

Learning Difficulties *and Ethnicity*

*Ghazala Mir, Andrew Nocon and
Waqar Ahmad, with Lesley Jones*

Report to the Department of Health

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EXECUTIVE SUMMARY

The Centre for Research in Primary Care at the University of Leeds was commissioned by the Department of Health to conduct a scoping study of services for people with learning difficulties from minority ethnic communities. The study consisted of a review of the literature and interviews with key respondents.

While people with learning difficulties from minority ethnic communities and their carers face considerable problems in accessing relevant services, there are also examples of approaches and projects which seek to meet their needs more appropriately.

The main points highlighted in this report are as follows.

Introduction

- Minority ethnic communities face substantial inequalities and discrimination in employment, education, health and social services.
- The higher prevalence of learning difficulties in South Asian communities has been linked to high levels of material and social deprivation. These may combine with other factors such as poor access to maternal health care, misclassification and higher rates of environmental or genetic risk factors.
- People with learning difficulties from minority ethnic communities experience simultaneous disadvantage in relation to race, impairment and, for women, gender. Negative stereotypes and attitudes held by service professionals contribute to the disadvantage they face.

Service principles

- The principles which underpin service planning and provision need to take account of the particular needs and values of people from different minority ethnic communities.
- Partnership with minority ethnic community groups is needed to influence service planning, monitoring and evaluation and to meet local needs. Groups may need support to take part in joint ventures. Consultation exercises require the involvement and support of community organisations if they are to succeed.

- The concept of advocacy needs to be developed in some communities and advocacy or self-advocacy groups need secure resources in order to develop. Schemes promoting advocacy and independent living skills may need to work with families as well as individuals with learning difficulties in recognition of family structures which are different to those in majority ethnic communities.
- An understanding of independence that emphasises individuality may run counter to the values of collectivism and close family relationships that exist in some communities. The role of family and community networks needs to be taken into account when planning services for individuals.
- Barriers to independence in education and employment result in limited choices and low expectations. Restrictive attitudes towards disability within minority ethnic communities and in the wider context need to be addressed.
- Empowerment requires information, choice and involvement in decision-making. Support groups can increase participation and control for minority ethnic people with learning difficulties and their carers, as well as providing emotional support. However, such groups are generally small-scale and isolated and may be unable to provide progression to other provision if cultural needs are not recognised in other services.

Planning better services

- Support networks for minority ethnic carers and people with learning difficulties can act as gateways to a range of support services. Outreach is needed to include those who cannot attend groups. A variety of activities and appropriate publicity are needed to increase awareness of service provision within minority ethnic communities.
- Bilingual staff and interpreters are needed to improve communication and access to services. Recruitment of minority ethnic staff is needed at all levels in service organisations, with adequate support and training to help them perform their roles. Training for all staff is needed to improve competence in cultural awareness and prevent the marginalisation of minority needs. Cultural sensitivity and a level of continuity between home and other environments enable the greater involvement of people from minority ethnic communities and encourage the take-up of provision.

- Service providers need accurate and ongoing information from and about minority ethnic communities to meet their needs adequately. Monitoring procedures are currently insufficiently able to identify unmet need, general patterns of use or comparative service performance.
- Integrated services are likely to be better resourced and given a higher priority than specialist services. Although the ideal is a quality mainstream service that is sensitive to the needs of all users, the cultural needs of some minority ethnic service users are currently more likely to be met in specialist provision, though this is generally under-resourced and insecure. Decisions about the extent and nature of services should be made at a local level in consultation with service users and informal carers. Specialist services do not eliminate the need to remove racist practices and attitudes from mainstream provision and to develop accessible and appropriate integrated services that will meet the needs of all members of the community.

Conclusions

- Empowerment for communities requires that policies, principles and services be developed, in partnership with those communities, to meet the needs of people with learning difficulties and their carers more appropriately.
- Individuals are empowered through services which recognise their needs, including cultural needs, and offer information, choices and involvement in decision-making. Advocacy services are needed in order to access appropriate services and provide support to individuals to adopt roles that are appropriate within their own communities.
- Much information is already available about the needs of people from minority ethnic communities, though gaps remain (particularly in relation to the views of people with learning difficulties themselves). What is needed, now, is a commitment to develop services to address those needs.

CHAPTER ONE

INTRODUCTION

This report examines the needs of people with learning difficulties¹ from minority ethnic communities, the needs of their carers, and the services available to meet those needs. It draws on the available literature as well as interviews with service providers, users' groups, carers' organisations and researchers.² The report was commissioned by the Department of Health to inform the national Learning Disability Strategy. The material included here focuses on health and social care, though other areas are also touched upon.

The report has been prepared at the Centre for Research in Primary Care at the University of Leeds. In addition to its work as a primary care research unit, the Centre has built up a considerable body of expertise in the health and social care of people from minority ethnic communities: it is now the largest research unit working in this area in the UK. In carrying out this study, we have drawn upon that expertise in order to locate the needs of people with learning difficulties within the broader literature on ethnicity and disability.

The report accordingly begins with a sketch of the circumstances of minority ethnic communities in the UK, and specifically of people with learning difficulties. The following chapter examines the way that some of the key principles which currently underpin service policy and development address the needs of people from minority ethnic communities: partnership, advocacy, independent living and empowerment. It considers the extent to which those principles are appropriate to users' and carers' needs, shortcomings in the way the principles are translated into practice, and examples of approaches or initiatives which are particularly sensitive to the needs of people from minority ethnic communities.

Further examples of innovative approaches are given in the next chapter, which focuses on the way services are organised. Again, the discussion reviews users' and carers' experiences of services, with specific reference to communication and information, cultural and

1 The term 'learning difficulties' is the preferred term amongst user organisations and disability writers; 'learning disabilities' is generally used by service organisations. In this report, we use the former.

2 The Appendix describes the methods used in the study and includes a list of organisations which provided assistance through face-to-face or telephone discussions.

religious identity, staffing and training, funding and resources, and the debate around specialisation versus integration (whether services should be specifically for people from minority ethnic communities or for all people with learning difficulties, regardless of ethnic origin). The concluding section draws out some of the key features of the more innovative developments that have been identified, focusing on the twin themes of empowerment for communities and empowerment for individuals.

The report as a whole draws on the needs and experiences of both adults and children. In this way, it has been possible to integrate specific detail about specific groups or services without the repetition of broader overarching points that are common to all. Our review of the literature has indicated, however, that there are several areas in which material is limited. We found, for instance, that the needs of people from South Asian communities have been more intensively researched than those from African Caribbean backgrounds. Little information, too, is available about the needs of people with learning difficulties from other groups, such as the African, Chinese, Irish or Jewish communities, refugees or travellers. By not referring to them in detail in this report, we are aware that we are effectively contributing to this neglect, though we have been reliant on the available literature. In addition, little work has been undertaken with people with learning difficulties themselves from minority ethnic backgrounds. This situation is changing only slowly, though more research has been carried out with their carers. We recognise that the balance within the report fails to reflect the views of service users as comprehensively as we would have liked: further work with people with learning difficulties is clearly called for. Other areas warranting attention are highlighted in the conclusions.

Ethnicity: background issues

Ethnic minorities represent a significant part of the population in the UK (three million people in the 1991 Census). They face substantial inequalities, discrimination and disadvantage. They are more likely to live in inner city areas, in substandard housing and to suffer discrimination in employment, education, health and social services (Acheson 1998, Modood 1996).

In view of the evidence of a link between poor health and adverse socio-economic conditions, the above picture is clearly of concern. Socio-economic status makes an important contribution to ethnic variations in health and is linked to higher rates of chronic illness in the most disadvantaged minority ethnic communities (Acheson 1998, Nazroo 1997). Moreover, the effect of material disadvantage

cannot be controlled for completely as important differences in income between ethnic groups remain within each social class band. For example, the mean income of Pakistanis and Bangladeshis is about half that of White households in the same social class category (Nazroo 1997).

In addition to socio-economic deprivation, racism plays a part in the disadvantage experienced by people from minority ethnic communities. Within service provision, stereotypical opinions about South Asian families 'looking after their own' (Ahmad and Atkin 1996) can exacerbate the invisibility of South Asian carers and reinforce the neglect they experience from service planners. On the other hand, African Caribbean culture are often viewed either as impoverished variants of the 'British culture' and thus ignored, or seen as threatening and therefore in need of control (Ahmad *et al.* 1998, Sashidharan and Francis 1993).

Examples of racist attitudes have been shown in studies of South Asian children with learning difficulties, deafness and haemoglobin disorders. South Asian parents appear to receive later diagnosis partly because their concerns are not taken seriously by practitioners (Baxter *et al* 1990, Chamba *et al* 1998). Misinformation and bias concerning consanguineous (first-cousin) marriages as a cause of impairment may also affect professional practice adversely and alienate families, leading to low take-up of genetic counselling services (Baxter 1998, Chamba *et al* 1998). Atkin and Ahmad's (2000) study of parents of children with thalassaemia found that health professionals often relate the condition explicitly to consanguineous marriages and are consequently unsympathetic to parents as they consider the condition to be self-inflicted. Similar dynamics operate in the case of learning difficulties even though consanguinity has effectively been ruled out as a single explanation (Baxter 1998, Butt and Mirza 1996).

Some professionals assume that minority ethnic carers have a preference for surgery or technical interventions (even if evidence about the effectiveness of these may be lacking); studies have shown, however, that the assumptions themselves are often unfounded (Chamba *et al* 1998). Pre-natal diagnosis is sometimes withheld from Muslim families because it is assumed they will not accept termination of a pregnancy: this may both be incorrect and denies people information and choice (Atkin and Ahmad 1998). In addition, some practitioners appear to hold low expectations of language development in South Asian children, which affects the children's ability to benefit from speech therapy (Chamba *et al* 1998).

A 'colour-blind' approach, or assertion that 'we treat everyone the same', is often operated within organisations. Such statements may, however, disguise the fact that they have either not considered the needs of minority ethnic communities or have chosen to ignore them (Alexander 1999). The resulting lack of attention to meeting the needs of ethnic minorities has the consequence of underdeveloped policies and the lack of any mechanisms by which their needs can be explored and change effected. The 'colour-blind' approach has been shown to foster stereotypes and racist attitudes towards minority ethnic communities. At a grassroots level, such attitudes may influence the use of discretionary decision-making and deprive minority ethnic communities of their rights to services (Atkin and Ahmad 1998, 2000). What is needed, instead, is an approach which moves away from the notion of 'an average citizen' to an acknowledgement of the diversity of need and required services (and different service costs) (Alexander 1999).

A second approach has been for services to support 'special needs initiatives'. Such initiatives can provide a much needed focus on problems that need to be addressed. However, specialist provision may appear to be meeting the needs of minority communities while in fact retaining the structural disadvantage and power relationship between the majority community and others (Ahmad and Atkin 1996). Special needs initiatives by both statutory and voluntary organisations can reinforce racism through an emphasis on culture whilst obscuring differences of power between different groups (Priestley 1995). Such initiatives may act as a surrogate form of racism if they are inadequately funded but used nevertheless to absolve mainstream services of responsibility (Ahmad and Atkin 1996). Alternative approaches to meeting need require that the causes of disadvantage within wider society are recognised and addressed.

Institutional racism may also manifest itself through an 'information vacuum' in terms of the literature and information available to non-English speakers and the networks through which information is provided (Chamba *et al* 1998, 1999). Standards of communication when breaking the news of impairment may be very low for such parents and non-professional interpreting may increase the stress and barriers to information they face.

Traditionally information which has been translated has centred around hygiene, fertility control and other issues which imply inferior cultural practices (Ahmad 1996, Brent CHC 1981). A lower percentage of resources has historically been made available to meet the needs of disabled black people than their numbers require (Ahmad and Atkin 1996). At the same time a higher percentage of resources

seems to be available in the area of pre-natal screening and abortion. There is evidence that this imbalance has led to a mistrust within some minority communities of the motives of health service providers (Brent CHC 1981, Chamba *et al.* 1998). It has been argued in a number of studies that the situation requires a political solution as racism is based on power structures rather than simply on cultural differences (Ahmad and Atkin 1996, Priestley 1995).

Disability and ethnicity

Research into disability within minority ethnic communities has tended to focus on physical impairment and on South Asian communities. Areas which have been highlighted in service provision relate to

- the higher incidence of impairment in a number of areas
- low levels of knowledge of services available for the disabled person or carers
- poor standards of communication
- delays in diagnosis and treatment
- isolation, lack of support and high levels of carer stress
- low take-up and poor access to services
- high levels of unmet need
- lower levels of access to benefits and/or receipt of lower amounts of benefits compared to White claimants with similar needs (Atkin and Ahmad 2000a, Chamba *et al.* 1999, Mir *et al.* 2000)

Studies show that socio-economic disadvantage and financial insecurity may add significantly to the stress that carers experience (Atkin and Ahmad 2000a, Chamba *et al.* 1999). Caring obligations affect the employment opportunities of both parents and consequently reduce family income (Kagan *et al.* 1998). This situation is compounded by the additional costs which may be associated with caring for a disabled child, for example in relation to transport, clothing and heating (Dobson and Middleton 1998). Inequalities in income mean that the financial impact of caring may be even greater on minority ethnic families (Chamba *et al.* 1999).

A number of studies which have investigated the experiences of South Asian carers show that the traditional organisation of the extended family, which is viewed as the support structure for members of South Asian communities, has in fact been greatly modified through migration to Britain. Factors such as inappropriate housing, occupational mobility and immigration policies which

result in divided families have impacted on the ability of families to provide significant levels of support to South Asian parents of disabled children (Ahmad and Atkin 1996). Equally, the process of social change may result in a diversity of value systems within these communities.

Studies have also highlighted the need to consider inter-group variations within minority ethnic communities. For example within South Asian communities, the Pakistani and Bangladeshi populations appear more affected by impairment than Indian communities (Health and Lifestyles Survey 1994). Significant differences also exist between religious groups in terms of diet and lifestyle, socio-economic status and health experience (Nazroo 1997). Different ethnic groups also occupy differential socio-economic positions, with people of Indian origin relatively better off as compared with those of Pakistani, Bangladeshi and African Caribbean origin. These differentials are important in understanding the support needs of disabled people and carers in these groups.

Learning difficulties

In the area of learning difficulties, similar themes have emerged. The prevalence of learning difficulties in South Asians aged between 5 and 32 is up to three times higher than in other communities (Azmi *et al* 1996c). Lower rates of prevalence in under-5s are likely to be a result of South Asian children failing to be diagnosed until school age (CVS 1998). Of the South Asian families caring for family members with learning difficulties, 19 per cent had more than one member with a learning difficulty. Prevalence within other minority ethnic groups is not as well documented, however fieldwork impressions suggest a relatively high prevalence within the African Caribbean community too (*ibid.*).

The evidence points to a well-established link between socio-economic deprivation and the prevalence of mild or moderate learning difficulties (Emerson 1997). The link is reflected in lower income, poorer housing, higher unemployment and a greater reliance on welfare benefits. Some evidence of a link between severe learning difficulties and poverty has been reported in a US study (Baumeister *et al* 1993, noted in Hatton and Emerson, 2001 forthcoming).

High levels of material and social deprivation have been found amongst South Asian people with learning difficulties and their families (Azmi *et al* 1996). It has been suggested that such deprivation may combine with other factors – such as inequalities

in access to maternal health care, misclassification and higher rates of environmental or genetic risk factors – to produce the much higher prevalence rates (Baxter 1998, Emerson 1997). Other studies have supported some of these suggested reasons. Butt and Mirza (1996) found that carers from minority ethnic communities are often more affected than their White peers by problems of poverty and bad housing. The study also found evidence that the burden of care is greater both socially and financially, with more severe problems of poverty, bad housing, racism and higher levels of unemployment. Carers are likely to have limited access to financial resources because of low pay, minimal pension rights or less access to benefits because of residence status. In common with Baxter (1998), the study concluded that socio-economic factors such as poor housing, environmental pollution and inadequate or inappropriate education contributed to higher prevalence.

In relation to access to maternal health care, there is evidence that, because of their culturally inappropriate and unwelcoming nature, maternity services are underused by South Asian and African Caribbean women (Baxter *et al* 1990). Practitioner attitudes can also lead to discriminatory outcomes for patients: the quality of care received by South Asian women from midwives and GPs has been shown to be affected by negative stereotypes and culture-blaming explanations for a host of conditions (Ahmad and Jones 1998). Studies have further shown that parents' concerns may be dismissed by practitioners. This situation is often compounded by poor standards of communication and the routine use of non-professional interpreters (Azmi *et al* 1996a, Baxter 1998, Butt and Mirza 1996).

The emphasis placed on consanguineous marriages as a cause of impairment may also affect professional practice adversely by emphasising a medical and reductionist model of disability which ignores socio-economic factors (Ahmad 1996). In the process, responsibility and blame for impairment are shifted to parents and reinforce negative stereotypes of other cultures and traditions. Racist treatment and abuse by professionals and by other service users have been mentioned in a number of studies (Baxter *et al* 1990, Butt and Mirza 1996, Morris 1998). The simultaneous disadvantage experienced by individuals in relation to race, disability and gender has been termed 'double disadvantage' or 'triple jeopardy' in some research studies (Butt and Mirza 1996). However, Begum (1995) argues that the specific nature of this experience must be recognised as comprising more than a number of superimposed layers of discrimination. The interaction of multiple kinds of discrimination produces its own particular effect on individuals, which is more than the sum of its parts.

Key points

- Minority ethnic communities face substantial inequalities and discrimination in employment, education, health and social services.
- The higher prevalence of learning difficulties in South Asian communities has been linked to high levels of material and social deprivation. These may combine with other factors such as poor access to maternal health care, misclassification and higher rates of environmental or genetic risk factors.
- People with learning difficulties from minority ethnic communities experience simultaneous disadvantage in relation to race, impairment and, for women, gender. Negative stereotypes and attitudes held by service professionals contribute to the disadvantage they face.

CHAPTER TWO

SERVICE PRINCIPLES

The personal and collective values and experiences of people within minority groups are often different from those of the majority population. The concepts of individuality, rights and relationships, for instance, differ substantially between different cultures: what may seem morally and ethically correct behaviour towards disabled people can vary from one culture to another (Miles 1996). Although there is often an assumption that such concepts are universally applicable, the way they are interpreted within the majority population may be inappropriate for some current or potential service users, whose values have not been considered. Minority ethnic groups have significant separate interests to which service development is not yet adequately responding and they currently appear to feel alienated from many services which do not recognise their concerns.

Both service development and research need to take account of such differences, in consultation with disabled people from minority ethnic communities themselves and other community members such as sociologists (Miles 1996). 'Good health care', for example, needs to be defined in ways that accord with the norms and expectations of particular groups rather than be simply transplanted from traditional Western concepts (Ong *et al* 1998).

In this chapter, we consider some of the key principles which underpin current policy and practice development: partnership working, advocacy, independence and empowerment. We discuss the extent to which those principles are helping to shape better services for people from minority ethnic communities, and the need to take particular account of different cultural values and meanings when seeking to provide services that are appropriate to people from different ethnic and cultural backgrounds.

Partnership working

Partnership working is a concept which is currently at the forefront of many exciting initiatives. By April 2001 local and health authorities will be required to have established relationships with a

wide range of agencies in order to develop Joint Investment Plans for their learning disability services (Giraud-Saunders and Greig 2000). The concept of partnership working involves joint work on policy and practice issues between:

- service users and service providers
- diverse groups within geographical areas
- different areas of service provision
- voluntary and statutory services
- local and national agencies

Guidelines for such partnerships envisage a process in which all relevant stakeholders are identified, data is obtained about the needs of a population, plans to deliver services reflect those needs and investment intentions are demonstrably linked to needs analysis (Giraud-Saunders and Greig 2000). The aim of partnership is to improve service provision through a greater awareness of user views, more responsiveness to need and better co-ordination of services. In practice the concept can be used to enable valuable learning experiences for people with learning difficulties and their carers. Engaging in a partnership forum can also develop independence and leadership amongst individuals and groups of service users (Barenock and Wieck 1998).

Partnership with users and carers

Studies show, however, that links between statutory services and minority ethnic communities are a long way from being able to achieve these aims. Links between local authorities and South Asian community groups in a number of areas have been found to be poor, with little consultation over needs and services despite the knowledge that available services were not being used (Azmi *et al.* 1996c, Butt and Mirza 1996, Lewis 1996). One study (CVS 1998) found that only a handful of the 73 community health trusts and 108 Social Service departments they approached could point to specific work on needs analysis or targeted services for minority ethnic communities. Quality control procedures, too, are usually carried out without the involvement of minority ethnic groups. Feedback is rarely available through complaints procedures: these are often doubly inaccessible, both to people with learning difficulties and to people from minority ethnic communities (Lewis 1996).

Better formal links need to be developed between service providers and minority ethnic groups at both a collective and an individual level. Need is currently determined by service providers rather than

by users and their families, despite moves towards user-centred assessment. Moreover, it is important not to underestimate the ability of people with learning difficulties to be involved (Bignall and Butt 2000, Tait *et al* 1998). In the field of education, for instance, Sutcliffe and Jacobsen (1998) emphasise the need to involve students in decision-making. Partnership with the parents of younger children would similarly help to determine appropriate responses to individual needs as well as, for example, the development of appropriate curricula. Pasha (1996) suggests that such an approach would provide a more comprehensive view of children's needs by encompassing the different perspectives of family members and professionals. This would also lead to a greater awareness of the contribution of each partner to the child's development. Other studies support the need for increased contact between minority ethnic carers and educational institutions (Baxter 1998, Sutcliffe and Jacobsen 1998).

A lack of consultation means that services remain inappropriate and inflexible, service staff do not develop a sensitivity to the circumstances of minority ethnic groups or to the support needs which they themselves identify, and users feel under-valued (Butt and Mirza 1996). Equally relevant is the ambivalence felt by families towards service provision. Of the South Asian families surveyed in a study of two local authority areas, 61 per cent had little confidence in services, 48 per cent felt they were not receiving enough services to comment and only 17 per cent felt confident that services would help in times of crisis (Hatton *et al* 1998). The study suggests that lack of involvement with services not only leaves families vulnerable to breakdown in times of crisis, but also results in high cost admissions to largely inappropriate residential services (*ibid*). Studies have also shown a perception amongst some minority ethnic families that statutory services create obstacles and difficulties rather than providing support. Social Services and education providers, in particular, are sometimes considered intrusive and insensitive by people from South Asian and other minority ethnic communities (Nothard 1993, Pasha 1996). This image needs to be addressed in any attempt to increase take-up and build up trust.

Community partnerships

The drive for partnership working assumes to some extent that groups of service users will be already established or easily formed. This may only be true of some areas in which minority ethnic communities may be living. A range of active groups exists in some localities, is easily accessible and, indeed, may be actively involved in

lobbying for involvement in consultation and partnership structures. However, in other areas there is a dearth of minority ethnic groups which focus on learning difficulties or indeed on disability in general.

We found that the groups formed by minority ethnic people with learning difficulties or their families are generally small-scale and under-funded, with little political power and few resources. Where groups are run entirely by people with learning difficulties, the logistics of actually running the group can also be difficult. Members sometimes need substantial support and time to come together, discuss issues and make decisions. For this reason, there may be resistance to partnership arrangements. There is a danger that in partnership structures small, poorly supported groups may be overshadowed by organisations which have a history of political involvement, better resources and perhaps national connections. To ensure that minority ethnic groups are able to take on the partnership role effectively there may be a need for more joint working between larger, well-resourced organisations which focus on disabled people generally and those which serve the needs of disabled people from minority ethnic communities (Priestley 1995). Differences in the perspectives of groups that attempt to develop such partnerships will need to be addressed. We found that organisations may foster the development of groups for minority ethnic people with learning difficulties; however, the relationship between the two could break down and different service principles appear to be one reason behind this deterioration.

Some good examples of user involvement were highlighted by those we interviewed, such as the participation of an advocacy organisation on a joint commissioning body set up by the local authority and health trust. However, it was commonly accepted that user participation is often tokenistic rather than empowering. Complaints were made that strategies concerning people with learning difficulties involved them in a minority position and often only lip service was paid to listening to their views. Assumptions are sometimes made that there will be problems in understanding or communicating with people with learning difficulties from minority ethnic communities. Some respondents argue that service users should be seen as part of their ethnic community and that the collective experiences of communities should be recognised in planning procedures and partnership arrangements.

Community groups within minority ethnic communities may need support to become involved in planning and managing services and to secure service contracts. Such groups often provide a range of services that do not mesh well with the structures of local authorities or other purchasing agencies. The bidding process works against

small organisations and groups may need assistance to apply for such contracts effectively. It has been suggested that service contracts should require funding organisations to ensure the involvement of all ethnic groups at all levels and that service contracts should be evaluated and monitored by people who are representative of the local population (Lewis 1996).

Traditional methods of consultation using public meetings are not recommended in the literature. Baxter *et al* (1990) noted that consultation should be carried out at local level with community organisations rather than through public meetings. Such links improve understanding of the experiences that are common to different minority ethnic communities, any differences from majority needs, and provide an opportunity to develop proposals for specific action.

Winn and Chotai (1992), writing about the work of an ethnic minorities development worker in Haringey Health Authority, recommend community development as a means of gaining regular and systematic information about needs rather than the snapshot pictures obtained through one-off consultations. The worker's role involved initiating and sustaining contact with local minority ethnic community groups and involving them in health service planning. This led not just to informal consultation but to membership of formal mechanisms such as planning committees and sub-committees. Managers and relevant staff within the Health Authority were encouraged to make links with community groups as part of their work so that dependency on one or two health professionals was avoided. The development worker had access to key decision-makers and planners in the district and could feed directly into decision-making where needed.

One of the pitfalls of the scheme outlined above was that the development worker was expected to deal with problems which fell outside her remit, such as complaints about GPs. Intervention in such other areas requires legitimisation. In addition, development workers are often seen as experts on 'the community': the responsibility for development work does, however, need to be distributed more widely. While networks fostered by the worker were seen as a resource by enthusiastic NHS workers, it is necessary to set down clear goals about the joint work and service development that are envisaged, so as to avoid overloading groups with unnecessary and unproductive contacts. Moreover, an over-reliance on any one group could result in a loss of community perspectives if group members increasingly identify with NHS

structures. Individual groups may themselves be unable to represent the views and perspectives of other groups within the community. In addition, it is vital that any initiatives emanating from within the community should take their place alongside those initiated by statutory bodies. A community development approach takes time but can be a sensitive means of identifying needs which may otherwise not be apparent. Ongoing dialogue offers a proactive way of generating appropriate ideas for service development, whether in relation to learning difficulties or to other needs (Azmi *et al* 1996b, Simons 1998).

The Asian Disability Joint Planning Team (ADJPT) in Bradford is an example of partnership working involving community groups as well as statutory agencies (including Education as well as Health and Social Services). Although its origins lie in the community care planning structure, it arose following discussion with South Asian disabled people and their carers about ways of ensuring that health and social services were more appropriate to the needs of South Asian disabled people. Consultation with users and carers is a key component of its approach, all plans made by any of its constituent members are required to include support for South Asian disabled people, some meetings are open to the public, and public participation is enhanced through community conferences and bilingual workshops. One of its written principles stresses the need for members to listen to each other's views without antagonism, so that they can express their views (and ignorance) in an atmosphere of mutual support and thereby learn from one another. While specific plans may require implementation by individual agencies, being able to discuss them in a joint forum means there is more opportunity to ensure their relevance to the needs of the local community. To ensure that all partners have their views heard, ADJPT has an independent chairperson and is supported by a worker jointly funded by the local authority and Barnardo's. ADJPT has played an important role in the development of the local South Asian voluntary sector.

In Sheffield, the ARC 'Services for All' project (funded by the Department of Health) and the Sheffield Black and Ethnic Minority Community Disability Project jointly organised a 'Moving Forward Day' in 1999, which involved a range of voluntary and statutory organisations as well as users and carers, with the aim of more appropriately meeting the needs of adults with learning difficulties from minority ethnic communities – and the needs of their carers (ARC 1999). This enabled policy-makers to hear directly about users' and carers' needs. Subsequent meetings were held and the statutory bodies have drawn up action plans. The discussions have begun to influence service planning and provision, with a specific impact in initial months on the development of a One Stop Shop, to make it more accessible, and a needs assessment project to examine the needs of individuals with learning difficulties and their families. One of the additional benefits of this process is that it has reportedly overcome the inaction that results from a 'fear of getting it wrong'.

Some of the most successful further education courses identified in the study by Sutcliffe and Jacobson (1998) were the result of joint ventures between further education colleges, social services and community groups and were based on a negotiated curriculum. Failure to recruit students from different cultures to courses was often a result of poor access to relevant communities.

A good example of joint working with service users and carers within a wider community context was provided by a local library that we came across. The Shipley Leisure Library in Bradford provides equipment and books on loan to people with learning difficulties and their carers. As a result of suggestions from South Asian workers within the library, local groups and a member of the library's management committee, the idea was proposed of establishing a second leisure club aimed particularly at South Asian communities. Further incentives included the availability of funding and encouragement from a senior officer of the local council. Suggestions made by South Asian workers working within the library building, local groups and a member of the library's management committee all contributed to the development of the idea. Further incentives included the availability of funding and encouragement from a senior officer of the local council.

The combination of these factors resulted in a considerable effort to contact and involve individuals and organisations that would form a partnership with the library to launch the scheme. A number of groups suggested by local South Asian workers were contacted. These included a group of South Asian women with learning difficulties, a carers' group and local disability organisations which had experience of working within the South Asian community. Ideas for suitable equipment and books were discussed at length. Some equipment was specifically chosen to provide recognisable images and culturally familiar activities. For example, cooking utensils included equipment to make chappatis; musical instruments included some which were specifically South Asian. Awareness packs and information leaflets were also included in the materials: although these were not strictly related to leisure, high priority was accorded to accessible information by the South Asian workers involved. It was intended that the initial purchases would be further developed through continuous feedback from service users. Much of the equipment and material which had been bought duplicated what the leisure library already offered; however, the fact that it was in a more local environment which offered more private space was identified as making an important difference to South Asian service users and their carers.

Although the initiative is still in process, more and more people have asked to join the partnership as a result of information being passed on through group members. This has happened without any other form of publicity – which is not intended until the project has a name and base and is well established. The concept of leisure which the club operates may be widened as a result of the demand for trips and social contact as well as equipment and materials. The group aims to enable the leisure club to become independent of the original leisure library. However, the process has been a valuable learning experience and will have a future impact on the leisure library, which is considering another joint project to gain funding for a South Asian librarian in Bradford.

Advocacy

Advocacy has been defined as 'a way to defend the interest of a person, and to make sure their needs are met, especially someone who already feels disempowered' (Atkinson 1999, p.16). It is concerned with empowerment, autonomy and self-determination,

the safeguarding of citizenship rights and the inclusion of otherwise marginalised people (*ibid*). The principles of advocacy have been used as a basis for arguing that services should involve people with learning difficulties in all aspects of organisation, including monitoring and development of community care plans.

Advocacy is an important concept for people from minority ethnic communities. Prejudices about disabled people exist within as well as outside minority ethnic communities and disabled people often have little power, are patronised or seen as threatening. Through advocacy, citizenship rights can be safeguarded, negative images challenged and positive identity developed (Begum 1992, Downer and Ferns 1998).

Current gaps in advocacy provision particularly affect disabled minority ethnic children and young people, victims of racial harassment, women, asylum seekers and refugees (Atkinson 1999). The potential for people from minority ethnic communities to be excluded clearly therefore exists at a number of levels and studies have highlighted the high levels of isolation that people in these communities experience. Many people with learning difficulties have few friendships, even within their own communities, and are unable to go out as often as they wish (Bignall and Butt 2000, Lewis 1996). Advocacy support has benefits for people in this position. Such support has also been identified as a particular issue for people with challenging behaviour who may be placed out of their locality and disconnected from their own community, with little practical or emotional help (Downer and Ferns 1999, Lewis 1996). Research evidence shows that the concerns of minority ethnic carers are not taken seriously in a number of areas, such as developmental delay and abuse. Advocacy support would play a role in ensuring that concerns are taken seriously and that feedback is given on follow-up action (Morris 1998).

The disabling effect and feeling of total helplessness that can result from a lack of advocacy was made clear by one person we spoke to during the course of our fieldwork. Despite her complaints, this person was forced to use a wheelchair simply because suitable shoes were not provided by health care staff. She felt that she was not given a chance to speak or voice her concerns. Her attempts to enlist the help of her GP proved useless and she felt there was no-one to turn to on her behalf.

Support groups that can lobby for change or enable people with learning difficulties to gain greater autonomy play an important part in advocacy. Carers and people with learning difficulties often find support groups useful. Chamba *et al.* (1999) report that African Caribbean and Asian parents of severely impaired children are less

likely to know about support groups in their areas and are less likely to be members of such groups. A lack of transport and funding can also be barriers to group development. Staff in residential settings may feel threatened by the idea of people from minority ethnic communities meeting separately and may seek to control attendance (Downer and Ferns 1998). Groups need help from services to initiate and publicise them, provide assistance and resources and train staff to understand the importance of this kind of support (Atkinson 1999, Lewis 1996). The development of African Caribbean and South Asian support groups in the field of sickle cell disorder and thalassaemia demonstrates that such groups can be formed and are regarded as valuable by members (Atkin and Ahmad 2000a).

Self-advocacy groups for minority ethnic adults tend to be marginalised and receive fragile support which is constantly under threat. Groups need time and space to develop and their input into decision-making must be taken seriously if quality services are to be achieved (Black People First 1994). Many South Asian self-advocacy groups for people with learning difficulties have developed within continuing education (Sutcliffe and Jacobsen 1999); however, people from minority ethnic communities are more likely to be under-represented in this area, which further restricts the potential for self-advocacy groups to emerge.

Again, we noted regional and ethnic differences in access to such groups. For example in London, far more groups exist for African Caribbean people with learning difficulties than for other minority ethnic communities. These provide much needed opportunities to ensure that Black people with learning difficulties can increase their self-confidence and express their own views with assurance. These groups are successful in attracting funding and building on their previous development; however, they are not able to give equal access to people with learning difficulties from every minority community. Funding bodies therefore need to address the gaps in provision and ensure that all minority ethnic communities within an area have access to such opportunities.

Ethnic minority advocates

A general shortage of advocates has been identified (Lewis 1996) and our own fieldwork revealed an acute shortage of minority ethnic advocates in particular. Ahmad *et al.* (1998) reported a similar shortage of advocates in relation to ethnicity and deafness. In addition, we found that, as a concept, advocacy is not necessarily

understood or accepted by all communities. We encountered different approaches to this situation.

One advocacy group we spoke to found that the employment of a South Asian worker on a part-time contract had not resulted in any significant caseload of service users from minority ethnic communities. Very few people with learning difficulties from these communities or their families had approached the organisation for advocacy services during its history. The South Asian worker who was appointed had no previous experience of disability work and had not been able to identify individuals who required advocates. A pilot research project to assess the feasibility of specific advocacy services drew on the experiences of local community groups which addressed ethnicity but did not have a focus on disability generally or on learning difficulties specifically. These organisations had no contact with individuals with learning difficulties and were unable to make referrals. They perceived minority ethnic families as being hostile to the idea of advocacy for cultural reasons and a failure to understand or accept the clinical diagnosis of their relative. As a result, no further work was considered viable in this area. Once the South Asian worker left the organisation, she was replaced with a White member of staff whose remit did not include a focus on minority ethnic users.

The above case study raises a number of issues. More effective preparation for identifying the needs of people from minority ethnic communities would involve appropriate training for staff, which may not be available within an organisation and may have to be sought from further afield. In addition, it is important to recognise that minority ethnic community organisations cannot act as a 'catch-all' for any issues relating to these communities. Lessons will need to be drawn from organisations which focus specifically on both disability and ethnicity if service development is to actually take place. Their experience is vital to finding ways of identifying individuals who might benefit from an advocacy service.

The model of advocacy described by this project also appeared to work against the development of an appropriate service. Self-referral was seen as central to the concept of citizen advocacy and actively recruiting people for the service was not therefore viewed as a course which should be followed. This would seem to preclude attempts to enhance take-up through direct approaches to individuals or families. In addition, the advocate's role focused on empowering the individual with learning difficulties, which might involve conflicts

with family and professionals. Accountability was thus perceived only towards the person receiving advocacy and carers' needs or roles were not considered. Such an approach might be difficult for the family of a person with learning difficulties to accept. For communities that place a high value on collectivity and interdependence, it could well be alienating and be seen to consciously undermine the principles on which a family structure may be based.

Sheffield Citizen Advocacy also identified low take-up by South Asian service users as a problem which it needed to address. It established a joint project with the Youth Service, with a focus on working with young South Asian women to increase confidence, independence and participation in a range of activities. It recognised, however, that, in order to enable this particular group to participate, there was a need to work with families in the first instance. The South Asian worker who was appointed was vital to this aspect of the project; at the same time, other workers used their broader experience of advocacy work to support her. Home visits were used to strengthen her existing familiarity with families' beliefs and cultures and families were invited to attend with the young women with learning difficulties if they wished. In this way, parents were encouraged to build up a relationship of trust with workers; through their participation in the group they were also able to appreciate the skills their daughters already had and were developing. Parents valued these skills and approved of the group activities. They also gained opportunities for support from other parents: this helped them to increase their own support network.

The above example highlights the need to adopt an approach which, by involving family carers, runs counter to the argument that carers' needs and views should not influence the way that disabled people decide to lead their lives. In respect of the needs of people with learning difficulties from at least some minority ethnic groups, such an argument would be both simplistic and potentially detrimental to the well-being of the person with a learning difficulty.

Minority ethnic communities are not necessarily resistant to the idea of advocacy and we came across a number of self-advocacy groups set up by people from these communities themselves. However, the role of the advocate may need to include work with families rather than be independent of them. Considering the importance of family to many disabled people from minority cultures (Bignall and Butt 2000, Priestley 1995), outcomes which do not alienate family

members will most often accord with the wishes and interests of individuals with learning difficulties themselves.

Independence

The current focus on promoting independence can encompass independent living skills, control over one's own situation, independent housing and financial independence. This reflects the wishes of those young people who complain of boredom at home, a wish for employment, accommodation of their own and personal relationships leading to having a family of their own (Mental Health Media 1998). For them, existing educational courses may be lacking in interest and they may feel they have little or no opportunity to voice their own wishes or to determine what options will be available. The support they want is to achieve their own goals, which essentially centre around being 'like anyone else' and to have an opportunity to talk to their families about the possibilities for greater independence (*ibid.*).

The Personal Assistant Support Scheme (PASS) in Birmingham offers one example of how such aspirations might be met. Focused specifically on the need for personal choices for minority ethnic adults with a learning difficulty (from African Caribbean and South Asian communities), this scheme provides individual support for a small number of people to enhance their access to leisure, art and education programmes, develop self-help, social and domestic skills, and, in some instances, provide assistance to identify and sustain opportunities for employment. The scheme itself is supported by the Birmingham Independent Living Project, with funding provided initially through joint finance, though the Specialist Community Health Trust is likely to provide ongoing support. The scheme operates in partnership with users' families and evaluation takes account of outcomes for both users and family carers.

The concept of independence can, however, be problematic. There is, in particular, an assumption on the part of many policy-makers and service providers that a Western approach to independence will be shared and understood in the same way by people from all ethnic and faith groups (Bignall and Butt 2000). According to the mainstream position, independence is intertwined with a focus on individuality. This theme runs through service provision and is taken for granted as the basis for achieving the best interests of a person

with learning difficulties. Individual programme planning, for example, aims essentially to focus on the individual with far less attention being paid to family dynamics. This could alienate families which value their collective nature more highly than individualism and may conflict with a tradition of extended family living (Baxter 1998). The evidence shows that members of South Asian communities often perceive kinship-based groups as an important source of identity and support (Ahmad and Atkin 1996). Our fieldwork confirmed this, in that African Caribbean people with learning difficulties were also positive about families and felt that independence could be achieved within a family setting. Small steps towards doing things on their own, such as coming to a social group for people with learning difficulties, is seen as independence. Leaving one's family and living on one's own is therefore not the only kind of 'independence' that has value.

However, the low status given to this more collectivist philosophy by mainstream services may place them in direct conflict with families of people with learning difficulties, consequently hampering trust and the ability to work in partnership (Baxter 1998, Bignall and Butt 2000). Within some disabled people's organisations, too, reliance on family members may be seen as disabling. However, the family system has been the primary bulwark against racism for many people in Britain and this extra support may be considered vital by minority ethnic members (Begum *et al.* 1994, Priestley 1995).

Within support groups a similar underlying concept tends to be applied. Independence from the family is valued for people with learning difficulties and it is assumed that the exclusion of family members from groups which are run by and for people with learning difficulties is the ideal. However, the active involvement of families may be seen as vital to success by some groups of disabled people. South Asian disabled members in one study perceived the need to use existing family support structures to build up the organisation (Priestley 1995). This runs counter to the views of many within the disability movement about reliance on non-disabled members; from their perspective, the support given by families would itself become disabling in terms of the extent of reliance upon them.

Independent living schemes may similarly ignore the importance of family connections and base supported housing away from areas in which there is cultural diversity. This can result in individuals with learning difficulties having to face the dilemma of living far away from the family in supported housing or living nearby without adequate support (Begum 1995). Bignall and Butt's (2000) study of young people shows that, although some wish to move away and live in their own homes, many want to stay with their families but be

able to do more for themselves and have increased control over decision-making. They suggest that total self-sufficiency is an unrealistic concept: interdependence may be a more appropriate cross-cultural notion. The issue to be resolved, then, is how such interdependence can be harnessed to everyone's benefit.

We found that groups often recognised the need to involve families in order to build up trust but that the motives for doing this differed according to how much status was given to a collectivist culture. One advocacy scheme undertook work with families in the first five to six months of their involvement in the project. However, the aim of such work was to build up trust and eventually discourage attendance by family members so that the group could then work exclusively with the young women with learning difficulties. Primacy was therefore ultimately given to an individualistic concept of advocacy.

South Asian workers in the Parvaaz Project, Berkshire, and Shared Care, Leeds, on the other hand saw working with families as a long term part of their work – developing independent living skills in young people with learning difficulties also involved enabling some parents to acknowledge that these were necessary and important. Family structures for decision-making require that parents and grandparents should be involved in the work that the project is doing.

The Parvaaz project has organised computer training and other skills courses which have been related to the needs of local employers. These are combined with placements and introductions to local companies. In addition, a wide range of leisure activities is offered and a traditional dance group has been developed to a stage where it is performing on a commercial basis. Although such activities will not necessarily be equally acceptable to all communities – many Muslim families, for example, would frown on the provision of dance whereas Hindu and Sikh families are more likely to welcome it – for the community in which this group is active these opportunities have been an important means of raising self-confidence and self-esteem. The money earned by group members has helped them to gain financial independence and this in turn has enabled them to challenge negative perceptions of their abilities. The coordinator for the project has addressed parents' fears about the vulnerability of their son or daughter, particularly in the case of teenage girls, without trying to undermine those fears or object to them. Recently, the project has tried to overcome a drop in the numbers of girls attending the group and it is recognised that better attendance will need to be negotiated with girls' families.

Options that are acceptable to families are felt to be the key to improving opportunities for young people with learning difficulties – something that Atkin *et al.* (forthcoming) have noted in relation to minority ethnic deaf young people. As with White families, there is a growing recognition that negotiated provision is more effective than pushing parents reluctantly into avenues with which they feel uncomfortable or trying to ease them out of the picture altogether. Addressing attitudes within families and communities towards the opportunities provided by projects is thus seen as a significant part of the work with young disabled people.

The roles of women and girls, in particular, are interpreted differently in different communities and across generations. Parents who restrict the activities of their daughters may feel they are safeguarding them from situations in which they are vulnerable to abuse or more open to unacceptable behaviour, such as mixed gender environments. Parents may also feel under social pressure from within their communities to uphold such restrictions and to maintain the existing boundaries of appropriate behaviour between (particularly younger) men and women (Dwyer 1998, Kelleher 1996). There may be a feeling that traditional values and beliefs are undermined by services which attempt to encourage young women to spend more time out of their homes in environments that are considered unsuitable (Dwyer 1998, Jacobson 1998).

These restrictions, however, are often interpreted as oppressive and stifling by service professionals, and sometimes by young people themselves. Media attacks on the role of South Asian, particularly Muslim, women contribute to the way this situation is interpreted. Stereotyped images of young South Asian women suffering from ‘culture-clash’ may be reinforced when staff promoting independent living skills feel obstructed by family members. Where single gender settings have been provided for South Asian women to learn such skills however, we found that parents value such opportunities for their daughters. The key to widening opportunities for young women would seem to lie in respecting their cultural identity and the values and beliefs of their families, rather than in persuading them that the majority culture is necessarily better. Whereas respecting young people’s rights is important, it has sometimes proved to be a convenient pretext for undermining non-White cultures (Ahmad *et al.* 2000). Pursuing a balanced approach will be far from easy for professionals; not appearing to be balanced will risk alienating young people or parents, or perhaps both.

Barriers to independence

Restrictive expectations about the social roles of disabled people need to be addressed if people with learning difficulties are to achieve their own goals. Attitudes within different communities may contribute to the exclusion of disabled people from work, marriage, education, and from access to public places (Bignall and Butt 2000, Begum 1992, Westbrook *et al* 1993). Similarly, expectations about the role of carers may restrict the opportunities available to people with learning difficulties. An emphasis on 'loving duty' may, for example, preclude the success of programmes that would help someone acquire life skills and independence (Bignall and Butt 2000, Westbrook *et al* 1993).

Studies have shown that negative attitudes to disability have not been specifically addressed within minority ethnic communities. Westbrook found that, in some communities, people may feel greater shame in respect of a disabled family member and attempts may be made to keep the existence of such members a secret (Westbrook *et al* 1993). At a broader level, a study of deaf South Asian children found that many South Asian families reported less acceptance of their deaf child by the South Asian community than by members of the White community (Chamba *et al* 1998). Bignall and Butt reported that young disabled people feel such prejudice must be dealt with if individuals are to receive enough support to develop more independent lives (Bignall and Butt 2000). Katbamna *et al* (2000) report that carers, too, suffer from these negative attitudes and are often left unsupported by both services and their extended families.

Negative attitudes are compounded by a lack of information about the facilities and opportunities that are available to people with learning difficulties. These reinforce the notion that individuals with impairments are a 'burden'. Low take-up of services may be in part a consequence of negative attitudes towards disability – this does not, however, remove the responsibility for addressing such attitudes on the part of service providers (Begum 1992, 1995). In addition, there is a need for carers to be trained in practical skills associated with encouraging independent living skills. This could make their role easier to manage and help their relative become less reliant on them (Baxter *et al* 1990).

Poverty is a further factor which may deter minority ethnic families from encouraging financial independence for a person with learning difficulties. Poverty may mean that families may not be able to provide financial support to disabled relatives living away from home. People with learning difficulties themselves may not be aware

of the benefits being received on their behalf and a family's reliance on these benefits may act as a disincentive to enabling more financial control. Such concerns are often accompanied by fears about the type of care and support that would be provided away from the family home, whether this care and support would be appropriate in relation to the family's culture or religion, and worries about possible sexual impropriety and vulnerability. All these issues would need to be addressed as part of the context in which people with learning difficulties must negotiate independence.

Barriers to independence from within their own communities are compounded for many by racism. Discrimination operates across the fields of education and employment and young people can experience great difficulty in joining adult society (Bignall and Butt 2000, Doyle *et al* 1994). Research suggests that, not only do disabled people encounter a negative response when seeking employment, but also racial prejudice appears to play a significant part in their being made redundant from jobs that they have managed to secure (Doyle *et al* 1994). Our own research showed that people with learning difficulties experienced racism on the streets, in shops and on work placements.

Sexuality and the perception of appropriate adult roles are both issues which need to be addressed. The discussion of sexuality is surrounded by taboos, more so in some communities than others, and people with learning difficulties may have little access to relevant and necessary information. Communication about such issues and about individual needs may also be difficult and this could hamper the disclosure of abuse. Appropriate roles may be perceived differently in individual families; one project worker referred to a parent who would not accept that his daughters had a learning difficulty and was arranging their marriages with partners from abroad. At the same time, the literature shows evidence of other dynamics, particularly within South Asian communities, where marriage may not be seen as an option or there is resistance to the idea of marriage between two people with learning difficulties (CVS 1998), as may indeed be the case within White communities, too. Equally, marriage may be more easily accommodated where the aptitude or skills of the marriage partner are only one part of the whole equation. If marriages are a key part of re-affirming or reflecting kin relationships rather than emotional involvement or attraction between the couple, then South Asian cultures may be more accommodating of disabled people. Without empirical data, however, this remains an interesting but hopeful hypothesis.

Work on sexuality is fraught with problems, and not only in relation to people from minority ethnic communities. An experienced

sexuality advisor related a difficulty she encountered when working with a group of people in a supported employment project. The parents of a young Hindu girl gave their consent to their daughter being given information about sexuality as part of the development of self-assertiveness within the project. After the girl's brother got married, she herself became angry that she was not getting married and then developed a relationship with a young White man from the project. This transgressed her parents' wishes and caused extreme problems within the family. While such a difficulty could occur with White families with strong moral beliefs, the experience highlights the need to balance individuals' and families' wishes, given that, in the advisor's words, "the young person is rooted in their own culture, family and beliefs". Moreover, there is a need for accessible and appropriate information for people with learning difficulties. Staff working in this field have complained, however, that insufficient resources were allocated to providing information about sexuality and personal relationships to people from minority ethnic communities.

Empowerment

It is clear from the above that the concepts of partnership, advocacy and independence are not always being applied in ways which empower minority ethnic individuals or communities.

Empowerment implies involvement, control and the ability to make choices. However, our study highlights the invisibility, conflict and barriers many people with learning difficulties and their carers experience in their interactions with service providers.

The literature points to a number of areas in which services have failed to empower people with learning difficulties. Assessment methods which do not look at all aspects of an individual's life but only those defined by professionals do not enable users to specify their own needs. Baxter (1998) suggests methods which increase the involvement of people with learning difficulties and their carers in the assessment process. Empowerment in this process requires more information about procedures, the removal of cultural bias from assessment tests and the recognition of languages other than English. A more equal relationship between professionals, service users and carers reduces the possibility of inaccurate assessments which may contribute to the disproportionate number of children from some ethnic groups assessed as having severe learning difficulties. (The question of assessment will be discussed in more detail in relation to cultural sensitivity in Chapter Three).

Choice and control also appear to be missing from the experience of young disabled people from minority ethnic communities who take

up employment training and work placement opportunities. Bignall and Butt (2000) found that many had little choice in the type of placement they were allocated and that this might be vastly different to what they actually wanted to do. Young people felt pushed into certain types of work as a result of the low expectations of their teachers, staff in Youth Training Schemes and employers. This had a disempowering effect as individuals lowered their own ambitions and brought them into line with what others thought they were capable of. A lack of information about the support available if they applied for jobs or attended interviews also affected their perceptions of what they were able to do in the future. Problems can arise if all students or trainees with learning difficulties are treated in a standard way, rather than recognising that their level and type of need may vary immensely. Although able to exercise choice in respect of course modules, some of the young people we spoke to expressed considerable frustration that their own individual potential was not being fully realised and that their aspirations were not being met: work in groups tended to be based on the abilities of those whose needs were greatest rather than developing the skills of those who were more able. There is thus a need to explore options rather than simply slotting individuals into existing schemes. Success in areas valued by people with learning difficulties and others can have greatly empowering repercussions.

One means of empowering individuals is through the use of direct payments under the Community Care (Direct Payments) Act 1996. The literature indicates that there are still few instances of such payments being made to people with learning difficulties – and even fewer for people from minority ethnic communities, though examples do exist (Holman and Collins 1998). In our own fieldwork, we came across just one instance of such a payment, which happened to be the first that was made to a person with learning difficulties within that authority. Direct payments might potentially be more attractive for people with learning difficulties from minority ethnic communities if they were seen as a means of giving the disabled person some standing in the family home, for instance through having income to pay for support from outside sources while continuing to receive informal family support at home.

Support for people with learning difficulties from voluntary organisations and religious bodies is not widespread, although there is some evidence that some African Caribbean churches provide support with practical needs and self-awareness (CVS 1998). Our study found that support groups are currently one of the most widely available methods of enabling participation and control for people with learning difficulties and carers. The literature shows that such groups can be valuable for emotional support and sharing

mutual problems and can become a source of regular social contact. (Begum 1995; CVS 1998). They are also used as a forum for community development: for example, as a lobbying group for better services. Groups may provide a point of access for services wishing to do outreach or to consult particular communities (Black People First 1994).

The Black People First groups that we contacted, for example, aim to build up confidence and provide role models for people with learning difficulties from minority ethnic communities. Groups are run by people with learning difficulties and have been set up in different localities to provide information, training and social activities for members. Groups communicate with service professionals and campaign on issues such as education, pay, public attitudes and equal rights. The groups have also organised conferences and other public events to raise the profile of these issues. The Swindon group has recently (summer 2000) produced a video about members' views about their lives and experiences of services.

However, support groups vary in the degree to which they can assist people to become empowered. Members of Justajoo, a group for young South Asian women with learning difficulties in Bradford, complained about the powerlessness they felt vis-a-vis GPs who refused to make home visits. The group aims to increase self-confidence and skills: however, the range of activities that it could offer was limited. There was a recognition by the worker that this could lead to underachievement for some young women. Those who came because of the women-only setting could not move on to other provision which would help them develop their skills because these were mixed-gender activities. Isolated projects such as this could not, therefore, act as stepping-stones for South Asian women with learning difficulties to access activities which would be more challenging and would develop their skills further. There was also a need for single-gender day services to supplement the group, which only ran once a week. Women in the group complained about being bored because they had nowhere to go at other times. They were clear in their expressed need for training, jobs and more activities.

Emotional support seems to be severely lacking for people with learning difficulties from minority ethnic communities. Many experience isolation as a result of family restrictions and a lack of opportunity for social contact (Bignall and Butt 2000, Butt and Mirza 1996). Racism and harassment may further increase feelings of isolation and emotional stress (Butt and Mirza 1996). Studies show that the initial diagnosis and continuing effects of impairment or chronic illness have a strong impact on many of these already disadvantaged families. Parents and disabled children often refer to

depression when they think about their situation. However, concerns about worrying others may often lead to both parents and children trying to ensure that their distress is concealed from other family members (Atkin and Ahmad 1998, Atkin *et al* 1997).

Carers

Existing provision is generally inappropriate and unacceptable in supporting carers to take more control over their situation. While White carers also receive very limited support, the picture which emerges from studies of minority ethnic carers is of ethnocentric services that are geared to meeting the needs of the ethnic majority population. Only a third of South Asian carers in one study, for example, used short-term breaks for their child with learning difficulties. The inflexibility of these arrangements was not appropriate for the needs of many families. For example, it was only available in blocks of one or two weeks (which ruled out visits to family abroad) and did not allow for occasional nights to allow attendance at weddings or other family events (Hatton *et al.* 1997). There is also a need for services to take account of changing needs over time (Butt and Mirza 1996).

Short-term breaks are often underused because of a failure to identify the needs of carers in assessments, which tend to focus only on the person being cared for. Carers' work and personal and family commitments may not be taken into account during assessments and little opportunity afforded for them to define their own needs (Butt and Mirza 1996). Many carers spend a considerable amount of their lives caring and a high proportion live with those cared for. Unlike at least some White carers, carers from minority ethnic communities do not report support from neighbours in their caring responsibilities (Butt and Mirza 1996). South Asian carers generally have little recourse to informal support, either from within the family or from extended family members, contradicting the myth of extended family support networks for South Asian people (Butt and Mirza 1996, Hatton *et al* 1997, Steele *et al.* 2000). Contrary to popular misconceptions, low levels of take-up have not been found to be the result of support from other sources (Hatton *et al* 1997). The myth is perpetuated, however, by a failure by agencies to investigate carers' circumstances. A large proportion of South Asian families have few relatives in the UK (Ahmad and Atkin 1996); it has become increasingly difficult for families to continue extended kinship networks as a result of the changes in household structure brought about by migration, geographical dispersal and possibly changing social attitudes. Help from other family members is

restricted to close relatives for South Asian and African Caribbean carers. Those living outside the household are not usually directly involved in caring. Studies also show that living in large families does not necessarily mean that support is available: there is sometimes conflict and loneliness within large households. South Asian families have, indeed, expressed a need for short-term breaks which is double that of White families (Butt and Mirza 1996).

The well-recognised inverse care law seems to apply equally to learning difficulties. Services are not always targeted at those families in the greatest need: for example, high parental stress is associated with lower household income but receipt of services appears to be associated with higher household income (Hatton 1998). Services appear to be disproportionately used by those parents who have the resources to put pressure on service providers (Azmi *et al* 1997). There is a reluctance to voice needs for services as a result of negative experiences with professionals and difficulties in communication (*ibid.*, Butt and Mirza 1996). Carers may also fear that complaints about provision may threaten services which they are already receiving (Nothard 1993).

The wider literature on ethnicity and disability shows that many carers experience a 'learned helplessness' towards services (Mir *et al* 2000). Non-response, racism and difficulties in communication lead many carers to feel that no-one will help them and there is nothing they can do to improve their circumstances (*ibid.*). The experience of practitioners making racist assumptions may cause parents to be reluctant to use services, leaving them more vulnerable to feelings of being overwhelmed by their situation (Atkin and Ahmad 2000a).

A partnership approach to setting up such services empowers carers, as well as individuals with learning difficulties and consultation can result in the development of flexible schemes which suit their requirements. Schemes that have worked well have tackled information and communication difficulties, parents' concerns about the care of their son or daughter and the availability of carers and professionals from within their own communities (Prewett 1999).

A further issue which we came across involves young women and girls who had adopted the role of carer for their relative with learning difficulties. The lack of support they received with this role restricted their own opportunities to pursue education or work. Lack of access to support with caring appears to have significant consequences generally in terms of carers' ability to cope. Hatton *et al.* (1998) report very high levels of distress amongst South Asian carers with 78 per cent at risk of developing psychiatric problems. Studies also report high levels of hospital attendance for carers both as in-patients and out-patients (Azmi *et al.* 1997, Mir *et al* 2000).

Low household income and more than one person with learning difficulties in the household is particularly associated with high carer stress (Azmi *et al* 1997).

Evidence suggests that at times carers can feel overwhelmed by their situation. Studies in the field of physical impairment report mothers who suffer long-term depression, health problems and even attempted suicides, as a result of worrying about their child. In most cases such a collapse of coping resources is temporary and the majority of parents are able to manage their situation on a daily basis (Atkin *et al* 1997, Chamba *et al* 1998). Nevertheless, the high levels of stress that have been reported need to be addressed. Studies in the field of learning difficulties report only informal and variable counselling support provided by outreach workers in contact with some families (Azmi *et al* 1997, CVS 1998).

The Himmat Asian Women's Group in Manchester has demonstrated an approach which can empower carers. Women in the group organised training sessions for carers providing short-term breaks, leading to shared care arrangements. These sessions covered issues such as where halaal food could be bought, acceptable clothing for people from Muslim communities, and removal of unwanted hair. This kind of very practical training could not be learnt from written material and involving group members in its delivery was a clear recognition of their skills. The group also invites speakers such as care managers of whom carers can ask questions and from whom an improved knowledge of services can be obtained. These interactions are an opportunity for carers to have a voice in service planning and help to encourage skills and confidence in public speaking.

The evidence points to a number of areas in which individuals with learning difficulties and their carers from minority ethnic communities appear to experience greater obstacles and difficulties than their White counterparts. As noted earlier, the support received by White people with learning difficulties and carers is itself limited. However, the hurdles faced by people from already disadvantaged communities constitute additional strains on their capacity to manage their situation. The difficulties outlined above are not inevitable and the studies indicate that, if obstacles are addressed, service providers can help to increase the ability of people with learning difficulties and their carers to have more choice, involvement and control.

Key points

- The principles which underpin service planning and provision need to take account of the particular needs and values of people from different minority ethnic communities
- Partnership with minority ethnic community groups is needed to influence service planning, monitoring and evaluation and to meet local needs. Groups may need support to take part in joint ventures. Consultation exercises require the involvement and support of community organisations if they are to succeed.
- The concept of advocacy needs to be developed in some communities and advocacy or self-advocacy groups need secure resources in order to develop. Schemes promoting advocacy and independent living skills may need to work with families as well as individuals with learning difficulties in recognition of family structures which are different to those in majority ethnic communities.
- An understanding of independence that emphasises individuality may run counter to the values of collectivism and close family relationships that exist in some communities. The role of family and community networks needs to be taken into account when planning services for individuals.
- Barriers to independence in education and employment result in limited choices and low expectations. Restrictive attitudes towards disability within minority ethnic communities and in the wider context need to be addressed.
- Information, choice and involvement in decision-making are essential for the empowerment of people with learning difficulties.
- Support groups can provide emotional support and increase participation and control for minority ethnic people with learning difficulties and their carers. Such groups are generally small-scale and isolated, however, and may be unable to provide progression to other provision if cultural needs are not recognised in other services.

CHAPTER THREE

PLANNING BETTER SERVICES

The younger age profile of people within some, particularly South Asian, communities, has been highlighted as an important factor in the future planning of services for people with learning difficulties and their carers (Emerson 1998). Current projections show that the number of South Asian adults with learning difficulties will have more than doubled by 2007 (ibid.). Demand for primary health care services is already high within these communities (Nazroo 1997), yet there remains a considerable level of unmet need for health and social care services generally, which is higher than in the majority community (Chamba *et al.* 1999).

Studies of services for minority ethnic communities have highlighted a number of problems. A lack of information and awareness of services, lack of staff who could speak the same language as the carer, the cultural inappropriateness of existing services in terms of diet, activities and staff provision, and racial discrimination within services have all contributed to low take-up and poor provision (Baxter 1998, Chamba *et al.* 1999, CVS 1998, Hatton *et al.* 1998, 2000).

Areas of concern fall under the following headings:

- communication between service users and service providers and access to relevant information
- the improvement of cultural sensitivity and flexibility
- personnel recruitment and training
- funding and resources
- whether services should be specialised for particular communities or integrated into general service provision.

Communication and information

Several questions arise in relation to communication. How aware are minority ethnic families about services available? How aware are service providers about their needs? How much information about the needs of people with learning difficulties is gathered by service providers? How accessible is this information to service planners and

what is its relevance to the effective delivery of services? Research in these areas has concentrated on the information needs and barriers to communication faced by carers, mainly in the South Asian communities. There is less research about the experiences and views of people with learning difficulties themselves, and this is reflected in the limited literature available.

Users and carers

Nothard's (1993) study in Leeds found that people with learning difficulties and their carers from a wide range of minority ethnic communities had poor knowledge of the services available and of the roles of different services, such as the Community Learning Disabilities Team. Similar problems have been found elsewhere in relation to the types and range of support services available in the areas of housing, short-term breaks and social security benefits (Butt and Mirza 1996, Chamba *et al* 1999, Tait *et al* 1998).

In other localities, few South Asian carers of children with learning difficulties knew what services were available and only about one quarter of those with incontinent children knew about the laundry scheme (Hatton *et al* 1998). Almost half did not know about short-term breaks. These carers were found to have a reduced possibility of 'chance encounters' with professionals or other carers, which for White carers had been the first step in getting help from statutory or voluntary agencies. Many minority ethnic carers do not become aware of their right to apply for personal care, community nursing or financial benefits until many years after their son or daughter has been diagnosed as having an impairment (Mir *et al* 2000). A lack of information disenfranchises carers and people with learning difficulties from their rights to services and clearly affects take-up (Butt and Mirza 1996). Minority ethnic families of disabled children are generally less likely to access benefits and they receive benefits at a lower level than White families whose children have comparable impairments (Chamba *et al* 1999). Even after recognition of eligibility for benefits or services, they face a long delay before they receive these (Butt and Mirza 1996).

For South Asian carers of an adult with learning difficulties, access to relevant services can be particularly difficult (Hatton *et al.* 1998). Despite a high awareness amongst carers of general community health and social services, knowledge and use of specialist services appears to be low, with the exception of day care (Azmi *et al* 1996a). As in other communities, South Asian mothers bear the greatest responsibility for caring for their disabled child. However, women who do not speak English often have more limited contact with

service providers and lack information about their child's impairment or services that would make caring easier. The inability of services to fully overcome the language barrier may combine with external factors such as racial hostility, resulting in South Asian women carers experiencing more isolation and loneliness than others (Atkin and Ahmad 2000, Azmi *et al* 1996a, Chamba *et al.* 1998).

The consequences of poor communication are serious. Studies show that it is a factor in misdiagnosis, inappropriate assessments and interventions, non-receipt of welfare entitlements and the blocking of opportunities for disclosure of abuse (Azmi *et al* 1997, Baxter 1998, CVS 1998, Morris 1998). Poor explanations and a low level of information may not be questioned by many parents who rely on professional decisions about what information they should have. This has implications for the coping and decision-making abilities of carers (Chamba *et al* 1998, Hatton *et al* 1998). South Asian carers' knowledge of services is directly related to their length of residence in the UK and to whether they can speak and write English. This would appear to indicate that services are currently being taken up more by those who can communicate effectively, not necessarily by those in most need (Hatton *et al* 1998).

Many people with learning difficulties rely on their families for information (Bignall and Butt 2000) and therefore poor communication with carers has implications for the person cared for too. Better awareness of potential benefits could encourage people from minority ethnic communities to seek services (Begum 1992).

One important way of providing information to people and providing a gateway to services is through key workers (Mukherjee *et al.* 1999). Chamba *et al.* (1999) noted that the availability of a key worker was associated with fewer unmet needs, though the availability of such a service is often ad hoc and depends on the initiative of individual services, schemes or professionals (JRF 1999). Moreover, not all professionals identified as key workers had truly taken on that role (*ibid.*). In a recent study of 95 South Asian families with children with learning difficulties, Hatton *et al.* (2000) found that having a key worker was associated with high levels of parental distress, depression and anxiety. This surprising finding (from the initial analysis of interviews) was due to be further explored. One possibility, however, was that it was those families who experienced the greatest problems who had been allocated a key worker.

The role of community based organisations

Our fieldwork, for its part, showed that, in terms of information to improve service take-up, a single point of contact with services and access to appropriate language provision are more effective than having to approach a range of different services and staff. The response of carers to services may in fact be partly based on local service reputation and word-of-mouth recommendations. Support groups for minority ethnic carers and people with learning difficulties are consequently a helpful way for people to support each other and raise awareness. Such groups can act as a gateway to a range of services, with staff addressing a range of information needs. Becoming involved with one group can lead to people with learning difficulties and their carers gaining access to a network of other services and opportunities. The experience of meeting others with similar experiences is also a valued source of information; however, groups are often extremely small-scale and appear to exist in isolated pockets rather than being widely available.

The development of community activity is often linked to the work of one charismatic individual who is committed and energetic. The worker with Justajoo, mentioned earlier, was instrumental in contacting families and giving oral information to them about the group and other services that are available. The relationship she built up with families was an important element in the success of the group. The group acted as a source of information for families which would effectively not be available otherwise. Outreach was essential to include parents who could not attend the group.

The importance of outreach has been highlighted in relation to other communities where language may be a barrier to access (Nothard 1993). Refugees, who have different needs to those established in the UK, are even less aware of services and entitlements than other minority ethnic groups and creative ways of outreach need to be found. In Kensington and Chelsea, outreach workers used a video recording to communicate information about registering with a GP. The video used images and drama to overcome the problem of catering for a potential 80 to 90 different languages (Lewis 1996).

Lambeth Accord, a Black self-advocacy group, provides information to group members through the use of pictures, photos, tapes, slides and videos. BSL, Deaf-Blind Communication and Plain English are used to communicate whilst drama and role-play techniques facilitate discussion. The range of media used to raise awareness aims to overcome the limitations of traditional text-based information.

The Parvaaz Project (as described in the previous chapter) has secured funds for a South Asian development officer to work with families and other agencies to effect change in mainstream services. The job will involve holding seminars, meetings and generally creating awareness amongst South Asian parents about entitlements, benefits, rights and equipment which could be of benefit to them. It was envisaged that the development officer would work with national and local organisations to help them become more sensitive and responsive to the needs of South Asian people with learning difficulties and their carers.

Language

ACCESSIBILITY

Access to services for people from all communities is hampered by the use of complex jargon. Increased use of plain language and Makaton would improve communication for many people with learning difficulties from minority ethnic groups and their carers (Black People First 1994, Nothard 1993). There is evidence of a failure to provide information to carers about services in appropriate languages and locations and this particularly affects those carers who have least access to provision (Azmi *et al* 1997, Steele *et al.* 2000). Various methods of disseminating information are needed to enable those without literacy skills to access material (Butt and Mirza 1996).

The absence of translated or accessible materials contributes to low awareness and take-up of services. This may mean carers struggling to carry on even though support is available (Azmi *et al* 1996c). A number of studies have highlighted the need for literature in appropriate languages and formats. Lack of information in other languages is a particular issue for South Asian communities, whether in relation to the nature of the impairment, understanding of its implications or reasons for attendance at a special school (Azmi *et al.* 1997, Butt and Mirza 1996, Hatton *et al* 2000). Parents from minority ethnic backgrounds are particularly likely to feel ill-equipped to help their child and to be unaware of the specialist services that are available (Hatton *et al* 2000).

Publicity about services may be more effective through community centres and on community radio and TV, especially as not all carers or people with learning difficulties are literate (Nothard 1993). Video and audio-tapes and face-to-face communication may also be effective means of passing on information orally. Translations that are provided in a vacuum and not linked to staff who can respond to queries are not entirely useful if language remains a barrier to

applying for services. Moreover, some concepts such as ‘carer’ are not as meaningful in some communities as they have become within the ethnic majority. Translations that try to include such concepts without explanation ignore the cultural and linguistic realities of groups (ibid.). Attempts to promote such concepts within communities will need to ensure that the roles and expectations of the parties involved are made clear (Baxter *et al* 1990).

BILINGUAL STAFF

The cultural background of practitioners themselves has implications for the support individuals receive. It may be difficult to assess speech development, for example, if therapists have no knowledge of the home language of the person they are working with. Although there is a need for bilingual staff and interpreters who are trained and experienced in the area of provision in which they give language support (Ahmad and Atkin 1996, Butt and Mirza 1996, Hatton *et al* 1998), they are not always available. When they are, there is often inappropriate filtering of information by professionals and interpreters who have little understanding of each other’s areas of work (Chamba *et al* 1998). Hatton *et al*s (1998) study further suggests that language training for a wide range of front-line staff, such as receptionists, could increase the confidence of carers when accessing services.

The literature on managing caring obligations shows that a clear understanding of the condition, with appropriate professional support, can help reduce stress and facilitate coping (Cocking and Athwal 1990). The use of family members as interpreters has a number of negative consequences in this respect. Fathers, who are most often used as interpreters by health, social care and education services, may deny access to essential information to their wives, sometimes as a way of protecting them from the negative aspects of their child’s condition. This can cause distress for the father himself who is in the position of dealing with his own emotions, filtering information and feeling unable to talk to his wife about his own concerns and worries. The situation also results in mothers’ concerns being marginalised and restrictions on their ability to discuss issues they consider important. More importantly, mothers cope with caring tasks without access to relevant information about the condition, its consequences for the disabled person and implications for carers, or sources of support (Atkin and Ahmad 2000, Azmi *et al* 1996c, Butt and Mirza 1996).

The evidence shows that siblings of a disabled child may also be used as interpreters, sometimes against the wishes of their parents.

Consequently, such children, usually South Asian school-age children, may have to miss school and cope with 'adult' problems and situations without either the technical skills of an interpreter or the emotional maturity of an adult (Atkin *et al* 1997, Butt and Mirza 1996). Service providers need to ensure that professional interpreting is not subsidised by the use of family members, at the expense of service quality and with the ensuing emotional repercussions for individuals placed in this role. Where there are significant numbers of people from particular linguistic communities, the appointment of dedicated interpreting staff who can build up their knowledge of specialist terminology, become integral members of professional teams, and develop good knowledge of the service context and ethos has been recommended (Ahmad and Atkin 1996, Chamba *et al* 1998, Hatton *et al* 1998).

Some advisors recommend that, in the field of education, bilingual support workers should always be actively involved and educational aims should include language and cultural needs (Cline 1998). This is based on evidence that bilingual children make greater educational progress if they are taught at least partly in the language they speak at home (Collier 1989). In areas where children come from a wide range of backgrounds, however, ethnic and linguistic matching may not always be possible: in this case, it is essential that staff should be trained to work with the full range of ethnic and linguistic groups in their area (Cline 1998). As well as helping to avoid the inappropriate labelling of children as having learning difficulties when difference is based on ethnic factors, this should assist, conversely, with the recognition of such difficulties when they do indeed exist: at present, there is evidence of the under-representation of minority ethnic children with moderate learning difficulties, possibly due to teachers 'playing safe' and not wishing to confuse difficulties with the use of English as a second language (Diniz 1999).

INVOLVEMENT

Communication difficulty is also a reason for low levels of contact between parents from minority ethnic communities where English is not a first language and school teachers or day centre staff. Home-school liaison is often poor: parents may feel alienated by their inability to communicate with staff and the lack of effort on the part of schools to involve them and, as a result, may not participate in organised activities. Information about assessment, the nature of special education and service provision needs to be provided in accessible formats. Flexible ways of involving parents and providing opportunities to express their views in languages other than English

are needed (CVS 1998). It is also important to use home languages with bilingual children to avoid creating two separate environments of communication with little continuity (Baxter *et al* 1990). A failure to recognise other languages can lead to difficulties in communication between parents and disabled children. It also gives the unspoken message that the language spoken at home is inferior (Baxter *et al* 1990, Bignall and Butt 2000, CVS 1998).

GOOD PRACTICE

An example of good communication practice involved a touring exhibition in Bradford using South Asian staff in public places accessible to South Asian people. The exhibition, which aimed to increase awareness of short-term breaks, visited the Bradford Mela, the city centre, mosques, community centres, temples, street corners and open events. Photographs (especially of South Asian users with South Asian staff) were used as well as a video in Urdu. The display was advertised on a local South Asian radio station, the local press and local South Asian publications. The initiative showed that families do come forward when contact methods are relevant to their background and experiences. The result was not only a considerable increase in South Asian referrals to the services publicised but increased awareness of disability within local communities, especially as media images of disabled people are currently missing from both the minority and majority media (Begum 1994).

Another example of good practice can be found in the training for providers of short-term breaks, who do not necessarily require fluency in English, that was carried out in Urdu by Bradford Social Services. They found that Urdu and Hindi were commonly used languages that could span a number of South Asian communities. However, in some places other languages would be more commonly used – such as Gujarati in Leicester or Punjabi in Southall. In areas where no single community predominates, it is important to identify the dominant languages to ensure a high level of communication.

Service professionals

The information needs of service providers must also be borne in mind: communication must be regarded as a two-way process that is not just about the dissemination of material to people in minority

ethnic communities. Misinformation, for example about the universal unacceptability of abortion in South Asian communities, adversely affects the choices offered to some people from these groups (Ahmad and Atkin 1998, Butt and Mirza 1996).

Both the literature and our own fieldwork indicate that acquiring accurate information about needs and consulting people from multi-ethnic communities are essential. These need to be carried out at a local level as there is likely to be substantial local variation in the composition and material circumstances of different local communities (Ahmad and Atkin 1996, Hatton *et al* 1998). Service providers need to communicate directly with service users to identify their needs. The best examples of further education provision, for example, result from inter-agency co-operation and a curriculum negotiated with local multi-ethnic community groups (Sutcliffe and Jacobsen 1998). Inter-agency liaison is also important to ensure consistency in the principles of speech development which are being used so that education and health professionals are not working in conflicting ways: the role of the head teacher is particularly crucial in determining to what extent English is used as the normative language, and how well children's language needs are met.

At a broader level, statistical information about people from minority ethnic groups is needed to deliver services equitably. Pro-active attempts to identify families currently unknown to services have been recommended, for example through GP surgeries and multi-ethnic support groups. Studies suggest that monitoring service take-up and minority ethnic staff numbers at different levels within the service would increase awareness and potentially lead to targeted action on the part of service planners (Chamba *et al* 1998, Hatton *et al* 1998, 2000). Lewis (1996) suggests that there is considerable scope for service contracts to include a requirement that funded organisations should not only inform all communities about their services but also monitor the ethnic origin of users and workers and make this representative of the local population.

Unmet need can only be adequately specified in such contracts, however, after it has been identified. Our study confirmed some previous findings (Butt and Mirza 1996) that monitoring procedures are inadequate for such purposes. Records generally fail to identify who is getting which service, or general patterns of use and experience. User feedback is considered by those active in the field as an essential tool in performance management: some argue that the criteria for monitoring performance should be set by those receiving the services.

Cultural and religious identity

A number of studies have highlighted the importance of religious and cultural values for minority ethnic families. Beliefs and values are integral to people's self-concept and will affect their willingness to take up any services on offer (Azmi *et al* 1997, Baxter 1998, Bignall and Butt 2000). At the same time, however, stereotyped assumptions may work to the disadvantage of carers and individuals with learning difficulties by failing to acknowledge individual choice (Ahmad and Atkin 1996, Azmi *et al* 1997, Chamba *et al* 1998). Attention to cultural practices and religious beliefs is important in the achievement of quality in service provision. However, it is important to recognise that other dynamics may also prevent the use of services on offer. Attempts to make services appropriate must, in addition to cultural sensitivity, focus on other matters which may prevent access, such as a poor understanding of administrative procedures or the need for child care provision, whether for carers or for parents with learning difficulties themselves (Ganguly 1995).

Recognition

Research shows that, for many parents of people with physical impairments or learning difficulties, religious beliefs play a significant role in enabling the acceptance of impairments. Parents often rely on faith to provide the strength and resources to help them manage their caring role (Mir *et al* 2000). Studies have shown that beliefs play an important role in providing emotional support to carers (*ibid.*). The importance of such beliefs, however, is seldom acknowledged by services. Service professionals may also lack respect for views about the cause or future prognosis of impairments which are not based on a Western medical model (Baxter 1998).

For people with learning difficulties themselves, the issue of identity formation is an area in which disability and ethnicity interact within the wider context of social position, gender roles and minority status in an often racially hostile society. There is substantial evidence that adolescents and adults with impairments have a positive sense of their ethnic and religious identities and value their individual and social history (Ahmad and Atkin 1996, Bignall and Butt 2000, Black People First 1994, Butt and Mirza 1996). There is a keen sense of awareness about the lack of attention paid by service providers to ethnicity and culture and a demand that services should respect rather than neglect or undermine these identities (Butt and Mirza 1996, CVS 1999, Hatton *et al* 1998). Studies have shown that many people with learning difficulties from African Caribbean

communities who have been in residential care have low self-esteem due to the limited contact with people from their own cultures (CVS 1998, Lewis 1996, Morris 1998). Within institutions, any acknowledgement of their cultural ties may be limited to private spaces such as bedrooms. Residential or group homes may be isolated from areas of cultural diversity. Few services have links with minority ethnic groups and most do not address cultural identity unless specifically requested to do so (Lewis 96). Attempts to provide culturally sensitive services do not always address individuals' different needs. One group for South Asian disabled women was simply provided with a room in which to sit all day. The young women with learning difficulties to whom we spoke did not feel comfortable in the same group as much older, physically disabled women, with whom they had little in common.

There is evidence of a strong feeling that voluntary disability organisations in the UK have also failed to acknowledge cultural differences and have marginalised disabled people and carers who are not from the ethnic majority (Priestley 1995). However, self-help groups can help overcome this: the Black People Friendly group in London, for instance, provides a forum for African Caribbean people with learning difficulties to come together, share information and offer mutual support within the context of a shared cultural heritage: the informal nature of the group is one of its key attractions.

Insensitivity

A failure to recognise the differences within and between different communities can lead to a view that there is no difference between groups which in fact have different languages, religious beliefs and lifestyles, and may also differ in terms of socio-economic position. The Vietnamese community, for example, may object to being classified together with Chinese people (Nothard 1993). Ahmad and Atkin (1996) point out that the term South Asian is itself misleading as it encompasses a range of very different religious and ethnic communities and there are differences as well as similarities between these different community groups. Dietary provision, language needs and beliefs may therefore vary, both between and within communities (Baxter 1998).

The link between language and cultural identity is still not recognised by all health and education professionals. Although some assessment procedures have been standardised so as to be appropriate to children from different ethnic backgrounds, they do need to be interpreted sensitively – and some tools remain culturally biased with, for example, tests based on White suburban lifestyles and

Western cultural norms. Traditional images used for assessment such as pictures of pigs are culturally inappropriate for certain groups and may contribute to inaccurate assessments of ability if children fail to respond in what is considered an appropriate way (Lewis 1996, Ward 1990). Ignorance about different cultural norms may lead to misinterpretations of behaviour and may result not only in an overclassification of people from some communities as, say, having challenging behaviour but also in procedures which maintain such behaviour (di Terlizzi *et al* 1999).

There is a need for staff working with children to develop an appreciation of their cultural norms if assessments are to be of real use. Although testing materials have been produced in some languages, in other instances tools need to be adapted in order to be linguistically and culturally appropriate: funding is needed to develop materials in a wider range of languages. Assessment materials for bilingual children should be subject to item bias review, a full bilingual assessment should be carried out at the outset, and bilingual children should be dealt with exclusively by workers who are knowledgeable about and sensitive to key features of the children's culture and language (Cline 1998). While good practice guidelines on working with people from linguistic minority communities have been produced (Raval *et al*/undated, RCSLT 1998), they remain to be fully adopted around the country.

Modes of learning are themselves socially and culturally determined and children may be taught to play 'the White way': that is, following White family roles. Services may not acknowledge different ways of playing, for example, the use of everyday objects as toys, which is common in some cultures and can be used for the same educational purposes as bought toys (Baxter 1998, Ward 1990).

Routine procedures and systems may be assumed to be appropriate when in fact they cause difficulties for many families with differing norms and values. Review meetings or negotiations with families which involve discussion of conflicting family views may, for instance, be unacceptable and uncomfortable in some cultures in the presence of non-family members or between people of different gender in relation to some issues (Baxter 1998).

An example of a creative approach to the specific needs of people from minority ethnic communities can be seen in the work of Shared Care (Bradford), which has moved away from the traditional idea that relatives should not be used as providers of short-term breaks within a statutory framework. The scheme recognises the importance of trust and familiarity to families and is open to the nomination of family members. Take-up of shared care arrangements has been very high and the scheme has been successful in recruiting large numbers of volunteer carers, particularly from South Asian communities. As yet, siblings are excluded from the scheme even if they live in separate households. However, in view of fostering guidelines which encourage the use of close family members as carers this is being reviewed. A decision to include siblings living outside the household would appear to be supported by research which shows family support is generally limited to household members (Atkin and Ahmad 2000, Chamba *et al* 1998, Mir *et al* 2000).

Insensitivity in service provision fosters stereotypes and racism. Studies indicate that services are rejected if they are insensitive to cultural difference or fail to acknowledge the need for specific provision. Carers understandably may not want to use services which put them into contact with hostile or racist staff. Such barriers may reinforce cultural values which disapprove of help being sought outside the family (Baxter *et al* 1990, Mir *et al* 2000).

Skills and attitudes

The provision of culturally sensitive services requires particular attitudes and skills within service staff. Services need to develop a sense of belonging for people from a variety of cultures so that they feel comfortable about using them (Lewis 1996). A picture of each individual with learning difficulties and their carer needs to be built up with the help of others from the same culture, as well as from family and friends. Knowledge about religious beliefs and cultural preferences can enable services to ensure that people with learning difficulties experience a range of relevant cultural events and influences (Lewis 96).

The Rainbow Project, run by the Leeds Jewish Welfare Board, highlights the importance of cultural heritage, including for former residents of a long-stay hospital who had no contact with their culture over many years (Kurtz, undated). As well as providing a lifestyle based on Jewish tradition, it offers integration into the local Jewish

community. This project is additionally unusual in that it supports people with both learning difficulties and mental health problems. At a more general level, Bradford Social Services Department has produced a policy document on the spiritual well-being of adults with a learning difficulty (Bradford SSD 1998). This sets out a set of principles which are intended to inform work with all users and includes descriptions of several religious faiths as well as guidelines concerning personal care, diet, religious observances and festivals.

Service users in various studies have identified a number of improvements which they felt would make an impact on take-up and satisfaction with services. Recurrent themes have been the need to meet dietary requirements and provide culturally appropriate activities. Carers also suggest same-sex carers for women and an increase in the number of staff from minority cultures throughout mainstream services (Azmi *et al* 1997, Baxter 1998, Begum 1995, Butt and Mirza 1996). Training in appropriate hair and skin care is of particular importance for African Caribbean people (Lewis 1996, Nothard 1993).

Physiotherapy activities such as massage, limb manipulation, dancing and swimming need to address family wishes regarding modesty and appropriate behaviour. Same-sex therapists, single-sex group activities and costumes which provide sufficient covering have all been suggested as ways of accommodating these needs (Baxter *et al* 1990). In some communities, local supported living services are desired which are near to places of worship. As visiting is a social responsibility in some cultures this requires suitable space for large groups of family members to meet their learning disabled relative in some privacy (Tait *et al* 1998). Families may, however, assume that service staff will not understand their needs: they may not be aware what options are available unless the choices are made clear to them (Lewis 1996).

Particular skills are needed in schemes that interact with a range of family structures and different priorities to avoid according primacy being given to any particular cultural or ethnic approach. Portage, for instance, is a home-visiting scheme in which parents of children with learning difficulties are trained how to teach their children particular skills and tasks. There is a need to ensure that parents understand the aims of the system and can discuss their role in their child's learning. Such schemes may need to adapt to different family structures if, for example, a grandmother is substantially involved in childcare. Adaptation of materials using sensitive written or oral translations, interpreters or, ideally, bilingual portage workers may also be necessary (Baxter *et al* 1990).

An ability to appreciate the wider context within which education takes place will also be necessary. For example, the family's ability to spend time with their child may be adversely affected by insufficient financial or practical support. Staff may be drawn into counselling, especially if parents have not fully accepted or realised the nature of their child's learning difficulty. Understanding a parent's cultural and religious values is necessary for this to be effective. An individually-based, as well as wider, knowledge is important so that assumptions about people from certain communities are not based on stereotypes or generalisations.

The level of contact outside their own ethnic group affects the perceptions and lifestyles of different generations. Efforts made within families and community groups to preserve their culture enable values, say in relation to family obligation, to be continued; however, norms of behaviour and different roles within the family are likely to be affected by the effects of a nuclear family structure (Ahmad and Atkin 1996). It is important that services address the range of influences that may exist within community groups. For example, although South Asian communities may retain many features of a collectivist community, the process and effects of migration have altered a number of cultural norms and second and third generation South Asians may have very different attitudes from their predecessors (Ahmad and Atkin 1996).

Perceptions of disability and of services may differ between minority ethnic communities. Chinese families in one study believed services were for people who are unable to cope financially: use of services thus indicated poverty and this perception acted as a disincentive to take-up (Nothard 1993). Confidentiality must also be given a high profile in close-knit communities where staff may be from within the same community (Baxter *et al* 1990).

Appropriate skills and attitudes have most commonly been found within services run by and for people from particular communities themselves. The Jewish Welfare Board provides a service which includes residential accommodation, meals on wheels and other services sensitive to Jewish needs (Nothard 1993). Accommodation used for short-term breaks was seen by residents as home-from-home: this sense of belonging reduced stress and anxiety for carers and increased take-up.

Our own fieldwork found that the best examples of culturally sensitive services were staffed and organised by members of minority ethnic communities themselves. Activities such as swimming and family outings took account of the need for single-gender sessions and acceptable environments. Family norms were thus given a high

priority and there was a strong sense of involvement and control by group members.

Cultural sensitivity is only one element of quality in service provision. A number of people we interviewed placed an emphasis on the need for well-resourced schemes offering a variety of activities and opportunities. What was actually being provided was more important than who was providing it. The schemes described above offered a variety of activities but were subject to cuts in funding which limited the activities they could offer as well as the ability to build on previous work. In one project, the withdrawal of funding for outings after a year, for example, resulted in the loss of regular contact with many families of disabled children, which had taken around six months to develop.

An emphasis on overall quality rather than exclusively on cultural sensitivity has been highlighted in relation to 'same-race' policies on short-term placements. Although many schemes operate such a policy to ensure cultural and religious needs are followed through, this has to be balanced against the need for staff and providers of short-term breaks who understand the range of needs of people with learning difficulties (Baxter *et al* 1990).

Staff and training

The availability of minority ethnic staff helps to improve access to services and users' and carers' ability to make informed choices; they can also advise service organisations on appropriate policy and practice to meet users' needs. However, numbers of minority ethnic staff are often low, with numbers of managers being even lower (Butt and Mirza 1996, Hatton *et al* 1998, Lewis 1996). At the same time, some minority ethnic groups, such as African Caribbean workers, are over-represented in day care and residential units but under-represented in community services (Lewis 1996; CVS 1998).

Appropriate publicity is needed to attract workers to health and social care work and to ensure their proportional representation (Baxter *et al* 1990, Emerson and Hatton 1998). While qualifications and the opportunity for training are essential ingredients in a quality service (DH 2000a), strict adherence to qualification requirements at entry can impede the appointment of appropriate staff (Ganguly 1995). The lack of minority ethnic staff in such settings sends negative messages to staff and service users alike about the status of people from minority ethnic communities within the organisation (Azmi *et al* 1996a, Baxter *et al* 1990).

Interpreters are often employed on low grades and on short-term contracts. Many are dissatisfied with their role and feel neither recognised nor valued, receiving little training or support. Counsellors complain of being assigned all the minority ethnic clients even when the number of counsellors is low (Azmi *et al* 1997). Professionals we spoke to complained about the lack of career development they face and the enormous range of work which they are expected to take on. The majority of staff were on part-time, insecure contracts, yet were involved in work which required long hours and long-term development. It is essential that such staff can establish their credibility with clients; however, low status can work against this relationship.

Staff from minority communities are often treated both as experts and troublemakers. As 'experts', they are often consulted on any issues relating to minority ethnic service users. Acting as advocates for the person with learning difficulties may result in their being seen as 'troublemakers': this can bring them into conflict with managers as well as with other colleagues (Baxter 1998). Staff may also feel under pressure from their own communities and feel responsible if users or carers cause difficulties for other staff. One person we spoke to said she felt it reflected on herself when carers let service staff down by not ringing to say they did not need transport. This person felt caught between the different expectations of her colleagues and carers from her own community. Appropriate support is not always available, nor is there training to equip staff with the skills needed in such a situation (Baxter 1998). One possibility is to establish minority ethnic workers' support groups, as has been the case in Leicestershire; in that instance, the group was also consulted on major policy issues (Lewis 1996).

A further issue relates to the shortage of volunteers from minority ethnic communities. One advocacy group which had made a sustained effort to recruit minority ethnic advocates held an open day but found that this attracted workers who were already employed in the field of disability and who wanted to find out more about the project rather than volunteer their services. Another South Asian interviewee complained that people from her own community were not willing to give the time and effort required to volunteer as befrienders or advocates.

The shortage of volunteers from these communities may be related to inappropriate publicity: the advocacy scheme mentioned above intended to try again targeting college and university locations to recruit young South Asian women students as volunteer advocates. However, there may be other factors which deter volunteers, related to the ability and motivation to volunteer. Atkinson (1999) points

out that lack of funding is a barrier to the recruitment of advocates and that secure funding makes it possible to invest in training, support and payment. Payment for such services and accredited training may be particularly important for people from disadvantaged communities, who face greater barriers to employment and education. The skills that such volunteers could bring to organisations are often central to the success of work envisaged with these communities, which cannot effectively be carried out without them. Such a pivotal role may need special resourcing to ensure that it is carried out.

At the same time, it should not be assumed that families will necessarily want support from someone from their own community. Some of the professionals we interviewed pointed out that families may prefer White advocates, for example, as this may feel less intrusive and they may wish to keep some distance between themselves and the professionals with whom they have contact. White professionals need to be aware of their own prejudices, however, and these can be particularly damaging in the dynamics of inter-racial work.

Racism and material or social disadvantage affecting families must be appreciated if service professionals are to provide an effective service (Baxter *et al* 1990). In education, anti-racist principles continue to be important in curriculum development and general school ethos to avoid stereotyping and low expectations (Mason 2000). Educational experiences play an important part in helping young disabled people to develop and achieve their ambitions (Bignall and Butt 2000). An anti-racist approach requires specific staff training and the permeation of a multi-racial perspective throughout the educational establishment and curriculum (Baxter *et al* 1990).

Many professionals currently feel ill-equipped to respond to people from a different culture and often rely on specialist workers who share the same linguistic and cultural background (Atkin and Ahmad 2000, Mir *et al* 2000). Minority ethnic professionals play a vital role in enabling access to services for many families; however, studies have recommended that all professionals should increase their competence in this area by improving their awareness of the cultural backgrounds of the population they serve (Acheson 1998, Chamba *et al* 1999, Hatton *et al* 1998). This would also have positive consequences for minority ethnic staff. A culture of joint responsibility towards non-English speaking service users could prevent them, and bilingual staff members, from being marginalised within service organisations. It would also ensure that both staff and users have access to the whole range of opportunities that are available (Ahmad *et al.* 1998).

All staff within service organisations need training on how to achieve equity in service delivery (Azmi *et al* 1996a, Baxter 1998, Bignall and Butt 2000, CVS 1998, Lewis 1996). Areas specified for staff development have included:

- increased awareness of organisational policies on anti-racist practice and how these are to be implemented
- dealing with racial harassment
- training in language issues for relevant staff, which would include the training needs of interpreters and of staff who work with them
- opportunities and training for minority ethnic staff to gain qualifications and move into more senior positions
- cultural competence training, including an awareness of conceptual differences and the skills to deliver appropriate services.

Funding and resources

Cuts in resources have affected the level of provision for people in minority communities. The location and quality of services are also affected by funding shortages. Insufficient resource allocations often mean that services aimed at improving delivery are not local to many people and do not have the resources to provide an adequate services. The high levels of stress and material disadvantage caused to individuals and families through lack of service support have been well documented (Azmi *et al* 1997, Baxter *et al* 1990, Begum 1992, Butt and Mirza 1996, Hatton 1997). There is evidence, for example, that advocacy groups for these communities have been reduced in recent years. Such groups are marginalised and are often the first to receive cuts in funding (Alexander 1999, Ward 1998). A similar picture of limited opportunities emerges in further education and training provision (Sutcliffe and West 1998).

Staff who wish to improve working practices within organisations may be thwarted by attempts to achieve economies and resistance to changes in resource allocation. Beginning with small numbers may be important in building up the reputation of a scheme within a community. However, this makes schemes more expensive to run. The drive to make public sector establishments economically accountable has resulted in either no expansion or a cut-back in services that are accorded a low priority. This leads to further rationing for vulnerable groups (Jukes and O'Shea 1998).

Himmat (the Asian women's group in Manchester, as described in the previous chapter) was an example of this kind of resourcing. The group was insecurely funded despite its successful activity over a period of six years. Initial funding by Social Services was cut and taken over by the Education Department but funding which had been provided to arrange outings for families and carers was no longer available and the substantial work put into gradually increasing women's confidence through such activities was brought to an abrupt end. The inadequacy of funding was compounded by the lack of similar groups elsewhere, which meant that, despite having a local remit, the group felt obliged to allow carers from much further afield to join, thus spreading the available resources even more thinly. Cuts in other services, such as the number of social workers and the closure of homes providing short-term breaks, also had a serious impact on the support available to members of the group. The insecurity created by cuts and threats to funding caused difficulties for staff running the group. Although the project needed time to build up confidence with carers, the regular threat of closure meant that it was difficult for carers to perceive the group as something on which they could rely for support.

Another advocacy group received funding from a variety of charitable and statutory sources. The South Asian worker they employed had sessional funding for only one year and the general insecurity meant that the successful work she had embarked on could be ended at short notice with the loss of much valuable expertise which had been built up.

The general picture which emerges is of small-scale projects addressing wide-ranging areas of unmet need but run on tight budgets. It is perhaps not surprising that competition between groups from different minority ethnic communities exist over funding and we found instances where relationships between them had broken down as a result. The situation encourages a sense of unfairness in funding allocations and communities may blame each other rather than the fact that there is insufficient funding overall.

Even schemes run by statutory organisations, and which are working well, may struggle with finances. One large local authority scheme which has been evaluated as an example of good practice (Prewett 1999) works well for minority ethnic families but has a disincentive to pay more than minimum expenses to volunteer carers as this would then mean fewer families receive short-term breaks. However, there is a constant threat of closure hanging over such work, implying low priority and poor status with funding bodies.

Current resource allocations need to be reviewed in order to meet the service needs of individuals with learning difficulties from minority groups and their carers. Budgets should reflect local demographic profiles and allow for resources to undertake ethnic monitoring of service use, employment of minority ethnic staff and training relevant to achieving improved services (Hatton *et al.* 1997, Tait *et al.* 1998).

In addition, procedures for the allocation of funds need to be more flexible if they are to encompass the services needed. Non-traditional purchasing sources may need to be considered, for instance, to cater for different diets or to produce appropriate publicity. The pooling of budgets, as outlined in the Health Act 1999 and NHS Plan (DH 2000b,c), should, for its part, provide a mechanism to ensure the better co-ordination of services.

Specialisation or integration?

It has been suggested that a concern for emphasising differences in the experience of minority ethnic communities is a reaction to the imposition of White culture as the norm within service provision (Priestley 1995). In our fieldwork, we found that professionals working in the field of learning difficulties recognised that within mainstream services a lack of awareness of, or focus on, different cultural values could prevent attention being paid to diversity in the needs of service users. Staff attitudes could be patronising or hostile to change. The views of people from disadvantaged groups were likely to be overshadowed by the majority views because they were a minority and might have more difficulty expressing their opinions as a result of power differentials and the inability of services to include non-speakers of English.

However, some members of minority ethnic communities preferred a more cross-cultural environment or were untroubled by who ran the service so long as it was there. Integrated services for people with learning difficulties, regardless of their ethnic origin, offer a number of benefits: mainstream services are generally better funded with a long-term future to enable the development of staff expertise and user confidence. Perhaps most importantly, responsibility towards service users then remains within mainstream structures and is not delegated to under-resourced and marginalised projects. In addition, the focus remains on the quality of the service provided rather than on the ethnicity of users: services that address each person's individual needs would enable the same high standard of provision to be available to everyone.

These are service ideals which are not always achieved. Structural power differences remain and are exacerbated by the absence of people from minority ethnic groups at the higher levels of organisational hierarchies where decisions about service provision are made. Consequently the needs of people from these groups may be inadequately met.

One advocacy organisation which assisted a number of Jewish service users noted that, although the ideal might be to provide an integrated service for all people with learning difficulties, whether this was practical was another question. It pointed out that Jewish beliefs and culture do not fit neatly into a culture which is determined by the majority group in the UK. Separate groups and organisations may be preferred by users because they are better able to provide appropriate facilities.

Provision based on specific ethnic or cultural identity can serve a number of purposes. Such groups provide a chance to socialise with others and reduce isolation. They feel more welcoming for members than some events organised by White groups, which could exclude people by failing to consider their needs (Black People First 1994, Priestley 1995). For some groups this may become the primary focus of their membership and may be more important than whether members do or do not have a learning difficulty.

Specialist services meet the immediate needs of hard-pressed families by providing easier access to support and a voice in the type of provision offered. Control over the delivery of services and an innate appreciation of underlying values and cultural requirements enable minority ethnic communities to reinforce and maintain the cultural and religious identity which many consider a priority. The particular strengths and approaches of specialist organisations are often not recognised by mainstream provision (Tait *et al* 1998). However, these probably provide the best examples of the principles which need to be incorporated into integrated services if they are to be effective.

Many people involved in community groups feel there is a continuing need for specialist services for people from particular minority ethnic communities alongside improvements in general service provision. Integrated services for all people with learning difficulties are seen as a long-term aim which would not be possible without great improvements in mainstream services. Even so, there may still remain a need for specialist services which could provide access for particular groups, particularly those who are most under-represented in mainstream services. Some people may always feel a need for specific services which would reinforce personal identity and provide a familiar and safe setting. In such cases, targeted

services could provide a more acceptable focus than would be likely in a more integrated setting.

At the same time, groups which are based on cultural and ethnic identity enable members to become involved in campaigning and to challenge inequity in services, whether voluntary or statutory. In the face of external hostility and concerns about institutional racism, members of ethnic groups may become more insular but such challenges also foster identity formation (Ahmad and Atkin 1996). 'Culture' can become a means of constructing a 'positive collective identity' (Priestley 1995). In our fieldwork we found that African Caribbean groups emphasised ethnicity as the most important aspect of group identity, whereas South Asian groups placed more emphasis on having a common language and culture.

The debate about specialist or integrated services echoes wider debates relating to disability and to ethnicity. One worker drew a parallel with specific services for learning difficulties and more general disability services:

On disability issues the learning disabilities are always forgotten, always at the bottom of the agenda ... the need is for their own services so they are actually empowered in a way, so they feel comfortable to say things ... I think [people from minority ethnic communities] would be marginalised, being from ethnic minorities and then they are disabled, there is a double discrimination there isn't there? So I think to a certain extent there should be somewhere where they have their own space.

Similarly, an organisation that focused on advocacy for people with learning difficulties felt that generic advocacy services could not offer the same quality of service. A wider remit means that less attention can be paid to the specific needs of people with learning difficulties and that 'huge mistakes' would have been made following the closure of a residential institution if a specialist service had not been available. The parallel with specific and generic services for disabled people is an important one. If separate groups and facilities are seen as necessary to an adequate service for different types of impairment, the same justification may be used for an extra layer of provision relating to ethnicity.

Debates about the recognition of diversity have also taken place in the field of ethnicity. Proponents for the use of 'black' as a self-definition of all minority ethnic groups have argued that the common experience of racism ought to lead to a common identity. A lack of differentiation between groups has been promoted as a means of mobilising support and enabling greater resistance to

discrimination: this echoes the debate around the social model of disability, which focuses on disability as a whole and not the implications of particular impairments. The more recent sociological literature on ethnicity, however, accepts the benefits of recognising the diversity of cultural identities within the UK and the different ways in which racism may be experienced (Mason 2000, Modood 1995).

During fieldwork we found different attitudes towards the question of specialist or integrated services. Service providers within mainstream services sometimes felt that, as a matter of policy, integrated services must be pursued. This was, however, a statement of principle rather than a view based on the wishes of service users themselves. Amongst people with learning difficulties and carers, both kinds of provision were valued and strong views were expressed in favour of each. Specialist services were felt to be easily accessible and to offer familiar, appropriate and comfortable environments. Integrated services, on the other hand, could offer wider opportunities and the ability to meet a wider range of people. The problems with both types of service were recognised. People with learning difficulties complained of not being listened to, and of experiencing racism in mainstream services. Carers felt they had little access to services or information that would help them; appropriate facilities with which they felt comfortable were not provided and staff with the necessary skills to communicate and involve them were also often not available.

Tait *et al.* (1998) found that South Asian people in Leicester wanted an integrated service, not a specialist one. Other studies have found positive responses to specialist services (Butt and Mirza 1996, CVS 1998). The key issue is the quality of the services available. Where inclusive services are sensitive to cultural and religious needs, there will be no need for specialist services. For that to occur, mainstream services and organisations need to address their shortcomings, whether or not specialist provision exists, in order to remove racist and insensitive practices and attitudes from provision. At the same time, recognition and resources will be needed to enable separate provision where this provides a more effective service. The need for specialist services will remain to a greater or lesser extent so long as they represent the only available means of addressing issues of identity and access for people from minority ethnic communities. Decisions about the extent and nature of any specialist services need to be made at a local level in consultation with service users and carers.

Key points

- Support groups for minority ethnic carers and people with learning difficulties can act as gateways to a range of support services. Outreach is needed to include those who cannot attend groups. A variety of activities and appropriate publicity are needed to increase awareness of service provision within minority ethnic communities.
- More bilingual staff and interpreters are needed to improve communication and access to services. Recruitment of minority ethnic staff is needed at all levels in service organisations, with adequate support and training to help them perform their roles. Training for all staff is needed to improve competence in cultural awareness and prevent the marginalisation of minority needs. Cultural sensitivity and a level of continuity between home and other environments enable the greater involvement of people from minority ethnic communities and encourage the take-up of provision.
- Service providers need accurate and ongoing information from and about minority ethnic communities to meet their needs adequately. Monitoring procedures are currently insufficiently able to identify unmet need, general patterns of use or comparative service performance.
- Integrated services are likely to be better resourced and given a higher priority than specialist services. Although the ideal is a quality mainstream service that is sensitive to the needs of all users, the cultural needs of some minority ethnic service users are currently more likely to be met in specialist provision, though this is generally under-resourced and insecure. Decisions about the extent and nature of services should be made at a local level in consultation with service users and informal carers. Specialist services do not eliminate the need to remove racist practices and attitudes from mainstream provision and to develop accessible and appropriate integrated services that will meet the needs of all members of the community.

CHAPTER FOUR

CONCLUSIONS

People from minority ethnic communities who have learning difficulties currently experience a wide range of problems. This report has shown, however, that those problems are not insurmountable and initiatives do exist which seek to meet their needs, and those of their carers, more appropriately. The key features of those initiatives can be summarised as empowerment for communities and empowerment for individuals.

Empowerment for communities

A specific focus is needed, first, on the needs of people from minority ethnic communities. This calls for policies which commit organisations to recognising and addressing those needs. It is not enough to assume that this will occur if greater attention is paid to the needs of people with learning difficulties as a whole: people from minority ethnic communities have been badly served to date and there is no reason to believe that this will not continue in the future, unless specific action is taken to cater for their needs. In order to develop appropriate policies, partnership with communities is essential – whether users' groups, carers' organisations or wider community networks. Only such bodies will fully understand the specific needs of members of their community and the extent to which mainstream practices may fail to address those needs. This report has highlighted the dangers of stereotyped views by people from other backgrounds and the difficulties associated with the principles that currently underpin service development and provision. It also emphasises the central importance of appreciating that cultural values and ethnic background are central features of every individual's personal heritage and identity which cannot be subjected to policies which seek to standardise experiences and values: any such policies will only be perceived as irrelevant, basic human needs will remain unmet and divisions within society will only grow wider. Only by enabling communities to identify needs and design policies alongside statutory agencies will it be possible to ensure that the needs of all people with learning difficulties can be met more appropriately.

Specific operational practices need to be put in place to ensure that issues such as racism and ethnic and cultural diversity can be addressed. Those practices are likely to be wide-ranging: they will need to be taken on board by all members of an organisation but they will also be applicable in relation to all service users, from whatever background. Crucially, they will highlight diversity rather than deviation from any supposed 'norm'.

In identifying need, providing appropriate services and facilitating access to those services, it is vital to employ minority ethnic staff who understand the values and concerns of particular communities and who can communicate effectively with members of those communities. As we have shown, this does not mean that such staff should necessarily be solely responsible for such work: people from different communities are likely to require a wide range of services, both specialist and mainstream, and all staff need to possess sufficient understanding of their various needs in order to provide a service for the community as a whole: there is, otherwise, a danger of ghettoisation within services. Equally importantly, minority ethnic staff should not be confined to simply working with minority ethnic users – this form of ghettoisation is common and rarely serves the employing organisation, the workers or service users well (Ahmad *et al.* 1998). Nor should professional staff from minority ethnic backgrounds be expected to interpret for others: language needs have to be met appropriately through the ready availability of staff who understand the service area in question and can genuinely act as liaison workers, communicating for both service users and service providers without fear of jeopardising their own position with regard to either.

Empowerment for individuals

Several approaches exist which can facilitate the empowerment of individuals. Advocacy and self-advocacy projects that work with people from minority ethnic communities are currently few and far between – and sometimes unavailable even in areas with large minority ethnic populations. However, they offer an important means of supporting individuals to seek and access services that are relevant to their particular needs. Individuals need to know where to obtain help when they need it and statutory mainstream services may not always be the easiest to approach. The advantage of specialist advocacy organisations is that they can provide support to individuals to lead lives that they themselves find satisfactory and that are also integrated into the cultural values and practices of the individuals' own communities.

The same principles apply in contacts between professional staff and service users. Listening, offering choices and tailoring options to individuals' needs are key features of any assessment process and design of support packages. For users from different ethnic backgrounds, there is the additional issue of understanding those backgrounds and different cultural needs. Training is certainly a prerequisite, but consultation with other community members is likely to be needed as well in order to explore the nature and implications of people's cultural heritage: in doing so, it is important to take account of the views of people of, say, a similar age-group to the potential service user as well as community elders. As with any person with learning difficulties, consultation with other family members is likely to be a prerequisite but, again, more so when roles within family and community networks are different from those of the professional's own community.

Access to information, similarly, is crucial for any potential service user or carer. Such information needs to be readily available, in an appropriate format (with culturally appropriate illustrations), in appropriate and accessible locations, and with opportunities for discussion at a pace that can ensure it can be put to good use. Knowledge about service options is currently poor and individuals may feel obliged to accept second- or third-rate alternatives simply because the range of possibilities has not been fully laid out. If an aim of services is to enhance the life-chances and develop the potential of all people with learning difficulties and promote empowerment, it is essential that appropriate and accessible information should be available. As with families from the majority community, having a single point of contact for a range of services is an important starting-point, as is the availability of a key worker. However, all services will need to be responsive to individual needs: specialist support may not be available to assist with all the contacts that an individual may have with services.

A better knowledge base

Ethnic minority organisations increasingly complain that the needs of their communities have been well documented for some time, yet little has been done to address their needs. This is as true of the field of learning difficulties as elsewhere. This report has, accordingly, sought to identify not just the problems and needs, which are many, but also the ways in which those needs are being met around the country, albeit often in small ways and for small numbers of people. We do not pretend that the same solutions can be applied in all areas, but some of the underlying approaches do provide a basis for better services, given sufficient political will and commitment.

There do, nonetheless, remain gaps in our knowledge. As noted earlier, the literature focuses on people from South Asian communities. Less is known about the needs of those of, for instance, African, African Caribbean, Chinese, Irish, Jewish or traveller backgrounds. Where numbers are small or language needs are not an issue, there is frequently an assumption that little need needs to be taken of cultural or identity issues. People to whom we spoke would dispute this. The needs of women with learning difficulties often receive little specific attention generally. But what does it mean to be a woman with learning difficulties from a minority ethnic community, and how might her needs be addressed more appropriately? What are the specific needs of the substantial number of people who have both learning difficulties and mental health problems? We were unable to identify any research or specialists in this area, as related to people from minority ethnic backgrounds.

Underpinning the need for better knowledge is the need for more information on the views of minority ethnic people with learning difficulties themselves. We cannot make assumptions on the basis of information from other family members, communities, service planners and providers with specialist knowledge, about the needs or wishes of people with learning difficulties from minority ethnic groups. As part of the ongoing emphasis on user involvement, empowerment and participation in the research process, service users must be enabled to shape and inform services and research if these are to be relevant to their needs. Their views will, moreover, be part of a constantly changing picture that reflects the different views of different generations with different cultural attachments. Listening is a continuing process and an essential one if needs are to be met and the quality of services is to be assured for all members of the community.

APPENDIX

METHODOLOGY

Literature review

Literature was identified using the BIDS, Department of Health, HELMIS and King's Fund databases. Information about additional material was provided by other organisations and individuals that we contacted.

Interviews

Face-to-face and telephone discussions were held with users' groups, carers' organisations, service providers and researchers. They included:

African Caribbean Project, Relatives Association, London

Asian Disability Joint Planning Team, Bradford

Asian People with Disabilities Alliance, London

Barnardo's Queens Road Project, Bradford

Bibini Centre, Manchester

Birmingham Social Services Department

Birmingham Specialist Community Health Trust

Black Community Disability Project, Sheffield

Black People First, Swindon

Bradford Community Health Trust

Bradford People First

Bradford Social Services Department

Bristol Social Services Department

British Institute of Learning Disabilities, Kidderminster

CHANGE, London

CHOICE, London

Department of Sociological Studies, University of Sheffield

Disability Research Unit, University of Leeds

Ethnic Minority Children with Learning Disabilities Project,
Huddersfield NHS Trust
Hester Adrian Research Centre, University of Manchester
Himmat Asian Women's Carers Group, Manchester
Institute for Health Research, University of Lancaster
The Judith Trust, London
Justajoo Asian Women's Group, Bradford
Leeds Citizen Advocacy
Mary Seacole Research Centre, de Montfort University, Leicester
NAZ Project, London
National Development Team, Manchester
National Institute for Adult and Continuing Education, Leicester
Norah Fry Research Centre, University of Bristol
Norwood Ravenswood, London
Parents' group, Bradford
Parvaaz Project, Berkshire
People First, Bristol
People First, Lambeth
Race Equality Unit, London
Services for All Project, ARC, Chesterfield
Shared Care, Bradford
Sharing Care, Leeds
Sheffield Citizen Advocacy
Special Parenting Service, Truro
Speech and Language Therapy Services, Dewsbury Community
Health Trust
Students at a Further Education College
Values into Action, London

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