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**RIHSC Research Reports and Occasional Papers:  
Number 06/04**

**Responsive Services  
For Learning Disabled People  
From Minority Ethnic Communities**

**Samantha Starling, Sue Caton, Mark Burton  
Sabiha Azmi, Melanie Chapman**

**May 2004**

Responsive Services For Learning  
Disabled People From Minority Ethnic Communities  
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RIHSC Research Reports and Occasional Papers

Published occasionally by the RIHSC: Research Institute for Health and Social Change

For information contact the publishers at the address below

ISSN 1-359-9089

ISBN 1-900139-86-3

Printed by the Manchester Metropolitan University

**RIHSC: Research Institute for Health and Social Change:**

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## **Acknowledgements**

The authors would like to thank the North West Valuing People Support Team for help with identifying participants. We would also like to thank the participants for taking the time to complete our questionnaire.

## Summary

**Background:** An increasing body of research suggests that, despite prevalence rates of learning disability among minority ethnic communities being similar to or greater than prevalence rates among majority ethnic communities, learning disabled people from minority ethnic communities and their families are particularly disadvantaged. They often have very high support needs yet their uptake of services, which often fail to take people's ethnic, cultural or religious needs into account, is low. Recent policy initiatives emphasise the importance of improving services for learning disabled people from minority ethnic communities. This study focuses on service delivery within the North West Region of the UK and reviews the impact of the recommendations from existing studies on current service responsiveness to the needs of learning disabled people from minority ethnic communities and their carers.

**Methods:** A postal questionnaire was sent out to learning disability service commissioners, service providers and other non-service provision organisations (including advocacy, consultancy, organisational development, advice, training, policy development and implementation) in the North West region. Fixed-choice questions were used to gather demographic information about the general population resident in the area covered by each service, about the people who use the service and specifically about people who use the service from minority ethnic communities. Open-ended questions were used to obtain details of any specific policies, procedures or practices, regarding meeting the needs of people from minority ethnic communities. The quantitative data was presented as tabulations and frequencies. The information from the open-ended questions was analysed by two researchers reading and re-reading the responses and grouping them into themes.

**Results:** Qualitative results indicated that service providers and commissioners were influenced by legislation and guidelines. These regulations play a role in services developing more focused, local services where staff teams or specific programmes aim to meet the needs of learning disabled people from ethnic minority communities. Organisational culture also played a large role in how services respond. An important theme was the regularity of respondents stating that new services were currently being developed. New services were commonly initiated by both families of learning disabled people and by dissatisfaction amongst service staff. Individual staff members and good organisational support were most cited as the factors that facilitate effective policies/practices/procedures. Problems regarding funding were most frequently cited as barriers to effective policies/practices/procedures.

**Discussion:** The respondents detailed evidence of some work being carried out at grass root level. Unfortunately, the responses very much indicate marginalisation as a core theme. It is important to ensure that it is a mainstream issue, so that every aspect of service development aims to meet the needs of people from minority ethnic communities. Indeed, there needs to be a greater recognition of ensuring that there should be a commitment to long term funding for sustainable projects within service development.

## **Section A. Introduction**

This report describes a postal questionnaire survey carried out to explore the responsiveness and appropriateness of services for learning disabled people from minority ethnic communities within the North West. The report summarises the existing research and ideas for improvement of services, the study methods and findings. Implications for service provision are then discussed.

### **Background**

The UK population is becoming increasingly diverse in terms of ethnicity, culture, language, and religion, and this increasing diversification is predicted to continue (Hatton, 2002). Broad population projections combined with the 1991 Census data suggest that the non-White population of the UK will increase from 5% in 1991 to 8% in 2021 (Emerson & Hatton, 1999). The largest ethnic minority group in the UK is made up of British citizens of South Asian origin (populations originating from India, Pakistan and Bangladesh) and this group constituted 4% of the UK population, 2 million people, in 2001 (Hatton et al 2003).

An increasing body of research suggests that, prevalence rates of learning disability among minority ethnic communities are similar to or greater than prevalence rates among majority ethnic communities (Hatton, 2002). Predictions suggest a steady growth in the population of learning disabled people from all minority ethnic groups both in absolute numbers and in proportion to the general population (Emerson & Hatton, 1999). Current epidemiological trends suggest a projected 70% increase in the number of non-White learning disabled people between 1991 and 2021 compared to an increase of only 3% in the White learning disabled population (Emerson & Hatton, 1999). It is predicted that by 2021, one in ten of all learning disabled people in the UK will belong to a non-White minority ethnic group (Emerson & Hatton, 1999).

A number of explanations for such higher prevalence rates of learning disability among minority ethnic groups have been suggested including: material/economic disadvantage (Baxter et al 1990), differences in health and in access to health care services (Hatton, 2002; Baxter et al, 1990; Atkin & Ahmed, 1998 in Mir et al) and consanguineous (first cousin) marriages. However, there has been little research investigating consanguinity and Mir et al (2001) argue that misinformation and bias concerning consanguineous marriages as a cause of impairment may affect professional practice adversely and alienate families, leading to low uptake of genetic counselling services.

Despite such high prevalence rates, studies suggest that learning disabled people from minority ethnic communities and their families are particularly disadvantaged. They often have very high support needs yet their uptake of services is low. Services often fail to take people's ethnic, cultural or religious needs into account (Ladyman, 2004; Hatton, 2002; Mir et al, 2001; Azmi et al, 1996; Shah, 1992; Baxter et al, 1990).

Recent policy initiatives recognise that the needs of learning disabled people from minority ethnic communities and their carers are often overlooked and emphasise the

importance of improving services for this group (Valuing People Support Team/DH, 2004; Mir et al, 2001; DoH, 2001). *Valuing People* (DoH, 2001) argues that people from minority ethnic communities experience barriers to services disproportionately to those not from minority ethnic communities, facing “insensitivity to issues of culture and language and false assumptions about communities wishing to provide care within their own family environment or putting up barriers against statutory agencies” (Section 5.12). *Valuing People* points to the need for Councils to identify service users and carers from minority ethnic communities and for the NHS to provide services that do not discriminate against minority ethnic communities in order not to violate Race Discrimination legislation.

Hatton (2002) summarises the literature to date including a three-phase study by the Hester Adrian Research Centre (HARC) in two Metropolitan Boroughs in the North West of England where the Asian community constituted the largest minority ethnic group (Azmi et al, 1996a, b, c). The findings suggest that such issues are particularly relevant in the North West region.

The local research, national policy initiatives and existing research literature suggests that a number of improvements need to be made in the areas of:

- a) Staff recruitment, retainment and development, equal opportunities and anti-racist policy
- b) Increasing service responsiveness to cultural and linguistic needs for both learning disabled people and carers from minority ethnic communities.

#### **a) Staff recruitment, retainment and development**

Azmi et al (1996) concluded from the findings of phase one that: employing staff who can communicate with people who do not speak English and who can relate to their cultural background can and does result in a significant uptake of services; services successful in recruiting staff from minority ethnic communities used alternative methods of advertising; anti-racist education for people who use services was seen as low priority, and services perceived race as a black responsibility. Phase one also concluded that staff from minority ethnic communities were seen as “race experts” when in fact had the same training as white colleagues, were often recruited as specialist workers, mostly on temporary contracts with no clear next career step, were exploited to perform additional work for which they were not trained, worked under unclear job descriptions, received inadequate training and poor salaries, had no career structures or access to decision making, and were often made to feel as though their religious and cultural requirements were a privilege.

Suggested means of increasing equal opportunities and reducing racism include training for all staff in order to improve competence in cultural awareness and to prevent the marginalisation of minority needs.

A number of checklists have also been developed to improve practice with regard to recruitment, ethnic monitoring, equal opportunities and anti-racist policy, staff development and support, and challenging racism (Azmi et al, 1996; Baxter et al 1990; Shah, 1992; Akram et al, 1998 and Evans & Banton, 2001).



## **b) Service provision for learning disabled people and carers from minority ethnic communities**

Several studies have explored the circumstances, resources and needs of families from minority ethnic communities with a learning disabled person with the majority focusing on people from South Asian communities. In the North West, Azmi et al (1996) interviewed 54 carers of learning disabled Asians aged fourteen or over regarding family circumstances, service supports and levels of stress, and case studies based on the lives of 14 carers were completed. 21 learning disabled Asians aged 14 or over were also interviewed.

The findings from this study corroborate those from other studies including studies of other minority ethnic communities (Baxter et al, 1990; Shah, 1992 & 1998; McGrother et al, 2002; Evans & Banton, 2001.) (See Mir et al, 2001, Hatton et al, 2002, and Hatton, 2002 for reviews of the existing literature.) These studies suggest that:

- Black and Asian carers report low awareness and uptake of specialist services for learning disabled people and that existing services ignore their cultural and religious needs. Many black and Asian carers feel that white service providers use stereotypes about extended families as an excuse not to provide services.
- Almost all learning disabled Asian adults live with their families and have high support needs.
- Almost all main carers are mothers who cannot communicate in English.
- Asian families experience considerable material disadvantage.
- Asian families have little or no extended family networks.
- Significant numbers of Asian families are headed by a single parent and contain more than one learning disabled person.
- Wealthier carers who speak and write English were more likely to receive specialist services.
- Large numbers of the carers reported very serious physical and emotional health problems.
- The learning disabled Asians were found to have a positive sense of ethnic & religious identity but to face routine racism and stigma, leading to a limited social life.

Carers' ideas for improving services focus on three main areas (Azmi et al, 1996; Baxter et al, 1990; Shah, 1992; Akram et al, 1998; Emerson & Robertson, 1998; and Reading, 1999):

- Improving communication i.e. increasing carer awareness of available services through providing information in appropriate languages and formats and in places where carers would have access to them (Perepa, 2002 suggested producing audiotapes and videos in community languages and the enhanced translation of leaflets), and employing Asian/Black staff with appropriate language skills throughout mainstream services, to ensure that carers and staff could communicate without using family members as interpreters.

- Increasing cultural sensitivity i.e. employing more Asian/Black staff throughout mainstream services, appropriate diet for service users, recognition and celebration of cultural and religious festivals and special occasions, same-sex carers for Asian service users.
- Increasing the flexibility of service responses i.e. increased flexibility of domiciliary support and respite care to allow carers to meet other commitments, provision of flexible short-term adult family placement schemes with other Asian/Black families, possibly other families with a learning disabled person

An important theme for all of the recommendations was awareness of and consultation with people from the minority ethnic communities in the area that a service covers.

### **Local Implementation**

A variety of means has been used to implement the findings from research studies within service provision in the North West Region. Azmi et al (1996) sought to assist the process of change through dissemination of reports & papers, training and presentations to managers and professionals and by facilitating contacts between carers, service managers and users. It involved attempting to use the information gained to assist the process of change in two local authority areas. Strategies used included: inviting key service managers to carer group meetings, present findings to project steering group and relevant committees within services, being active participants of a Joint Commissioning Team (JCT), planning future developments in respite services and hosting a one-day national conference.

## **Study Aims and Objectives**

This study reviews progress since the previous studies were conducted (in particular the Azmi et al study) in terms of current service responsiveness to the needs of learning disabled people from minority ethnic communities and their carers. The study focuses on service delivery within the North West Region.

### *Overall aim:*

To assess responsiveness and appropriateness of services for learning disabled people from minority ethnic communities.

### *Specific objectives:*

- To gain a picture of the range of services available and of who uses the services.
- To explore the level of commissioner and provider knowledge about ethnic minority users of services.
- To identify any specific policies, procedures or practices regarding meeting the needs of learning disabled people from minority ethnic communities, and what has made these effective / ineffective.
- To compare the findings of the present study with the recommendations of the HARC studies (1996).
- To make conclusions and recommendations for service commissioners and providers.

## **Section B. Methods**

### **Sample Selection**

The North West Valuing People Support Team provided a database containing contact details for a total of 98 learning disability service commissioners, service providers and other non-service provision organisations (including advocacy, consultancy, organisational development, advice, training, policy development and implementation) in the North West region.

### **Data Collection**

A postal questionnaire with both fixed-choice and open-ended questions was used to collect data. The fixed-choice questions were developed using census categories and were mostly used to gather demographic information about the general population resident in the area covered by each service, about the people who use the service and specifically about people who use the service from minority ethnic communities. The open-ended questions were used to obtain details of any specific policies, procedures or practices, regarding meeting the needs of people from minority ethnic communities, and were developed using the areas for service development identified in the HARC report (Azmi et al, 1996), "Learning Difficulties and Ethnicity" (DOH, Mir et al, 2001) and in "Double Discrimination" (Baxter et al, 1990). The default option for participants was anonymity.

Initially, the questionnaire was sent out to three providers/commissioners who agreed to complete it for the pilot study. The pilot participants identified no problems with the questionnaire and therefore no changes were made prior to mailing the questionnaire out to the whole sample.

A postal reminder was sent out to respondents after four weeks and the deadline for responses extended due to the initial low response rate. An email request for further information was sent out to several of the respondents following initial analysis of the qualitative data.

### **Ethics Committee Approval**

As the project involved NHS staff from several organisations, it was necessary to obtain ethical approval from the Multi-Centre Research Ethics Committee (MREC).

### **Data Analysis**

The quantitative data was presented as tabulations and frequencies. The information from the open-ended questions was analysed by two researchers (SS and SC) reading and re-reading the responses and grouping them into themes. Broad, overarching themes were developed to organise the common themes.

## **Section C. Results**

### **Quantitative**

#### **Participants**

A total of eighteen participants (18.4% of total sample) returned completed questionnaires. Three of the respondents completed both the provider and commissioner sections of the questionnaire, making a total of 21 responses, twelve from providers and nine from commissioners.

#### **Reliability**

As the response rate was low (18.4%), with possible bias towards respondents that were doing the most with relation to this service, all figures should be treated with caution. Potential reasons for the low response rate are discussed in Section E. However consensus on emergent themes and similarity of the findings with previous studies means that results can be discussed with some degree of confidence.

#### **Validity**

In order to lend some validity to the findings, participants were required to indicate on the questionnaire, what information they based their responses on: census data, intelligent guess or other. Clear patterns emerged. For the three questions regarding general populations, the clear majority of respondents claimed to have got their information from census data, whilst the remaining minority used intelligent guesses.

For the five questions regarding the people who use the service, including people from minority ethnic communities, most respondents claimed to have obtained their information from other sources, which included: databases, data returns, provider returns, SSI monitoring returns, own statistics, internal census, audit, service records, management information, contract service information, criteria, service specification, business planning, local register, local information resource, mapping studies, research studies and knowledge of caseload. The remaining minority of respondents used intelligent guesses for their answers regarding the people who use the service.

#### **Services**

The nature of services provided or commissioned by the respondents included: health, social, residential, day, respite, domiciliary, field, advocacy, advice/support, direct payments, adult placements, befriending, media, quality, research and service development. The providers operated under the following organisations: local government (N=8), NHS (N=4), voluntary organisations (N=2) and private/commercial organisations (N=1). The majority of services were based in metropolitan authorities (N=12), whilst the others were based in either unitary (N=4) or county (N=3) authorities, and one covered more than one type of authority. The majority of services covered general population size 100,000 – 500,000 (N=16). Four respondents provided/commissioned services for less than 100 people, six for 100-499, seven for 500-999, and four for 1,000-1,999 people.

### People from Minority Ethnic Communities

The proportion of people from minority ethnic communities in the general populations covered by the services surveyed, ranged from 0.3% - 20%. Eleven (58%) respondents reported providing services for less than 25 people from ethnic minority communities, three for 25-49, three for 50-99, and two for 100-499.

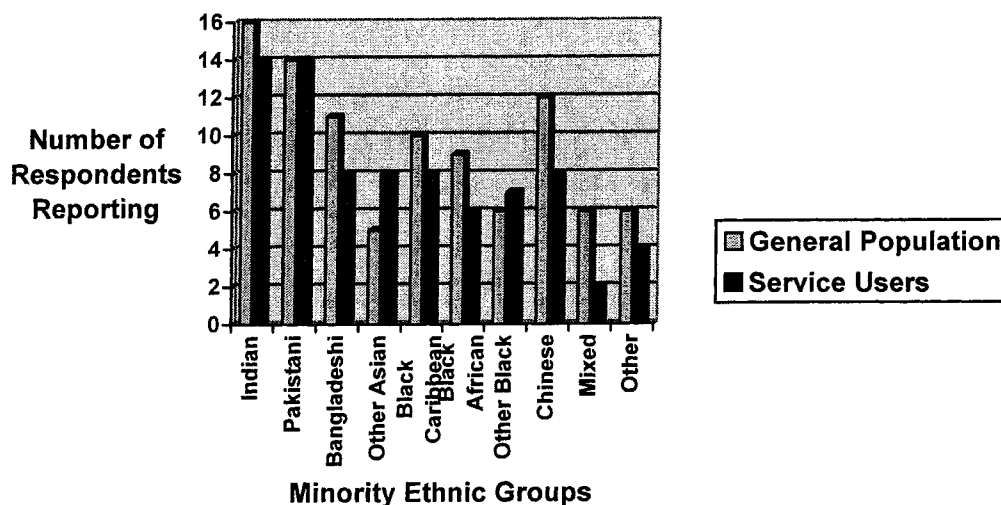
Table A and Graph A show the proportion of respondents reporting that specified minority ethnic groups are particularly represented in their locality and the proportion reporting that they have specified minority ethnic groups of service users.

Table A: Minority Ethnic Communities Represented In Each Locality And Using Services

Minority Ethnic Groups (Registrar General's Census Categories)	Number of respondents reporting minority ethnic groups particularly represented in general population.		Number of respondents reporting having service users from each minority ethnic group.	
	N (=20)	Proportion	N (=19)	Proportion
Indian	16	0.8	14	0.74
Pakistani	14	0.7	14	0.74
Bangladeshi	11	0.55	8	0.42
Other Asian	5	0.25	8	0.42
Black Caribbean	10	0.5	8	0.42
Black African	9	0.45	6	0.32
Other Black	6	0.3	7	0.37
Chinese	12	0.6	8	0.42
Mixed	6	0.3	2	0.1
Other*	6	0.3	4	0.19

\*The other groups reported included Irish, Middle Eastern, Ukrainian, Polish, Eastern European, German, Italian, Jewish and refugee communities.

**Graph A: Minority Ethnic Communities Represented in Each Locality And Using Services**



### Age Range

Table B summarises the percentage of respondents reporting providing/commissioning services for people from specified age groups and the percentage reporting providing/commissioning services for specific age groups from minority ethnic communities. It can be seen that the minority ethnic population served is predominantly below retirement age. The proportion of respondents reporting that they serve children is small because in general services for children with learning disabilities are part of generic children's services and these were not surveyed.

Table B

Age Range	Number reporting service users.		Number reporting service users from minority ethnic communities.	
	N (=21)	Proportion	N (=19)	Proportion
0-17	3	0.14	1	0.5
18-25	19	0.9	19	1
26-60	21	1	18	0.95
61 and above	17	0.81	10	0.53
All ages	3	0.14	1	0.5

### **Qualitative**

Service providers and commissioners were asked to detail any specific policies, procedures or practices that their organisations followed regarding meeting the needs of people from minority ethnic communities.

The following section headings have emerged from both the questions within the questionnaire and also themes that emerged from analysis of the data. The sections start with influences at a macro level – legislation and guidelines, and continue down to a micro level of individual programmes developed within services.

### Policy

#### *Legislation and Guidelines*

Much of the work described by respondents was governed by legislation and/or local guidelines. Specifically, respondents referred to the Race Relations Amendment Act 2000, the Disability Discrimination Act 1996, National Equality Standards, the Sex Discrimination Act, local Council's Race to Equality Scheme, Welfare to Work, Council Community Care Plan, Department Business Plan, and Joint Investment Plan\*. Interestingly no respondents referred to the Mir et al (2001) Department of Health, Learning Disabilities and Ethnicity paper. The framework for Action on Ethnicity (Valuing People Support Team, 2004) did not appear until after data collection.

Staff recruitment and retention is an example of an area mentioned by respondents where legislation and guidelines must be followed. In addition to the above legislation, respondents mentioned that all advertisements for new staff follow custom and practice for each local authority, and that there are targets to employ

minority ethnic staff across all spheres - provisions, managerial, and strategic. These targets to increase numbers of staff from minority ethnic communities were mentioned by most respondents. However, while the Race Relations Act (2000) allows employers to recruit on the basis of ethnicity if this is necessary for the performance of the duties of the job, this was not specifically mentioned by any respondents.

### Organisational Culture

Following on from the macro level of influence, organisational culture also plays a part in how services respond to the needs of learning disabled people from minority ethnic communities. Many of the respondents stated that their services as a whole aimed to provide a genuine service to all of their clients. Providers reported that work with learning disabled people, families, parents and carers was often not governed by policy, but was part of the culture of the organisation. Indeed, one respondent used the term, "No policy but part of culture". This was often the case, whereby, it was a general acceptance that equality issues were important, but that there was not a specific policy in place and hence no framework for monitoring and evaluating the outcome.

An example of how 'no policy but part of culture' operates can be seen in terms of recruitment of staff. One respondent referred to the fact that they aimed to recruit from the local area, which leads to a roughly equal number of applicants from a similar background to their client group.

More generally, many providers responded that their organisations were committed to person centred planning (Sanderson et al, 1998) and the individual assessment of need within person centred planning took account of cultural differences which achieved many of their organisations aims with regard cultural sensitivity. Broad gender specific provision was also referred to in this category. Commissioners who responded to the questionnaire referred to both country wide and local PCT anti-discriminatory policies that cover the need to be aware and responsive to needs and to develop a commissioning response appropriate to meeting the specific needs of people from minority ethnic communities.

### *Awareness raising*

Respondents were asked to consider aspects of access and awareness such as publicity, referrals, and monitoring unmet need. Responses to this generally referred to organisational culture. For instance, providers responded that access and awareness were developed through word of mouth in the local community. In addition to this there were more specific programmes that had been developed to increase awareness. Programmes included an information service, an access programme, a link group who ensure information is available through open days and taking part in community events, and publicity being offered in (usually, although not always) different languages. One provider referred to "wide consultation" on fair access to care and changing policies. One of the commissioners who responded referred to the fact that access and awareness were monitored through monitoring all cases, files, records, number of minority people referred to services – all mandatory fields on assessments.



## Focused Services

At a more micro level, respondents referred to many cases where service providers had set up their own programmes, staff teams or services that were specifically aimed at meeting the needs of people from minority ethnic communities.

### *Personal Support*

There were a number of specific programmes mentioned in terms of supporting learning disabled adults, which celebrate cultural differences. This included specific schemes such as an ethnic minorities women's advocacy group, specific respite break, an Asian ladies drop-in session (health promotion), a religious needs project, a single sex supported living scheme, but also 'link teams', 'cultural development workers' and links with independent providers to advise and ensure that service delivery was culturally sensitive.

### *Families*

Service providers reported a number of programmes that had been established for parents, families or carers that were specifically for minority ethnic communities. Examples of these were focus groups that had been established with the South Asian community based on a parent support group, specific teams with language support & accessible communication channels for getting in touch with services, an Asian carers' group that provide breaks for carers through group, and an ethnic minority development worker whose role is to promote access & develop good practice, an Asian carers group developed by the local authority council for voluntary services carers support officer, and a Carers' Forum (Black & Asian).

### *Interpreters*

Providers often have Urdu & Gujarati speakers on their teams and reported that they do not often come across a need for anyone external. One provider reported that their service published their literature in the main languages of ethnic groups in the borough. It was common for respondents to state that interpreters were used when necessary (e.g. NHS Manchester Translation Services, Language Link). One provider mentioned that they were specifically linking person centred planning to local and county-wide interpreter services. Other specific projects included links and advice from local universities, and a development worker for ethnic minorities who goes to house visits with other workers to help with communication.

### *Staff*

Respondents generally referred to the fact that the proportion of staff from minority ethnic communities reflected or aimed to reflect the population figures. This was not always the case and some providers singled out groups who were underrepresented. Other providers mentioned efforts they were making to improve this such as one who was committed to take on 50% staff from minority ethnic communities. Specific programmes were also mentioned such as an Access programme, a subgroup, an open day, consultation events, link team co-ordinating volunteer work to enhance chances for local people to get jobs in the service via co-ordinated support.

## Recent revisions

Respondents frequently stated that they were currently revising their policies regarding aspects of provision for people from minority ethnic communities. For instance, one of the commissioners said that work is being developed to identify culturally sensitive service providers. A current revision of the aims of the organisation was a fairly common response from our respondents. For instance, in supporting learning disabled people, respondents referred to both diet and general support as areas where revisions of policy were currently taking place.

In some cases, a new project or scheme had been set up and the level of its effectiveness was still to emerge. One provider was starting to send letters out in a relevant language (Urdu) & prioritising unmet need. Another referred to social services currently being in the process of devising a consultation and participation strategy, particularly with regard to vulnerable groups.

Despite these ongoing revisions of aims of organisations and the development of specific programmes aimed at people from minority ethnic communities, there are still some absences in service provision.

## *Absences in Provision*

In some instances it was reported that the service did not have any specific policies, procedures or practices. In some cases it was thought that the need was not there. One respondent replied that, "We have a plethora of policies, procedures, protocols so must never have thought the need". In other cases there were currently plans to develop policies for instance by monitoring person centred planning to evaluate how providers can better respond to people from minority ethnic communities.

One provider mentioned that there had been difficulties attracting social workers with appropriate language skills / cultural knowledge to work with the Asian communities to help develop links with families. Many of the providers also had plans to try and improve the area of staff recruitment and retention.

Providers were asked what provision would be made should the need emerge. Responses included specialist press advertising for staff, and co-ordinating good practices to ensure it happens in the service for e.g. Muslim staff gender issues; Muslim & non-Muslim staff clear guidance & procedures for diet arrangements particularly in the supported living.

## Initiating and Monitoring Change

The initiative for all of the above policies, procedures or practices came from a variety of sources. The two responses that were the most common were that the initiative had come from a) feedback from existing service users/carers or parents and b) from managers and staff who were dissatisfied with the current response. Other responses included that change had taken place following core legislation. Other catalysts of change have included: the partnership board & its task group 'Valuing Diversity'; need had been identified based on census figures; past research;

housing corporation guidance; the policy unit of the council, specifically, the Equalities Officer; Valuing People strategy.

Respondents were asked to explain how these policies, procedures and practices were monitored. The most common answer was that monitoring was sporadic. However, despite this being the most common answer, it was apparent that monitoring was indeed taking place in some areas. One provider stated that monitoring had been introduced in the last six months. Ways in which monitoring took place included use of a focus group, liaising with community groups and other methods of monitoring such as keeping records with regard to numbers of service users from minority ethnic communities and unmet needs. In some cases, smaller organisations meant that all managers were able to have ground level contact with clients and families enabling ongoing monitoring.

Policies, procedures and practices that were reported to have worked well included the recruitment of carers from ethnic minorities, the Council Racial Equality Scheme, liaising with carers and an action research group that has been successful in developing initiatives that are lead from the practitioner level. One provider responded that it was policies that had been informed by good practice that tended to be the most successful.

A variety of topics were mentioned where there were difficulties in being responsive to people from minority ethnic communities. It was of some concern that there were a few quite broad responses stating the "uptake of services by service users from ethnic minorities", "lack of vision from the service – working from numbers rather than impact" and "marginalised service provision which is not extend & developing across the department as a good practice". Other less effective policies, procedures or practices included: communication through leaflets; and policies which exist but are not demonstrated in practice i.e. departmental equal opportunities policy.

Policies, procedures and practices were thought to be working well due to: partnership working; external facilitation; commitment and enthusiasm from both staff and senior management; focus groups and events have worked best when led by staff and community leaders from minority ethnic communities.

There appeared to be some question of whether services were being really culturally sensitive & not just paying lip service to provision; the recognised danger of starting initiatives with short-term funding; a lack of competent private service providers i.e. direct payments; the Independent Living Fund not working for people; lack of staff from communities who have specialist & generic roles within service; lack of ethnicity co-ordinated at departmental level; dedicated time required to promote trust, confidence & challenge cultural assumption; and not being able to work out how to pitch appropriately to target market.

Table C summarises the closed response questions indicating factors which made policies/practices/procedures work well or less effectively.

Table C

Facilitators / Barriers	Number reporting made work well.		Number reporting made less effective.	
	N (=11)	Proportion	N (=9)	Proportion
Funding	4	0.36	4	0.44
Short-term funding	-	-	4	0.44
Input from SUs/families	5	0.45	3	0.27
Individual Staff Members	11	1	1	0.11
Staff Generally	6	0.55	1	0.11
Providing badly needed service	2	0.18	-	-
Organisational support	7	0.64	-	-

Other reported facilitators included: commitment & enthusiasm, continual management input, staff response to service users & families, external facilitation, staff & community leaders from ethnic minority communities, serious commitment from senior management, partnership working.

Other reported barriers included: dedicated time required, perception of tokenism, lack of competent private providers, lack of staff from ethnic minority communities who have specialist & generic roles, lack of ethnicity co-ordinated at departmental level, not being able to pitch appropriately to target market.

In most cases providers and commissioners were able to provide details of local or national organisations that provide services for people from minority ethnic communities (either for the non-learning disabled population or specifically for learning disabled people). This was encouraging as it was indicative of the links with the minority ethnic communities.

## **Section D. Discussion**

### **Participants**

Although the number of responses was small, the sample represents a sizeable slice of learning disability provision. Eighteen authorities of average size 305,000 is approximately 5,490,000 of the general population, possibly more, and on this basis it is probably a fair slice of the national picture. However, the picture we find is the best-case scenario given reporting bias (see study limitations for further discussion of reporting bias).

The respondents provided and/or commissioned an extensive variety of services, with the majority operating under either local government or the NHS. Most were based in metropolitan authorities and covered general population size 100,000-500,000 people.

### **People From Minority Ethnic Communities**

The proportion of people from minority ethnic communities in the general populations covered by the services surveyed ranged from 0.3% to 20% thus providing a good range with areas with less than average proportion and areas with much higher than average proportion of people from minority ethnic communities (5% of total UK population, 1991). However, the results displayed in Table A indicate that some minority ethnic communities in the areas surveyed do not use the services as the number reporting service users from specific minority ethnic communities is less than number reporting minority ethnic communities in their general population.

The information that the respondents held about the ethnicity of their service users came from a variety of sources including audits, data returns, minority returns from providers, internal censuses, client records, service records, referrals and knowledge of workloads.

The results from Table B regarding age ranges represent the fact that in general, services for learning disabled children are part of generic children's services and these were not surveyed.

### **Services**

The findings from this study reflect those from previous research (Hatton, 2002; Mir et al, 2001; Azmi et al, 1996; Shah, 1992; Baxter et al, 1990) and indicate that whilst steps are being made there could still be improvements in service provision for learning disabled people from minority ethnic communities and carers. This study demonstrates the important role of legislation and guidelines, organisational culture and focused service provision for developing services for learning disabled people from minority ethnic communities and their carers. It also provides examples of good practice that other service providers may consider. For example, Azmi et al (1996) concluded from their findings that employing staff who can communicate with people who do not speak English and who can relate to their cultural background can and does result in a significant uptake of services. This study has shown that despite many services having targets to achieve in terms of employing staff from minority ethnic communities, it is still an area where respondents reported difficulties, often related to attracting staff. However, Mir et al's (2001) suggestions for service improvement included the recruitment of bilingual staff and interpreters and this is an area where respondents were more positive and interpreters were commonly used and services' literature was produced in a number of different languages.

Azmi et al's (1996, 1997) study also concluded that almost all learning disabled Asian adults live with their families. This leads in turn to specific service requirements whereby in many instances main carers are mothers who can not communicate in English and the family may have little or no extended family networks. In this study respondents reported on a number of new initiatives that aimed to support families and carers suggesting that improvements have been made in this sphere since Azmi et al's study.

Finally Azmi et al's study also highlighted carers' ideas for improving services. The three main areas identified and the means by which respondents were addressing these areas are outlined below:

1. *Improving Communication.* This included communicating to service users in appropriate languages (literature and translators) as discussed above. No respondents referred to initiating Perepa's (2002) suggestion that audiotapes and videos in community languages were used.
2. *Increasing cultural sensitivity.* Suggestions included sensitivity regarding appropriate diet for Asian service users, recognition and celebration of cultural and religious festivals, same-sex carers and possibly single-sex carers. Respondents were positive about this area and included many examples of the programmes, policies and staff team responsible for meeting these needs.
3. *Increasing flexibility of service responses.* Examples of this also gave a positive demonstration that services were meeting people's needs in terms of flexibility of service responses. Respondents referred to flexibility and development of respite care.

The study findings reflect the importance of key principles identified by Mir et al (2001):

"The key principles which underpin current policy and practice development: partnership working, advocacy, independence and empowerment.....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." P.13.

NB it is difficult to compare or relate the findings from the present study to those from the Azmi et al (1996, 1997) studies because the data collection methods and more saliently the samples used, are very different. Azmi et al (1996, 1997) interviewed staff, carers / families and service users from minority ethnic communities whilst the present study surveys service providers and commissioners.

### Facilitators & Barriers

Individual staff members and good organisational support were most cited as the factors that facilitate effective policies/practices/procedures. Problems regarding funding were most frequently cited as barriers to effective policies/practices/procedures. However, approximately 50% of the total participants did not complete this section of the survey, indicating that they might not have / have not yet established any specific policies/practices/procedures for people with learning disabilities from minority ethnic communities

## Information

In contrast to the availability of information about the general population and minority ethnic communities within the general population from Census data, a mix of sources were used to gather information about the numbers of learning disabled people from minority ethnic communities. This supports Mir et al's finding that

“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.”

(Mir et al, 2001, page 4)

The Valuing People Support Team Framework for Action on Ethnicity (2004) provides a helpful template for collecting this quantitative information, and since local Partnership Boards will have to implement it, there is now reason to expect improvement in this area.

## **Study Limitations**

- The findings need to be treated with caution because in addition to the sample being small, it may also be biased in that the providers/commissioners who had instigated specific policies/practices/procedures for people from minority ethnic communities would have been more likely to take part in the study than others who had no specific strategies planned or in place.
- The views represented in this study came from senior managers and commissioners. The perspective from the ground might differ.
- The low response rate could indicate that those contacted to complete the questionnaire did not have access to the information requested, that potential respondents did not consider the issues of high priority, or did not have time to complete a lengthy questionnaire. This is of concern as whilst much is already known of the cultural needs of people from minority ethnic communities and gaps in service provision, it is important for services to be committed to developing services to address these gaps. This suggests that the study describes a “best case” scenario. It would be interesting, and important to ascertain how much commitment there is to these issues from providers who did not respond to the questionnaire.
- The use of structured interviews instead of open-ended questions on a postal questionnaire, may have gathered richer and clearer qualitative information about policies/practices/procedures. Alternatively a quantitative scale for measuring service development in each of the areas identified, may have produced clearer results and allowed for comparison if used in other studies.

## **Section E. Recommendations**

### **For Practice & Service Development**

- Routine collection of information about people from minority ethnic communities and monitoring of this information to ensure uptake of services as expected. (This is now required by the Race Relations Amendment Act (2000), and the Ethnicity Framework (Valuing People Support Team, 2004) provides a model for doing it.)
- The present study highlights the need for long-term, secure funding for initiatives for learning disabled people from minority ethnic communities.
- The examples of good practice discussed in this report could be replicated in local areas.

### **For Research**

This study has a number of implications for future methodology and topics.

#### **Methodology**

- The low response rate suggests that a postal questionnaire is not the best way to get information from service providers/commissioners. The use of open-ended questions may have deterred potential participants as the questionnaire may have been perceived as overly time consuming. Structured interviews or a quantitative standardised tool may be more appropriate but both would be more costly and protracted.

#### **Topics**

- It would be interesting to take this study further to explore if the services shown to be provided for learning disabled people are constant for people from different ethnic groups. Additionally it would be interesting to interview learning disabled people to see if user experience matches the aims of the service providers.



## **Conclusion**

The respondents detailed evidence of some work being carried out at grass roots level. Unfortunately, much of this work is not reflected across or higher up the organisational structure. There is a widespread perception of the issue of meeting the needs of minority ethnic communities as still being marginal or something that needs to be added on, rather than seeing it as a central theme of service development and ongoing planning. The responses very much indicate marginalisation as a core theme. It is important to ensure that it is a mainstream issue, so that every aspect of service development aims to meet the needs of people from minority ethnic communities. Indeed, there needs to be a greater recognition of ensuring that there should be a commitment to long term funding for sustainable projects within service development.

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£5.00

ISSN 1-359-9089

ISBN 1-900139-86-3