








South Asian young disabled people and their families

A study in West Yorkshire and the West Midlands, by Yasmin Hussain, Karl Atkin and Waqar Ahmad at the Centre for Research in Primary Care, University of Leeds, talked to young South Asian people with impairments and their families. They were asked about their everyday lives and how these views could be reflected in the policy and practice of the services which affected them. The conversations focused on impairment and disability as well as religion, culture and ethnicity.

-  **South Asian young people's experiences of disability had important similarities with those described by their white peers.**
-  **Some young people complained of being denied the opportunities given to their non-disabled brothers and sisters because of social prejudice and discrimination against disabled people, particularly in relation to employment.**
-  **Young people generally described loving and supportive family relationships, although their families sometimes had low expectations of what they could do and were overprotective, particularly towards young women.**
-  **Independence, although important to young people, was about exercising control over their lives, and not just about leaving home.**
-  **There was a strong desire to hold on to their religion, culture and ethnicity by both young people and their families and little evidence of the struggle which is sometimes presumed to be taking place between generations of Asian families. However, young people also valued being British and felt that they were treated better in Britain than in South Asia.**
-  **Young people and their families felt discriminated against on the grounds of both ethnicity and disability.**
-  **There is a need for policy and practice to recognise diversity and not assume that Western ideas about disability and independence have the same meaning for Asian young people and their families.**

Introduction

The study set out to suggest ways of improving services to young Asian people with impairments and their families (14 parents and 15 brothers and sisters). Twenty-nine young people in West Yorkshire and West Midlands and their families were interviewed to find out their views on everyday life and the contact they had with services.

Family relationships and disability

The young people described loving and caring family relationships as well as their parents' low expectations and overprotectiveness. Parents tried to make sure their children got the best opportunities. These families faced similar difficulties to those described by white families with providing practical, social and financial support. They also experienced a lack of understanding from their own communities. Overprotectiveness was a particular cause of tension between the young people and their parents. Young people often interpreted their parents' actions as an over-reaction to the difficulties they faced. Twenty-six-year-old Hardeep said her family were supportive, although they sometimes irritated her by worrying about her too much:

"I'll get angry if they put me in cotton wool or something like that, if they watch me every minute."

Gender was of particular importance here. Female reputations were seen as more easily damaged and less easy to repair in South Asian communities. Families therefore placed more restrictions on the young women interviewed than they did on their (disabled and non-disabled) brothers and non-disabled sisters.

As with all young people – irrespective of impairment – they negotiated rules with their parents. They enjoyed being useful in the family, supporting their parents and offering advice to other family members. In keeping with young people in general, they also identified with youth culture – clothes, music and television – as well as the ordinary realities of school, employment and home life.

Young people and their families sometimes felt

discriminated against by their extended family. Shushma's sister, for example, described a recent family occasion: "We went to my aunt's house the other day and everyone said 'Why did you bring her?'"

Social networks

Other people's views of disability in the wider world also affected the young people in the study. Twenty-eight-year-old Gurupal said:

"The worst thing is that people do not understand what makes your life difficult, but it's their kind of ignorance that annoys you sometimes and makes you upset."

Young people felt that, compared to their brothers and sisters, they missed out on social opportunities and faced discrimination in education and, in particular, in employment. They also experienced discrimination on the grounds of ethnicity, which increased their feeling of being left out of things.

Compared to their brothers and sisters they felt isolated. Waseem expressed disappointment over how his friends had treated him since he became disabled: "They have all forgotten me". Some young people had few or no friendships beyond family life. Nineteen-year-old Shakeel, when asked what he did in his spare time, responded: "I think every day is spare time for me". A few young people saw disability more positively and drew strength from this. Twenty-eight-year-old Gurupal reflected on social disadvantage:

"I think it's important that we are given the opportunity to showcase our abilities. I don't think of myself as disabled. It's society who's disabled by not enabling me to do stuff."

Not all young people and their families had a politicised view of disability. Gaining independence, leaving home, living separately or having personal control of resources did not always have the same significance to these young people as it did to their white counterparts. Young people tried to balance

having control over their lives with taking an active role in their families and helping out family members.

Being a young disabled Asian person

As well as making sense of disability, young people wanted to enjoy their ethnic, cultural and religious identity. Popular discussions about second generation Asians seem to overemphasise cultural conflict between young people and their parents. This study suggested more continuity and negotiation. The ideas and values held by the young people and their families often combined elements of their British identity with their ethnic, religious and cultural heritage.

Many young people and their brothers and sisters identified with being British rather than Pakistani or Indian. Their sense of Britishness was based on being born and living in Britain. There was a general sense that the values of the South Asian community living in the UK were more supportive of disabled people than those held in their parents' countries of origin. Young disabled people felt they were respected more as impaired people in Britain than in South Asian countries.

Religion was important to young people, although they felt that they had limited access to its practice and education. Most had a working knowledge of religious and cultural traditions. Where they had only a little knowledge so did their brothers and sisters. In a sophisticated argument over Muslim identity and codes of dress, young Muslim women characterised their parents' religious objections to Western dress as being 'ethnic' rather than religious, arguing that Western dress which protected their modesty was entirely appropriate.

The role of services

A sense of difference was reinforced by racism and discrimination and influenced how South Asian young people made sense of their lives. Racism had important implications for services. Young people and their families often found that services were unable to respond to their needs. They felt excluded from services because of cultural insensitivity and by

stereotypes of both culture and disability which did not take account of their real life needs.

Nasira, for example, remarked: "We have to fight for everything." They felt it was more difficult for South Asians than it was for white disabled people to get what they wanted from the welfare state.

Conclusion

Disability was a powerful influence on how disabled young South Asian people saw themselves but so was racism and the low expectations of their parents and community. Young people had to deal with negative views of disability, both from their family and the wider society. This suggests people with impairments share a great deal beyond ethnicity.

Impairment can only be made sense of within the whole picture of someone's life. Ethnicity, youth culture, gender and religion were important aspects of their identity. Accepted ideas about disability and impairment are often based on the experience of general population and do not always recognise the diversity of people's experience of impairment and disability.

Although this sample consisted largely of Pakistani Muslim people, the Sikh respondents also reported similar experiences and views but more work is needed in this area.

Policy and practice should reflect this diversity of experience and not assume that Western ideas about disability and independence have the same meaning and appropriateness for South Asian young people and their families. In particular services need to become more sensitive to the cultural and religious values held by young people and their families and recognise how these interact with the experience of disability. Doing this will help to make sure that services are better informed about what minority ethnic people with impairments and their families want, rather than drawing on discriminatory stereotypes based on disability and/or race. This report helps provide some of the information for a fuller picture of what young people with impairments want.

About the project

This was a qualitative study. Of the 29 young people interviewed, 16 were men and 13 women aged between 11 and 30 years. Of these 19 were Muslim and 10 were Sikh. Eight were at college, one at university, nine on training courses and four were working. Most lived at home. Eleven were married and two were divorced. Fourteen parents were interviewed (five fathers and nine mothers). The researchers also spoke to 15 siblings (nine brothers and six sisters).

The interviews were in Punjabi, Urdu and English and were audio-recorded. Full transcripts were used for the analysis.

How to get further information

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The full report, **South Asian disabled young people and their families** by Yasmin Hussain, Karl Atkin and Waqar Ahmad, is published for the Foundation by The Policy Press as part of the Social Care: Race and Ethnicity series (ISBN 1 86134 326 4, price £10.95).