

User-defined outcomes of community care for Asian disabled people

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Introduction

The aim of the research was to seek the views of Asian disabled people (aged between 18 and 40) on their lives and on local services, with a view to understanding user-defined and culturally sensitive outcomes for community care services.

There were three main areas of interest in this study:

- Asian disabled people's views of their quality of life;
- Asian disabled people's views on services;
- service providers' views of service provision for Asian disabled people.

The research was conducted in two cities in West Yorkshire (Bradford and Leeds), with the support of two grassroots organisations: Asian Disability Network and the Association of Blind Asians. Twenty-eight Asian disabled people were involved (through individual interviews or focus groups) and interviews were also conducted with eight service providers (frontline workers and managers).

'Two different wars': racism and disability

Any study of the experiences of disabled black and ethnic minority people needs to start from an understanding of their position of having the multiple disadvantage of disability and 'race'. The social and economic disadvantage experienced by members of black and ethnic minority communities in Britain has already been well documented (Brown, 1984). In more recent years, disabled people have defined disability as the major factor contributing to their social and economic disadvantage (Oliver, 1990; Barnes, 1991). Thus, the term 'disability' here does not refer to particular medical conditions but to forms of disadvantage and discrimination. Disabled people in Britain have argued strongly that we should think about disability as a problem that is created by society, rather than a problem within the individual.

This way of interpreting disability, otherwise known as the 'social model of disability', is becoming more familiar within white British society (as evident, for example, in the introduction of the 1995 Disability Discrimination Act). However, black and minority ethnic

disabled people have been much less involved in these arguments than white disabled people. Consequently, social model ideas have been slower to spread into black British communities.

One explanation for this is that black and ethnic minority disabled people are a minority within a minority (Begum, 1994), on the margins of the non-disabled black community as well as on the margins of the white disability movement (Stuart, 1993). Both of these communities are engaged in fighting their own struggle against racism and disablism respectively, and consequently may overlook the experience of disabled black and ethnic minority people.

There isn't the time and the energy to fight two different wars.
(McDonald, 1991, p 3)

Millie Hill (in Campbell and Oliver, 1996, p 132), who founded the Black Disabled People's Association, described the same experience by saying:

I got fed up to the back teeth with being told by white disabled people that we shouldn't be concerned with issues of race.

It is impossible for disabled black and ethnic minority people to choose between disability and race as the prime reason for struggle:

The very nature of simultaneous oppression means that as Black Disabled men and women, and Black Disabled lesbians and gay men we cannot identify a single source of oppression to reflect the reality of our lives ... we cannot simply prioritise one aspect of our

oppression to the exclusion of others. (Begum, 1994, p 35)

As a result of this 'double' marginalisation from both communities, disabled black and ethnic minority people often experience isolation and lack the same social opportunities available to white disabled people (Shah and Priestley, 2001).

Some people describe this as 'double jeopardy', others as a unique type of institutionalised discrimination, quite different from the straightforward sum of the two different experiences (Stuart, 1993). However, Vernon (1999) states that there are similarities as well as differences between the experiences of disabled black people and disabled white people. Race, class, sexuality, age and disability are not invariably experienced at the same time. Although black and ethnic minority disabled people are simultaneously subject to institutional manifestations of racism and disablism, on an individual level, the experience varies considerably from day to day depending on the context. A complicated picture of discrimination emerges when all these factors are involved.

Community care: the policy context

Independence, as defined by disabled people, is still not easily achievable in terms of social care. There have been attempts over the last few years, however, to remove some of the barriers to independence in community care policy. For example:

- *Caring for people: Community care in the next decade and beyond* (DoH,

1989): this White Paper stressed the need to tailor care and support to individual needs, and for better access to assessment procedures for people from black and minority ethnic backgrounds, with an awareness that services geared to 'the majority' might not always be appropriate.

- 1990 NHS and Community Care Act: this legislation specifically emphasised the health and social care needs of disabled people from minority ethnic communities.

Cultural sensitivity emerged as an issue throughout the 1990s in relation to information, assessment and care planning, for example:

- *Social care and black communities: A review of recent studies* (Butt and Mirza, 1996);
- *Race, culture and community care: An agenda for action* (CRE, 1997);
- *They look after their own don't they?* (SSI, 1998).

In addition, the Department of Health White Paper on *Modernising social services* (1998) identified independence as the priority area linked to specific outcomes for individuals, and noted that:

Authorities are not using the commissioning process to secure appropriate services for specific groups of people who may not be best served by mainstream services. This is especially true of people from ethnic minorities. (para 2.46)

Developing services that are more sensitive to individual needs, and putting the user at the heart of all social services, can only be

delivered at local level. Councils must tackle these issues in partnership with other agencies, and importantly, in partnership with their local communities. (para 2.48)

More recent legislative and policy developments that are also of direct relevance in promoting increased equity in access to appropriate services for minority ethnic disabled people include:

- 2000 Race Relations (Amendment) Act;
- *Valuing people* (DoH, 2000);
- *Fair access to care services* (DoH, 2002; forthcoming policy and practice guidance).

The core issues which emerge from recent policy and legislation on community care with regard to black and minority ethnic disabled people are:

- access and information;
- promoting independence;
- recognition of and responding to the differing needs of individuals and communities;
- the provision of culturally sensitive and appropriate services;
- the difference between autonomy and independence.

Experiences of black and minority ethnic disabled people: the research context

Research which has been done in the past into black and ethnic minority disabled people and their families has revealed a number of issues which are important for service provision, and which have

informed the approach and analysis in this study.

The simultaneous discrimination faced by disabled people from black and ethnic minority communities shows itself in different ways in everyday life. The sparse evidence points to major barriers at all levels of institutional discrimination. For example, two studies of the families of Asian people with learning difficulties (ADAPT, 1993; Azmi et al, 1996) showed high levels of poverty, with 69% of families having no full-time wage earner, and half of the families being on Income Support. Significant language barriers were found in the same studies. Nadirshaw (1997) also found that 95% of carers had been born outside of Britain and only a minority could speak or write English.

However, there are dangers in such statistics. First, they can encourage stereotypes which work against diversity. Shah found in her study of Asian parents that “the majority of parents had a good command of English and, for some, English was their first language” (1998, p 186). She cites language barriers as an example of preconceived notions of discrimination experienced by Asian families, highlighting the danger in oversimplifying language barriers. Also, having a common language is no guarantee of shared understanding.

Language is often seen as the main barrier to effective service provision and it is assumed that an adequate supply of leaflets and interpreters in appropriate languages would solve this problem. It is clear, however, that communication consists of more than just language skills and literacy. The research suggests that even among British-born English-speaking Asians there is considerable lack of

knowledge of what services are on offer. Banton and Hirsch (2000) comment on formal communication problems and also on the effects of the separate lives led by ethnic groups, so reducing informal communications about services.

This is compounded by the attitudes and limited awareness of other people:

... there is a lack of understanding among the majority population concerning the life style, social customs and religious practices of people from ethnic minority groups. (French and Vernon, 1997, p 62)

Discrimination within the provision of services has received particular attention, but has sometimes been denied and rationalised through myths that, for instance, black families prefer to look after their own (Baxter, 1995). Although there is little literature on the views of black disabled people, the research that does exist consistently cites experiences of segregation and marginalisation within services. Summarising this evidence, Butt and Mirza (1996, p 94) comment:

Racism, sexism and disablism intermingle to amplify the need for supportive social care. However these same factors sometimes mean that black disabled people and their carers get a less than adequate service.

Perhaps the most consistent recommendation from research has been the necessity for the direct involvement of disabled clients, including black disabled clients, in the planning of services (Butt and Box, 1997; Butt et al, 2001). Again this needs to be understood within the context of multiple discrimination.

Concluding their study of Asian deaf young people and their families, Jones et al (2001, p 68) state:

... identities are not closely tied to single issues and young people and their families simultaneously held on to different identity claims. To this extent, it is not a question of forsaking one claim for another and choosing, for instance, 'deafness' over 'ethnicity', but to negotiate the space to be deaf and other things as well. It is only through addressing these tensions that services will adequately respond to the needs of Asian deaf people and their families.

Research methodology and sample

Twenty-eight disabled Asian people between the ages of 18-40 with a range of physical, sensory and cognitive impairments took part in this research. Sixteen were interviewed individually and 12 took part in a series of focus groups. A further eight interviews were conducted with service providers to discover how they were meeting the needs of minority ethnic disabled people. The sample was selected for the following reasons:

- Between the ages of 18 and 40 there may be many changes taking place, such as, growing up, finding a job, finding a partner, leaving home or having children. These changes could be potential sources of contact with social services.
- The sample reflected the high proportion of people below 40 years of age in the minority ethnic

community population (80% as compared to 39% of the white population).

- Additionally, all participants were at least second-generation Asian people, living in the UK, able to read and understand English, and therefore for whom the English language would not be the main barrier to access and use of the services.

Confidentiality has been respected throughout the research, pseudonyms have been used and reference to specific services has been omitted. Participants were recruited through a variety of methods, including social services registers, day centres, Asian radio programmes and by word of mouth. The participants were keen to point out that they were not fully representative of Asian disabled people nor the disabled community. They explained that many Asian disabled people do not identify themselves as 'disabled people' so might not want to take part in research on 'disability'.

The people contacted were asked to describe their everyday lives and their hopes for the future, as well as their views on service provision. In this way it was hoped to gain an understanding of wider quality of life outcomes as well as what users define as good outcomes for community care services. This approach draws on previous work with (mostly) white disabled people undertaken at the Social Policy Research Unit, University of York, on user-defined outcomes. In this work, user-defined outcomes:

... included a number of linked outcomes related to the business of daily living such as personal cleanliness, a clean home to one's

own standard, ability to move about freely at home and outside, social contact, interesting activity. These were continuously underpinned by issues of choice, independence and controls over one's life. (Vernon and Qureshi, 2000, p 261)

Chapter 5 offers some recommendations for improving service provision and making services more effective in meeting the outcomes identified through the study.

This approach was thought to offer a helpful perspective on what is required from the social services by looking at the effect that they have on people's lives and wider aspirations.

Additional details on the research methodology can be found in the Appendix.

Structure of the report

Chapters 2 and 3 of this report focus on what Asian disabled people involved in the study told the researcher about:

- what would make their lives better (Chapter 2);
- what would make services better (Chapter 3).

On the basis of participants' views, two lists of 'outcomes' are developed: wider 'quality of life' outcomes, and also 'quality of service' process outcomes.

Chapter 4 outlines the views of the small number of service providers (frontline workers and managers), who also took part in the study, on the difficulties they have experienced in trying to improve take-up of services.

Asian disabled people's views on what would make life better

In recent years there has been considerable emphasis on 'promoting independence', improving 'quality of life' and achieving positive 'outcomes' for disabled people and their families using community care services, including people from black and minority ethnic communities.

A central focus of this research study was to gain a better understanding of Asian disabled people's views about what would make their lives better. This was done to enable the identification of wider 'quality of life' outcomes for Asian disabled people – as a benchmark against which to measure current service provision, and as a tool to assist the development of more appropriate services to disabled people from minority ethnic communities.

What would make life better?

The Asian disabled people in this study had clear ideas about what would make their lives better. These ideas have been grouped into 10 outcomes.

1 *Moving about freely at home*

Access to basic amenities in the home was the first key determinant of people's quality of life and self-esteem.

Mehbub wanted a separate shower so he could wash without difficulty:

"I do need a shower... I've a bath but you have to go in the bath to have a shower, and it's quite difficult to get in and out of for me without any help..."

Similarly, Shehnaz wanted suitable adaptations to her home so that she did not have to rely on her mother and sister to help her get into the bath or to go up the stairs. She also wanted a powered wheelchair so that she could move about freely inside and outside her home, without having to have someone to push her.

"That's my worst problem going upstairs.... I've to do it on my bum! My sister helps me with the legs and then I lift up and go up.... Going up is hard, getting a bit harder now because, well don't forget I'm 38 now, so I'm a bit, getting old as well."

“I need a wheelchair where I can actually get around, you know, myself, instead of being pushed ... that made me feel like I’d totally lost my independence.”

2 Independence and choice

Everyone wanted independence and choice. The form this took and the specific meanings it held were different for different people.

For Mehbub and Nasmin, independence was about moving out of the parental home. In contrast, Sadiq felt that living with his parents did not compromise his independence. In his view, independence was not about living on his own; rather, independence was about having control over his own life:

“For me to be independent as a disabled person is having control over what you want to do. If you want to go out, socialise.... And to take care of your own finances as you get older.... It’s not the fact that I want to move out or anything.”

People wanted more choices and control about the support and services they received: who provides support, when, how, and so on. These issues are explored in more detail in the next chapter.

People wanted choice about their lifestyle including, for some people, how to live with their impairment. Anita described how she chose to put up with the pain in her back rather than have an epidural which would have meant that she could not do physical activities, such as picking

up her children from school or going out for a walk.

Moonier wanted to choose how to use his limited energy to do things he felt were important in his life, without fearing repercussions from the authorities:

“If I’m going out with friends we’ll go around town. I’ll walk around all day with them simply because they’re with me, but if the social see me doing that they’d say you’re not disabled.”

3 Fulfilling parenting and family roles and responsibilities

Ten of the Asian disabled people in this study were parents, and two were expecting their first baby at the time of the interview. They wanted information and assistance in relation to their parenting roles. For example, Iqbal and Samea, who were expecting their first baby, wanted information on the practicalities of becoming parents. Iqbal and Samea are deaf and their main concern was how they would know when their baby was crying at night.

Those who were already parents described wanting assistance so that they could fulfil their parenting roles within the home and outside the home, and were concerned that their parenting roles were not taken away from them. For example, one parent would have welcomed assistance with taking their young children to the park since they had no transport of their own.

Being able to fulfil wider family roles and to do things for family members was also important. Salma wanted to find ways to reciprocate for the help she received from

her parents. For example, she was the only one who had a car in the family and so was able to contribute to her family by giving people lifts:

“I do things for them as well like because I have a car – my mum and brothers are wanting me to give them a lift to places and I don't mind that.”

Usha wanted some equipment so that she could make rotis for her family to eat; for Usha this was a central part of her family roles and obligations.

4 Social contact and company

People wanted opportunities for peer support and friendship from other Asian disabled people. For Mehbub:

“... my ideal thing to do would be to go and see a lot of disabled people, to talk to them.”

Nasmin wanted to spend time with other Asian people in an environment that she felt comfortable in – she contrasted this with her experience of attending a day centre for white women.

Saleem wanted support so Asian disabled people could form “their own group ... like a support group”, because:

“... you can't do without your own community.”

5 Able to pursue leisure activities and interests

Faroq was one of several people who wanted to live a life that was more

interesting, and to enjoy leisure and sports activities:

“... work, home, work, home. I feel like there's a bit missing.... I'd like to do a bit more, physically, exercise and stuff like that.”

Nasmin wanted opportunities to do interesting things that reflected her culture and customs, unlike activities she had experienced in day centres, which she described as ‘menial’.

Mehbub wanted to be able to spend time in the public library – he was unable to do this because of lack of personal assistance.

6 Able to be part of religious and cultural life in the community

People in this study wanted integration into the cultural and religious aspects of Asian community life. In some cases they felt isolated from this.

Faroq wanted to *not* be ‘exempt’ from religious fasting. Mehbub wanted to go to a mosque and to read the Koran; he had not had access to either. Ishaq wanted to be able to go into the mosque to pray:

“They've got a ramp going into the mosque, but once you are in it, to get to the floor where they pray and hold out, you have to go up two flights of stairs.”

7 Equal access to public places and printed materials

There was a general desire among the participants for better access to public

places outside the home. As Abid commented:

“... transport ... buildings ... restaurants, wherever you want to go yeah, that you have access as much as a normal person.”

People wanted to be able to go to the same places as other people and to do so without having to feel embarrassed or awkward.

Equal access included:

- physical access to buildings (for example, restaurants and mosques);
- Braille labels in shops, Braille menus in restaurants, accessible formats for job advertisements and newspapers for visually impaired people;
- accessible transport for visually impaired people and others who did not have or use cars.

8 Equal access to valued roles (for example, work, marriage)

Usha described work as “the first step to independence”. Several participants who were not already in work expressed a strong desire to work. The barriers and discrimination they faced frustrated this wish:

“I do look for jobs everywhere possible, even agencies, but I’ve had a real problem ... I don’t understand, people with the same qualification can just walk into one and there’s me, struggling all these years.”

Saleem felt that negative attitudes towards his disability made it difficult for him to retain work: “they sacked me when I had

a fall and while I was off sick recovering they replaced me”.

Marriage was a particular issue for the majority of those who were unmarried and living with their parents. Some of the men in the study hoped that getting married would mean that their wives would take the place of their mothers in providing care and assistance. Sadiq commented:

“I know my parents won’t be there for ever and my brothers and sisters, especially in the Asian culture you know ... so I feel if I was to get married my partner would be a prime carer, you know, but at the minute I’m happy with life as it is.”

9 Being equipped to make informed choices and plans

People wanted access to good information and advice so that they could make informed choices about their lives and so that they could plan ahead.

Women, in particular, who lived with their parents, wanted to learn to become more self-sufficient and get good information on what options would be available to them once their parents were no longer alive or able to support them. This was also a concern for some of the men in the study.

10 Respect and equality

There was an overall desire among the people involved in the research to be treated like anyone else without having to deny any part of their identity. Usha said:

“I don't think the equality is there, we're not treated equal at all ... when they say we're living in an equal society ... we're not.”

Individual outcomes, family life and communities

In the course of the research, examples emerged where family life and community expectations were in conflict with individual disabled people's outcomes and aspirations. It is important to note that these examples reflect the complex nature of reciprocity in relationships and families generally.

It is also important to set these examples in context, and to remember that a key 'quality of life outcome' identified by the participants was 'being able to fulfil parenting and family roles and responsibilities'. A wish to move out of the parental home should not therefore be seen as necessarily conflicting with a wish to be part of wider family life, or with valuing one's family.

Moving out of the parental home

Mehbub wanted to move out of his family home, but his family did not think this was a good idea:

“I want to live on my own really. But at the moment it's not really possible.... You know what your mum's like. They don't want to let you go ... they worry about me. They think I can't cope but ... I know that I can cope....”

Mehbub thought that part of the reason for this was his family's fear of what the Asian community would say about how uncaring they were if he was allowed to live by himself: “If I go and live on my own, you know in an Asian community, it gets talked about”.

Similarly, Nasmin's wish to move out of her family home was also frustrated by a difference of opinion within her family: “My Dad says I should stay with him and he won't let me leave”.

Not being 'overprotected' by parents

Salma did not want to move away from her parental home; she enjoyed living with her family and was also worried that living on her own would mean doing things like cooking, washing and cleaning without support, things that would take a lot of time and energy. Salma was sometimes frustrated when her parents were 'overprotective' and stopped her from doing things she wanted to do for herself.

Marriage

Many people in this study felt that there was no possibility of marriage because general attitudes towards impairment and an emphasis on visual appearance, especially for women, made it difficult for parents to arrange marriages. Nasmin described her parent's attitude towards her future:

“I can't marry because only my sister and brother married. I asked my mum and she only laughing.”

Too many family demands

While being able to contribute to the family was generally valued, there were times when, for some people, inter-generational obligations and having to perform family roles were rather wearing. Saleem was finding it difficult to meet the needs both of his ageing parents as well as his children. Sometimes he felt that he would have welcomed “someone to depend on”. He also felt that his own needs as a person with an impairment were often overlooked by the needs of his family:

“Because I have a car, when anyone needs to go anywhere, they always come to me. Like this morning I was going to the sauna for my leg is very frozen and I have pain in my back, but my niece had a hospital appointment....”

Barriers to religious integration

In addition to physical access issues, some people described barriers as coming from attitudes in their families or the community. Mehbub said:

“I would love to go [to the mosque] ... my family have never taken me ... or shown the book [Koran] to me.”

Faroq’s mother’s ideas about impairment and disability meant that she did not want him to fast. But Faroq asked: “Why should I be exempt?”.

What are the implications of not achieving these wider ‘quality of life’ outcomes?

Throughout the course of the interviews and focus groups, the considerable implications of not achieving these outcomes became clear. People in the study described feelings of:

- frustration
- disempowerment
- isolation and loneliness
- forced dependency
- low self-esteem
- lives that were monotonous
- distress at not being able to fulfil important family roles
- anxiety about the future
- not feeling in control of one’s life.

Conclusion

This chapter has set out the views of Asian disabled people on what would make their lives better. It has also given some insight into some of the barriers that Asian disabled people face – from services, from society, and sometimes from their own families and communities.

Many of the daily frustrations with lack of access to public facilities that the non-disabled population take for granted, such as, buildings, transport, printed materials, come under the remit of the 1995 Disability Discrimination Act. The Disability Discrimination Act also legislates against some aspects of discrimination with regard to employment, leisure and education. Many feel that the Act has not yet gone far enough in legislating effectively against discrimination, and that more

needs to be done to enforce the law. Even so, it is hoped that the Disability Discrimination Act will, in time, create a more enabling and barrier-free society and environment for disabled people.

The research also identified some examples of where family life and community expectations may be in conflict with disabled people's needs and aspirations. However, these are not just issues for individuals, families and communities to deal with in isolation from others. Some ways in which service providers could play a useful role include:

- enabling Asian disabled people to access peer support;
- working with community groups and leaders around disability issues.

Finally, the views of Asian disabled people set out in this chapter constitute important messages for community care service providers about what 'quality of life' and 'promoting independence' mean for Asian disabled people. These wider 'quality of life' outcomes could play a helpful role in assisting service providers to measure their success in achieving good outcomes, as defined by Asian disabled people themselves, and to improve service provision.

The next chapter looks at Asian disabled people's views of existing service provision: their experiences and what they feel would make services more effective in achieving outcomes for Asian disabled people.

'Quality of life' outcomes for Asian disabled people

- Moving about freely at home
- Independence and choice
- Fulfilling parenting and family roles and responsibilities
- Social contact and company
- Able to pursue leisure activities and interests
- Able to be part of religious and cultural life in the community
- Equal access to public places and printed materials
- Equal access to valued roles (for example, work, marriage)
- Being equipped to make informed choices and plans
- Respect and equality.

3

Asian disabled people's views on what would make service provision better

A quality service from a user perspective is one which delivers the outcomes that service users are seeking, both in terms of specific aspects of *quality of life*, and also in terms of the important aspects of *process* (Vernon and Qureshi, 2000).

In the previous chapter, the focus was on Asian disabled people's views of wider quality of life outcomes. This chapter sets out Asian disabled people's views of process outcomes: how Asian disabled people define 'quality of service provision'. The chapter also looks at the implications of not achieving these outcomes (for example, low take-up of services, lack of confidence and trust in services), and concludes by looking at direct payments.

What would make services better?

The Asian disabled people in this study drew on their personal experiences of accessing and using community care services to be able to explain what would make services more effective at achieving the outcomes *they* wanted.

1 Consultation with Asian disabled people

Participants wanted regular, ongoing consultation and partnership with local groups of Asian disabled people and their supporters. As one focus group member advised:

"They should ask our needs, what we need."

2 Services that meet Asian disabled people's priority outcomes

First and foremost, Asian disabled people wanted services that would meet what *they* felt was important in making their lives better.

Among participants, there was an overwhelming concern about the inability of services to respond to individual needs. Adam summed this up:

"It's the lack of flexibility, to treat you as an individual and work with your needs from where you are. What they seem to do is, be fulfilling their needs by providing your service...."

People's life-style choices and quality of life were sometimes restricted by the limited hours of personal assistance or support that people could secure, through direct services or even direct payments. For example, Mehbub was frustrated that the hours allocated to him allowed only the bare necessity of personal care required in the home, such as getting washed and dressed. Mehbub wanted:

"... more hours ... but they won't give it ... I would like 25 hours a week ... go to library ... do lots of paper work."

It has long been a contention of disabled people that social care provision focuses only on people's physical needs, overlooking the importance of wider 'quality of life' outcomes and social needs, and the effect that these unmet needs have on people's mental and physical well-being. Evidence from previous research (see Bamford et al, 1998) suggests that service providers may view requests for such assistance as 'wants' rather than legitimate 'needs'.

3 Flexibility, choice and control

People wanted more flexibility in their lives and therefore also in the services provided. This included flexibility about who provides support, when, how and where.

... about who provides support

Some people wanted more choice about who could provide their personal assistance. Najma wanted to pay her friend to be her personal assistant, but this was against her council's policy:

"... the important thing is ... I like to get on with people ... I like someone of my own age."

Saleem said that he wanted to have assistance with parenting responsibilities from a Muslim female who would understand and respect how domestic tasks should be carried out:

"We wouldn't have to explain about cultural things."

... about when support is provided

Usha wanted occasional support, as and when she experienced difficulties, rather than help at home on a regular or fixed basis.

... about how support is provided

People wanted to have a say in how support was provided, as well as what support was provided.

With regard to parenting and other family roles, disabled parents wanted assistance to help them fulfil their parenting roles and responsibilities. They did not want someone to come in and 'take over' the parenting role.

... about what support is provided

People were critical of 'standard' service responses to their needs. For example, people who wanted peer support and social contact with other Asian disabled people felt strongly that just getting Asian disabled people together in a room or day centre was not the only answer.

... about where support is provided

Accessing support in a culturally sensitive environment was a high priority for all participants. There were also issues about being able to access support to do things *outside* the home, in the wider community, as well as *inside* the home.

4 Culturally competent and sensitive services

People wanted services to be delivered that respected, understood and accepted variations in individual and family expectations about:

- family life and obligations;
- use of space within the home;
- religious obligations (including those relating to self-care and domestic tasks).

“I want them to give me services that are culturally, religiously sensitive.”

Some people specifically wanted more Asian social workers, care workers and personal assistants. This would increase their confidence in the service and provide reassurance that workers would know about and respect different dimensions of family, cultural and religious life.

Usha described her difficulties with making rotis for her family. She had asked social services for a machine to help with this and had been refused on the basis of cost (£400). Usha felt that the refusal had more to do with being Asian.

The significance of an aid or service needs to be understood in relation to each individual's circumstances, including

those relating to family, religion and culture. This approach to assessing needs is likely to be more successful than operating to standard, often monocultural, 'rules' of what support and equipment can be provided, and what can be assessed as need.

5 Competent services

For the disabled people in this study, competent service provision was not just about cultural or religious competence. People wanted services that were well-informed about their individual needs and standards, and that ensured that these were met.

6 Information and advice

Information was both a 'quality of life' outcome and also a 'quality of service' outcome. People wanted information in accessible formats, but more importantly, they wanted someone they could talk to or meet who could set out all the available options:

“There's just so many things that they could have said ... you know, look this is available.”

“... information about all kinds of things, what your rights are, what services are out there for you.”

In most cases, the information people received about services came from other sources, often by chance. Ishaq happened to meet some people from the British Polio Association, through which he got £500 to pay for driving lessons. Saleem found out by chance about Motability from a colleague. Iqbal and Samea (both deaf and expecting their first

child) eventually got the vital information they needed about practical aids from another deaf friend who was English. This was despite repeated requests to agencies for information.

7 Timely services

Once assessments had been carried out, people wanted services, aids and adaptations to be provided in good time. However, many people experienced long delays with negative consequences for their quality of life in the interim.

One example of time spent waiting for services and equipment came from Anita, in one of the focus groups:

“I cannot sleep on a straight bed so I asked them, you know, this is what I need. This was about two and a half years ago.”

Sometimes, delays seemed to be worsened by inflexible approaches to meeting individual needs and preferences. Mehbub had applied for a shower:

“It's been over a year since I've applied. Someone have come, about four or five months ago ... because it's upstairs, he said I'd have to have a stair lift, but I don't want a stair lift, it won't go in because it's too narrow. They asked me to write a letter to say why I don't need a lift, which I did but I'm still waiting for the shower....”

8 Easy to access services

People wanted to be able to access services without complicated paperwork

and bureaucracy. Too much bureaucracy and a feeling of not knowing how to navigate the system were key factors in people giving up on services.

9 Equal and transparent decision making

People wanted social services to treat them equally and fairly, and to be transparent and not discriminatory when making decisions about people's needs for services, aids and adaptations.

Some participants could not understand why their support had suddenly stopped or been reduced, and/or whether they could appeal against such decisions. Mena talked about how she used to get help, but then:

“... my parents came from India to see me. They said when a person is here, according to the rules, it stops.”

Several other participants felt that decisions made about refusing an aid or adaptation were discriminatory, and that if they had been white disabled people then they would have received the support they needed.

10 Suitable aids, adaptations and equipment

The 1990 NHS and Community Care Act set out a commitment “to enable people to live as normal a life as possible in their own home”. Several people in this study identified aids, adaptations and equipment that would have a direct and immediate positive impact on their quality of life. Unfortunately, many people reported significant barriers in accessing these and, as a result, being made to feel

dependent. Specific difficulties included: lack of aids or adaptations; provision of unsuitable equipment; and long delays in getting adaptations even after these had been assessed as needed.

Lack of a stair lift meant Shehnaz had to rely on others to go to the toilet or her bedroom. Shehnaz was also frustrated about getting a manual wheelchair instead of a powered wheelchair – since this also meant she had to rely on other people to push her and she could not move about freely.

Mehbub had a similar experience of wheelchair provision:

“I used to rely on other people to push me around ... I couldn't move it to save my life ... it was so heavy!”

Ishaq felt inappropriate provision made life worse, not better:

“... why do they [social services] give those big, heavy pieces of metal to disabled people? That makes them more disabled!”

What are the implications of not achieving these 'quality of service' process outcomes?

The stories and experiences shared by Asian disabled people in this study gave clear insights into what happens when service providers are unable to achieve the process outcomes that are so important to service users.

The main implications appeared to be:

- unmet need;
- lack of confidence and trust in services and providers;
- low take-up of services;
- giving up on services.

Unmet need

Low take-up of services does not mean low levels of need.

It is clear from the experiences shared by the people in this study that there was significant unmet need. People reported being forced to be dependent on family members because of an inaccessible or disabling home or lack of other options for appropriate support. People reported feeling isolated, frustrated, anxious and disempowered because they were not able to access the support they needed to achieve a better quality of life. People talked about not having the support they needed to access leisure and work, or to fulfil their parenting and family responsibilities. The apparent focus on the most basic personal care needs meant that there were whole areas which were not catered for.

Lack of confidence and trust in services and providers

There were several factors that fed into low levels of confidence and trust among Asian disabled people and their families with respect to statutory service provision, in particular feeling discriminated against; poor experiences of services; and lack of confidence in the cultural competence and knowledge of services.

Discrimination was raised by many participants. For example, Shehnaz felt that the difficulties she had encountered

in getting a ramp and stair lift for her new house constituted discrimination. Shehnaz had lived in a small house for 10 years, which had received some adaptations. Religious obligations about the use of space in the family home, and having separate rooms for men and women, meant that her brother could not stay with the family. So, Shehnaz – after consultation with and agreement from her social worker – arranged to move into a larger house her brother had bought. However, her application for a ramp was refused on the basis that a ramp had been installed at her previous house. The ramp was agreed once Shehnaz threatened to go to the press. Shehnaz continued:

“It’s racism ’cos I know one person in here [day centre], he moves houses every couple of years and he gets everything. And when we Asian ask, we won’t get anything.”

Usha felt that the refusal of social services to provide a machine for making rotis for her family to eat was discriminatory because:

“... if they can provide white people with any kind of domestic aids to make life easier for them, they will, but because I’m Asian they won’t.”

Some participants felt discriminated against by the low aspirations they felt that service providers had for Asian disabled people. Usha said:

“We do want to be independent but sometimes I think they’re, they write us off.”

Poor experiences of using services also contributed to low levels of confidence.

One woman in the study described how her experience of a poor quality respite care service had resulted in her refusing to use the service again. She reported that she often had to wait half an hour after asking for help to go to the toilet before someone came to help her.

Low take-up of services

All of the above factors contributed to the low take-up of services among Asian disabled people that was noted both by Asian disabled people but also by service providers taking part in this study. Some of the difficulties service providers experienced in improving take-up are listed in the next chapter.

Negative perceptions of social services meant that some people were reluctant to approach social services. Samina explained:

“When I had my accident my parents wanted nothing to do with social services; they had a really negative image of them.”

Not knowing what is available and how to access it was felt to be one of the biggest barriers to getting hold of services. Getting information was a struggle, as one focus group member said: “They are not telling.... All the time I have to ask them”. For many people, getting the information they needed was a matter of chance.

Significantly, lack of information was not primarily a question of linguistic difference, as all the Asian disabled people who participated in this study were fluent in English. Indeed, lack of information to make informed choices, resulting in over-reliance on professional

opinion, has also been reported by large numbers of white disabled people as a key barrier (Bamford et al, 1999).

Charging policies for services, such as day centre attendance, were felt by many participants to discourage Asian disabled people from seeking and taking up services. For some of the people interviewed, attendance at a day centre was their only chance for social contact outside their family home. Charging for this service could compound isolation and loneliness if individuals or their families felt unable to pay. Reluctance of individuals and families to pay for services needs to be seen in the context of variations in family decisions about how best to use what may already be overstretched financial resources.

Local authority charging policies vary widely across the country, and have been criticised by both white and black disabled people. It could be argued that disabled black and ethnic minority people may be particularly and disproportionately affected, given higher rates of poverty and unemployment in some minority ethnic communities. It is unclear whether this constitutes indirect discrimination under the 2000 Race Relations (Amendment) Act.

Giving up on services: long delays, bureaucracy and 'wild goose chases'

It is a matter of concern that several participants in this study described giving up on trying to get appropriate services or adaptations – mostly as a result of feeling passed from pillar to post, experiencing long delays in getting anywhere, and the complicated bureaucracy.

“They send you to A, B and C and you’re still where you started....”

“You just go from one place to another, you don’t get anywhere.”

Saleem described giving up on trying to get a ramp:

“I have been and asked about that and they were going to get back to me but no one has. It’s so much hassle so I have given up trying.”

A focus group participant who had a visual impairment requested mobility training, but explained:

“... they didn’t get back to me ... [after further difficulties] then I decided to give up.”

Ishaq said:

“I could be doing something better in my life ... instead that time was taken up you know fighting for a lost cause.”

Another focus group participant suggested some people might give up out of deference to professional opinion:

“If you don’t get the thing then you’re thinking: they know best, you probably can’t get it.”

Some people in the study refused to give up on getting the support they needed. For example, Shehnaz threatened to go to the press if she did not get a ramp for her home; she got the ramp. Overall, however, there appears to be a marked difference between this study and the findings from previous research on user-defined outcomes of mostly white disabled people (Bamford et al, 1999).

White disabled people seemed to persist longer in getting what they wanted from the social services system than the Asian disabled people involved in this study.

Direct payments

Only one of the 28 disabled people who took part in this study used direct payments. The majority of participants reported that they were not aware of direct payments schemes and their benefits even though both local authorities were running direct payments schemes.

This is not surprising given the general rate of low take-up of direct payments among black and ethnic minority disabled people (Bignall and Butt, 2000; Butt et al, 2000). However, evidence from previous research (including the study of user-defined outcomes reported in Vernon and Qureshi, 2000 and Bamford et al, 1999) has shown a marked difference in achieving quality of life outcomes where disabled people accessed direct payments to purchase personal assistance.

There is no evidence to suggest that direct payments would not make a real difference to Asian disabled people who wish to use them in making their lives better. However, there are some specific issues that will need to be tackled to enable this. First, people will need access to information backed up by independent advice and support about what direct payments are, how to get them, how to use them, and so on. Second, there may need to be greater flexibility about the employment of close family members as personal assistants.

Currently, there is wide variation at local level about employing close family and friends. Several difficult issues are involved, for example, preventing misuse of funds and exploitation, either by the family or the individual disabled person; concerns about the reduced choice and control a disabled person might have; and whether it is unreasonable to expect black and minority ethnic disabled people to disengage from close family and community support networks, or to enjoy the same chances of success in recruiting personal assistance from outside those networks as white disabled people.

Conclusion

Asian disabled people identified many ways in which service provision hindered rather than enabled them in the ways in which services were delivered. This reduced their quality of life, and their confidence and trust in service provision and providers.

A key message from this study is the need for service providers to invest time and resources in *building trust and confidence in services*. Factors that contributed to lack of confidence in services included: inflexible, culturally inappropriate and poor quality services; long delays and complicated bureaucracy; lack of transparency about the 'rules'; and discrimination.

Some people felt they had been discriminated against by service providers because they were Asian. Irrespective of whether or not a white disabled person with similar support needs in similar circumstances would have received the service or not, the fact that participants *felt* discriminated against indicates the

extent to which people had lost confidence in service providers.

A previous study (Bamford et al, 1998) of user-defined outcomes among mostly white disabled people found similar examples of inaccessible housing, enforced dependency, lack of knowledge, and not accessing support for needs other than basic personal care. However, there was one marked difference between the studies. The authors in that study found that white participants appeared likely to persist in their battle for services. In contrast, participants in this study appeared to give up on the system more readily. This may reflect:

- low awareness of rights and entitlements to services;
- less confidence and greater barriers in navigating the system;
- limited access to peer support (that is, not knowing other people who may have received similar services successfully);
- less incentive to battle for services that might not be worth the fight (culturally inappropriate, not meeting people's priority needs, and so on).

In the next chapter, the views of a small sample of service providers about providing services to Asian disabled people are outlined, to learn what they feel are the main barriers to improving take-up of services.

'Quality of service' process outcomes for Asian disabled people

- Consultation with Asian disabled people
- Services that meet Asian disabled people's priority outcomes
- Flexibility, choice and control (about who provides support, when, how and where)
- Culturally competent and sensitive services
- Competent services
- Information and advice
- Timely services
- Easy to access services
- Equal and transparent decision making
- Suitable aids, adaptations and equipment.

Service providers' views on the difficulties of improving take-up of services

Although the focus of the research was on the views of Asian disabled people themselves, it was thought to be useful to add to this picture by including the views of a small number of service providers on the nature of provision, and on the difficulties they faced in trying to improve services and take-up of services among Asian disabled people in their localities.

The service providers interviewed were: two service managers and three frontline workers from statutory services; and one manager and two frontline care workers from the voluntary sector. Five were white and three were Asian people. Six were non-disabled people and two people were disabled (one white, one Asian).

Barriers to improving take-up of services

The views of these providers on the causes of low take-up of services fell mainly into two categories:

- those who blamed the lack of commitment and resources from the top (mainly the frontline workers);
- those who blamed the communities themselves (mainly the managers).

Apparent lack of interest from communities

Several people described attempts they had made to improve awareness of available services within Asian communities. People reported not being able to stimulate good turn-outs despite their best efforts, including consultation with representatives from the communities they were targeting.

For example, one manager of a resource centre had organised an Asian awareness day:

“It was poorly responded in that nobody came at all despite all the prior publicity. Asian community ... were consulted about what they wanted. The community felt that there was a need for day centre provision if proper access to facilities that were appropriate could be ensured. A publicity day was also held in 1997. Again, minimal attendance from the Asian community despite having

publicised in mosques, temples and gurdwaras.”

Another manager gave his explanation for low take-up of services:

- “
- The reluctance of the Asian community to come forward to take part in western society
 - They want to hide disability
 - They want to provide for their own.”

It must be noted that placing blame on communities, rather than looking critically at what services and providers need to do to raise interest and awareness in services, and to improve the effectiveness of services in meeting the needs of Asian disabled people, may be seen as ‘passing the buck’. Services may also be considered to be ‘failing’ with regard to new duties under the 2000 Race Relations (Amendment) Act to promote racial equality and to address indirect as well as direct discrimination, and institutional discrimination.

Misplaced emphasis on translating information as the ‘key’

Making information accessible is important, but there is a risk of relying on the translation of written information leaflets into different minority ethnic languages as the ‘magic solution’ for reaching service users from those communities. Then, when the leaflets fail to change anything, there is a further risk that the lack of response may be blamed on lack of interest within minority ethnic communities, rather than the need for different ways to provide information and to raise awareness. For example, one service provider reported:

“... information was translated into Asian languages before we found out that there is a high rate of illiteracy among the older Asian population.”

Lack of support from senior management

Several interviewees had a strong personal commitment to improving access to services for minority ethnic disabled people but they, mainly frontline workers, felt frustrated at the apparent lack of support from senior managers within social services. For example, one centre worker commented:

“There is will on the part of the frontline staff but without a clear lead from the department of social services.... As always, it is left to individual managers and their personal level of commitment.”

Under-resourcing and lack of sustained funding

Lack of financial resources was felt to be a major barrier in improving take-up of services, and in sustaining any positive change. This was seen, by frontline workers, to be closely linked to the lack of interest and commitment they perceived in management.

“There is no financial backup so even with individual commitment from staff, it is next to impossible to make lasting progress.”

As a result, workers with commitment were stretching their resources to try and meet needs in the Asian community.

Insufficient workers with the right skills

Frontline workers also felt over-stretched in terms of their personal skills and resources, and the number of roles they had to take on with insufficient support or funding. As one participant commented:

“... incidental additional skills are being called upon to do something, rather than it being their specific role.”

Small and short-term initiatives

One of the voluntary sector workers who took part was critical of the number of patchy and piecemeal initiatives that had been set up, only to fail and fold in a short period of time:

“There have been several initiatives started in the past but nothing ever progresses or lasts.”

The worker listed several examples:

“There have been a number of small initiatives such as an information day organised by ... and held at X centre. But only two or three people came to that. An information desk from social services was based at Y ... but that has now stopped. There was a luncheon group but that has folded too.”

Insufficient local evidence and pressure to argue for more resources

Some workers were frustrated that there were no reliable figures on the extent and type of unmet need in their local

communities. Such evidence would have been helpful in persuading social services managers to commit resources, and to sustain such commitments over a long period of time. Workers also felt that the comparative ‘invisibility’ of Asian disabled people also conspired to weaken the case for more resources:

“Social services respond to a perceived need. And that because Asian disabled people are not as visible, the numbers are not there to act as an incentive for service managers to provide a service.”

Piecemeal rather than strategic responses to grassroots demand

Some people gave examples of services being set up as a response to demand from a particularly proactive individual or group in the community:

“... responding to pressure from some forceful individuals. For example, Pakistani elders luncheon club took off as a result of pressure from B.”

This is positive, in that it demonstrates services listening to and responding to grassroots demand; but there are also risks that services only get set up where there are powerful community voices advocating for change. This may be disadvantageous to groups such as Asian disabled people who may be less visible and involved in their communities, and who may not know how to make their voices heard and apply pressure on agencies.

Lack of disability awareness in local black and minority ethnic organisations

It was felt that there was a lack of black and ethnic minority voluntary organisations with an interest in disability and disabled people. In Leeds and Bradford, the main organisations seemed to focus on older people rather than on disabled people of working age.

Lack of training and support for workers across voluntary and statutory sectors

Related to a lack of interest, it was felt that many black and minority ethnic voluntary groups lacked the organisational skills and capacity they would need to become service providers or advocates for Asian disabled people in their communities. One local worker explained:

“The problem is that for a voluntary group to start up to provide services geared to community needs, first there are other skills they need to learn such as committee management, organisational and recruitment, financial management...”

Statutory sector workers also expressed a concern about the lack of training and support.

Conclusion

Frontline workers and managers identified a range of barriers that they felt contributed to the low take-up of services among Asian disabled people in their areas:

- apparent lack of interest from communities (mainly identified by managers);
- misplaced emphasis on translating information as the ‘key’;
- lack of support from senior management (mainly identified by frontline staff);
- under-resourcing and lack of sustained funding;
- insufficient workers with the right skills;
- small and short-term initiatives;
- insufficient local evidence and pressure to argue for more resources;
- piecemeal rather than strategic responses to grassroots demand;
- lack of disability awareness in local black and minority ethnic organisations;
- lack of training and support for workers in voluntary and statutory sectors.

This list gives some indication of the difficulties and frustrations that service providers may face in trying to improve services and take-up.

Under-resourcing, overstretched workers, short-term and short-lived initiatives and unsuccessful attempts to reach communities are likely to compound the lack of confidence in services expressed by most of the Asian disabled people in this study.

Several workers identified things that they would like to do if they had the resources, such as:

- developing specific and appropriate services for each community;
- spending more time on building trust and confidence in services;

- employing, for example, an Asian woman worker specifically to go and talk to parents in the community in their own language to build up trust and confidence.

These suggestions and other ideas that came from Asian disabled people are included in the next and final chapter, which draws out some recommendations for service provision.

5

Conclusion and recommendations

This study sought the views of 28 Asian disabled people on what would make their lives better ('quality of life' outcomes); and what would make services better ('quality of service' process outcomes).

The study also explored issues concerned with: low take-up of services among Asian disabled people; difficulties faced by service providers in improving take-up (based on interviews with eight frontline workers and managers); Asian disabled people's experiences of seeking and using services; issues around individual outcomes, family life and community expectations; and the implications of not meeting people's wider 'quality of life' outcomes.

The aim of this study was to get a better understanding of Asian disabled people's views about what would make their lives and the services they use better. This was done to enable the identification of user-defined outcomes as a benchmark against which to measure current service provision, and as a tool to assist the development of more appropriate services to disabled people from minority ethnic communities.

'Quality of life' outcomes for Asian disabled people

- Moving about freely at home
- Independence and choice
- Fulfilling parenting and family roles and responsibilities
- Social contact and company
- Able to pursue leisure activities and interests
- Able to be part of religious and cultural life in the community
- Equal access to public places and printed materials
- Equal access to valued roles (for example, work, marriage)
- Being equipped to make informed choices and plans
- Respect and equality.

'Quality of service' process outcomes for Asian disabled people

- Consultation with Asian disabled people
- Services that meet Asian disabled people's priority outcomes
- Flexibility, choice and control (about who provides support, when, how and where)
- Culturally competent and sensitive services
- Competent services
- Information and advice
- Timely services
- Easy to access services
- Equal and transparent decision making
- Suitable aids, adaptations and equipment.

'Promoting independence' and 'quality of life'

In recent years, there has been considerable emphasis on 'promoting independence', improving 'quality of life' and achieving positive 'outcomes' for disabled people and their families using community care services, including people from black and minority ethnic communities.

An important theme that emerges from this study is what 'independence' and 'quality of life' mean for Asian disabled people.

A narrow definition of independence or independent living is that it means 'doing things for yourself' or 'living alone'. Some disabled people (as in this study) may wish to live alone or to move out of the family home, or to have aids or adaptations to enable greater self-

sufficiency in their home. However, a mistake that has been made within community care policy and service provision is to understand 'independence' in these narrow terms alone.

Disabled people have defined independence in ways which unambiguously reflect a concern with autonomy rather than self-sufficiency:

The concept of independent living is a broad one, embracing as it does the full range of human and civil rights. This means the right to have personal relationships, to be a parent, the right to equal access to education, training, employment and leisure activities and the right to participate in the life of the community. (Morris, 1993, p 7)

Disabled people's notion of independence is about *autonomy*, *choice* and *control*. It is about 'doing things with assistance' rather than having things 'done to' or 'for you'.

Choice and control were of central importance to the Asian disabled people in this study, as well as having the support and adaptations that would enable people to move about freely inside and outside their home. In addition, however, another concept emerged as important to participants. This might be called 'interdependence', which related to Asian culture and customs, and the ways in which young and old people may be mutually interdependent on one another for different things to varying degrees from context to context. 'Interdependence' is about being able to contribute to family life and reciprocate. For the people in this study (including those who wanted to move out of their family home), this was

a core plank of what ‘independence’ meant for them.

Similarly, narrow definitions of ‘quality of life’ that were focused only on basic needs such as personal care conflicted with participants’ views of what would make their lives better and their sense of priority needs and outcomes. Restrictive definitions of ‘need’ for services and adaptations are unlikely to go any way towards achieving the wider outcomes described by Asian disabled people in this study as so important to their quality of life.

Another key message for service providers and policy makers, therefore, is to look beyond people’s basic ‘health and social functioning’ towards people’s wider quality of life. The implication of this research is that having some quality of life which is acceptable and having control over the way that life is lived, may be much more desirable and a higher priority for service users than self-sufficiency (Vernon and Qureshi, 2000).

Making services more effective in achieving user-defined outcomes and cultural competence

Participants and some workers felt that there was still considerable lack of knowledge and understanding among service providers and social services staff about minority ethnic cultures and religions. Some people felt that service providers saw cultural knowledge as irrelevant to service provision, taking the attitude that service users would have to ‘fit in’ to existing services, rather than receive services that were responsive to their needs.

“If I were a social services boss then I should go to university to learn about different religions, about the cultural backgrounds.”

Translating ideas of ‘cultural competence’ into practice means ensuring that staff learn about different cultures as an essential part of training for all social services professionals. It also requires that services should be delivered with respect for, and acceptance of, variations in expectations about:

- family life and family obligations;
- use of space and resources within the family home;
- religious obligations relating to the performance of self-care and domestic tasks.

Often, relatively little change is required to make services more user-friendly and inviting to Asian disabled people and their families. For example, somewhere for prayer; Halal food; separate facilities for men and women in the Muslim community; Asian vegetarian food; and different activities at resource centres that are more interesting for Asian people.

Service providers who took part also felt that there could be benefits from funding, training and building the capacity of local black and minority ethnic voluntary groups to become providers of good quality and culturally appropriate services for Asian disabled people in their community. This would take time and resources, but could yield good results.

Peer support

Access to peer support, social contact and company emerged as important areas of unmet need for many of the participants in this study. Because many Asian disabled people did not attend meeting places either in their own communities (such as mosques) or day centres, they often felt very isolated. People particularly wanted contact with other Asian disabled people for sharing experiences and information.

The best person to talk to an African-Caribbean disabled person is an African-Caribbean disabled person. As black and disabled people we are so used to being told what is ‘good for us’ that the value of having support from someone in a similar situation is invaluable. (Banton and Jain, 2000, p 21)

It is also possible that enabling peer support for Asian disabled people would create opportunities for people to talk through any conflicts they may experience arising out of differences between their needs and aspirations and those of their family, or wider community expectations and attitudes.

Improving take-up of services

This study found low take-up and under-use of services among Asian disabled people, coupled with significant levels of unmet need, and low levels of knowledge of community care services and how to access them. These findings echo those of previous research (for example, Atkin and Rollings, 1993). Atkin and Rollings

(1993) also found that people from minority ethnic communities were interested in using services once they knew about what was available.

It cannot be stressed enough that low take-up of services does not mean low need.

There was an overwhelming feeling in the Asian community that services were not designed for them. A majority of disabled people in the study were relying on family members to provide personal assistance on a daily basis. This is not evidence that Asian people “look after their own”. Rather, it shows how, faced with the barriers identified in this research, many of the Asian disabled people and family members in this study were left with little choice but to rely on each other. People felt forced to depend on family members out of necessity, owing to lack of support or adaptations.

A strong message from this study is that improving take-up of services will require sustained action by service providers on several fronts. In particular:

- spending time to build confidence and trust in services;
- improving people’s knowledge about services;
- making it easier for people to access services;
- ensuring that services are flexible, culturally competent and good quality;
- ensuring that services address people’s wider ‘quality of life’ outcomes.

Suggestions for improving take-up of services

What is needed

- Regular, ongoing consultation and partnership with local groups of Asian disabled people and their supporters: “They should ask our needs, what we need”.
- A clear lead and commitment from senior management in commissioning and provider agencies, backed by adequate resources, to commission and provide culturally competent and person-centred services for Asian disabled people.
- Recognition of the importance of meeting Asian disabled people’s needs for:
 - flexibility, choice and control in service provision;
 - reduced waiting time and less complicated bureaucracy;
 - opportunities for cultural, religious and social integration;
 - peer support from other Asian disabled people;
 - suitable aids, adaptations and housing;
 - accessible information with advice and advocacy;
 - support to fulfil parenting and family roles and obligations;
 - understanding of religious obligations around self-care, domestic tasks, use of space within the family home, and so on;
 - respect and equal treatment by service providers and staff.

Practical ideas for statutory and voluntary sector agencies

- Employing skilled outreach, information and advocacy workers to build confidence and awareness in the Asian community about available services.
- Finding ways to make services easier to use, with less bureaucracy.
- Ensuring knowledge about different cultures and disabling barriers is a core part of training and staff development for social services professionals at all levels.
- Small changes that would help make services more user-friendly and inviting: for example, somewhere for prayer; Halal food; separate facilities for men and women in the Muslim community; Asian vegetarian food; different activities at resource centres.
- Funding, training and building the capacity of voluntary groups from minority ethnic communities to provide quality culturally competent services to Asian disabled people.
- Gathering local evidence and information about need and unmet need.

Regularly reviewing practice

In order to avoid racism becoming a barrier to service provision, service providers need to ask the following questions on a regular basis:

- How are individual practitioners relating to their minority ethnic clients?
- How are service priorities and policies decided, by whom, and for whose interests?

References and further reading

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Appendix: Methodology

Collaboration with grassroots groups

Many disabled, anti-racist and feminist academics have argued that research should employ more collaborative methods, including involving research participants in the choice of topic and identifying the research questions, as well as informing the analysis and use of the findings.

This research was done in close collaboration with two leading grassroots organisations of Asian disabled people: Asian Disability Network (ADN) in Bradford and the Association of Blind Asians (ABA) in Leeds. Regular meetings took place between the researcher and ADN and ABA to provide an opportunity for Asian disabled people to inform and shape every stage of the research process, from agenda setting to dissemination. In order to acknowledge their expertise, value their time and avoid exploitation, each organisation was paid a consultation fee of £150 per meeting plus £70 for members' travel expenses.

The research was conducted in two consecutive phases.

Phase one: preparation and recruitment

First, written documents such as policies and procedures relating to service provision and minority ethnic communities were collected from both local authorities from key informants working within the sector. This was done in order to compare the policies with the reality experienced by disabled minority ethnic service users in the two areas. A literature review was completed.

Twenty-eight disabled Asian people between the ages of 18 to 40 with a range of physical and sensory impairments, and some also with learning difficulties, took part in the research. They were approached through a variety of methods including: opt-out letters to those on social services registers via the information section; publicity to a range of community organisations such as temples, gurdwaras and community associations; visits to day centres; and a slot involving the researcher on a radio programme for the Asian community.

Phase two: data collection and analysis

Twenty-eight disabled people took part in the research: 16 through individual interviews and 12 through a series of three focus group meetings – depending on the preference of each participant.

All the spoken one-to-one interviews and also the group discussions were tape recorded and transcribed to ensure that there was an accurate record for analysis. This was done with the consent of the participants.

In order to preserve confidentiality, pseudonyms are used in place of real names for all the participants throughout this report.