telephone 028 3741 4602
Website www.southernareacsp.n-i.nhs.uk/
minority%20ethnic%20childen.htm

Portsmouth Ethnic Minority Achievement Service
Telephone 023 9273 3130
Website
www.blss.portsmouth.sch.uk/emtag/
index.shtml

REU
Telephone 020 7619 6220
Website www.reu.org.uk

Valuing People Support Team
Website www.valuingpeople.gov.uk

References and further reading

Descriptions of publications are mostly taken from the National Children's Bureau Library and BME Spark (www.ncb.org.uk/library, www.bmespark.org.uk).

Ahmad W I U (ed) (2000) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University.
Explores the experiences of minority ethnic users of services for disabled children and young people with chronic illness. Examines the conceptualisation of disability and chronic illness and the implications of particular definitions.

Ahmad W I U and Atkin K (1996) 'Ethnicity and caring for a disabled child: the case of children with sickle cell or thalassaemia', *British Journal of Social Work*, 26, 6 (Dec), 755.
Provides an overview of the literature on sickle cell disorders and thalassaemia in the broader context of debates on childhood disability and chronic illness, and on ethnicity, racism and health care.

Ahmad W and others (1998) *Deafness and Ethnicity: Services, policy and politics*. Bristol: The Policy Press.
These findings note that 'while statutory and voluntary sectors are beginning to respond to the needs of deaf people from minority ethnic groups, many barriers to social inclusion and appropriate services remain to be tackled'.

Alexander, C and others (2004) *Access to services with interpreters: user views*. York: Joseph Rowntree Foundation.

Ali, Z and others (2001) 'Disability, ethnicity and childhood: a critical review of research', *Disability and Society*, 16, 7, 949–68.

Audit Commission (2003) *Services for Disabled Children. A review of services for disabled children and their families*. London: Audit Commission.
The findings of a study of over 240 disabled children and young people and their siblings, parents and carers regarding their experiences as service users. Key issues addressed include play, leisure, friendships, school and education, health, housing, social services and transport. The findings were intended to provide evidence for the improvement of service planning and delivery.

Audit Commission (2003) *Let Me Be Me: A handbook for managers and staff working with disabled children and their families*. London: Audit Commission.
Handbook for managers and staff who work with disabled children and their families across different agencies and disciplines. One chapter specifically addresses 'meeting the needs of a culturally diverse population'. Includes factsheets for parents and carers, research findings, self-evaluation checklists and case studies.

Bailey, D B and others (1999) 'Awareness, use, and satisfaction with services for Latino parents of young children with disabilities', *Exceptional Children*, 65, 3 (Spring), 367–81.

Banton, M and others (2001) *Involving Black Disabled People in Shaping Services*. Leamington: The Council of Disabled People, Warwickshire and Joseph Rowntree Foundation.
This research explores one organisation's experiences in developing the involvement of black disabled people.

Baxter, C and others (1990) *Double Discrimination: Issues and services for people with learning difficulties from black and ethnic minority communities*. London: King's Fund/Commission for Racial Equality.

Bayley, C (2005) *All Things Being Equal … A guide to learning disability for race equality officers*. Chesterfield: Association for Real Change.

Begum, N (1995) *Beyond Samosas and Reggae – A guide for developing services for black disabled people*, London: Kings Fund.

Belman, J (2004) *Black and Other Minority Ethnic Communities and Primary Care. Key Points briefing*. London: Voluntary Service Council.

Beresford, B (1995) *Expert Opinions: A national survey of parents caring for a severely disabled child*. Bristol: The Policy Press.

Beresford, B and others (1996) *What Works in Services for Families with a Disabled Child?* Essex: Barnardo's.

Bernard, C (1999) 'Child sexual abuse and the black disabled child', *Disability and Society*, 14, 3, 325–39.

Bignall, T and Butt J (2000) *Between Ambition and Achievement. Young black disabled people's views and experiences of independence and independent living*. Bristol: The Policy Press.
    Based on interviews with 44 young disabled people of Asian, African and Caribbean origin, this study looks at their experience of independence and the influences on them leading active independent lives.

Bignall, T (2000) 'Issues for black disabled children and their families', *REU Network*, 9 (Oct).
    Research and testimonies indicate a lack of appropriate information on services and entitlements, feelings of isolation and loneliness, and an insensitivity on the part of professionals to cultural and religious needs.

Bignall, T, Butt, J and Pagarani, D (2002) *Something to Do: The development of peer support groups for young black and minority ethnic disabled people*. Bristol: Policy Press.
    Using young people's own words, this report explores the development of these informal support groups, including: the purpose of peer support groups; how the groups have formed; what the groups do; what works with the groups and why; what affects the growth and maintenance of such groups; examples of processes, such as decision making and planning.

Broomfield, A (ed) (2004) *All Our Children Belong: Exploring the experiences of black and minority parents of disabled children*. London: Parents for Inclusion.
    Report on the result of a three-year pilot project which examined the experiences of minority ethnic families seeking inclusion for their disabled children. Families described being subject to discrimination and negative stereotyping when trying to access services, information or support.

Butt, J, Bignall, T and Stone E (ed) (2000) *Directing Support. Report from a workshop on direct payments and black and minority ethnic disabled people*. York: Joseph Rowntree Foundation.

Butt, J, Patel, B and Stuart, O (2005) *Race Equality Discussion Papers*. London: Social Care Institute for Excellence.
    Three discussion papers focus on independent living, refugees and asylum seekers, and the characteristics of social care organisations that successfully promote diversity.

Carlin, J and others (2005) *All Kinds of Short Breaks: A guide to providing a range of quality services to disabled children and young people*. Bristol: Shared Care Network.
    A practical toolkit for practitioners and managers working in family support services for disabled children. Provides factual material and examples of good practice, which reflect the diverse services short break or respite schemes now provide. Chapters present issues and

evidence, provide examples of good practice and outline critical success factors.

Carpenter, J and others (2005) *The impact of Sure Start on Social Services.* Durham: Centre for Applied Social Research University of Durham.

Chahal, K and Ullah, A (2004) *Experiencing Ethnicity: Discrimination and service provision.* Foundations series. York: Joseph Rowntree Foundation.
Highlights themes including racial harassment, age and the black voluntary sector.

Chamba, R, Ahmad, W and Jones, L (1998) *Improving Services for Deaf Asian Children: Parents' and professionals' perspective*s. Bristol: The Policy Press.

Chamba, R and others (1999) *On the Edge: Minority ethnic families caring for a severely disabled child.* Bristol: The Policy Press.
Reports findings from a national survey. Findings confirm that considerable problems exist in terms of quality of statutory service provision and also in relation to income, employment and housing, access to information and the opportunity to communicate and express needs in a familiar language. Implications for policy and practice are highlighted.

Chan, T (2003) *Meeting the needs of Chinese disabled people in London.* London: Chinese in Britain Forum.

Commission for Racial Equality (2002) *Code of Practice on the Duty to Promote Race Equality.*
This guide aims to help public authorities to follow this statutory code.

Commission for Social Care Inspection and others (2005) *Safeguarding Children*
The second joint Chief Inspector's Report on Arrangements to Safeguard Children Newcastle: Commission for Social Care Inspection.
Five years after the death of Victoria Climbié and more than two years after Lord Laming's inquiry, a joint review by eight government inspectorates has found that there are still 'serious failings' in the safeguarding of children by services including the health service, the justice system and local councils. Concerns are raised about disabled children, particularly those with communication impairments, and about young people who spend long periods in hospital. Among its recommendations, the report calls for registration and tougher vetting of staff, and greater cooperation between agencies working with children and young people.

Darr, A and others (1997) *A directory of projects and initiatives with deaf people from minority ethnic communities.* Bradford: Ethnicity and Social Policy Research Unit.

Department for Education and Skills/Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services.* London: Department of Health.

Department for Education and Skills (2004) *Aiming High: Understanding the educational needs of minority ethnic pupils in mainly white schools. A Guide to Good Practice.* London: Department for Education and Skills.

Department for Education and Skills (2005) *Ethnicity and Education – the evidence on minority ethnic pupils* (Reference: Research Topic paper: RTP01-05).Nottingham: Department for Education and Skills.

Disability Rights Commission (April 2004) *Our Rights, Our choices: Meeting the information needs of black and minority ethnic disabled people.* DRC and Centre for Education in Racial Equality in Scotland.
The report finds that many black and minority ethnic disabled people have difficulty finding information about services. There remains a separation between black and other minority ethnic and disability organisations. Includes recommendations targeting minority ethnic organisations and disability organisations.

Flynn, R (2002) *Short breaks: Providing better access and more choice for black disabled children and their parents*. Bristol: The Policy Press.

  Reviews literature and examines practice in relation to access to short breaks by black disabled children and their families. Includes interviews with children, young people and their parents, as well as with short break carers and providers.

George, M (1999) 'Services to culture', *Community Care*, 1278 (24 Jun), 26.

  Looks at how agencies and councils are trying to improve care for ethnic minority families with disabled children by developing culturally appropriate services.

Hanson, M J and others (1998) 'The culture of inclusion: recognising diversity at multiple levels', *Early Childhood Research Quarterly*, 13, 1, 185–209.

  Examines how preschool programmes and community sites acknowledge, adapt, and match the cultural preferences and/or expectations of participating disabled children and their families. Themes related to culture and diversity are discussed.

Harding, J (2001) 'A community on a learning curve: spotlight on Sandwell', *Talking Sense*, 47, 1.

  Discusses the work of a joint Sense/Sandwell Social Services project and considers how services can provide effective support to deaf-blind people in minority ethnic communities.

Hatton, C and others (2004) *Supporting South Asian families with a Child with Severe Disabilities*. London: Jessica Kingsley.

  Research study examining the experiences of parents in South Asian families who have a child with severe learning disabilities. Highlights ways of improving the cultural sensitivity of disability services and parental and family support. Discusses findings in relation to recent policy initiatives.

Husain, F (2005) *Cultural Competence in Family Support: A toolkit for working with black, minority ethnic and faith families*.

London: National Family and Parenting Institute.

  Provides a range of practical tools for practitioners and sections on culture, discrimination, family, communication and different religions. Outlines key issues regarding cultural competence and family support.

Hussain, Y, Atkin, K and Ahmad, W (2002) *South Asian Young Disabled People and Their Families*. York: Joseph Rowntree Foundation.

  Outlines research on the views of South Asian young people with impairments and explores the meaning and experience of disability. Concludes that policy and practice need to reflect differences in culture, religion and ethnicity.

Jones B (2003) *Childhood Disability in a Multicultural Society*. Abingdon: Radcliffe Medical.

  Examines the problems inherent in the medical, social and educational management of children with developmental disability in populations which have value systems different to the majority culture, using a Hasidic Jewish community as an example.

Jordan, R (2001) 'The effects of culture on service provision for people with an autistic spectrum disorder', *Good Autism Practice*, 2, 2 (Oct), 2–12.

  This paper uses Japan and the UK as examples to examine cultural influences on provision for children and adults with autistic spectrum disorder.

Kaushal, M and Nawaz, S (due for publication in 2006) *A Process for Change: A practical guide to improving access to services for black and minority ethnic disabled children and their families*. Bristol: Shared Care Network.

Kennedy, M, and Gordon, G (eds) (1993) *The ABCD Pack: Abuse and children who are disabled: training and resource pack for trainers in child protection and disability*. Keysoe: ABCD Consortium.

  Working within the framework of the Children Act 1989, consists of a training pack with resource materials and case

studies and a reader containing support papers for the five modules: foundation and awareness; prevention; investigation and assessment; survival; management and policy. Includes sections on special issues relating to sex education and minority groups). (ABCD consortium: Way Ahead Disability Consultancy, NSPCC, National Deaf Children's Society, Chailey Heritage.

Kidane, S (2001) *Food, Shelter and Half a Chance: Assessing the needs of unaccompanied asylum seeking and refugee children*. London: British Association for Adoption and Fostering.
   A practice guide for professionals working with unaccompanied asylum seeking and refugee children. Examines their special needs and the importance of appropriate care arrangements and placement choices. Raises a number of good practice issues.

Kings Fund (2004) *Ethnic Health and Social Care Organisations*. London: Information and Library Service.

Madge, N (2001) *Understanding Difference: The meaning of ethnicity for young lives*. London: National Children's Bureau.
   Brings together information and evidence on what ethnicity means for young lives. Looks at the personal meaning of ethnicity, home circumstances, health, education, welfare, experiences of racist behaviour, and the special case of young refugees and asylum seekers. Discusses implications for policy and practice.

Marchant, R (1999) *Listening on All Channels: Consulting with disabled children and young people*. Hove: Triangle.
   Report summarising a consultation exercise with learning disabled children and young people about their use of a residential respite care service. A range of approaches was used and the young people communicated their views through speech, sign, symbols, body language, facial expression, gesture, behaviour, art, photographs, objects of reference, games, drawing and playing.

Marchant, R and Jones, M (2003) *Getting It Right: Involving disabled children in assessment, planning and review processes*. Hove: Triangle.
   Provides information and advice about involving disabled children in a wide range of consultation, assessment, planning and review processes. It considers the systematic and practical challenges to involvement and suggests approaches and resources to meet these.

Maudslay, L and others (2003) *Aasha: Working with young people with a learning difficulty from a South Asian background*. Bedford: SKILL (National Bureau for Students with Disabilities).

McBride, M (2004) *Parent Participation: Improving services for disabled children: parents' guide*. London: Council for Disabled Children and Contact a Family.
   Guide for parents who want to find out more about participation, parents groups called upon to provide a collective parent view, and parents who take on the role of parent representative on working parties and strategy groups. Offers practical examples and suggestions for effective participation and cooperation with professionals in the planning and delivery of services for disabled children. This guide complements another written for professionals.

McDonald, P (1999) *The Experience of the Black Child Who is Disabled*. Reading: Umbrella Equality Services.
   Paper presented at a NSPCC conference on child protection and disabled children. Briefly discusses key issues relating to black children and disability.

Mir, G and others (2001) *Learning Difficulties and Ethnicity*. London: Department of Health.
   This report was published and distributed within the pack for the White Paper Valuing People: A new Strategy for Learning Disability for the 21st century. It covers services for both adults and children, identifies gaps in services, such as advocacy for minority ethnic disabled

children, and recommends a focus on empowerment for communities and individuals.

Morris, J (1995) *Gone Missing? A research and policy review of disabled children living away from their families*, London: Who Cares? Trust.

Morris' report draws on ten stories of adults with experience of living away from their families for large parts of their childhood, on a sample of eight social services departments which were asked for information about how they were implementing the Children Act 1989 as it concerns disabled children, and on a review of the existing research about disabled children living away from home. Areas examined include: definitions of disability, statistics, reasons for entering residential care, education provision, respite care, needs assessment, and access to services.

Morris, J (1998) *Still Missing?* Volumes 1 & 2. London: The Who Cares? Trust/Joseph Rowntree Trust

These reports attempt to answer some of the questions raised by the earlier publication Gone Missing? They present the experiences and accounts of 30 disabled people who spent most of their childhoods away from their families, and detail the practice of three local authorities.

National Statistics (2004) 'The health of children and young people', Chapter 10, *Disability*. London: National Statistics.

Examines the prevalence rates of disability by demographic characteristics, assesses changes in rates from 1990 to 2000, provides information on the number of children with a severe disabling condition who are dependent on medical technology and provides information on disabled children and their access to sporting activities and facilities. Available at: www.statistics.gov.uk.

Nazroo, J Y (2001) *Ethnicity, Class and Health*. PSI report no. 880. London: Policy Studies Institute.

Uses the mental and physical health data from the Fourth National Survey of Ethnic Minorities, also published by the Policy Studies Institute, to address key questions of inequalities in health.

North West Quality Protects Reference Group (2003) *Services for Black and Ethnic Minority Children and Young People Toolkit* Department of Health (available from: www.doh.gov.uk/qualityprotects).

Office of the Deputy Prime Minister (2005) *Diversity and Equality in Planning: A good practice guide* London: Office of the Deputy Prime Minister

This guide is aimed primarily at local planning authorities and is intended to help them address issues of diversity and equality in their policies and practice. It includes sections on: equality and the law; recognising diversity; effective community engagement; securing benefits through policies and procedures; organisational culture; monitoring; learning and self-assessment, and it has case studies.

O'Neale, V (2000) *Excellence Not Excuses: Inspection of services for ethnic minority children and families*. London: Department of Health/Social Services Inspectorate.

The inspection found little evidence that authorities had implemented anti-racist or equal opportunities policies. Policies on training and recruitment were variable, families seeking to access services often experienced difficulties, and placements for black and mixed parentage looked after children often fell below the ideal of finding carers from the same cultural background. The report gives standards by which services can be evaluated.

Patel, V K P (2002) *Not More But the Same. The voices and views of disabled children from black minority ethnic communities in Scotland*. York: Joseph Rowntree Foundation.

The views of a small number of black and minority ethnic disabled children and their families in Scotland.

Perepa, P (2005) *Invisible Families. Experiences of minority ethnic families*. London: National Autistic Society.
  A collection of stories written by parents of children with autism.

Powell, Elaine (2002) *We Care Too: A good practice guide for people working with black carers*. London: Afiya Trust.

Roberts, K and Harris, J (2002) *Disabled People in Refugee and Asylum Seeking Communities*. Bristol: The Policy Press.
  Details demographic data as well as summarising interviews with 38 disabled refugees and asylum seekers and 11 service providers. Recommendations are made to social care practitioners, housing and policymakers.

Russell, P (1997) *Disability in a Multicultural Society: Meeting the needs of families from minority ethnic groups*. Occasional papers, no. 4. London: Council for Disabled Children.
  Examines the social model of disability, what makes for effective services, and the importance of parent partnership and equality of opportunity.

Sachdev, D and van Meeuwen, A (2002) *Are We Listening Yet? Working with minority ethnic communities – some models of practice*. Essex: Barnardo's.
  Provides a collection of case studies and examples of good practice models for working with disadvantaged children from minority ethnic communities.

Save the Children (2003) *Young Refugees: Providing emotional support to young separated refugees in the UK*. Can be downloaded from the Save the Children website: www.savethechildren.org.uk

Sense (1999) 'Celebrating diversity', *Talking Sense*, 45, 2.
  Considers work on a national and local level aiming to increase the cultural sensitivity of services and addresses what still needs to be done.

Shah, R (1995) *The Silent Minority: Children with disabilities in Asian families*. Second edition. London: National Children's Bureau.
  Focuses on services for disabled children in Asian families, challenging many of the stereotypes which may be held by service providers about parents' attitudes towards their child's special needs. Explores parents' awareness of the services available to help them and their perceptions about the effectiveness of these services in meeting their needs.

Shah, R (1998) 'Ethnicity and Learning Disabilities', in *Working with people with profound multiple learning disabilities* University Of Birmingham

Sharma, N (2002) *Still Missing Out? Ending poverty and social exclusion: messages to government from families with disabled children*. Essex: Barnardo's.

Shelley, P and Winters, L (2004) *Parent Participation: Improving services for disabled children: professionals' guide*. London: Council for Disabled Children and Contact a Family.
  Covers key principles involved in successful participation with examples detailing methods and good practice on consulting with parents in order to improve services for disabled children. Includes a section on monitoring and evaluation. This guide complements another written for parents.

Social Services Inspectorate/Department of Health (1995) *Unaccompanied Asylum Seeking Children Training Pack*. London: Department of Health.
  Compiled to accompany the Department of Health publication Unaccompanied Asylum-Seeking Children: A practice guide, a copy of which is included in the pack. Covers the social and historical contexts which have compelled various groups to seek asylum; the refugee experience; the legal framework; cross-cultural communication; social care difficulties and responses.

Taylor, G (1999) 'Empowerment, identity and participatory research: using social action research to challenge isolation for deaf and hard of hearing problems from ethnic minority communities', *Disability and Society*, 14, 3, 369–84.

> The social model of disability and the concept of Deaf culture are used to explore the complex set of relationships that characterise the day-to-day reality for deaf people from minority ethnic communities. Recommendations are made to assist researchers and service providers in developing a more empowering practice.

Thoburn, J, **Chand**, A and **Procter**, J (2005) *Child Welfare Services for Minority Ethnic Families: The research reviewed*. London: Jessica Kingsley.

> Explores the nature and outcomes of child welfare services for minority ethnic families. Includes extended commentaries on family support services; child protection services and the family courts; children looked after away from home or placed for adoption; social work practice. Provides detailed summaries of research.

Todd, H (1999) 'The hidden communities in our midst', *Talking Sense*, 45, 2.

> Analyses the finding of Deafness and Ethnicity (Ahmad and others 1998 op cit), which focuses on deaf people from black and other minority ethnic communities and the development of services for them.

Valuing People Support Team/Department of Health (2004) *Learning Difficulties and Ethnicity: A framework for action*. London: Department of Health.

> An audit tool to help Learning Disability Partnership Boards find out the number of minority ethnic children and adults with learning disabilities who live in a particular area. Available from www. valuingpeople.gov.uk/EthnicityFramework .htm

Ward, L (1991) 'Double discrimination', *Health Service Journal*, 101, 5248 (18 Apr).

> Checklist to help health services become more sensitive to needs of minority ethnic people with learning difficulties.