

Short breaks

Providing better access and more choice for Black disabled children and their parents

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Contents

| | |
|--|-----------|
| Acknowledgements | vi |
| Executive summary | vii |
| <hr/> | |
| 1 Setting the context | 1 |
| Aims and scope of the study | 2 |
| Legislative and policy context | 5 |
| <hr/> | |
| 2 What we do and do not know from existing research | 9 |
| Information: gaps and limitations | 9 |
| Patterns of use of short break services that emerge from research | 11 |
| Children with complex medical needs | 15 |
| What Black disabled children and young people think of short break services | 16 |
| <hr/> | |
| 3 Barriers to accessing short breaks | 17 |
| Separation of disability and ethnicity; a lack of service coordination | 17 |
| Poor leadership, policies, planning, consultation | 18 |
| Inflexibility of some short break services | 19 |
| Information about services and perception/understanding of them | 19 |
| Perceptions about disability | 20 |
| Lack of an ethnically diverse workforce | 20 |
| Lack of diversity in short break carers, sitters and other service providers | 21 |
| Myths about kin and community support | 21 |
| Inadequate assessment of need and restrictive referral practices | 23 |
| Appropriateness of services | 23 |
| <hr/> | |
| 4 What works? | 26 |
| Acknowledge barriers to access for families | 26 |
| Plan clearly, prioritise policies and offer management guidance | 27 |
| Adequately resource short break provision | 30 |
| Know your locality: use outreach and community development | 30 |
| Record and monitor ethnicity | 31 |
| Ensure workforce diversity | 32 |
| Ask children and young people what they want | 33 |
| Ask other family members what they want | 33 |
| Communicate effectively | 34 |
| Disseminate information | 34 |
| Stimulate access and demand | 35 |
| Accept kin as carers | 36 |
| Ensure diversity of short break carers | 36 |
| Increase choice and flexibility of services | 38 |
| Facilitate support groups | 39 |

| | |
|---|-----------|
| Review and evaluate | 39 |
| Train and develop staff, carers and short break panel members | 40 |
| Network and share information and practice | 40 |
| Prioritise culturally competent practice | 40 |
| | |
| 5 Recommendations | 42 |
| For central government | 42 |
| For local authorities | 43 |
| For the providers of short break schemes | 44 |
| Gaps in local and national knowledge | 44 |
| Conclusion | 45 |
| | |
| Bibliography | 46 |

“Many Black people do not know about such services or do not want social services’ involvement. They tend to struggle on and only seek outside help when they reach breakdown.”

(African Caribbean short break carer)

“Parents don’t have close family to help. They need a lot of encouragement to use services for short breaks. I was encouraged by the previous headteacher of my child’s school.”

(South Asian mother)

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Members were:

| | |
|--------------------|----------------|
| Nasa Begum | Sue Mennear |
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| Marion Lowe | Julie Thompson |
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Executive summary

The term ‘short break’ has been used to describe a range of services that have developed and changed over time. These are referred to variously as ‘respite care’, ‘shared care’, ‘family link’, ‘short-term break’ and ‘short-term care’. ‘Sitting services’ and ‘befriending schemes’ are types of services that are now included as short breaks. Prior to 1976, when the first family-based schemes were pioneered in Leeds and Somerset, these services were usually based in institutions. In contrast, since the 1990s, short breaks have been provided mainly through family-based services. Family-based short breaks involve carers being approved as foster carers to have a disabled child in their own home, usually for one weekend a month. The model has now broadened considerably to include daytime services in children’s own homes and other kinds of provision.

This project has a number of aims:

- to review literature on short breaks for disabled children specifically from Black minority ethnic groups;
- to summarise recent and current developments as outlined in the literature;
- to identify good and innovative practices from the literature and in front-line work;
- to clarify and explain strengths and weaknesses in how families gain access to provision;
- to highlight any differential take-up of the various forms of provision;
- to locate gaps in provision and problems of access to provision;
- to locate existing networks in the field, and recommend ways in which networks can be formed, adapted or strengthened;
- to recommend research, practice initiatives or changes in policy that can improve access to short breaks.

In order to identify and summarise key findings and recommendations for policy and practice, I have reviewed UK literature going back some 15 years.

In addition, the following fieldwork has been undertaken to supplement the literature review:

- In Scotland, nine disabled children and young people of South Asian¹ and

¹ In this report, ‘South Asian’ is used to refer to people whose origins are in India, Pakistan, Bangladesh or Sri Lanka, or any of the aforementioned whose families have lived in African countries for a substantial period of time.

Chinese origins were interviewed about their lives and use of services. (A summary of the report by Vijay Patel is included in this publication).

- Two parents and three carers involved in family-based short break schemes were interviewed in London and Nottingham. Two short break carers from Dudley were also interviewed. Carers and parents were of African-Caribbean and South Asian origins.
- A postal survey of 24 family-based short break schemes was undertaken to gather information on policies and practices and ‘what works’. Details were obtained from 13 such schemes.

From these 13, six schemes were either visited by one of the research team, or in-depth telephone interviews were carried out with project managers.

Policy and practice

There have been changes in the past 20 years to the way research, policy and practice in children’s services considers disability and ethnicity. The social model of disability has influenced children’s services (Marchant, 2001) and the disability movement has been instrumental in the move from institutional to community care (Oliver, 1996).

It is no longer acceptable for agencies to develop services without paying attention to the ethnic composition of the population to be served; or, if particular ethnic groups do not use a service, to conclude that “they don’t need it” or that “we’re here – it’s up to them to come and find us”. There is more acknowledgement now of how institutional racism may have operated to keep these families out of services, and

that it is the responsibility of service providers to try to be inclusive.

Researchers too are aware that the inclusion of Black families is essential in policy and practice-related research, and that the omission of them from samples is increasingly an embarrassment. The English government has introduced compulsory ethnic monitoring in children’s services, and there is an expectation under the 2000 Race Relations (Amendment) Act that services in all UK countries will demonstrate how they *promote* racial equality. It will no longer be assumed that they do so.

Disabled children are also becoming more ‘noticeable by their absence’ and services are increasingly expected to cater for disabled children as part of their provision to *all* children. The 2001 Special Educational Needs and Disability Act, for example, sets an expectation that children and young people with special educational needs will be educated in mainstream schools, and that disabled pupils shall not be ‘substantially disadvantaged’ in their education. Disability and ethnicity are also beginning to appear together on the same agendas – for example, in English government policies such as *Quality Protects* as well as in research and local statutory and voluntary sector practice. Policy changes in Scotland are suggested in a number of commissioned studies mentioned in Vijay Patel’s report, but we were only able to find evidence of a few initiatives in Wales and Northern Ireland.

What helps access?

Agencies are more likely to be inclusive if they acknowledge that their routine practices may be excluding some families,

and that they need to identify and target under-represented groups. Crucial in promoting access seem to be:

- knowledge of, and consultation with, the local community;
- effective ethnic record keeping and monitoring;
- the existence and active use of equal opportunities and anti-racism policies and procedures;
- clear commitment, leadership and resourcing.

Community relations are also important, as is the appointment of staff from the minority ethnic groups that the services are trying to reach. Both are significant in building trust between services and communities, and in dispelling myths about social work being about stigma, intrusion and the removal of children from families.

It is also evident that it helps if agencies provide clear explanations about the differences between services, assessment, need and entitlements. Linked to this is the ability for services to be culturally competent. This includes being alert to racism, and continually reviewing and improving their practices. Consultation with minority ethnic groups is crucial. Services should be prepared to seek advice on need and be finding ways of meeting it flexibly – for example, by increased use of sitting services.

Networking with other providers is important. In most communities, there is a great deal of expertise.

What are the barriers to access?

Lack of information about the different services for families with disabled

children is a recurring theme. The terminology used just to describe a service such as short breaks can be confusing and off-putting to some parents, especially when it also seems to be frequently changing. Agencies are unlikely to be inclusive if they fail to acknowledge different needs, and insist that they ‘treat everyone equally’ without examining what this means. Similarly, it is important to recognise and develop strategies for different communities within the locality – for example, for different African or South Asian communities.

Poor communication between service providers and users, leading to misconceptions about the role of short break services, is common. Some services were developed with a monocultural user group in mind, resulting in cultural features that make some parents reluctant to use them. Some services lack the policies, appropriate personnel and leadership to reach out to minority ethnic families. Racism, narrow definitions of what services offer and inflexibility about who might provide them also serve as barriers to take-up.

Recommendations

A detailed list of recommendations for central governments, local authorities and providers of short break schemes, along with key gaps in knowledge (local and national) is provided at the end of this report. A Joseph Rowntree Foundation (JRF) *Findings* summarising the key messages from this report is available from the JRF and on the JRF website: www.jrf.org.uk.

Setting the context

The needs of black children were more likely to remain unmet compared with white children. This effect was consistent across the whole range of needs covered by the questionnaire. Similarly, there were higher levels of unmet need among black parents compared with white parents. Of particular note were unmet needs related to information about services. (Beresford, 1995, p 35)

The majority of parents said they needed more breaks from caring for their child but most did not use short-term care services. Many were unaware that such services might be available in their area while others had chosen not to use such provision. (Chamba et al, 1999, p 25)

More short-term care and holiday play schemes should be made available which meet the cultural, linguistic and dietary needs of parents and children. (Chamba et al, 1999, p 33)

These quotations summarise the issues at the heart of this review. Is there continuing unmet need for short breaks among Black families? If so, why is this,

and what can assist services in addressing this unmet need?

The views of Black disabled children (and disabled children overall) were not well represented in the literature on access to short breaks by disabled children and their families, so the bulk of the information is obtained from parents and other carers, and from service providers. The term 'families' is often used when it is the child's parents who are consulted; sisters, brothers, relations and other kin are rarely included. Authors such as Jenny Morris and Ruth Marchant have written extensively on the need to consult with disabled children and provided suggestions for what can work (Morris, 1998a, 1999; Marchant and Martyn, 1999; Marchant et al, 1999).

The decision to focus on this aspect of services for disabled children and families stemmed both from a gathering body of research that has identified low take-up of short breaks by minority ethnic families, and from research funded by the JRF, specifically by Bryony Beresford (*Expert opinions*, 1995) and by Rampaul Chamba and colleagues (*On the edge*, 1999). Beresford's research had only included the experiences of 94 parents from minority ethnic groups in a study of 1,142 families. The subsequent study by

Chamba and colleagues sought the views of some 600 parents of African Caribbean, Indian, Pakistani and Bangladeshi origins who cared for a 'severely disabled' child. It represents the most comprehensive study of Black families with a disabled child to date.

In both studies, a substantial mismatch was found between parents' need for short break services and their actual use of them. Many families who did not use these services did not know they existed. Other families faced barriers to accessing available services such as level of speaking and comprehending English, and the appropriateness of the service. Short breaks had consistently been viewed as positive and desirable by parents, yet take-up was patchy and by no means universal.

The JRF wished to have more detail on this area of unmet need and so funded this review of literature and practice. In producing this document I have concentrated on minority ethnic groups of South Asian, African and Caribbean origins whom I have defined as Black, but I acknowledge that other minority ethnic groups (such as Chinese, Jewish, Irish and Traveller people) face similar situations over access, and they too are under-represented in research. Disabled refugee children also are a neglected group.

By focusing on what needs to be done to ensure that Black disabled children and their families receive services they are entitled to, it has been necessary to focus on institutional barriers and other negative aspects. It is not my intention to portray Black families as 'victims' but to acknowledge the effects of racism and exclusion on the quality of life for many families. Members of Black communities do get on with their lives, support each

other and are not always dependent on services being 'handed down' by professionals. But with access to appropriate resources and support, they can do so much more for their children and young people.

Aims and scope of the study

This project had a number of aims:

- to review literature on short breaks for disabled children, specifically from minority ethnic groups surveyed by Chamba and colleagues, whom we define as 'Black';
- to summarise recent and current developments as outlined in the literature;
- to identify good and innovative practices from the literature and front-line work;
- to clarify strengths and weaknesses in how families gain access to provision, and reasons for these;
- to highlight any differential take-up of the various forms of provision;
- to locate gaps in provision and problems of access to provision;
- to locate existing networks for services to Black families in the field, and recommend ways in which networks can be formed, adapted or strengthened;
- to recommend research, practice initiatives or changes in policy that can improve access to short breaks.

The review covers literature relating to England, Wales, Northern Ireland and Scotland, though the case examples of short break schemes are located in England only.

In Northern Ireland, services are beginning to address minority ethnic

inclusion but, as yet, disability and ethnicity are rarely considered together. However, there are indications that this could happen in the near future. Two reports on minority ethnic needs in Northern Ireland mention that the needs of children with learning difficulties are just beginning to be highlighted: the Northern Ireland Council for Ethnic Minorities (NICEM, 1996) notes of the Indian community, “We are beginning to learn about small groups within our community such as children with learning disabilities and the elderly”; and the Chinese Welfare Association and Barnardo’s Northern Ireland (1998, p 26) note that one of the most common problems from caseloads in the Belfast area related to child-focused issues and reported by Lay Health Workers was learning disabilities. In Scotland, interviews were carried out with nine Black disabled children, focusing on friendships, pastimes, likes and dislikes, religion, culture and language. Short breaks were not specifically featured in Scotland as it was felt that comments on access to wider services would be more appropriate for Black families at this point in time.

In Wales, we were unable to find much literature on short breaks for minority ethnic families. A report by Beth Prewett on children’s shared care services only had two Black children recorded out of the 540 in the survey (Prewett, 1999b). However, a report by Jaswant Singh for Barnardo’s in Cardiff has raised identical issues to this review (Singh, 1992). There are gaps in information regarding the situation in Wales that need to be filled.

Language of disability and ethnicity

The language of disability and ethnicity reflects changes in awareness and

inclusion. Terminology in reports is therefore inconsistent and has changed over time. Researchers, funders and service users have different preferences and the language of legislation, policy and practice may be different yet again. This report favours the use of terms consistent with the social model of disability, which avoids defining a child by her or his impairment, thereby locating ‘the problem’ within the disabled person, but focuses instead on removing disabling barriers to quality of life erected by society’s attitudes to disability (Marchant, 2001; Mir et al, 2001).

This report also uses ‘Black’ in a unifying sense to refer to people of African, Caribbean and South Asian origins, and distinguishes between different minority ethnic groups where possible. However, ‘Black’ and ‘Black minority ethnic’ are sometimes used interchangeably. It is accepted that White minority ethnic groups can also experience racism and cultural and religious oppression, but that racism based on skin colour adds a different dimension. However, where we have information on some groups in relation to short breaks – for example, Chinese families – who are sometimes included in definitions of ‘Black’ and sometimes not, the group has been included.

Short breaks: definitions and debates

Prior to 1976, short break services were usually referred to as ‘respite care’. They were institutionally based and run predominantly by the health or social services. The introduction of family-based short break services in 1976 seemed to be welcomed by parents and this provision grew enormously during the 1980s. In the 1990s, short-term care seemed to be taken universally to mean

family-based services, and it has enjoyed increased levels of government recognition and support (Prewett, 1999a).

Some family-based services involve the disabled child being cared for outside the home – typically the child leaves the home to stay somewhere overnight (Morris, 1998b). Breaks outside the home can also involve using leisure facilities or taking part in a range of social activities with other children. Other provision includes support in the child's home while family members go out or choose to spend time in other ways (Stalker, 1991 and 1996 describes the development of short break services).

There is debate about who short break services are *really* for. There is no doubt of the commitment, skills and enjoyment of short break carers doing the job, and the positive feelings and experiences of the many children who use short breaks (Prewett, 1999a).

However, it has been argued that the term 'short breaks for disabled children' is misleading and discriminatory, as its concept and origins are parent-centred; a service requested by parents not children, and offering the adult carers 'a break' (that is, 'relief') from the child. It sets disabled children apart from their sisters and brothers and friends, who do not have their time away from their family described as 'short breaks'; and who, moreover, are not able to go with the disabled child on these short breaks (Marchant, 2001, p 218). It has also been argued that a whole 'short break industry' has developed that creates jobs for local authority and voluntary agency staff, and pays allowances to non-family members of a child to care for them, and that this can have the effect of undermining the family (Cocks, 2000, pp 509-10). While this is clearly not the intention behind

short break schemes and the reason why carers take on the work, it is important that these debates are heard.

If services and society removed disabling barriers, children could be accommodated without separate services. Also there is a stigma attached to these services, as they are only offered after an external assessment of family need is carried out rather than being offered as a matter of right (for an elaboration of these points, see Marchant, 2001, and Morris, 1998b). Sometimes these schemes have been set up without consulting children, young people and their families. Because they are now part of a system, they can be resistant to change. And families may have to fit in with what is offered rather than being able to request services that meet their needs.

It is only relatively recently that disabled children and young people have been consulted about the services and support they would like, and prepared for the services they receive. They overwhelmingly want to do the things non-disabled children and young people do. They acknowledge the need for them and their parents to have a break from each other, and enjoy their time with carers. They make new friends and take part in a range of social opportunities. But they generally miss their families when away and do not want to be apart from them for too long (the views of disabled children and young people are summarised in JRF, 2001a and the Children's Society, 2001).

The study carried out in Scotland with nine children and young people highlighted these and other messages:

- Like all children their age, they want to do things that other children do. They are not asking for more, but the same

access as their peers. Their impairment prevents some adults from acknowledging that they have the same needs as non-disabled children.

- The education setting was a positive place for all the children and this clearly related to its focus on their abilities and not the effects of their impairments.
- All had friends, but few were able to maintain contact outside the educational setting (Patel, 2002).

There is frequent change in the management and aims of short break services, and tensions inevitably arise in the attempts to balance the needs of the different parties involved (children, parents, short break carers, project staff, and so on) while keeping the goal of child-centred services in sight. But the inclusion of disabled children's voices and the voices of other marginalised groups brings different kinds of change – centrally to do with the shifting of power and control to service users. Listening to these voices and acting on them may make a real difference to the shape of services.

Legislative and policy context

This is a time of much change in public services. There are currently many legislative and policy initiatives within which this review is located. Some of the recommendations in this review are already being addressed.

Children's services

In 1998, a report by the Department of Health (DoH), England and Wales Social Services Inspectorate (SSI) and the

Council for Disabled Children (CDC) stated that:

Respite or short-term breaks has been an important component of family support within all local authority planning structures and has been universally regarded by parents as essential. But despite the positive messages emerging from a number of reviews of respite care, anomalies and challenges remain for purchasers, providers and service users. (DoH/SSI/CDC, 1998, p 48)

Other SSI reports have identified gaps in provision of services for Black families (DoH/SSI, 1994, 2000).

The *Quality Protects* initiative in England specifies as one of its sub-objectives that services should “increase the number of disabled children in receipt of family support services – including short-term breaks” (DoH, 2001a).

The English government's 1998 Sixth Objective for Children's Social Services (DoH, 1998) concerns disabled children, and the *Quality Protects* programme requires that local authorities prioritise short breaks and “ensure that services are appropriate for ethnic minority communities”. The *Third annual overview report of the Quality Protects programme* notes that very few of the Management Action Plans included systematic accounts of how councils were meeting the special needs of Black and minority ethnic disabled children. They noted that overall this was a relatively underdeveloped aspect of work (DoH, 2001b, p 62). The *Quality Protects* programme now requires local authorities to allocate monies to services for disabled children. It also requires them to specify how each objective will meet the needs

of disabled children and their families, and the needs of Black and minority ethnic groups in their area. Objective 6 of the *Quality Protects* Disabled Children's Objectives and Sub-objectives has been revised to specifically include expenditure on short breaks and ensuring services are appropriate for minority ethnic communities (DoH, 2001c).

In Wales, the *Children First* Programme Guidance for 2001-02 specifies short breaks for inclusion in local authority revised Action Plans, albeit with no apparent mention of minority ethnic groups (National Assembly for Wales, 2000).

In December 2001, the Northern Ireland Executive published its *Programme for government*. This has gone some way toward putting ethnicity on the agenda in services, and the Programme does acknowledge that "people from ethnic minorities and people with disabilities experience particular difficulties in accessing some public services" (Northern Ireland Executive, 2001, pp 135-6). NICEM, the voluntary sector, membership-based umbrella organisation, is representative of the Black and minority ethnic sector in Northern Ireland. Following its submission in response to the draft *Programme for government* in November 2001, some of NICEM's concerns (about data collection on ethnicity and evidence of racism in public attitudes) seem to have been addressed.

In Scotland, the 1995 Children (Scotland) Act brought Scotland in line with England in relation to the requirement that local authorities need to pay heed to a child's racial, linguistic, cultural and religious persuasion. It also brought in many aspects of the United Nations' Convention on the Rights of the Child. The research in Scotland, carried out by Vijay Patel,

reviews service developments regarding ethnicity and disability, and notes that progress has been relatively slow to date but that there is optimism for the future. He observes that issues of racism and diversity have tended to remain invisible within a policy context, and that a major review of learning disability, *The same as you* (CRU, 2000) by the Scottish Executive, while providing a number of good recommendations, did not touch on the issues. However, it is hoped that this will change in the next few years with the introduction/implementation of the following:

- 2000 Race Relations Amendment Act, which sets out new requirements for public services;
- 2001 Regulation of Care Act, which introduces a new commission to inspect social care services in accordance with an agreed set of national care standards;
- Race Equality Action Forum action plans for the Scottish Executive – a set of recommendations to ministers, which set out plans to mainstream race equality within the Scottish Executive and further afield (Patel, 2002).

So most of the UK nations are addressing ethnicity and disability, though not all are bringing the two together yet, or setting specific objectives with ring-fenced resources. All have frameworks within which they can locate initiatives.

The Children's Task Force, which will oversee the development of the National Service Framework (NSF) for Children in England, is committed to inclusion and participation. The NSF will explicitly cover disabled children. The relevant section states:

Taskforce projects should give special care to ensure participation

is inclusive and reaches children and young people from black and ethnic minority groups. Care should also be taken to ensure inclusion of disabled children, and representation in terms of age and gender. The work being undertaken by the Children's Society provides an excellent model for other projects starting work with disabled children. (www.doh.gov.uk/childrenstaskforce/participation.htm)

The Audit Commission is currently carrying out a survey of services to disabled children that could provide valuable information about short breaks (Davies, 2001).

At the time of writing, a new consultation strategy from the Children and Young People's Unit includes among its principles those of equitable, inclusive and non-discriminatory services, which all children and young people should be able to have access to, and participate in, when they need them. This is a good basis on which to argue for short break provision.

Thus in 2002 there is quite an impetus for improving short break provision.

Support for parent/carers of disabled children and young people

Both the 2000 Carers and Disabled Children Act in England and Wales and the 2001 Health and Social Care Act allow for direct payments to people with parental responsibility for disabled children, and also to disabled young people aged 16 or 17 in their own right. In Scotland, there is equivalent legislation in the form of the 2001 Community Care (Direct Payments) (Scotland) Amendment

Regulations. However, although direct payments may offer more choice and flexibility for parents, it is not yet clear how they will operate within existing children's services. In addition, relatives are excluded from being paid as 'carers' under this scheme except in "exceptional circumstances". The legislation also provides for local authority social services departments to run short break voucher schemes. Voucher schemes are designed to offer flexibility and choice in the way services are delivered to persons cared for, while their usual carer is taking a break. Guidance for the Carers Special Grant, which in Year 2 (2000/01) included caring for disabled children and young people, has asked English local authorities to record any specific developments for carers from minority ethnic backgrounds. In Year 3 (2001/02), agencies are being asked to publicise any difficulties relating to short breaks.

Learning difficulties

Valuing people (DoH, 2001e), the learning disability strategy for England, notes the barriers to participation in society faced by minority ethnic families and how these are disproportionate in comparison with other sections of the population. Specifically mentioned as areas needing attention are more short breaks and early diagnosis of impairment (which is a particular issue for some South Asian groups). Ethnicity is not mentioned here in detail and not included specifically in the objectives and sub-objectives as it now is in the *Quality Protects* guidance. The Department of Health commissioned a report by Ghazala Mir and colleagues, which reviews literature on disability and ethnicity and has much to say about access to services and what needs to be done. It remains to be seen whether *Valuing people* will be able to prioritise

the needs of Black disabled children and young people (Ward, 2001).

Anti-discrimination and human rights legislation

The 1998 Human Rights Act is linked to the European Convention of Human Rights, to which the UK is a signatory. The United Nations Convention on the Rights of the Child is international legislation that aims to promote all children's rights and protect children and young people. All four UK countries are covered by this legislation. Services to disabled children from minority ethnic groups and their families are also covered by anti-discrimination legislation. All four UK countries are covered by the 1995 Disability Discrimination Act. The 2000 Race Relations (Amendment) Act in England and Wales, and the same in Scotland, will require public services to show how they promote racial equality – a more active requirement than before. In Northern Ireland, the 1997 Race Relations (Northern Ireland) Order makes it unlawful to discriminate against anyone on the grounds of race, colour, nationality, or national or ethnic origin. The international context is therefore one that is compatible with the work carried out in this review.

Regarding anti-discrimination, *Best value performance indicators 2002-2003* has strong performance indicators relating to equality that specify racial and disability equality. These should greatly assist local services to work within a framework of anti-discrimination and inclusion (DTLR, 2001).

The Equality Standard for Local Government provides a systematic framework for the mainstreaming of equalities. It has been developed by the

Commission for Racial Equality, the Equal Opportunities Commission, the Disability Rights Commission and the Employers Organisation for Local Government. Suggested best value performance indicators for 2002/03 include compliance with the Equality Standard, the number of Black and minority ethnic staff in senior management, and those users/carers in social services who said that matters relating to race, culture or religion were noted by service providers.

What we do and do not know from existing research

In this section, I review the contribution of research to the development of policy and practice. Research is an integral part of the wider process of improving services such as short break schemes and so it is important to recognise that, as with practice, the strengths and weaknesses of research need to be critically examined. In subsequent chapters, analysis will focus on barriers to accessing short break services (Chapter 3) and consideration of good practice and ‘what works’ (Chapter 4).

Information: gaps and limitations

Information on ethnicity and disability

Information on disabled children, and on children from minority ethnic groups, has not been routinely collected in the past, neither by local authorities nor by researchers. Information specifically on disabled children from minority ethnic groups is even harder to find. Though there is now more data available, it is still patchy and uncoordinated. The way information has been obtained and presented in the past has varied, and it is not possible to compare like with like. For example, in England, it is only since 2000 that the Department of Health has

expected social services departments to include the ethnicity of children in need in their statistical returns. As yet, data on ethnicity is not required to be collected in Northern Ireland, though data on religion is.

Information on ethnicity is notorious for its high non-completion rates, and these rates are not always stated in findings. Studies use different ways of classifying ethnicity, not always separating out the different South Asian groups, or African from African Caribbean people. It is now acknowledged that groups united under the political term ‘Black’ may have very different living circumstances and experiences of services, and have different life chances and outcomes compared with the majority of White ethnic groups (Modood et al, 1997; Erens et al, 1999). In England it will be possible to analyse the ‘Children in need’ Census data in terms of disability and ethnicity, and obtain valuable information.

Statistics and context

Figures from the 1998 England national statistics estimate 7.3% of the combined adult and child population are from groups defined as of African, Caribbean, South Asian, Chinese or ‘mixed’ origins

(ONS, 1998). In 2000 the estimated size of the minority ethnic population was four million, or 7.1% of the total population. Initial estimates from the 2001 Census make this figure 10% (Singh, 2001). Between 1992-94 and 1997-99 the minority ethnic population grew by 15%, compared to an increase of 1% in the White population. Fifty per cent of the total minority ethnic population in 1997-99 were born in the UK; the corresponding figure for those aged 0-14 was 90%. The group with the lowest proportion born in the UK were Chinese people at 25% (ONS, 2001). In Northern Ireland the minority ethnic population is estimated as 0.9%, which includes Chinese (the largest minority ethnic group), Jewish and Traveller people. In Wales and in Scotland the minority ethnic populations are similar, at approximately 1.5% of the total population (ONS, 1998). The Office for National Statistics (ONS) population trends for September 2001 show the Black (mixed) population to be growing at 49% and the Bangladeshi population to be growing at 30% (ONS, 2001). The Black minority ethnic population is overall a younger population than the White population, and growing faster, which needs to be taken into account when researching and planning services.

Black families differ from the majority of the White population in the conditions in which they live. Poverty, poor housing, unemployment and discrimination disproportionately affect Black families, with Pakistani, Bangladeshi and African Caribbean families being the most disadvantaged (Modood et al, 1997; JRF, 1999b). There is also evidence that these adverse social and environmental conditions, plus issues concerned with access to services, are linked to the higher incidence of some impairments in some minority ethnic groups (Mir et al, 2001).

So Black families with disabled children may be further disadvantaged.

Sample sizes, data collection and comparisons

Research has often been carried out with small samples of minority ethnic families, making generalisation and replication difficult. Researchers sometimes compare their findings with national statistics on minority ethnic groups when local comparisons would be more useful, since in some local authorities Black people are a majority of the population. Also, an inaccurate picture is produced when several schemes are aggregated. One, for example, may have a high number of Black users.

Some studies compare their findings with statistics on the combined adult and child minority ethnic population in the local area. Often it would be more useful to make comparisons with the overall children and young people population only, since it is often these age groups that have the largest proportion from minority ethnic groups (ONS, 2001).

Lack of information on some Black groups and in some geographical areas

There is little detailed information on many aspects of Black and minority ethnic children and families and their use of short breaks. For example:

- How are they used by specific groups such as Bangladeshi or African Caribbean families?
- How do children and young people describe their experience of such breaks, and what changes would they like to see?

- How is the use of short breaks influenced by gender, or age or impairment?
- What are the specific needs of refugee and asylum-seeking children and young people, another diverse minority group that is only beginning to be researched?
- How do the needs of Black families with disabled children vary between different localities and different parts of the UK?

The re-analysis of the Office of Population Censuses and Surveys Disability Survey data sheds some light on the under-representation of African and African Caribbean children in short-term care, though the data for this was collected in the 1980s. The survey found that children from these ethnic groups were more likely to be cared for away from home in long-term residential care (Gordon et al, 2000).

Changes in short break services

Reflecting changes over time in short break practice, research studies have looked at different aspects of what were once routinely called ‘respite care’ services. Early studies included residential institutional provision provided by health as well as social services, while later studies focused more on family-based short break provision, provided by social services and voluntary agencies. More recently, home-based services such as sitting and befriending have become popular, and this is backed up by evidence from the survey of practice carried out for this review, where they were valued in particular by South Asian families. Information on provision appears patchy and uncoordinated. Shared Care Network, the national umbrella organisation representing short

break schemes, and the Norah Fry Research Centre, University of Bristol, have up-to-date information on family-based short break provision, but the current extent of non-family-based provision appears unknown. The latest survey by Shared Care Network notes that less than 5% of schemes said they provided long-term care, although this is not the focus for Shared Care Network’s members (Prewett, 1999a). Anecdotal evidence from the Council for Disabled Children in London shows regional variations in bed-based provision – for example, 85% in Northern Ireland compared with 30% in London – so generalisations may not be possible.

Patterns of use of short break services that emerge from research

Black families with disabled children

More is known about services Black families *do not* use than the ones they do. Evidence points to low take-up of family support services by South Asian communities with non-disabled children (Qureshi et al, 2000). A study of Black families’ use of family centres found that most centres were not accessible for disabled users and that because the administration of services for disabled children was separate from those for non-disabled children, the inclusion of disabled children did not seem to be routine. This was identified as an area of concern (Butt and Box, 1998). African and African Caribbean children and young people may be more likely to live away from their families in residential care. Other studies support the finding that disabled children in general are more likely to live away from home as looked-after children, or be in residential

educational provision, than non-disabled children (Morris, 1995, 1998b; Gordon et al, 2000; DoH, 2000²; Abbott et al, 2001a, 2001b; DTLR, 2001).

In relation to short break services, these services have been available for more than 25 years in one form or another, but research studies are still finding low take-up from Black families, particularly from Bangladeshi, African and Caribbean communities. Evidence from literature of families 'choosing' not to use services was hard to qualify. It was sometimes clear that the reasons for not using a service offered were because it was disliked by the child, or perceived as culturally inappropriate (Hatton et al, 2001). Some families associated social services and social work with removal of their children, or accepting 'charity', or as evidence that they could not cope (Shah, 1992; Singh, 1992). One recent study found reasonable awareness among health, social services and education staff of unequal access to services by minority ethnic families and how processes they use might be biased and excluding of them (Steele and Sergison, 2001).

More Black families use institutional residential provision

Black families (in particular those from South Asian groups) seem more likely to use residential provision for their children, both from health and social services, and less likely to use family-based short break care. This finding was first reported by Carol Robinson and Kirsten Stalker in 1989, with more than

60% of Black families using residential institutions. Ten years later it was still the case, when just over half of the Black families in Chamba's national survey reported using a short-term care 'centre', a greater proportion than found in Beresford's survey of predominantly White families (Robinson and Stalker, 1989; Beresford, 1995; Chamba et al, 1999).

It is not clear from these studies whether this difference is because parents are not offered alternatives to residential care, or if family-based services are not seen as desirable by Black parents. Robinson and Stalker offer a number of possible explanations. One is the requirement for families to negotiate directly with the family link carers. Another is the shortage of Black carers and Black link workers. There is then the possibility of parental anxieties about their child staying with families who may not meet cultural and religious needs – in their study, there was evidence that family link carers were predominantly White and middle class. There is also the likelihood that in 1989 parents lacked information on family-based provision as, at that time, it was relatively new (Robinson and Stalker, 1989).

Parents in Robina Shah's study, and also in Hatton et al's and Chamba et al's studies, expressed anxieties about the cultural appropriateness of the services, which may explain their reluctance to take them up, regardless of their need. However, short break services are changing rapidly so this information needs to be updated. Also we did not specifically ask for information on residential care establishments.

² Note that, in this study, 36% of disabled looked-after children were in residential care compared with 13% of all looked-after children.

Unmet need: waiting lists, non-users and insufficient services

There is over-representation of Black families on the waiting lists for family-based care, and as non-users of all short break services (Stalker and Robinson, 1991a, 1991b; Prewett, 1999a).

The overall message of recent research is that there may now be more Black families using short break services than in the past, but there is still unmet need.

It might be assumed that Black families are not using family-based services because they are using residential provision (as previously discussed). However, Black families have also been disproportionately represented on short break waiting lists, and as non-users of short break services (not only family-based ones). Beth Prewett's recent survey of family-based short break schemes noted that half as many children were on waiting lists as were receiving services, and that nearly 90% of schemes had waiting lists. The reason given for 2% of children on the waiting list was there being a shortage of support carers from particular ethnic groups (Prewett, 1999a). This may be an underestimate if lack of appropriate carers prevent referrals in the first place (Stalker and Robinson, 1991a, 1991b). Families often have to be referred to a scheme by professionals before they can go on a waiting list, and there is evidence that some do not even get that far.

In Chamba et al's study, no more than one in four parents was using any kind of short-term care. Less than one in five Bangladeshi families said they used a short-term care service. Only 10% of Hatton's sample of 136 parents reported receiving 'respite care', and this was

mostly in specialist centres managed by social services.

In the survey of short break schemes carried out for this project by Shared Care Network, nine of the 13 schemes provided information on the ethnic composition of their waiting lists. Though some of the total numbers were small, five schemes reported that more than 40% of families on their waiting lists were of minority ethnic origin, and in one scheme this was nine out of the 11 families on the list. These were schemes that were aware of their responsibilities to Black families and were actively providing a service for them, but demand was outstripping supply.

Rosemary Tozer undertook a study of 24 families with more than one disabled child. Through a voluntary agency and a consultant, she recruited and interviewed parents in six Pakistani families. Though matched by the extent of their need with the White families, none were receiving assistance from social services, and none were receiving any kind of short breaks. This was not true of the White families in her study (Tozer, 1999). Bryony Beresford also identified higher levels of unmet need in Black families, compared with White families. In her study of more than 1,100 parents, 94 (8%) of whom were from minority ethnic groups, more than two in three of the minority ethnic families said they did not have a break from looking after their child as often as they needed. Yet, as in Chamba et al's study, three quarters of the parents did not use short-term care. A third of the non-users did not know the service existed and the others had 'chosen' not to use it. There were no details on the reasons for 'non-using'. However, of those who *did* use short breaks, two-thirds felt they needed more. Although data from the minority ethnic families was

not analysed in detail, or by specific ethnic group, there were clearly barriers to access for all families. These need to be researched in more detail (Beresford, 1995; Chamba et al, 1999).

A study published in 1990 found that Leeds social services' family placement scheme catered for 168 children, plus 90 children receiving short-term care in two residential homes. But, despite the ethnic make-up of the local population, only 10 children from Black and minority ethnic communities were being supported (Baxter et al, 1990). The Leeds family placement scheme was one of the projects visited as part of this review, and the short break scheme made changes to the service in 1996 that were moving toward an increased uptake by Black families.

A study by Jaswant Singh, carried out in Cardiff around the same time, describes the process used by one Barnardo's short break project that had only one Black service user and wanted to increase access to others – of whom there were at least 22 children and young people eligible. It is a good example of proactive work aimed at identifying and alleviating unmet need (Singh, 1992).

The Office for Population Censuses and Surveys study found under-representation of disabled children from minority ethnic groups as users of 'respite' care. This survey noted that no child from an Asian family had received a short break in the previous year, and that only 18% of Asian parents had heard of 'respite' care (Gordon et al, 2000). Barriers to access will be discussed in detail in the next chapter.

Although most parents who used a short break service were satisfied with it, two out of five in Chamba et al's large survey

were dissatisfied with the *amount* of care that was available. In Hatton's study, parents who used short breaks also felt that the amount they received was not sufficient, much as they valued the service (Hatton et al, 2001). This is unsurprising, given that short breaks are clearly a strained service faced with much unmet need.

Overnight stays versus home-based family link services

Evidence from the survey carried out by Shared Care Network for this project showed a marked preference for home-based and sitting services rather than overnight stays. This was explicitly mentioned by a number of schemes.

Two recent studies found low take-up of overnight short breaks by South Asian children and young people, one by Pakistani young people in general (Rabiee et al, 2001) and the other particularly by Indian and Pakistani girls (Steele and Sergison, 2001). In contrast, these young people were making good use of after-school daytime services and home care support. It is not clear whether, in the past, overnight or institutional provision was the only type of short break on offer to parents who may have lacked the information needed to request alternative services. We also do not have information on how the local employment situation, housing need or density of the population might affect the ability of schemes to provide different types of short break care. However, if in some areas of the UK parents and young people now have more information and choice, they may prefer to use day services. (It is worth noting that the study by Rabiee et al (2001) interviewed the young people, not their parents, unlike virtually all other studies.)

Evidence from two short break projects visited as part of this research confirmed the popularity of sitting and other daytime services with Black families (see Chapter 4 on increasing choice and flexibility of services).

Those 'in the know' are more likely to get services

Some studies point to services being disproportionately used by families with higher incomes, and by those who have the resources to put pressure on service providers. This is likely to put some Black families at a disadvantage, as they are more likely than White families to be on a low income (Mir et al, 2001). Black families are also less likely to have 'culturally collective power'; that is, White families are more likely to know how to negotiate and engage with the systems surrounding public services or know someone who can offer a 'way in' to them. South Asian parents have been found to be disadvantaged in this way. Almost half of the South Asian parents in a study by Hatton and colleagues did not know about 'respite care':

These carers [here: parents] were found to have a reduced possibility of 'chance encounters' with professionals and other carers, which for White carers had been the first step in getting help from statutory and voluntary agencies. (Hatton et al, 1998, quoted in Mir et al, 2001, p 39)

When looking at patterns of use, then, it is necessary to examine separately each kind of short break service and the locality and population, as well as examining use by each minority ethnic group.

Children with complex medical needs

Short breaks have traditionally catered for disabled children and young people with learning difficulties rather than those with other impairments. A survey from the Norah Fry Research Centre found that although this was still the case in 1999, schemes are becoming more inclusive of all disabled children, including those with complex healthcare needs (Prewett, 1999a). Most local studies do not analyse data by ethnicity, type of service and impairment, possibly because numbers are often small.

Noyes' study of a group of 18 young people who used assisted ventilation included young people who came from six different ethnic/cultural backgrounds, including three young people for whom English was not their first language (Noyes, 1999, p 12). These young people and their parents said that, even though taking a break was very important for them, frequently 'respite care' had not been considered or the provision was totally inadequate. For the parents, the lack of this service was a source of significant stress. The young people said they did not want to go to hospital or hospices when their parents had a break, as they did not consider themselves ill.

A current study by the Norah Fry Research Centre is looking at the experiences of using services of a diverse group of children and young people with complex health needs, including those from Black families. Figures from Bradford social services indicated that in 1996, 37% of children on their database for complex health and serious illness were of Asian origin, which meant they were over-represented (Green, 2001). More analysis of this kind of data that

exists in NHS and social services statistics is necessary to help with understanding relationships between impairment, illness and ethnicity.

What Black disabled children and young people think of short break services

A recent review of literature, undertaken by Ali and colleagues, noted that “the voices of Black and Asian children in disability research have been almost silent” (Ali et al, 2001, p 949). Although some of the studies had included minority ethnic children and young people, their contributions have not been referred to specifically, so remain invisible.

Three studies are exceptions to this. One is Noyes’ (1999) study of children and young people using assisted ventilation. The second looks at young people and independent living (Bignall and Butt, 2000), and the third at young people leaving care (Rabiee et al, 2001). It is significant that two of these studies were carried out by Black researchers. But there are changes in hand. Recently, a number of initiatives have put disabled children and young people’s views centre stage, though the focus is general, or on access to leisure, or inclusion in schools. These include Black disabled children and young people, though there are still virtually no studies that have focused specifically on their views about services (JRF Findings 2001a, 2001b; Murray, 2002: forthcoming).

There is evidence that local authority practice in consulting in general is at an early stage, so Black children and young people are even less likely to have been consulted without specific effort (DoH, 2001b, p 61). Steele and Sergison’s study

in Huddersfield interviewed 18 children and young people from minority ethnic groups who had learning difficulties, though not specifically about short breaks. They noted that ethnicity and religion were more important to these children than to White children, and stressed that this should be taken into account in services.

As part of this JRF project, interviews were carried out in Scotland with nine Black disabled children and young people aged between six and 25 years. There were six males and three females, seven of whom were defined by their parents as Pakistani and two as Chinese. Three were using short break services, two with a family and one in a residential unit. The young people commented on how difficult it was to maintain contact with friends outside school times. They wanted to have access to the opportunities their non-disabled peers had, and knew that there were barriers to this. Culture and faith were important to them, but these aspects did not seem to be supported in their schools. Moreover they were also denied, to some extent, within their children’s own communities.

There is evidence of change, however. Two projects currently in progress at the Norah Fry Research Centre in Bristol have included interviews with Black disabled young people (Heslop, work in progress), and the Audit Commission study is also currently seeking their views (Davies, 2001).

Barriers to accessing short breaks

If Black families with disabled children are not using services, it is no longer acceptable to see it as their responsibility: it is not down to them to find out what is available and to make their own arrangements to use services. It is now recognised that institutional barriers exist, and that racism as a barrier runs through all services unless clear steps are taken to arrest it. The main barriers are summarised below.

Separation of disability and ethnicity; a lack of service coordination

One of the young men interviewed in the Scottish study (Patel, 2002) commented that “Disability organisations do not understand issues of culture and religion whilst ethnic minority organisations do not understand issues of disability”. This has been a central theme in regard to multiple oppressions. It reflects who has institutional power, and who may be threatening it (Vernon, 1996; Diniz, 1999; Banton and Hirsch, 2000). The creation by those who have power of services that suit themselves has a long history, and the reluctance to address diversity in services at the outset has resulted in services such as ‘family placement’,

‘family support’ and ‘disabled children’s services’ running on parallel tracks. A study of family centre use by Black families noted the administrative separation of family support and services for disabled children (Butt and Box, 1998). Ethnicity in services has frequently not featured at all, or has suffered from the separation described earlier. In addition, services may not work together effectively. For example, poverty affects families with disabled children more than those with non-disabled children, but is more likely to affect Black families. Both groups also have greater housing needs. The Chamba et al (1999) survey found that six out of 10 families reported their home to be unsuitable for the care of their child. Pakistani and Bangladeshi families reported the most housing problems. Poor housing raises the level of stress in a family and affects the quality of life and care for children in many ways. A recent report on the involvement of Black disabled adults in Warwickshire details the effects of this exclusion and the separation of disability and ethnicity within voluntary and statutory organisations (Banton and Hirsch, 2000).

Poor leadership, policies, planning, consultation

Though there were few studies in the short break literature that focused specifically on the management of culturally competent and ethnically inclusive services, it was possible to extract aspects of service development and delivery that could act as barriers to access.

It was common for work with minority ethnic groups to be seen in the literature and in practice as an 'add-on' rather than as an integral part of mainstream service planning and provision. Integrated services were likely to be better resourced and given higher priority than separate services and, ideally, they should be able to meet all users' needs. However, as they did not, specialist services were necessary as well, but these were generally under-resourced and insecure (Ahmad et al, 1998; Mir et al, 2001).

Funding placed many constraints on services in both statutory and voluntary sectors. Few initiatives had mainstream budgets; most were supported through short-term funding. Initiatives therefore had uncertain futures. Initiatives in the voluntary sector were especially vulnerable to funding crises. Tight remits often hampered flexibility and thus the ability to respond to user wishes. (Mir et al, 2001)

An insecure service is less likely to give positive messages to service users. Lone Black workers on short-term contracts can shoulder a disproportionate share of the responsibility for making services inclusive. Many central government initiatives such as *Quality Protects* and *Health Action Zones* are short term, and

services are dependent on them for resources needed to encompass diversity in services. This situation is likely to continue unless active policy decisions are made to bring such marginal and short-term initiatives into the mainstream.

Lack of specific racial and disability equality policies and procedures for planning and service delivery, lack of leadership and management responsibility for carrying them out, and lack of monitoring, can all be barriers. Services that do not know the ethnic make-up of their local population, and do not include them in their consultation process, will not gain the confidence of groups that are already marginalised. If there is an unwillingness to engage with how racism operates in services, and to debate this openly and challenge deep-rooted assumptions about Black families, services cannot move forward.

The role of training is important here. Beth Prewett's study identifies a need for training in equalities and anti-oppressive practice for short break panel members. Some years before that, other researchers from the Norah Fry Centre, having found evidence of a lack of awareness, were also recommending staff training in cultural sensitivity (Robinson et al, 1993; Prewett, 1999a). Such training still does not appear to be routine, however. A recent report on minority ethnic children and young people with learning difficulties in the Huddersfield area included interviews with 49 health, education and social services staff. A high proportion had no training in cultural competence, and the majority felt they would like to have more (Steele and Sergison, 2001).

Jenny Morris, in her study of the implementation of the 1989 Children Act as it related to disabled children in three

local authorities, found a lack of social work support for families who used ‘respite care’ and who should be covered under the children’s legislation (Morris, 1998b, p 69). This is likely to be more prominent for Black families who under-use services, leading to an even greater level of unmet need.

Inflexibility of some short break services

Some studies have found short break provision to be insufficiently flexible for some Black parents. There are examples where the definition of ‘respite care’ did not include breaks while parents visited their country of origin to attend a funeral, religious or cultural events (Baxter et al, 1990, p 40).

Another study found that because of the inflexibility of services, only a third of South Asian families with a child with learning difficulties used short breaks. For example, they were only available in blocks of one or two weeks, which ruled out visits abroad, and did not allow for ‘occasional’ nights – to attend weddings or other family events, for example (Hatton et al, 1997, cited in Mir et al, 2001, p 34).

The six South Asian families interviewed as part of Rosemary Tozer’s study felt that: “the provision on offer was culturally inappropriate, that the language and customs of the children would not be understood. Parents would have preferred day care and support at home from someone who could play with the children for a few hours, rather than overnight respite” (Tozer, 1999, p 41).

While short break provision has definitely become more flexible and includes home-

based services, provision of the full range of services is not universal, and what parents are offered can depend on where they live (Prewett, 1999a).

Information about services and perception/understanding of them

A consistent theme across all the literature and maintained over time is that Black families, and in particular those for whom English is not their first language, do not know about services and entitlements (Chamba et al, 1999; Hatton et al, 2001). They also may have low expectations of access to services and reservations about using them, even when offered, although in Hatton et al’s study, once parents had been told about short breaks, almost half of them wanted to use the service.

An institutionally racist approach to service delivery would locate the responsibility for finding out about and accessing services with families themselves, arguing that the service is available to all, regardless of ethnicity, language and religion. An inclusive service that understands how institutional racism works to keep families out of services would see their role in a proactive way and would work to dispel myths, find out what the barriers to access are, and remove them. There are examples of South Asian mothers believing that their disabled child would be removed from the family permanently if they agreed to receive help from social services (Poonia and Ward, 1990; Shah, 1992) and of parental concerns about potential child abuse (Hatton et al, 2001). Studies show a reluctance to ask for help due to the stigma associated with ‘charity’ in accepting welfare, and with acknowledging their child as disabled

(Singh, 1992; Butt et al, 2000; Jones et al, 2002).

The language and terminology of short break care needs to be examined as parents may not understand the terms or may misinterpret them. This message applies equally to the language used to describe other forms of provision such as 'direct payments' to which parent/carers of disabled children may be entitled (Butt et al, 2000).

There are overlaps here with processes that exclude families, both Black and White, who live in poverty. The effects of disadvantage, a lack of information and difficulties with communication can lower expectations of support from statutory services. This may explain the under-representation of Bangladeshi families in services. Chamba et al's (1999) survey of some 600 families found that fewer than half the Bangladeshi parents could speak English, and that this was consistent with their greater need for an interpreter when talking to professionals. More than a third of parents felt they had less than a full understanding of spoken English, with only 25% of Bangladeshi parents saying they understood spoken English completely (see also Chamba and Ahmad, 2000).

Chamba et al found that, although the provision of interpreters was only reported by six out of 10 families that needed them, the majority of Bangladeshi families (who expressed the most need for this service) were usually provided with one. Across all ethnic groups, parents were least at ease with writing English compared with speaking or reading it.

One of the parents interviewed for this report echoed many of the views in the literature about parents' awareness and

perceptions of services: fear that the child's religious and cultural needs would not be met, not knowing about the service, seeing accepting the service as charity when they had nothing to give back, and feeling that asking for help was somehow shirking responsibility. There was also shame at being thought not to be coping.

Perceptions about disability

In a study carried out in Wales, Jaswant Singh (1992) interviewed all known parents of a child or young person with learning difficulties in one particular locality. He found that parents did not know how to ask for help, that some saw their child in a stigmatising way and therefore did not want to draw attention to themselves, and they equated asking for help with accepting 'charity', which was perceived negatively. Singh recommended that family-link schemes should take time and effort to break down these barriers to access, dispel the myths, and engage parents in support for their children and themselves. Although discriminatory attitudes toward disability are widespread across all ethnic groups, racism can mean that workers collude with Black families' attitudes, explaining this as 'being in their culture' instead of challenging them.

Lack of an ethnically diverse workforce

Every study looking at access to services by Black and minority ethnic families mentions the importance of providers having a workforce that reflects the communities they are trying to serve. This applies to social and health workers

as well as to short break carers. Many of those interviewed in studies where this was not the case, were aware of the barrier this created but had not always found ways of changing the status quo. Parents drew attention to this fact when discussing take-up of services. Where English was not the first language of hard-to-reach communities, monolingual workers could not do their job properly. Communities lacked role models to demonstrate that the services would cater for them. Parents worried that their child would not have her or his cultural needs met by someone from another ethnic group. This last finding was consistent across the many studies referenced.

‘Ethnically diverse’ does not mean a service having a single Black worker who then takes all the responsibility for work with Black and minority ethnic communities. This can lead to burn-out, alienation and marginalisation.

Lack of diversity in short break carers, sitters and other service providers

Several studies pointed to a severe shortage of short break carers for disabled children and their families from minority ethnic groups. The shortage of Black short break carers and sitters was frequently raised by providers as a reason for low take-up of services. Others had noted no mention of minority ethnic carers; for example, in local authorities visited by the Social Services Inspectorate in England and Wales (DHSS/SSI, 1987).

Beth Prewett’s national survey found that there were less short break carers from minority ethnic groups than children and young people who needed them, and that this need had not been reducing. She

found that 25% of children’s schemes identified a need to recruit short break carers from South Asian communities, and 10% needed more carers of African origins. Schemes felt that lack of staff and resources prevented them from giving this enough priority (Prewett, 1999a).

In the field of children’s social services, there is now more emphasis placed on keeping children linked to their kin and communities and, for looked-after children, the recruitment and support of kin as foster carers (DoH, 1991, 2001c). It is surprising then, that Prewett’s study found that only 3.5% of children’s support carers were relations. She also found some schemes who said they were ‘not allowed’ to use relatives. However, one study notes delay in linking children that was attributed to a shortage of Asian carers, but gives an example of close relatives willing to be carers but the agency refusing to approve them, as it was not their policy (Stalker and Robinson, 1991b). The authors note that, in contrast, the recruitment of kin as carers had met with success in other places – for example, in Bradford.

Myths about kin and community support

The following messages may seem to contradict those in the previous section. If kin support can be a myth, how can recruiting kin as carers be possible? But the two can coexist. It is important here to acknowledge differences between ethnic groups, geographical location of communities and patterns of employment, for example. Each local area will have different potential for kin relationships.

The belief is commonly expressed by service providers that Black families (in

particular, those from South Asian communities) are under-represented in services because they 'look after their own' and get support from the extended family. This has been continually challenged by research evidence. Singh (1992) describes this as a myth, and suggests that it is the characteristics of the services, not the families, that are responsible for low take-up. Beresford found that Black parents were significantly less likely to be receiving support from extended family members than White parents. She argues that this "contradicts the belief that minority ethnic families tend to be well supported by their extended family" (1995, p 22). Black parents were also less likely than White parents to belong to a support group, and a third of parents from these minority ethnic groups did not know what a support group was. This is not surprising if support groups have predominantly White members, and if Black families do not find them welcoming places.

Chamba et al's (1999) survey of some 600 Black families also found parents receiving less emotional and practical support from their partners/spouses than the mainly White parents in Beresford's study. Black African Caribbean and Indian groups received less support from the extended family than other groups. The main reason is that family members lived too far away. Parents, particularly Pakistani parents, were less likely to belong to, or know about, support groups than parents in Beresford's survey.

Over two thirds of the 136 South Asian parents in the study by Hatton and colleagues reported no help from extended family networks – a greater proportion than in Chamba et al's study. However, higher levels of support from within the immediate family compared to

Chamba et al's findings were reported (Hatton et al, 2001).

The six Pakistani families interviewed by Robina Shah in Tozer's study (Tozer, 1999) also reported less support from the wider family than White families, and a lack of contact with other parents of disabled children in that they were "least likely to be in touch with other parents except within the family" (Tozer, 1999, p 24).

In Shah's (1992) study, low take-up of short breaks was often interpreted by providers as the service not being needed rather than a lack of understanding or knowledge of it (1992, p 48).

In a study focusing on minority ethnic children with learning disabilities, carried out for Huddersfield NHS Trust some 10 years later, Steele and Sergison (2001) interviewed 38 parents/carers and 22 children, as well as a large number of staff. They still found a general perception among staff that South Asians had extended family support, commenting, "Whether this is true in general of 'Asian populations' it is not true of the families involved in our study. Carers and children had little such support and lacked confidence with external agencies"(p 8).

Lack of support in South Asian families, and the research evidence for this is summarised in the publication by Mir and colleagues, *Learning difficulties and ethnicity* (2001), emphasising that assumptions about families having kin and community support should not be given as a reason for low take-up of short breaks.

Inadequate assessment of need and restrictive referral practices

Mir and colleagues (2001) suggest that the circumstances of carers (taken here to mean parents) are not adequately investigated in the assessment of need. Interpretations of what people are saying, and a tendency for White workers to take information at 'face value', can compound their disadvantage.

The ability of short break service personnel to assess need effectively depends on a number of factors. The criteria used need to be free of cultural bias, and those undertaking assessments need to be aware of how the assessment process can unintentionally as well as intentionally discriminate against Black families. Those carrying out assessments have to be sure they are asking the right questions, that the answers are being interpreted correctly within the realms of someone's experience, and that the family is in a position to make an informed decision about what is available for them.

The majority of short break projects contacted, and those described in the literature, did not accept direct referrals from families and communities. Even voluntary organisations felt they were tied to accepting referrals from social services personnel through service-level agreements. Yet the stigma attached to asking for social services help can be a barrier. In addition, if projects and social workers are not linked into minority ethnic communities or if they feel uncomfortable in their presence, they are unlikely to engage with families long enough to make a referral. South Asian parents' lack of access to referral systems is also likely to be linked to the ability of service personnel to assess them appropriately.

Appropriateness of services

Racism

As early as 1990, the study by Baxter and colleagues identified the concerns of parents about the appropriateness of placements. Religion, language, racism and culture were all found to be significant barriers that needed to be addressed (Baxter et al, 1990). Parents have also reported experiencing racism directly in services and in everyday life. In Rosemary Tozer's (1999) study of parents with more than one disabled child, all families reported hostility towards them, but the Pakistani families specifically reported experiences of racism. Atkin and Ahmad (2000), in their work on parents' views of service support for sickle-cell or thalassaemia, noted that racism was reported by a number of parents, particularly those of African Caribbean origin. Parents felt that sickle-cell disease was seen as a 'Black problem' and therefore it received little attention.

Ethnic matching

With studies showing an under-representation of Black short break carers, there is less likelihood of ethnic matching – that is, the provision of 'same race' placements. Beckford and Robinson in 1993 found 267 children (46% of Black children) to be in trans-racial placements, and the proportion of Black carers has not risen significantly since then. Prewett's study shows a high percentage of schemes reporting 'same race' placements, which she explains as Black carers frequently being linked with more than one disabled child (Prewett, 1999a). This has implications for the support and workload of Black carers.

Choice for children and families is important here. Schemes should be trying to recruit a wide range of carers, sitters, and so on, so they can match by ethnicity, language and religion where possible. However, children and young people are living with their families who can also provide for their identity needs. So in discussion it may sometimes be possible for parents to accept White carers if they can make an informed choice. A mother in Vijay Patel's (2002) Scottish study had got to know a White carer who had been a sitter for her children. This carer was trusted, respected the family's religious and cultural beliefs and the children were therefore able to stay overnight with her. Similarly, Black families may have White neighbours or kin who know the children well and would be suitable as carers. While the possibility of non-ethnically matched placements exists, it should not be used by services as a reason for not diversifying the pool of carers.

Culture

A number of studies draw attention to the reluctance of families to take up services on offer due to their anxieties that, in doing so, the child would experience a loss of culture or religion. Both a study of Asian families with preschool deaf children, and another of deafness and ethnicity, mentioned parents' anxieties about the appropriateness of services (Ahmad et al, 1998; Chamba et al, 1998). This was also a reason given by 59% of Hatton's South Asian parents (Hatton et al, 2001).

In *Double discrimination* Baxter and colleagues (1990) reported that: "Many families would prefer to see their relatives placed in situations where their individual cultural, religious and physical needs will

be met and where their differing needs are not seen as a problem" (p 40).

Robina Shah's (1992) interview study of 35 Asian families found a lack of reassurance that families would be able to have carers who shared the language, religion and culture of their child, although they overwhelmingly desired this. Shah also found services unable to guarantee other needs – for example, that only women would carry out personal care for girls. She also noted difficulties in the provision of appropriate food, and respect for other religious and cultural needs.

Steele and Sergison's (2001) research in Huddersfield noted that social services' support with 'residential breaks for children' seemed to have been designed with the White majority in mind. The survey suggested that this did not always fit with some minority ethnic cultures and that services should reconsider how to meet minority groups' needs (p 43).

The Pakistani families in Rosemary Tozer's (1999) study also felt that the provision on offer was culturally inappropriate, that the language and customs of the children would not be understood, and that day care and support at home from someone who could play with the children for a few hours, were preferred, rather than overnight 'respite'.

It is not clear from the research whether these were the experiences of the Black young people as well as their parents, but as an example of a different type of cultural inappropriateness, some young people using assisted ventilation in one study had inappropriate short break experiences (Noyes, 1999). They did not want to go to hospital or hospices when their parents had a break, as they did not

consider themselves ill, but this is all that they had been offered. Jenny Morris's study of three local authorities also found hospices being used as a 'respite' facility for disabled children who were not terminally ill, and who may not have been ill at all. Very young children were staying in this provision. This was not necessarily good practice (Morris, 1999).

A recent study of four children's hospices found that three were not addressing issues of culture or 'race', and were likely to be off-putting to non-Christians; for example, by having crucifixes on the walls and being located in monastery grounds (Robinson and Jackson, 2000, and personal communication with Carol Robinson, 2001).

The report of the Social Services Inspectorate on services to minority ethnic children and families mentioned the importance of cultural identity, parents' fear of 'losing' a child to residential care, and the different cultural environments they would experience in education and training settings (DoH/SSI, 2000).

Another issue that is mentioned in research literature is that of definitions of 'independence' for young people. One study found that independence in a Western model was associated with individuality and living separately from family and other kin. This was not shared by some of the Black young disabled people (Bignall and Butt, 2000). Others also note that people with learning difficulties from South Asian and African Caribbean communities felt that independence could be achieved within a family setting, which favoured collectivity rather than individuality. This could account for some families' reluctance to use short break services where children

have to stay away overnight (Mir et al, 2001).

In drawing conclusions from this evidence, it is important not to fix on narrow definitions of what 'culture' is, as it varies from family to family and over time. The overarching message is that people should be asked what they want and what kind of support they would consider appropriate.

What works?

An important objective in this study is to find out what works: to identify the messages coming from successful schemes and good practice.

The evidence for this section comes from a number of sources. Thirteen family-based short break schemes replied to a questionnaire sent out via Shared Care Network, the national coordinating organisation for short break care. The questionnaire asked for examples of good practice, and what was working for them in relation to Black and minority ethnic families and short break carers. The 13 schemes included some with quite small Black populations. However, these schemes provided few ideas on what works, unlike those with larger Black populations. Six of these schemes were then visited, in order to collect more detailed information. Three were Barnardo's schemes and three were run by local authorities. The majority had been established for more than 10 years. The six schemes were in Bradford, Dudley, Leeds, London Newham, London Tower Hamlets and Liverpool. Interviews were carried out in Nottingham and London with three Black short break carers and two Black parents, and two Black short break carers in Dudley were also interviewed.

Although 'size' of Black populations need not be the reason for good practice (or lack of it) as Richards and Ince found (2000), there is a need to collect and disseminate good practice from areas with small Black populations. Some schemes may be undervaluing what they are doing.

Practice and research literature also offers a number of messages and these references are highlighted in bold in the Bibliography.

Messages are summarised as follows.

Acknowledge barriers to access for families

One of the first stages in the process of solving problems is acknowledging that they exist. Some short break schemes had been operating in areas with high minority ethnic populations for a number of years before they had identified and tackled under-representation. For them, an initial review of how the scheme was operating was necessary to identify where the service needed to improve. The next step was often to employ a Black development worker, who would provide a 'way in' to local communities. From

this, other initiatives would follow – for example, improving communication, providing information or undertaking more appropriate assessments.

“After three years it was clear that the scheme was not being sufficiently used by the Asian Community ... we decided our first priority ... would be to see if the structure and presentation of the scheme could be made more appropriate.... We first looked at the Asian families we had on the scheme already. It appeared that the families were difficult to match with our current ‘carer families’ for three main reasons – language, transport and lack of phones. These factors were present with white families of course, but seemed magnified with the Asian families. The answer to language was obviously to recruit more Asian families as carers, and the answer to the second was to find families in the locality of those needing the service. These initial thoughts led us to the more fundamental problem of our own language and knowledge base. If we were to recruit people as helpers in on the schemes and if we wanted to understand what Asian families might want from a respite care scheme we needed to know how to communicate, where to communicate and with whom to communicate. Our next steps were therefore to talk to Asian people, both parents and professionals, about the scheme and to try and find funds for an Asian social worker. The latter point was the catalyst to our later improvement.” (Bradford)

Plan clearly, prioritise policies and offer management guidance

Building in diversity from the outset can avoid provision for Black families being ‘added on’ as an afterthought. This can ensure that the services reflect their needs. Policies and procedures are needed to affirm an organisation’s commitment to diversity and access, and strong leadership helps with management and implementation.

The opportunity to set up a new scheme, or to rework and expand an existing one, means that planning for diversity can be built in from the beginning.

The success of enabling Black and minority ethnic families access is that this was thought of at the outset and not as an add-on. The project leader knew that the service had to be representative at the outset of meeting diverse community needs, resulting in less strenuous work later on. (Newham)

Barnardo’s Families Together Project in Tower Hamlets was set up in 1987 as a pilot scheme. The staffing at the time was a project leader, an administrator and a part-time Bangladeshi man. It was recognised by the staff that Bangladeshi carers and families need to be approached through the men, hence the Bengali-speaking male worker. (Tower Hamlets)

The schemes that seem to have the clearest practices in relation to access by Black families also have specific policy statements about service provision that include clear statements about non-

discrimination, inclusion and access. All schemes that replied to the questionnaire were able to refer to the corporate equal opportunities policies of their parent organisation or social services department. However, not all could produce these, or actively link them to the service they provided. Children and family services do not always have their own policy, let alone one on racial equality in services. One scheme worker commented: "It has taken a while to assemble the info and docs or find out they don't exist ... it's been an interesting exercise".

These are examples of the kind of messages that Barnardo's Hamara, Spectrum and Family Link projects have in their policies:

The Project will endeavour to link children and young people with carers/sitters/volunteers from their own racial, linguistic, religious and cultural group as we believe that a child's inheritance is an essential part of their identity – an important part of what makes them the way they are, and one of the strengths which will help them grow up confidently. If this is not possible, the child will only be placed within a family that has a clear understanding of the issues of race and culture. Should this happen, the Project will continue to search for a carer reflecting the child's background. (Hamara)

The Project actively works to increase accessibility and appropriateness of service for potential and current black service users. This will be achieved by:

- Staff ensuring that all service users' cultural background is

clearly recorded on all Project documents.

- Staff to give consideration to service users' language needs and to discuss with Project managers about use of interpreters and translation.
- Staff to make themselves familiar with the complaints procedures and the languages this is available in.
- When vacancies occur, consideration will be given to filling this vacancy with a member of staff from a specific cultural background of current and potential service users.
- The Project in its entirety (décor, publicity, food, and so on) will strive to represent the cultural background of current and potential service users. (Spectrum)

Spectrum has a set of Race Equality Standards that, for each standard, outlines how it will be achieved. The example above is from Standard 1.

Within Family Link we take our Equal Opportunities Policy and Basis and Values statement very seriously. This means that our staff, carers, sitters and volunteers will always reflect the racial, cultural and religious diversity of Newham and will be welcomed and respected for the skills and commitment they bring to the project, regardless of their disability, gender, sexuality, marital status and class. In the same way, we are committed to equality of access to our service for the

children, young people and families who are referred.... Staff, carers, sitters and volunteers will therefore work in partnership with the children, young people and their families who receive our services to achieve this aim.
(Family Link)

Sense, the national voluntary organisation for deafblind people, though not a short break scheme as such, runs residential holiday provision. Its representatives replied to the questionnaire and the organisation's policy states:

... We recognise that membership of the race and culture into which a person was born is their right, regardless of disability. Sense clients from minority communities will, therefore, have particular needs in the areas of race and culture which we must seek to meet. (*Equal access and equal opportunities in Sense: A statement of intent*)

Other schemes have yet to reach Black families with their service. The Short Break Care scheme run by North Tyneside Children's Services, for example, serves a population with a percentage from minority ethnic groups of 1.1%. However, its service handbook has an equal opportunities and anti-discrimination statement, and it also states that:

A child's religious background must be considered. The information will be recorded and they will be given the opportunity to attend religious services where requested. Children/young people will attend services of a different faith where permission from child and parent has been sought. The

religious denomination of a child's family will be taken into account wherever possible when matching a child/family to a carer.

This kind of statement is a start toward inclusion.

In Liverpool, a Black Development Working Group has been set up and has planned a series of meetings with community groups in the area. These meetings have confirmed that there is a lack of knowledge about the work of Barnardo's as an organisation and also about what fostering (where the short break scheme is located) involves. Having now made a number of important community links, the project is now able to work to rectify this.

In Leeds, since 1996, the family placement team of the social services department as a whole (covering services to disabled children and adults) has been working to an action plan for minority ethnic development work. The children's sitting and short break services are components of these. In addition, Leeds has recruited a working group to advise and assist, drawing on the skills of Black staff in other parts of the City Council. This group is still in operation and sets yearly targets for the service.

In Bolton and Tameside, multidisciplinary workshops were held to look at issues of access to services by Black families (who were generically defined as carers). Though not specifically about children's services, all the recommendations and points in the two summary reports are relevant and echo findings from this study (Hepworth, 2000a, 2000b).

Adequately resource short break provision

Messages from the literature emphasise the short-term nature of funding for ‘minority ethnic’ type initiatives. We did not ask about the resourcing of schemes in the survey, but a number of them are funded as an integral part of service provision – including minority ethnic workers – and so have some security and stability. Schemes in Bradford, Leeds and many of the Barnardo’s projects, are not one-offs but have long-term organisational commitment. Although this kind of service can never have enough funds, the Barnardo’s schemes seem particularly well resourced. But this is due to fundraising efforts. Family Link in Newham has benefited from being one of the year 2000 appeal charities of the Lord Mayor of London, enabling it to move to a new building in 2001. Different aspects of project work draw on funds from different sources – for example, from the Carers Special Grant, Children’s Promise and the Children’s Fund. So funding is never assumed and is always being sought.

Organisations with limited funds may be tempted to look for low-cost forms of provision. They may decide to expand their sitting services, for example. If so, they may find that this is not a cheaper option as sitters can be paid more per hour than approved carers. Nevertheless, such costs can be balanced against the attraction of providing a service that is valued by neglected groups and thereby meeting the needs of more families from minority ethnic groups.

Know your locality: use outreach and community development

The barriers to accessing services mentioned in Chapter 3 can have the effect of rendering minority ethnic families invisible to the majority who provide the services. Even White workers who live locally may not know where to ‘find’ African Caribbean and South Asian families. In these situations, community work skills have been found to be useful. Places of worship, community projects, cinemas showing Asian films, and other cultural and social events, are useful starting points.

“She [the Asian social worker] was able to use her contacts in the community to help give the scheme respectability. She was able to suggest new avenues to present publicity, ie corner shops, particular clinics used by Asians.” (Bradford)

“Word of mouth has been successful as has been the raising of the scheme’s and Barnardo’s profile within the community by the Black development worker.” (Liverpool)

“Tapping into existing groups and networks such as women’s language classes has been quite useful.” (Bradford)

“There was a lengthy consultation period where a number of people were approached. The male heads of households [sic] of families known to have disabled children were approached. The workers went to visit families, health centres, schools, GPs and community groups. A parent carer

was involved in this process to encourage parents to come forward and use the service.”
(Tower Hamlets)

One of the carers interviewed directly for this study affirmed the importance of outreach, and even of social workers going from door to door, informing people about the service. She felt a social worker from the same ethnic group would be better able to encourage potential users.

Outreach, of course, is a continuous process. Needs and communities change, and a competent service will always be looking to match its services to local need. In particular, when working with marginalised and excluded groups, outreach is essential. Schemes that build this into their normal running costs and procedures are more likely to succeed. In Leeds, the Asian development worker regularly visits nurseries and schools, community centres, neighbourhood projects and local groups. Having a stall at the Mela (festival) in Roundhay Park, for example, was described as “a very enjoyable, fun day”.

“[We] need to do ground work before targeting [recruitment of carers]. Helping people to have an understanding by speaking about the services to groups, community authorities etc before targeting.”
(Newham)

“A proactive community development approach [for recruiting carers] had been fairly successfully tried out by Sharing Care [the short break scheme in Dudley]. This was very staff intensive and a major problem was the team’s ability to continue this level of involvement.” (Dudley)

Record and monitor ethnicity

The importance of accurate record keeping on ethnicity is stressed in the literature, and also by schemes aiming for good practice. It is only by regularly collecting the statistics, and then using them to implement and change services, that progress on inclusion can be made. Schemes that analyse their information on families by ethnicity are much clearer about the need to develop services. As populations change, services need to change to suit. Even where schemes are successfully including families from diverse communities, they still need to recognise and investigate the possibility that there are others not being reached. Barnardo’s Family Link project in Newham is finding increasing need among different African communities, including refugees and asylum seekers. As ‘African’ covers such a diverse group of people, the project is having to think and work strategically. This involves networking, outreach, and support with language skills, to identify barriers to access, and then changing practices to accommodate accordingly.

The examples below show attempts by a number of schemes to address unmet need:

“We need to recruit [carers] from Somali and Turkish communities.”
(Hamara)

“There are a few African children but we have not really got short break carers for them, and African Caribbean carers are also sought.”
(Newham)

“A male worker has attracted male sitters, and we now have eight, all from Black and minority ethnic

groups. The male sitters seem to prefer to talk to a male worker (they are working with male teenagers)....” (Newham)

“The majority of the [minority ethnic] users and carers are Pakistani Muslim with not many from Bangladeshi and African Caribbean communities. Eastern European communities are not thought to be reached.” (Bradford)

“There is a need for more carers from the Sikh community. There has not been a representative response from the Bangladeshi community.” (Leeds)

The Leeds project also provided a copy of a Race Equality Impact Assessment report that they developed in December 2001. In this, it has set targets for improving its ethnic monitoring – for example, by specifying each of the different ethnic and nationality groups covered under the category ‘Asian’.

Barnardo’s Families Together scheme in Tower Hamlets is aware that it is still not reaching all the communities the service needs to reflect, but it is committed to trying:

“There is a significant Chinese community but no Chinese users of the Project’s services. The Project staff have tried to encourage Chinese families to use the services but without success ... likewise they have not been able to recruit carers from the Chinese community.... They have used the radio and worked with a Turkish community centre in a nearby borough but have had no success.... This is largely due to

the stigma – some families feel they cannot use outside services. The Project has not given up and is still looking at trying to find the right way to get other ethnic groups to use the service ... they have gone into other boroughs to find carers from the Turkish community. They have spoken to parents at schools in an effort to recruit minority ethnic carers.”

Ensure workforce diversity

All studies and all projects included in this review are in agreement that having Black staff makes a difference to the perception and uptake of the service among Black groups. Barnardo’s North West scheme recruited a Black development worker two years ago, an active member of the African Caribbean community. This worker has built links between the community and the scheme. The project leader wrote: “In the mid-1990s we recognised we were an all-white staff group. Barnardo’s had little service provision within the black and ethnic communities in Liverpool”.

Both the Bradford and Leeds schemes have also changed the nature of their services by the recruitment of just one Black worker. The Bradford scheme now has one more. In Tower Hamlets, the project specifically recruited an African Caribbean social worker “... to enable Black carers [of African origins] to come forward. This clearly bears out research findings that projects need Black staff to recruit and support Black carers and families”.

Schemes in Liverpool and Leeds had tackled the implications of employing a

lone Black worker as a training issue for them. In Liverpool, the scheme had networked with others in a similar position. Barnardo's scheme workers have access to a regional Black Workers' Forum for support. Other positive strategies were an explicit commitment to joint responsibility for 'minority ethnic' issues, long-term security of employment for such workers, and clear peer and management support.

Gender diversity is also important. Barnardo's Family Link in Newham has recently recruited a White male deputy project leader. This seems to have enabled the recruitment of male sitters, particularly from Black groups.

Ask children and young people what they want

There is quite a gap in practice in respect to asking children and young people what they want. Reviews were mentioned as providing a chance for children and young people to be consulted. Even schemes that do communicate regularly with children and young people, and observe their well-being, feel more could be done to involve them in shaping services. Family Link in Newham does work proactively with some children to match needs and services: "Generally with the Asian communities networking seemed to be successful; ie asking the children on the waiting list if they would like someone that they know of to offer care such as a cousin and/or an existing carer".

Disabled children in Newham Borough as a whole have been part of a significant consultation exercise coordinated by Jenny Morris. Local project workers (including Family Link staff) received

training in communication skills so they can interview disabled children and young people, many of whom are from Black groups.

In Tower Hamlets, most of the staff have communication skills, such as in the use of Makaton, and ensure that children and young people are included. More needs to be done in this area, but there are a number of national initiatives and available resources that demonstrate that policy and practice is changing (Ward, 1998; JRF, 2001a, 2001b; Triangle, 2001). Vijay Patel's (2002) work for this project is again relevant here. The nine children and young people he interviewed were interested in making and maintaining friendships, having assistance so they could play outside and go where other children go rather than using short break services as such. Thus access to leisure facilities and personal assistance seems crucial.

Ask other family members what they want

Only three of the 13 schemes in the survey specifically said they assess what families require of the service, but these schemes had noted that parents want flexible and culturally appropriate services and "an extension of services to include clubs, and so on". There is a consensus that parents want more sitting and home-based services. This links with the broadening concept of short breaks noted in Chapter 1.

Barnardo's Family Link in Newham took the opportunity to consult with families before moving into its new purpose-built premises in 2001. The project staff had regular consultation meetings and sent a questionnaire, receiving a response from

over a third of the families. They now hold consultation meetings four times a year and draw on parent involvement in their annual reviews, recognising that this is a way of getting feedback for service planning. In Leeds, the short break scheme sent a questionnaire to all parents using the service in April 2000-01 and just over 40% replied. Although the replies were not analysed by ethnicity (which would have been extremely helpful), parents were overwhelmingly positive about the service.

Communicate effectively

Once families have referred themselves to a scheme or to social services as a result of effective outreach work, are they able to find someone sympathetic and able to communicate with them? For some under-represented groups, an answerphone message in their first language, or being able to speak with someone in their first language, can make a service seem really welcoming. Schemes in Leeds and Spectrum in Hanworth, London, have answerphone messages, and in London someone will call back and speak in a caller's first language. Barnet also has different-language telephone numbers on leaflets. "We have three Asian social workers who between them speak Urdu, Punjabi, Hindi, Gujarati and Somali" (Barnardo's Hamara Project, Walthamstow, London).

Similarly service users of Sense can request information in different languages, or can use an interpreter by telephone via a language line.

Barnardo's Families Together project in Tower Hamlets has a bilingual secretary/receptionist who is the first point of reference for most users. The scheme

also employs interpreters and translators as well as having bilingual social workers.

In Bradford, the interpreting unit can engage an interpreter through a three-way telephone link, if staff who speak the relevant language are not available.

Disseminate information

Lack of available information is recognised as a key explanation of why services are not taken up by those in need, and why it is difficult to recruit short break carers from under-represented groups. Many schemes feel they already provide enough information, but often this is not wholly appropriate or accessible or properly targeted. The information produced needs to be in a variety of media – such as video, audiotapes, posters and leaflets – as well as spread by word of mouth. It needs to be inclusive of the families that schemes are trying to reach. This means paying attention to images, photos and pictures, and making sure that the text or other messages contain positive and welcoming messages, "putting things like 'all communities are welcome' on information" (Newham).

This attention to diversity is desirable not 'just' because there may be Black families needing the service locally, but also because reflecting diversity is an essential part of good practice. Translating leaflets into languages used in the local community and having answerphone messages and audiotapes for loan in different languages were all mentioned. Getting the local press interested in featuring short break care, and using the publicity mechanisms of community, religious and other groups have also worked well.

The Asian development worker in Leeds has regular slots on Radio Ramadan, where she promotes the short break (and other) services. Leeds also has leaflets in different community languages. Bradford has tried a number of strategies, including a range of leaflets in different languages, radio slots and video:

“We made a video using Asian families with an Urdu commentary, which could be lent to either potential carers or users for the whole family to view.”

“Our initial meetings for potential carers were offered in a choice of English, Punjabi or Bengali. Transport was offered to the people attending the meetings.”
(Bradford)

Translations have not always worked well, though. In Barnet, the scheme worker commented: “Earlier distribution and mailing of other language leaflets was not at all successful. Translating the leaflet did not necessarily translate the concepts. A different approach needs to be thought through”.

It is important to have members of the same language group involved in the translation and proofing – and, better still, in writing appropriate text drawing on commonly shared cultural concepts.

In Dudley, the questionnaire for families with a disabled child is available on the council website, so parents can complete it there and be included on the register. The question asks them to state their ethnicity (in an open box with no categories suggested) and also to state the first language of all those they list on the form.

Stimulate access and demand

Several themes emerge here. One is accepting referrals directly from parents or other members of the community. Another is making links with local minority ethnic groups and involving them in the dissemination of information, identification of need and the planning of the service. Third, a diversity of short break carers and also project staff can be obtained by actively networking with local people.

One parent interviewed for this study intended to apply to her local scheme to be a carer as she wanted to “give something back”. She felt it important that children from minority ethnic groups had carers they could relate to. This parent said that every day she recommended the short break service to other Black parents.

It has to be acknowledged that there is rarely going to be enough provision to meet all needs. However, various aspects of the referral process have clearly acted as a barrier for minority ethnic families. Family Link in Newham encourages word-of-mouth information so that families can refer themselves to social services, though not directly to the project itself. If social services are working with schemes in this way to include rather than exclude families, this can result in increased access as personal contact brings with it reassurance that the family will be treated fairly.

In Barnardo’s Hamara project in Walthamstow, 30% of referrals were from parents in 2000-01. In Liverpool, “Word of mouth has been successful, as has been the raising of the scheme’s and Barnardo’s profile within the community by the Black development worker. The aim of

the scheme is to place Black children in culturally appropriate care, which includes disability” (Telephone conversation with Barnardo’s Liverpool project leader).

Accept kin as carers

From the questionnaire responses, it seems that schemes that are thinking about inclusion do accept kin as carers, sitters and befrienders. Project workers in Newham, for example, asked children on their waiting lists to recommend someone who could be approached. Nevertheless there are reservations. Bradford has made extensive use of kin in the past, but has reviewed its practices of using kin such as grandparents, sisters and brothers. Friends and neighbours are routinely welcomed as potential carers, but members of the household or immediate relations are not. In Leeds, too, close relatives were in the past approved as foster carers, but not if they were members of the same household. Current practice is to provide paid support for relatives offering short breaks under Section 17 of the 1989 Children Act.

The reasons for this need to be explored further. It may be necessary to keep an open mind about what may be in the best interests of the child, and to obtain the views of children about who they consider might be most suitable as carers. It will be worth monitoring policy changes such as those associated with Direct Payments to see if this allows family members or wider kin to be employed as personal assistants (who are paid to provide support asked for by a disabled person).

Ensure diversity of short break carers

Parents mostly want carers who reflect their children’s and their own ethnic group. Children need familiarity and role models. National and local policies support ethnic matching, but this will not happen unless actively promoted. Minority ethnic groups need to feel welcomed and to also see others like themselves involved in management, support and making policy. In this way, they feel represented at all levels. Schemes have realised this and many are working hard to develop or maintain diversity. The carers and parents interviewed for this study are keen to have Black staff assessing and supporting carers. Parents reported feeling more comfortable with someone from their own ethnic group, and they said they would bypass other workers to contact their preferred worker if necessary.

“We targeted national minority ethnic papers, eg *The Voice*. We also established a diversity forum to advise us.” (Sense)

“We have reviewed our processes, providing follow-up home visits following initial enquiries, to share details of our work. Panel is now representative of local black and ethnic communities.” (Barnardo’s North West, Liverpool)

Barnardo’s North West also has a specific leaflet on fostering in Black and minority ethnic communities, aimed at recruiting a diversity of carers.

In London Pimlico, the overnight short break scheme of Westminster social services advertised nationally in *The Voice*

newspaper, as well as in the local paper. Word of mouth has also been successful.

The Asian carer who was interviewed in Dudley felt that a face-to-face direct approach to potential carers could work well, and that someone doing this who spoke the language and understood the families' culture would be welcome. She advocated a higher public profile of the scheme at Asian community events and offered to assist.

Jewish communities in Barnet are the largest minority ethnic group at 16%, followed by Indian people at 7%. In 2000 and 2001, the short break scheme carried out recruitment campaigns to increase the number of Black and minority ethnic carers. This involved illustrated adverts, posters and leaflets in community languages. An advertisement in the local free newspaper generated as many as 150 enquiries. The scheme now feels it needs a more diverse staff group to follow this initiative up effectively, offering training in a range of languages, and providing ethnically matched and culturally comfortable support.

In order to recruit a wide group of carers, scheme workers in Bradford encouraged existing carers to "bring a friend along" to events. They provided stalls and displays in suitable places, carried out personal visits to homes, as well as visiting women's groups. In Newham, there have been targeted campaigns:

"... a campaign three years ago to African Caribbean communities; potential carers who might have appropriate accommodation (for mobility needs) and sometimes couples – not necessarily partners or husband and wife teams, but two people who would like to

work together to offer care i.e. an aunt and niece." (Newham)

Tower Hamlets' Families Together scheme staff very much value word of mouth as a way of recruiting more carers. They have held the equivalent of a Tupperware party, where one carer agrees to host an event and gets all the costs covered. As a result, friends and relations have a social event as well as hearing about short breaks and becoming carers.

"In the Bangladeshi community the main form of recruitment is 'word of mouth'. The project has never had problems recruiting Bangladeshi carers." (Tower Hamlets)

This is helped greatly by having staff who are comfortable in diverse social settings, and who can interpret the responsibilities of the job in a flexible way. Also they are still reaping benefits from an earlier recruitment campaign, demonstrating that concentrated investment can have long-term payoffs:

"A most successful piece of work for the Project was their recruitment campaign/drive seven years ago. They are still getting enquiries from posters put up all around the community: GP surgeries, libraries, schools, community centres, etc. It was a targeted recruitment, which highlighted the ethnic background of children on the waiting list." (Tower Hamlets)

With regard to actually appointing people as short break carers, Bradford has found Asian families uncomfortable with giving names and addresses of referees. The scheme has adopted the practice of taking verbal information from referees, as there

is a mistrust of official paperwork and form filling that is not necessarily to do with literacy but with intrusion.

Increase choice and flexibility of services

The concept of short breaks has broadened out considerably since the time when schemes offered just overnight stays with a short break carer. This is very welcome, since evidence from existing research as well as several of the short break schemes that took part in this study points to the popularity of sitting services and other day services with Black families.

In Tower Hamlets, the original Barnardo's Families Together project has now been divided into two separate projects. Families Together deals with home-based and overnight stays carried out by short break carers, and Tower Hamlets' Disability Resource Centre deals with sitting and accessible leisure provision.

Leeds also keeps its special-needs sitting and home-based care scheme separate from its short break scheme. The sitting scheme can be directly accessed by parents and is often the first point of contact for support to families. It is now operating to full capacity and needs to expand. It is worth noting that this short break project is finding that it is not cheaper to provide sitting services, as the hourly rate paid to sitters is higher than for short break carers.

Barnardo's Newham project introduced sitting services in 1996, two years after the project was launched. This has proved so popular with parents (who seem to feel that this service will be more accessible) that there is substantial unmet need. The

project has applied for and received extra funding to deal with the unmet need, and can now offer sitting services to more families.

In common with other schemes, Barnardo's Hamara project in Walthamstow reports:

“... a continuing demand from parents ... the sitting service has expanded from 40 in 1998-99 to 120 this year [2001]. We also have a waiting list. The flexibility of the service – siblings can be cared for, children can be taken out, invasive care can be offered etc – and the skills and continuity of the sitters seem to be the features of the service valued most by parents.”
(Hamara)

Flexibility of provision in some schemes extends itself to after-school and holiday play schemes, advocacy/befriending schemes, holiday clubs and leisure groups. These are best run with the aim of supporting disabled children and young people to take part in activities with non-disabled young people. Barnardo's Hamara project in Walthamstow, for example, has a wide range of provision, including those just mentioned, and also analyses users of each of them by ethnic group.

Family Link in Newham sends newsletters to and consults with all families on the waiting list, as well as those in receipt of services. This demonstrates that they are valued and keeps communication open.

We asked schemes about their use of Direct Payments, schemes whereby older disabled young people and adults can directly employ someone to provide personal assistance for them. We found that schemes are aware of this but that

the implications for their services are not yet clear. This area is worth some attention as there is evidence of low take-up by adults from minority ethnic groups due to many of the barriers Black families with disabled children face to accessing services (Butt et al, 2000). Several schemes commented on the lack of sitters for 'older' young people, especially young men, and it could be that Direct Payments will provide a way for them to employ people from their own networks as sitters.

Direct Payments can be seen as providing an alternative to short breaks. The report *Whatever next? Young disabled people leaving care* says: "The Government have suggested that this [Direct Payments to 16- and 17-year-olds] might alleviate the need for short break services for some families" (Rabiee et al, 2001).

Facilitate support groups

Barnardo's Hamara project workers in London reported that they facilitate support groups for African, African Caribbean and Asian parents in the area they serve. The project also has support groups for Black short break carers that meet every month. Sense (see page 29) has a national minority ethnic network and a local support group for minority ethnic families in Manchester. Short break carers in Liverpool are offered the opportunity to be part of a Black carers' support group. In Bradford, a group is facilitated by an Asian social worker and there is also a self-help group. In Barnet, a primary school for disabled children has a parent-organised sitting circle. A residential 'respite' facility has also been set up by parents and is now funded by the local authority. It is a purpose-built house with eight to ten places (information on minority ethnic groups

using these facilities was not provided). It is worth bearing in mind that in areas where Black families are in a numerical minority, attending all-White support groups can be difficult and needs addressing.

Review and evaluate

Monitoring, reviewing and evaluating the provision of services are now required by central government. Equalities legislation and guidance is now much more 'mainstream' and is finding its way into general monitoring processes. Managers are sharing responsibility for the process, rather than it being a separate activity of an Equal Opportunities Unit. This trend is reflected in a number of scheme documents that we obtained. Six out of the 13 schemes have evaluated their existing services for Black families.

A number of shared care schemes that provide services to Asian families are involved in a benchmarking exercise – those in Bradford, Bolton, Tower Hamlets and Newham.

Barnardo's in Liverpool has carried out a formal evaluation of its Black development work, two years after the appointment of its first Black worker. At the time of writing, it is due to be published.

The Leeds scheme had recently carried out a postal survey of all families using the short break scheme, and Barnardo's Newham has built in service evaluations as part of carer and service reviews with families.

Train and develop staff, carers and short break panel members

Promoting equality and working inclusively are skills that need to be learned by some and continuously developed in everyone. Recruiting staff with these skills in the first place is ideal, but staff development, supervision, management and training is essential to develop these competencies in the workforce.

The Leeds Family Placement scheme and Barnardo's North West Fostering in Liverpool both organised staff training in equalities and anti-racism practice *before* a Black worker was appointed. A Black disabled woman ran the training in Leeds, so bringing a range of perspectives and expertise to the work. The Liverpool project leader also wrote that, "ongoing training in managing diversity and cultural awareness is essential for staff". This project also acknowledged that the issues might be different for projects working with a sole Black staff member, and sought advice and built this aspect into its training.

In Liverpool, carers also receive equal opportunities training, as they do in many other projects that replied to our questionnaire. A number of schemes offer carer training in a choice of languages – some in gender-specific groups. Accommodating carer needs and circumstances gives clear messages that the service will value their skills. The short break carers interviewed directly for this work said they valued training very much. In particular, their level of awareness about disability had been raised, and they had lost their previous fear of disabled people and impairment. Carers in a recent survey also found training valuable as a way of "building

non-judgemental, appropriate and professional attitudes" (Prewett, 2000, p 48).

Network and share information and practice

Some of the schemes had benefited from pooling experiences and strategies with others. Shared Care Network is a good catalyst for this, and can arrange national and regional events. The benchmarking exercise, undertaken by four short break schemes and mentioned earlier, provides an opportunity for discussion of practice as well as setting standards. The Barnardo's scheme in Liverpool has networked with others in the North West of England.

Prioritise culturally competent practice

All the components of practice mentioned in this section of the book go toward making up culturally competent practice. When discussing barriers to access for families, it is easy to spot examples of racism, stereotyping and lack of competence.

A recent initiative in cultural competence has developed a *ToolKit* for personnel, available from the organisation below. The stages that it proposes organisations should work through are as follows:

1. Who are we here to serve? (community profiling)
2. Who are the users? (ethnic monitoring)
3. Who does what? (organisational responsibility)
4. Involving the user (public involvement in decision making)

5. Working with others (partnerships)
6. Respecting, accepting and celebrating diversity (multicultural awareness)
7. Respecting and valuing staff (human resources issues)

Each section is followed by a set of maintenance, developing and action planning templates, which support individuals, teams and organisations in moving forward. In this way they aid professional and/or team development plans. For further information on the *ToolKit*, go to www.culturalcompetence.org.uk.

An openness and willingness to reflect on practice and improve it, as well as seek and take advice from Black people, are prerequisites for cultural competence. Another fundamental principle is, 'If you don't know, don't assume, just ask'.

Recommendations

Good coordination, dissemination and implementation of these recommendations will be important. An overarching recommendation is therefore that a national organisation (such as Shared Care Network) is funded to oversee, campaign for, disseminate and develop practice, particularly in geographical areas where Black populations are relatively small, and where short break services are relatively poorly resourced. This national role, with associated personnel, could also develop support for Black short break staff and carers, and network with organisations such as Barnardo's, which already provides some of this.

For central government

- Guide local authorities to ringfence monies allocated through government programmes such as *Quality Protects* and *Children First* so that they identify and specifically target under-represented groups – for example, by allocating specific worker time to outreach activities.
- Encourage local authorities to actively monitor their services to ensure they are ethnically representative by making this a key feature of Social Services Inspectorate inspections.
- Many central government initiatives such as *Quality Protects* and *Health Action Zones* are short term, and services are dependent on them for resources needed to encompass diversity in services. This situation is likely to continue unless active policy decisions are made to bring such marginal and short-term initiatives into the mainstream.
- Issue guidance to local authorities regarding their responses to the 2000 Race Relations (Amendment) Act that encourages them to actively promote services to Black and minority ethnic families and to encourage partnership working. Specifically mention short breaks for families with disabled children and young disabled people in this guidance.
- Encourage local authorities to monitor their referral and assessment processes to see how services to disabled children and their families are meeting the needs of Black disabled children and families.

For local authorities

- Know the population you serve. Ensure ethnic monitoring and record keeping is implemented, updated, reviewed and monitored. Use the information continuously to improve services and target under-represented groups.
- Ensure that your equal opportunities policy includes disabled children from Black and minority ethnic groups, and that specifically brings together disability and ethnicity. Use the guidance provided by *The Equality Standard for Local Government* and the proposed *Best value performance indicators 2002-2003* (DTLR, 2001) to help you set goals.
- Target increased access by Black children and their families when acting on the *Quality Protects* sub-objective to increase the provision of short breaks to disabled children and their families.
- Include the views of Black disabled children and young people in consultation and planning.
- Consult with a range of Black and minority ethnic families, including children and young people, *before* setting up new schemes or other services, recognising that ‘culture’ varies from family to family and changes over time.
- Ensure that regular feedback is obtained from Black users and carers (including children and young people) on access to services and on how appropriate they feel they are.
- In children’s services planning, ask that short break services specify how they are ensuring take-up by Black minority ethnic groups.
- Examine the funding base of services involving Black families. Is the funding an integral part of mainstream services, or is it short term, insecure and seen as an ‘add-on’?
- Use opportunities presented by new legislation and policy (for example, the 2000 Race Relations (Amendment) Act, the 2000 Carers and Disabled Children Act and the *Valuing people* initiative [DoH, 2001e]) to strengthen services and affirm your commitment to inclusion.
- Even if contracted out to voluntary agencies, the referrals of families often have to go through the local authority. Yet there is evidence of stigma attached to social work and local authority services that can prevent Black families from wanting to use them. Consider referrals in different ways – via families themselves, community groups or other trusted routes.
- Audit or review workforce recruitment across your services. Identify gaps and inequalities. Identify if, and why, some groups are under-represented in the workforce.
- Proactively promote social work to target communities – both to aid recruitment and alleviate anxieties, and to dispel myths about services.
- Network with other local authorities to share good practice and get ideas. The process and principles of inclusion are similar whether or not you have a large Black population. Research has shown that, in advancing effective services, it is leadership that counts more than the size of the local authority or the size of ethnic groups.
- Interpret short break services flexibly. Sitting services are consistently proving popular with Black families, and in particular with South Asian families. Make sure your service can encompass this in planning.
- Attention is increasingly being drawn to the need for male sitters and carers. Take this seriously and investigate the potential.

For the providers of short break schemes

- Inclusion is a process. There can never be enough of it, and who needs to be included is constantly changing. The organisers of the best schemes realise that there is no ‘quick fix’ and will just keep on trying and changing what they do, and how, accordingly.
 - Ensure you have clear equal opportunities policies and procedures that are understood by scheme employees, volunteers and service users alike, and that these cover access to services and user involvement.
 - Leadership and teamwork are important. All scheme staff should share responsibility for access and the inclusiveness of services. Regular discussion of what this means is crucial. In particular, there is a danger that lone Black workers become responsible for ‘minority ethnic’ work, and can therefore be marginalised.
 - Review the referral processes and assessment procedures used, and check they do not discriminate against and exclude Black families. This particularly applies to referral and assessment panels. In order to do this well, you may need to take advice from Black people. Can you consider self-referral from families in under-represented groups?
 - As a way of increasing access, do not underestimate the value of outreach and development work, with clear goals and targets.
 - Include sitting services and other home-based provision in your plans. Some Black families prefer them.
 - Keep checking out the assumptions about families and culture upon which your service is based. If in doubt, ask people what is right for them.
- Examine the make up of your scheme’s workforce and carers. Are they representative of the communities being served? If not, how could they be made more so?
 - Consider the balance between women and men. The recruitment of male carers is proving successful in some schemes and can be enabled by recruitment of male project staff.
 - Build on your successes. For example, even one Black family using a scheme, or one Black carer being recruited, can introduce you to others and provide you with a way into a previously excluded community.
 - Prioritise the goal of a diverse group of carers, and check that your recruitment processes do not exclude or disadvantage particular groups; for example, at the panel approval stage.
 - Provide support for all staff while recognising that Black staff may have additional support needs.
 - Training should draw on the views of service users and under-represented groups. Training for cultural competence should be continuously available.

Gaps in local and national knowledge

In order to fill current knowledge gaps, it is essential that researchers, local authorities and other providers take action in the following areas:

- Detailed knowledge of the different types of short break services used (especially sitting services and also non-family-based provision), the patterns of use by different ethnic groups and by children’s age, gender and impairment, and the geographical

location of *each* provision. Aggregated information is not always helpful.

- Qualitative data on the perceptions by Black families of social work services, linked to patterns of use.
- Evaluation of kin recruitment as short break carers, sitters or befrienders, exploring outcomes for children and access to services by Black families.
- Take-up of direct payments by Black families with disabled children, and by Black disabled young people.
- Under-representation of African and African Caribbean children and young people in short break care compared with their presence in institutional, long-term residential care.
- Over-representation of Black children from some ethnic groups in special (segregated) schools.
- Experiences and needs of other minority ethnic groups (Chinese, Jewish, Traveller, Irish, for example), and refugees and asylum seekers.
- The role of men – as fathers, as carers and as children’s services staff. Currently ethnic by gender data is often missing.
- Perceptions of social work in some Black communities and how more Black people might be encouraged to join.
- Collating and sharing good practice in local authorities with ‘small’ Black populations: work in Scotland, Wales or Northern Ireland could be particularly helpful.

Conclusion

Arguably families from Black and ethnic minority groups who have disabled children are among the most disadvantaged and isolated in Britain. In this report, I have reviewed their current position in regard to gaining access to, and choice of, short break care.

It is clear that policy and practice is changing rapidly and these changes draw on a growing recognition that the needs of Black families have been marginalised and neglected. Barriers still remain, however, largely as a result of institutional discrimination that results in services failing to address diversity of need. There is no alternative to time being invested in local research and outreach work. This local development work could benefit from having an organisation taking on a national coordinating and disseminating role.

There is some understanding of the anxieties of families regarding culturally competent practice and, in particular, their fear of children being removed from the family, even for just one night. Also there is a growing appreciation of the importance of support services being grounded in, and reflecting, the diversity of local communities. This has implications for the appointment and deployment of staff.

There is much to be learnt from the various successes of the schemes that have featured in this review. I have drawn out some of these lessons and I recommend them as a way forward in the further development of community-based support services. Short breaks can make a significant contribution to the care of Black disabled children and young people, but they need to be continually open to interpreting and changing what ‘short breaks’ can mean. As the situation changes, then, there will be a need for some kind of follow-up review, perhaps in three to five years’ time. This kind of practice-related research is an integral part of the developmental process in service provision.

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