Young South Asians with Learning Disabilities: Still Socially Excluded?

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Abstract

This paper reports on a study undertaken in Glasgow of young South Asian people with learning disabilities and their carers, and explores the extent to which they are socially excluded. Although there is an increasing political emphasis on the inclusion of people with learning disabilities, the families concerned continue to experience isolation, both socially and in terms of service provision. Access to services is often problematic, because of linguistic and cultural barriers and families appear to be reluctant to use day centres. Young people with learning disabilities themselves feel stigmatised, while carers are in need of support, and also apprehensive as to the future care of their children. Although government is promoting a range of relevant initiatives, young South Asians with learning disabilities continue to be an excluded group.

Keywords

Introduction

This paper explores the manner in which young South Asian people are socially excluded, particularly in regard to the provision of and use of services. (The term 'South Asian' is one generally accepted in the literature to refer to people of Indian, Pakistani, or Bangladeshi heritage.) We report on a study of both people with learning disabilities and their carers, exploring their needs and experiences. The research was carried out in Glasgow but the issues it raised are applicable across the UK.

People with learning disabilities are a group which has frequently experienced social exclusion. In England, the Department of Health has published a strategy for children and adults with learning disabilities, *Valuing People* (Department of Health, 2001), as well as commissioning research into the higher prevalence of learning disabilities within South Asian communities, often linked to high levels of deprivation (Mir *et al.,* 2001). This research identified a need to establish support groups for people with

learning disabilities and their carers from the minority communities, to extend specialist provision, for outreach work by services and for bilingual staff and interpreters.

In Scotland, the report, *Social Justice…a Scotland where everyone matters* (Scottish Executive, 1999), set out the Scottish Executive's commitment to promote social justice and equality of opportunity for everyone in Scotland. This was followed in June 2000 by a review of services to people with learning disabilities entitled *The Same as You?* (Scottish Executive, 2000). The review, which involved discussions with both users and carers, recommended the appointment of local area co-ordinators to take forward policies on learning disability. These would include community support, healthcare, improved transport, improved employment opportunities, support for carers, and the promotion of public awareness. The Executive has also established a Scottish Centre for Learning Disability, focusing on training, research,

advice, public education, and policy development.

But despite these developments, people with learning disabilities continue to experience exclusion and this is likely to be greater for people from the Black and minority ethnic communities. *Scottish Homes,* the national housing agency[2], and *Key Housing Association*, which specialises in the provision of housing and support for people with learning disabilities, commissioned research in this area, as part of a wider study of community care needs in Glasgow, in 2000. This paper re-analyses that research, published as Bowes, Sim and Srivastava (2001). Since this research was carried out, Scottish Homes has been renamed *Communities Scotland* under the *Housing (Scotland) Act 2001* and become an Executive Agency.

Background

Although there is an extensive literature on Black and minority ethnic (BME) groups and their use of care services (for example, Atkin and Rollings, 1993; Blakemore, 2000), there is a dearth of research on the needs and experiences of people with learning disabilities from Black and minority ethnic groups. Significantly, there are few studies which have attempted to ascertain the views of people themselves (Azmi *et al.,* 1997; Bignall and Butt, 2000, Emerson and Robertson, 2002). Views of carers are more likely to be examined (Chamba *et al.,* 1999).

The incidence of learning disabilities among minorities appears higher than in white communities (Emerson *et al.,* 1997). Possible reasons include the general effects of social and educational deprivation, inequalities in access to maternal health care and higher rates of genetic abnormalities and/or environmental risk factors. Butt and Mirza (1996) and Mir and colleagues (2001) similarly suggest a link to deprivation and poor socio-economic conditions.

Turning to studies which have explored the views of people with learning disabilities themselves, Azmi *et al*'s (1997) study revealed 'double discrimination', on the basis both of ethnicity and disability. Culturally appropriate services were not generally available, people lacked social contact, and their range of social activities was restricted. These findings parallel those of a Scottish study (Stalker *et al.,* 1999), which suggested that people with learning disabilities from Black and minority ethnic communities experienced additional exclusion on ethnic and racial grounds.

Bignall and Butt (2000), who interviewed 44 young people of Asian, African and Caribbean origin, most of whom had learning disabilities, found that people's most immediate concern was independence, although most relied on their families for support. Participants also reported loneliness and isolation, an issue which emerges consistently in other studies (Bignall *et al.,* 2002; Vernon, 2002; Atkin and Hussain, 2003) and is also experienced by many carers. For South Asian carers, there has been an assumption that support is available within extended family networks, but Baxter *et al* (1990), Hatton *et al* (1998), and Emerson and Robertson (2002) argue that this is not necessarily the case.

Support services for carers can combat exclusion but research shows that information about and use of services is often quite poor. Chamba *et al* (1999), for example, surveyed nationally nearly 600 South Asian and African Caribbean parents of severely disabled children, and compared their findings with those of a previous study of white families (Beresford, 1995). The study found that Black and minority ethnic parents and children with disabilities were at greater disadvantage, with less access to benefits, poorer information about services, less support from partners and families, higher reported unmet need, lower incomes, worse housing, fewer breaks from caring, and lower support group membership. For

many carers in Hatton *et al*'s (1998) study, adolescence proved to be a particularly difficult time, as people 'grew out of' support services aimed at children of school age. But carers had little informal support and a low awareness and use of specialist services. These findings are echoed in a later study by Hatton *et al* (2002), and by (Vernon, 2002). The appropriateness of services for people with learning disabilities has also been questioned by Azmi *et al* (1996), who argue that there is a need for the employment of more minority staff, whose understanding of issues of learning disability in their own communities must be taken into account in service development.

In summary, the literature paints a picture of a group of individuals and their carers who are quite isolated both socially and in terms of service provision. Needs have not always been adequately assessed and families have often had to undertake the caring themselves. There are problems in both accessing and using services, as communication strategies have not been sufficiently innovative to allow information to reach those who need it, and care services are not always culturally sensitive. There is the added problem for many parents and carers of looking ahead to a time when their children 'grow out of' the limited services which are available to them. Thus the experiences of both Black and minority ethnic people with learning disabilities and their carers seems to be at odds with government policies aimed at social inclusion. This suggests that the policies are not wholly effective and that services aimed at tackling exclusion are not reaching those most in need. Our research therefore sought to establish the extent to which the specific needs of people with learning disabilities from the minority ethnic population were being addressed, focusing in particular on their experiences.

Methods

The research reported in this paper was carried out as part of a study of community care services for Black and minority ethnic communities, funded by Scottish Homes, the Glasgow Community Care Joint Strategy Group and Key Housing Association. A series of semi-structured interviews was conducted with eight carers (who were looking after nine children with learning disabilities between them) and, separately, with six people with learning disabilities. This provided us with data on 15 people with learning disabilities. Interviewees were identified via the services they were using, and care was taken to seek volunteers, rather than nominees of the service organisers. The sample size was rather small, reflecting difficulty in identifying potential interviewees but the work was exploratory and the numbers were sufficient to provide us with many valuable insights into issues of exclusion. Within the paper, the views of both carers and people with learning disabilities are quoted to illustrate the issues.

The interviews with people with learning disabilities themselves explored the following topics:

- Basic demographic data about the service user, including sex, age, ethnicity, religion, languages spoken, household circumstances, and whether they had care at home;

- Their daily living circumstances, including their activities and outings;

- Their own perceptions of how well they were, physically and mentally;

- Whether they used a range of housing, health and social care services, their views and knowledge about these services, their experiences of using services, and the extent to which they felt they were getting all the help they needed.

The interviews with carers covered similar ground in terms of demographic data, living circumstances and use and experiences of services, and added questions about the

101

length, intensity and nature of the experience of caring.

The process of making contact with the families and the children with learning disabilities involved careful introductions through trusted intermediaries. Before interviews were held with the children, the researcher visited several times to build familiarity, and the process of interviewing itself took place informally, often in several stages, to enable the children to express their views at their own pace. Thus, the informed consent of all potential interviewees was obtained and they were assured of anonymity. Interviews were conducted by a South Asian researcher using the language preferred by the respondent (Hindu, Punjabi or English) and, where necessary, were then translated into English by the interviewer. Transcribed interview data were managed using the software package NUD.IST. Analysis initially involved sorting the topics on the basis of our questionnaire while looking for emerging issues and themes. As new themes emerged, these were identified and relevant data separated out and reported on; thus, the themes which emerged were very much from the standpoint of the interviewees themselves. We also looked at the interviews as a whole so we could obtain a grasp of individual views, as well as the balance of views across participants.

The study did not seek out people who were not using services, as this would have been disproportionately costly, but opportunities were taken during the interviews with service users to ascertain what they felt the limits of services to be, and also their views about the appropriateness of existing provision, as well as their knowledge of services.

The eight carers interviewed were all female. Their ages ranged from 30 to 43 and, between them, they cared for nine children with learning disabilities, aged from 3 to 15. Six carers were Muslim and of Pakistani heritage; the remaining two were Indian and

Hindu. All but one had lived in Scotland for either their whole life or a considerable part of it.

The ages of the 15 people with learning disabilities ranged from three to 32, but the average age was 14 and all but two were of school age. Eight were female and seven male. Ten were Muslim, four were Hindu, and one was a Sikh. Although there was a range of minority ethnic backgrounds within our sample, the experiences of the respondents did not vary according to their specific ethnic background; rather minority ethnicity in general appeared more important.

Two of the families were living in housing association accommodation, the remainder in owner-occupied housing. Houses ranged in size from two to five bedrooms and family size varied also from three to nine people. In four cases, grandparents or in-laws lived in the house, but mostly, there was no 'extended' family and, with a partner at work and other children at school, the carer and her child would be alone in the house.

Results

Some of the issues arising from the interviews appeared to have a general applicability to people with learning disabilities and their carers. Others were more specific to Black and minority ethnic households and demonstrated the 'double discrimination', based both on ethnicity and disability, described by Azmi *et al* (1997). Thus issues such as isolation, stigmatisation and the strain of caring apply widely, although they may be particularly problematic for Black and minority ethnic households. Issues of service access and service use and sensitivity to language and culture are more specific to Black and minority ethnic disabled people and their carers. In presenting the results, the quotations are identified as being those of carers or of young people with learning disabilities. The number is the reference number we used in our analysis.

Isolation

One of the most striking issues to emerge was the widespread experience of loneliness and isolation. Some people rarely went out, sometimes because of the difficulties in organising to leave the house and sometimes because the disabled child felt embarrassed by the hurtful comments of others:

> Because of his disability, he feels very shy, and so we are virtually confined to the house. It's very tiresome.
>
> (Carer, 3102)

Sometimes, carers would go to day centres, but such centres were not always very accessible and carers experienced difficulties in getting their children there without adequate transport:

> We spend most of our time at home. Recently, he's started going to this Centre, which is for disabled children, and I come here to this Centre for a change and relaxing ... It offers respite to carers like me. I get to meet other carers and that helps emotionally and mentally. [But] ... I would prefer it if they had a transport to pick me up and drop me back home.
>
> (Carer, 3103)

For carers, there appeared to be a need for respite and for greater home visiting. Young people with learning disabilities themselves also raised the need for more visitors:

> I want to play with another girl. She should speak my language. My brothers will stop playing with me, then I won't have anyone. I'll get very bored..
>
> (Young person, 2113)

Stigmatisation

Many of the interviewees with learning disabilities described feelings of self-consciousness, resulting from being 'looked at'. They felt stigmatised and the limited number of research studies which have interviewed Black and minority ethnic people with learning disabilities themselves emphasises their lack of voice (Stalker *et al.,* 1999). A number had both learning and physical disabilities and frequently had

mobility problems, their comments echoing earlier work by Connors and Stalker (2003):

> I want to go out but I can't walk and in the wheelchair, everyone looks at me.
>
> (Young person, 2114)

> I hate it in the wheelchair. I see other kids normal and I'm not like them.
>
> (Young person, 2117)

In describing the limitations on their activities and daily life, people with learning disabilities referred specifically to their inability to play with other children or attend school on a regular basis. Those who did manage to go out with their families often felt conspicuous:

> I like going out but people look at me so I don't like it.
>
> (Young person, 2113)

> I don't like people looking at me as if I was funny.
>
> (Young person, 2116)

Thus, many people felt restricted in their movements and activities. Because those who were cared for sometimes experienced embarrassment, this made carers more reluctant to go out, thus emphasising their isolation and exclusion.

The caring role

For the carers, daily life was largely absorbed by their caring role and many described themselves as doing 'everything' for the person they cared for. Others listed a range of tasks, including personal care and practical help:

> From morning to evening to night, I've to do everything for her - clothe her, feed her, help her with her bath, toilet, everything.
>
> (Carer, 3101)

> I do everything for him. I even wake up so many times in the night. Everything you can think of I do for him.
>
> (Carer, 3102)

103

A number of those cared for were severely impaired and their frustrations sometimes led to self-harm and challenging behaviour:

She can't walk very well. She's also not too quick mentally – or rather, she's slow. She loses her temper too quickly. She throws tantrums and I'm always worried that she may harm herself physically.

(Carer, 3101)

Her mind is not very well developed. She gets very angry and is prone to harming herself....I have to take care of her completely.

(Carer, 3105)

The support they received was also recognised by people with learning disabilities themselves:

She [Mother] dresses me in the morning, brushes my teeth, helps me with my toilet then we play. She reads to me many stories also.

(Young person, 2116)

My mummy does everything. Brushes my teeth in the morning, dresses me, feeds me breakfast, reads me stories, plays with me. When my brothers come home from school, they play with me.

(Young person, 2117)

Respondents were asked about their daily activities. Carers were almost completely occupied with their care work, so that they were sometimes prevented from doing other household tasks. Occasionally, however, housework could become a joint activity. Comments from those cared for included:

In the day, when my brothers are not home, mummy has to do housework and there's nobody to play with...I need another girl of my age, who can speak Punjabi, as that is the language I speak.

(Young person, 2117)

I help my mother in cleaning the house and tidying up. And I go out with her sometimes to visit my sister or my brother. In the evening, I am at the house.

(Young person, 2512)

The constant caring and the inability to pursue other activities sometimes became overwhelming for carers:

I get very tired looking after him. Sometimes I so wish to be able to go out for just some change, some company, but I can't leave him alone.

(Carer, 3102)

I get very tired and very bored. How much can you stay at home looking after the same person, day in and day out?

(Carer, 3103)

Many carers accepted their tasks as their duty, and did not seek any rewards:

She's my own daughter - you can call it rewards, but most of the time I feel sad about it. She's a girl who hardly has a future. My problems are nothing compared to hers. I just feel really sad and tired all the time.

(Carer, 3101).

He's my son. I don't think in terms of rewards. No rewards, no problems. No choice. It's my fate.

(Carer, 3102)

In terms of Parker and Lawton's (1994) classification of caring roles, our respondents were towards the extreme end of the classification, involved in the most arduous forms of informal care, living with the person for whom they cared, working long hours and completing a wide range of tasks. The interviews revealed a striking focus on home and family and there was little mention of school, other than the difficulties of attending. This compares with some other work (for example Hatton *et al.,* 2002), where experiences of schools featured more significantly.

Service use

Under-use of services by Black and minority ethnic groups in general is reported by Butt and Mirza (1996), and this is borne out by our own findings, which suggest that service use is an area where Black and minority ethnic carers and those cared for are particularly disadvantaged. All interviewees used services, but in a rather limited way. All 14 mentioned their GP and nine used a health visitor. Two people mentioned using a community nurse and two people made use of day centres run by the voluntary sector.

No interviewees had used the Social Work or Housing Departments or home help/home care services. Five of the eight carers and five of the six people with learning disabilities all stated that they would like more information on such services, so they could then make an informed decision on whether to use them. Despite expressing feelings of isolation, not all respondents were interested in finding out more about day centres (only five carers and two of those cared for). This could reflect a view that caring was seen as a responsibility of the family or it may be that day centres were not seen as providing the additional support which was required.

There certainly appeared to be a low usage of services by people with learning disabilities and their carers, and the lack of use of housing services appeared to be borne out by the obvious unsuitability of the housing of some of the respondents. People with learning disabilities emerged as a group lacking service use and service access, not least due to lack of knowledge of services. This echoes previous findings, for example Azmi *et al* (1997) and Chamba *et al* (1999).

Access to services

Respondents were asked how they gained access to services, in order to demonstrate the routes to service use and the existence of possible barriers. Few had contacted services without help and for many people, the GP surgery appeared the first point of contact with any services. Help had come from friends and relatives, indicating the importance of informal networks; word of mouth was particularly important in identifying those services where Asian languages were spoken:

> *[I] was told about this Asian GP by my neighbour, so I moved to her three years ago… She's a woman and can also speak Punjabi.*
>
> (Carer, 2518).

Although families had often received help in locating appropriate GPs, this was not the case for other services. People appeared to

lack social networks and were not involved in community groups. Thus, they had few means of contacting services, despite being in need. We explored service needs by examining potential gaps in provision, and by asking people what they felt their needs were.

A number of carers identified particular needs, often relating to a lack of information about what services were available:

> *More information given about public services would be useful, in our own language, as at present I have no knowledge about public services.*
>
> (Carer, 2514)

This lack of information about services, coupled with the fact that such services were not always culturally appropriate, has been established by research into other excluded groups such as South Asian older people (Bowes and Dar, 2000).

Issues of language and culture

A recurrent theme in the literature is the issue of language barriers (for example, Bowes and Dar 1996, 2000). As the previous quotation demonstrates, this was echoed by many of our respondents, who believed that there was a need for interpreting, due to difficulties with English:

> *The GP doesn't speak Urdu. I have to take someone with me. [I would like] an interpreter present at all times.*
>
> (Carer, 2517)

> *They [health visitor and community nurse] don't speak the language, so they have to come with an interpreter.*
>
> (Carer, 2514)

Language was not the only issue, however, and there was a belief that white health staff were less likely to understand the various culturally based needs of Asian families. Sometimes the gender of the GP was also an issue, with carers expressing a preference for an Asian woman:

> *I've been with my GP for over ten years…He's*

105

a good doctor. He's Asian so he understands our language, our family history.
(Carer, 2514)

Actually, both the health visitor and community nurse are white women. I'd prefer an Asian woman.
(Carer, 3101)

She [health visitor] is also an Asian woman, so we are very comfortable with her.
(Carer, 3107)

Services therefore required bilingual workers or interpreting facilities, cultural awareness, and often staff of a particular gender. The need for services in an appropriate language is likely to be particularly important for people with learning disabilities, who tend to be at home most of the time and learn only one language.

Looking to the future

The literature identifies a problem of insufficient support for carers with adolescent children (Hatton *et al.,* 1998) and a number of carers interviewed raised issues about the future. Some carers recognised that their families would probably help, but believed such help would be limited:

I have to carry my son, up and down. Even though I live in a joint family [with brother-in-law and his family], during the day, I have to do everything. My son is now nearly 15 and it's very difficult carrying him all the time. I need some help with him.
(Carer, 3103)

This person recognised the problem, but was unclear what alternatives were available. Indeed, there were sometimes concerns about how other members of the family would cope in a crisis:

That's what really worries me. My husband and sons care, but nobody can look after her like me.
(Carer, 3101)

There was also the question of the availability of emergency help. Some carers saw this as a particular problem, and it was not clear how they would have managed to

deal with such an eventuality. Sometimes, there had been a specific incident, as related by one of the people with a learning disability:

Once I fell down from my bed in the night. There was a big bang. I hurt my hand. We had to go to the hospital in the night.
(Young person, 2115)

In other instances, carers expressed fears about the potential for accident, aware that they might not be able to cope. One carer looked after a daughter who was likely to harm herself:

We'd like to be able to go out and how much can you sit at home, but what choice does one have? ... I'd like to lead a normal life but I can't leave her alone for a minute, because as I said she can harm herself physically. I need to keep an eye on her all the time.
(Carer, 3105)

In conversation with carers, it became clear that emergency help was likely to be provided by a relative; calls upon family help usually appear to have come first.

Respondents were asked to identify their biggest current problem. The carers picked out aspects of their caring roles, referring to the physical and mental strain they were experiencing:

I can either look after my daughter, or do all the housework. I cannot neglect my daughter.
(Carer, 3101)

Another carer stated that her biggest problem was:

Everything. It is not a very happy life. I am quite sad with my situation, but that is my fate.
(Carer, 3107)

Carers' worries focused on those they cared for, what their future would be, and who would look after them if the carer were unable to do so. Such responses indicated people at the end of their tether, surviving on stretched resources, who, from an outsider's perspective, certainly needed support.

Conclusions

A number of issues emerged from the study. Some issues would be common to a wide range of people with learning disabilities and their carers, notably isolation and exclusion, and related feelings of stigmatisation. The isolation of those cared for appeared to be worsened by absence from school attendance, although we did not explore this in detail. Secondly, the burden of caring was substantial. This suggests that both carers and cared for required support but both use of and access to services were poor. Day centres provide a useful service but were not easily accessed by public transport; alternative support, through the development of both home visiting and respite might be appropriate. There is often an assumption that home visiting is provided by relatives, but our study supported previous research findings that this was not always the case and carers could not necessarily rely on family support.

In most cases, the same issues were raised by both carers and cared for. The main difference related to the inability of carers to pursue other activities because of the demands made on them by those they cared for. Those cared for, understandably, did not always recognise this.

There were specific issues which were of particular relevance for Black and minority ethnic groups and one was the poor availability of information about services. There remains a need for information to be communicated in minority languages and this may be particularly necessary for people with learning disabilities whose command of English may be poor. The importance of having an Asian GP or health visitor was stressed by almost all those interviewed. The absence of translated material contributes to the double exclusion being experienced by minority ethnic people with learning disabilities.

Lastly, there are likely to be significant problems in the future in providing support for young people with learning disabilities, as they and their carers grow older. This confirms the findings of Hatton *et al* (1998), that adolescence was a particularly difficult time, as people 'grew out of' many of their support services, as well as the work by Katbamna and colleagues (2000) on the stress experienced by carers as they aged.

How are these issues being addressed? Strategies developed by the English Department of Health and by the Scottish Executive have helped to increase awareness of the needs of people with learning disabilities and there is a continuing drive to close long stay hospitals and move residents into communities. The new Scottish Consortium for Learning Disability (SCLD) has focused on building respect for people with learning disabilities, as well as encouraging the development of 'joined up' services. A significant initiative has been the establishment of local databases on people with learning disabilities and their needs, which will hopefully lead to better service provision.

There is, as yet, little specific focus on people with learning disabilities from the Black and minority ethnic communities, although this is now being addressed by the SCLD. There has been important liaison with the Minority Ethnic Learning Disability Initiative (MELDI). First established in Edinburgh but now also operating in Glasgow, this voluntary body aims to build links with existing agencies to improve access to services for people with learning disabilities and their families and carers. The group has received funding from the Scottish Executive for a bilingual worker and this represents a useful step in improving service provision. That said, its expansion has come rather late in the day and suggests that other groups (such as older people) have perhaps been seen as a greater priority within the Black and minority ethnic communities, although this was not mentioned by interviewees.

107

There can be little doubt that the needs of people with learning disabilities are being taken increasingly seriously. Within Scotland, reports such as *The Same as You?*, new legislation and the establishment of both the Consortium and initiatives such as MELDI, represent important steps forward. But, nevertheless, the continuing absence of culturally and linguistically sensitive services confirms Stalker's (2000, 2002) view that Black and minority ethnic care needs in particular have been given insufficient political prominence in Scotland.

Given the great difficulties experienced by those people in our study and the significant degree of isolation and loneliness experienced by both carers and cared for, it is clear that much still needs to be done. While progress is being made, people with learning difficulties from the Black and minority ethnic communities remain a particularly socially excluded group.

Acknowledgements

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110