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# **Cultural competency: professional action and South Asian carers**

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## **Abstract:**

Inequality and exclusion are characteristic of the experience of UK South Asian communities. In health care, community needs are often not addressed by health and social welfare services. An increase in cultural competency is now part of identified policy. The aim of this paper is to examine the extent to which there is evidence of cultural competency amongst professionals concerning South Asian parents caring for a person with cerebral palsy. Semi-structured interviews were conducted with respondents from 19 service organisations. Results are presented on perceptions of service delivery and on the dynamics of service development: evidence is found that inadequate service delivery continues despite professional knowledge that it exists. Conditions necessary for the achievement of cultural competence are discussed. We suggest that service development to meet the needs of South Asian carers must form part of an overall strategy geared to change at different levels within and outside service organisations.

## **Introduction**

There is considerable evidence that inequality and exclusion are characteristic of the experience of South Asian communities in the UK (Modood et al 1997). Socio-economic disadvantage is apparent in higher levels of poverty, poorer housing and higher unemployment than is found in majority ethnic communities. In health and healthcare this inequality is replicated, not least in the higher incidence of certain conditions such as cerebral palsy, learning disabilities, and chronic illness within some South Asian communities (Azmi et al 1996; Nazroo 1996; Sinha et al 1997). Moreover, it has been

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found that the needs of these communities are often not addressed by health and social welfare services, resulting in inappropriate provision and consequently low take-up of services (Chamba et al 1999; Atkin and Ahmad 2000).

Institutional racism has been a fundamental force in the difficulties faced by ethnic minority families with healthcare needs (Atkin and Ahmad 1998). Stereotypes of South Asian families 'looking after their own' are sometimes used by service providers to explain low take-up (Atkin and Ahmad 1998). In addition an 'information vacuum' exists in terms of literature available to non-English speakers (Chamba et al 1998). Carers and service users may lack awareness of services, there may be no minority ethnic staff that can speak their language or advise on their needs, existing services may be culturally inappropriate in terms of diet, activities and staff provision. Along with racial discrimination all these factors have been shown to contribute to low take-up of health and social services (Atkin and Ahmad 2000, Chamba et al 1999, Hatton et al 1998).

Service responses to these inequalities in provision have also provoked criticism. The 'colour blind' approach adopted by some service providers, in which services are offered on the same basis to all ethnic groups, fails to acknowledge that provision is geared towards the norms of white culture, ignoring the needs of minority ethnic communities and the barriers they may face in accessing services (Ahmad and Atkin 1996). 'Special needs initiatives' have supplied an alternative institutional response. Service provision can appear to be responding to the needs of minority communities by providing specialist services but these may function as surrogate forms of racism; although generally inadequately funded such services are used to absolve mainstream services of responsibility whilst sustaining structural inequalities in service delivery (Ahmad and Atkin 1996, Priestley 1995).

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The Acheson Inquiry into Inequalities in Health (1998) recommends an increase in 'cultural competency' on the part of service providers. It suggests that a greater sensitivity and response to the needs of minority ethnic communities would help to overcome the disadvantage they currently experience (Acheson 1998). The aim of this paper is to examine the extent to which there is evidence of 'cultural competency' in the action of professionals concerning South Asian parents caring for a person with cerebral palsy. Despite a higher incidence of cerebral palsy amongst South Asian communities (Sinha et al 1997), little is known about the experience of carers and the extent to which they are supported by service provision. We explore the response of health and social care organisations to the needs of these carers and highlight the barriers that may first need to be addressed before services can develop in ways that meet the needs of South Asian service users.

### **Methodology**

The study was the result of a joint initiative between the Centre for Research in Primary Care, the Asian Disability Network and SCOPE and was conducted in two cities in the North of England. Respondents from nineteen service organisations were included: five social service organisations, six statutory health services and eight voluntary bodies.

Qualitative interviews were carried out with two specialist health visitors, two consultant paediatricians, a genetic counsellor, a general practitioner, three social services officers, a residential care manager, a family placement officer, and eight people from voluntary organisations (see Appendix). In addition, as part of a wider study twenty South Asian carers were also interviewed. This paper draws heavily, though not exclusively, on the data from service professionals.

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A qualitative approach was adopted with the aim of providing in-depth contextualised data. The main method of the study was the semi-structured interview. A topic guide for use with respondents identified key themes developed from a review of literature on cerebral palsy, ethnicity and disability, and the development of health and social services. Interviews with service providers covered information about the services they offered as well as their perceptions of the needs of South Asian families caring for a disabled child. The topic guide also explored individual and organisational responses to these needs and the perceived strengths and weaknesses of the services offered to South Asian families.

Formal analysis of transcripts was based on the ‘framework’ approach (Ritchie and Spencer 1994). Information was taken from transcripts and transferred onto a map or framework, allowing comparison by theme and case. Use was made of polarities to explore themes and negative cases were pursued in order to challenge emerging interpretations of the data, and therefore, to enhance validity (*ibid*). A second member of the research team checked the reliability of coding. In the accounts below, pseudonyms are used to protect respondents’ identities.

## **Results**

The following presentation of results examines two broad themes relating to the achievement of cultural competency: perceptions of service delivery to South Asian families and the dynamics of policy implementation and service development. The discussion which follows explores how these themes relate to organisational change and highlights issues which may need to be addressed before effective steps can be taken to meet the needs of service users and carers from minority ethnic communities.

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### **Perceptions of service delivery to South Asian families**

Respondents from service organisations were all able to identify a range of barriers faced by South Asian people, which did not exist for the ethnic majority population.

Interviewees referred to the double potential for exclusion presented by disability and by belonging to an ethnic minority group. They recognised that services may be inappropriate for South Asian families and not designed to meet their needs.

Communication barriers were most commonly acknowledged, however all those interviewed also recognised that services currently suffer from a lack of ability to adapt to different cultures:

We're not very good at dealing with other cultures and have had some very difficult situations here

(Andrew Ellis)

Some professionals showed a more specific understanding of these barriers and their consequences. Carole Smith, Diane Baker and Ellen Martin all recognised that difficulties in communication would almost certainly prevent a relationship that offered much emotional support. They also recognised that this could encourage mistrust and prevent carers being open about their needs.

Although many of the specific needs of South Asian carers were clearly identified by service providers they were not, however, adequately addressed and in many cases were given a low priority, often falling into the category of 'future developments'. A number of professionals interviewed felt that barriers to service provision were symptoms of a wider problem in society. Harold Watson felt that feelings of alienation might lead

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South Asian people to perceive Social Services as not being relevant to their needs.

Andrew Ellis and Bill Jones pointed out that cities with large populations of South Asian communities were relatively under-resourced in view of the higher incidence of impairment and illness amongst these communities:

I don't even know if a high birth rate comes into it, because [this city's] birth rate is relatively high compared to other places. So if we have 370,000 people, we've probably got more children than most other communities with 370,000. Out of those children, we've more children with medical problems than other places

(Bill Jones)

Despite this level of awareness however, many of those interviewed failed to recognise that specific procedures and structures within their own organisations had a negative impact on access and also on the development of services for South Asian people. For example, our data showed that telephone help-lines for carers often assumed English language skills and the confidence to use the system, which many South Asian carers did not possess (Mir et al 2000). Respondents often referred non-English speakers to other agencies without knowing whether language support would be available. Standardised methods of inviting feedback from users of the service often excluded South Asian people from the process. Consultation and discussion groups were promoted in ways that attracted little if any participation from the South Asian communities. Written evaluation forms in English only were more likely to exclude comments from South Asian people than other service users. In one instance a group for South Asian carers which failed to attract parents was not evaluated at all and therefore nothing was learnt about parents' reasons for not wishing to take part.

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Where South Asian staff were employed by health and social care organisations, respondents felt the level of service delivery was much improved. Staff were able to facilitate communication between carers and professionals as well as taking on a consultative role with colleagues. Integral members of health and social care teams were felt to be more effective in this respect than peripatetic workers with whom neither service users nor co-workers could establish continuity and trust. However, we found that within teams, there was often an over-reliance on one or two South Asian individuals to deal with all issues relating to South Asian communities. In one Social Services department, for example, a major consultation exercise for disabled people and carers went ahead without the involvement of minority ethnic groups or individuals because a South Asian worker was on maternity leave.

Models used for consultation and evaluation appeared themselves to sustain inequalities in service provision and to prevent the development of policies that focused on South Asian service users. No specific measures were usually afforded to ensure that users and carers from minority ethnic groups were adequately involved. As a result, service developments that followed consultation focused on needs expressed by the majority ethnic population. It is likely that this would create an even wider gap between the quality and level of services they and members of minority ethnic communities experienced.

Recognition of inequity in service provision was expressed both by professionals who had taken specific action to counteract the bias they perceived and by those who had done, by their own admission, very little or nothing to improve services within their own or their team's remit. It appears, therefore, that an awareness of the barriers faced by



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South Asian people in service provision is by itself insufficient to motivate action towards change. Awareness of the issues, though an important condition for service development, in itself does not guarantee improved service provision for South Asian people. Other factors that may prevent or motivate service development to meet the needs of South Asian carers therefore require exploration and these are considered below.

### **Barriers to policy implementation and development**

Our study found a vagueness and misunderstanding amongst some service providers about the meaning of 'equal opportunities' leading to a lack of firm strategy in addressing the needs of South Asian families. A number of professionals felt that organisational policies had not moved beyond statements of principle. One specialist nurse felt that the hospital in which she worked has no practical commitment to its own equal opportunities statement. As an example, she mentioned the culture of disapproval towards the use of interpreters, a stance that had only begun to change in the last three years.

She also pointed to a general lack of understanding of the term 'equal opportunities' and felt that, if asked, everyone would give a different definition. Her feeling was confirmed by broader interview data which suggested that many professionals did not fully understand the implications of the equal opportunities statement. There was a general acceptance of the need for more sensitivity towards other cultures and some professionals refined this to recognition of differences between people from the same cultural group. However, reference was also made to a 'colour-blind' ethos underlying working practice and the fact that services were open to all, indicating poor awareness of

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institutional racism arising from structures and procedures which do not acknowledge the different needs of ethnic minority groups (Ahmad and Atkin 1996).

Similarly, the importance of ethnic monitoring was not appreciated by some professionals who were in a position to accurately highlight the incidence of cerebral palsy amongst different communities in West Yorkshire. Andrew Ellis expressed unease and uncertainty about possible adverse reaction to questions about ethnicity; his position conflicted with the policy of the hospital in which he worked, where ethnicity was routinely monitored through the Patient Administration System.

Another example of such inconsistency related to the use of family interpreters. Professional interpreters were not always used with non-English speakers despite an official hospital policy of professional interpreting. Service professionals spoke of incidents in which information, usually being passed on to the main carer, was obviously being edited by a family interpreter. Carers were sometimes themselves being upset by information they were interpreting for others; in one case a family interpreter refused to pass on information because it might cause distress to the mother of a child with cerebral palsy. Nevertheless many professionals felt they could not refuse to allow family members to interpret. One health visitor was reduced to visiting the mother of a child with cerebral palsy when her husband was not at home so that she could take an interpreter with her; she recognised that this had the consequence of excluding the child's father from the visit but felt unsure about what she should do. On other occasions the same health visitor accepted family interpreting both within and outside the hospital setting. Inconsistency and uncertainty appeared to arise from a lack of sustained direction at a policy level on how to best satisfy the needs of South Asian communities and provide the most effective service possible.

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### *Training*

Training was identified by many service professionals as vital to an awareness of other cultures and to an understanding of equal opportunities in practice. However there appeared to be a lack of such training available to staff. Courses on Cultural Awareness and Equal Opportunities were described as 'non-existent in Leeds'. When arranged elsewhere they were not compulsory and were usually run by outside agencies. These agencies might have 'more insight and enthusiasm' but were not directly involved in the organisation and would therefore not be able to follow up training or monitor outcomes. Some respondents felt that regular training and refresher courses rather than one-off events would ensure that staff remained up to date and motivated in terms of cultural sensitivity.

Our data also showed that health and social care staff were often unaware of existing evidence on disability and ethnicity. For example, research evidence has been in existence for many years showing that South Asian extended families do not always 'look after their own' and struggle to manage. Studies have also shown that some South Asian families do consider termination to be an option (Dominelli 1989; Brent Community Health Council 1981; Atkin et al 1998)). However a number of interviewees believed that South Asian communities will not accept termination and that extended families do not feel they need service support.

In the absence of evidence-based training, these stereotypical ideas about South Asian families were not challenged. For many professionals, anecdotes, impressions and individual incidents from their own experience formed the basis of their knowledge of

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South Asian cultures. Respondents who relied on anecdotal sources of knowledge had not taken any direct action to investigate other sources of information. As a result many expressed uncertainty about how to deal with South Asian families and about how different religions, values or family and community structures impinged on the service they were providing. Despite a recognition that current methods of service delivery were not effective in providing a reasonable level of service to South Asian people, most professionals had little idea of what to do to improve the situation.

### ***Motivation***

Our fieldwork revealed that motivation and direction may be provided by a focused discussion of services to minority ethnic communities. Issues raised during interviews with professionals appeared to motivate a number of people to commit themselves to specific action, even though this was not intended as an outcome of the interview. A number of professionals said that they would organise training on appropriate cultural issues for staff in their organisations and others were stimulated to investigate their own ideas for improved consultation with South Asian parents using their services.

This phenomenon suggests that enabling professionals to reflect on their own role in service delivery to South Asian families may be a stimulus to service developments. It would appear that this type of reflection is not currently required or facilitated within most service organisations. A number of professionals felt that the needs of South Asian families were given a low priority within their organisation. This dampened any motivation that individuals, already under pressure in other areas of their work, might have to commit the time and effort required to develop their own sphere of activity. A degree of management pressure was felt necessary to ensure that staff were able to deal

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in more than a superficial way with issues that are specific to minority ethnic communities:

Using links in the community that exist has not worked so I've thought 'Why don't I work with what I have got because I have to prioritise because my post is just for three years' ..... It's easy to give up too, nobody is bringing it back into being a priority for me at the moment

(Gail Norton)

Without an organisational focus and regular pressure to implement equal opportunities policies it appears that many professionals will not feel able or willing to commit time and resources in order to adapt their working practices. The specific needs of South Asian carers and communities thus remain unmet.

Some respondents felt that the pressure needed for organisations to begin to address carers' needs should come from within South Asian communities and from families themselves. Many professionals felt that until South Asian people start 'banging on doors' and 'organising vocal groups' service provision would not change. Organised, vocal groups and 'parents who know how to argue for what they want' were seen as able to obtain the most effective services and act as catalysts for policy development and implementation. This is, perhaps, an unrealistic expectation. Not only does it shift responsibility for primary action away from health and social care organisations, but it looks to families, who are already receiving insufficient support, to adopt a more proactive role than the organisations set up to meet their needs.

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Data from our study shows that carers' groups are few and far between. In addition, a significant proportion of South Asian parents felt they lacked the energy, skills or confidence to argue for what they wanted even when they felt that services were unresponsive. Those parents who had challenged service delivery described the consequences as 'traumatic'. It could be argued that non-implementation of policies regarding equity in service delivery is an issue for organisations themselves to take up. However if, as respondents suggest, external triggers are instrumental in enabling organisational change then alternative external triggers need to be explored.

### ***Conflicting priorities and interests***

Policy implementation is further hampered by the differing priorities of individual staff or by conflicts between different policies. For example, organisational attempts to promote professional interpreting for service users who do not speak English are sometimes overruled by other staff for 'practical reasons'. Despite the acknowledged disadvantages, family members continue to be used as interpreters because of the delays involved in organising professional interpreters, often from other departments or other organisations. Similarly a policy of anti-racism may clash with the policy of respecting service users' wishes; this clash led one Social Services department to withdraw a South Asian Home Care Assistant at the request of a white service user. How far one policy can or ought to take priority over the other is often unclear to professionals who may take decisions based on what is easiest at the time, rather than on long term principles.

### ***Service development***

Respondents' accounts show that individual, organisational and external factors all play a part in improving service provision for minority ethnic users. Carer interviews,

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discussed elsewhere (Mir et al 2000) confirmed that the quality of their interaction with individual professionals can make a huge difference to accessing services and to the emotional wellbeing of parents. Professional respondents often showed a willingness to respect and be sensitive to different cultures and religions. In some cases this was combined with an awareness of the dangers of stereotyping.

At an organisational level, a focus on addressing the needs of disabled South Asian people and their families could be communicated to all professionals within an organisation as well as to South Asian communities themselves. Bradford City Council's Asian Disability Strategy, for example, commits the Local Authority to improving awareness of services within the South Asian community as well as improving cultural awareness and sensitivity within staff groups. The formulation of the strategy came about, initially, as a response to growing pressure from South Asian community groups to provide a residential home for South Asian elders. These provided the external trigger to which a response was needed. The Asian Disability Network has subsequently collaborated with Bradford Social Services, SCOPE, Barnardos and a range of other organisations and has enabled widespread consultation with South Asian disabled people and carers in Bradford. This process has been instrumental in the development of the strategy.

One aim of the strategy has been to initiate a programme of staff training in order to tailor services more effectively to different communities within the city. Such programmes have been promoted through the efforts of individuals but are, importantly, backed up by organisational approval. This approval fulfils an important function in influencing the culture of the organisation and providing encouragement to individuals

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who are already committed to improved services for South Asian families. In addition, organisational approval provides some pressure, through formal channels of accountability, to prioritise the implementation of the strategy.

## **Discussion**

Our aim in this study was to assess the level of ‘cultural competence’ that service organisations display towards South Asian carers of an individual with cerebral palsy. Our findings support previous studies that show poor levels of health and social care provision to minority ethnic communities. However, we also present fresh insights into the determinants that may facilitate or prevent service development in this area and how inequalities in health and social care might be addressed.

Perhaps the principal finding of the research is that inadequate service delivery to South Asian carers continues despite professional knowledge that it exists. The problem of transforming knowledge into action is, of course, not peculiar to provision for people from minority ethnic communities and involves the wider issues of organisational change. The achievement of ‘cultural competence’ thus requires that barriers to such change be identified and addressed. Harrison (1994) identifies four conditions that must be present for effective implementation of research knowledge. Below, we relate each of these conditions to our findings. We suggest that service development to meet the needs of South Asian carers must form part of an overall strategy that takes into account the need for change at different levels within and outside service organisations.



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### Conditions necessary for organisational change

- *Specific methods of appropriate action must be known to professionals likely to encounter relevant service users.*

This condition implies the need for easily available training on issues relevant to South Asian service users. Our findings show that currently training is often not easily available and is usually an option rather than a requirement. Harrison's imperative suggests that compulsory training may be considered appropriate for those in regular contact with South Asian people.

Our findings show that many professional respondents often lack appropriate and necessary knowledge about the South Asian families they have contact with and do not understand how to adapt services to meet their cultural and religious values.

Furthermore, we found high levels of uncertainty amongst health and social care staff and poor direction about how policies should be implemented. This suggests a need for training that would facilitate adequate discussion and exploration of alternative ways of meeting the needs of South Asian people. Decisions about an organisation's policy stance on any particular issue could thus take into account the practicalities of service delivery. The need to consider research evidence and the views of service users would ensure that decisions made about appropriate action are validated externally.

It should also be recognised that the provision of training is itself not a straightforward solution as staff may feel threatened by the prospect of criticism (Azmi et al 1996).

Minority ethnic staff members may also need to be given specific support to avoid being overly relied upon and to ensure that their skills are used effectively for training or consultancy within an organisation.

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This condition for effective implementation of service policies further implies that inappropriate action is not promoted as appropriate (Harrison 1994). Where information about the needs of South Asian carers is not based on reliable evidence, there is a danger that resources will be shifted towards actions that are not yet shown conclusively to be necessary or appropriate. For example, inconclusive evidence, which has not been grounded in the experience of carers themselves, is currently being used to argue the need for more genetic counselling for South Asian parents rather than for the development of culturally appropriate services (Sinha et al 1997).

Difficulties in consulting South Asian carers or community groups also appear to be a result of poor knowledge of appropriate action. In many cases there is clearly an inadequate level of skill and experience within organisations to enable appropriate links to be made. The absence of minority ethnic representation on consultation forums means the loss of an important opportunity to give a voice to these populations with serious long-term consequences. Decision-making and planning groups will influence the services South Asian families receive without any input about their needs.

Continuing and increasing inequity is therefore likely as consultation groups prioritise activities that remain focused on the needs of disabled people and carers within the majority ethnic population. South Asian disabled people and their carers will consequently remain further and further behind the ethnic majority population in terms of having their needs acknowledged and met. Where separate measures are taken to specifically involve and consult South Asian families and groups, however, our findings show that this can have an important impact on strategic planning and organisational commitment to developing services for South Asian communities.

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- ***The required combination of resources to implement such action must be available.***

This condition implies sufficient finances, skills and time to adequately put policies into practice. Currently, funding for research into the causes of cerebral palsy in South Asian communities may be more available than funding for service development and this has the added impact of diverting the time and skill of staff in a particular direction. Funding allocations which bear little relevance to the concerns of South Asian families may thus help to sustain problems of inaccessibility to services, whilst at the same time appearing to focus on South Asian service users.

Our data shows that targeted funding can significantly improve access and the level of service delivery to South Asian families. South Asian staff members are clearly an effective means of combining the required resources to improve service delivery. However enabling other members of staff within an organisation to use their time in similar ways is also necessary to prevent the marginalisation of South Asian staff and service users. Our findings show a need to make all staff within an organisation feel that work in this area is within their remit and work for which they will be accountable.

- ***A minimum number of independent links in the chain of professional action is required.***

Perfect communication and co-ordination cannot be assumed across the range of professionals working with South Asian families. The greater the number of staff involved, the more the scope for errors and omissions, particularly if several agencies are

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involved. Minimising the number of players whose co-operation is required therefore reduces the complexity of implementing a policy.

The lack of direct links between service organisations and community groups may also help explain the failure of some organisations to consult South Asian groups or individuals. Where staff within an organisation do not have the necessary links, use is often made of South Asian community organisations to recruit disabled people or their carers. However many minority ethnic community groups do not themselves have the necessary contact with appropriate individuals (Mir et al 2001). Such approaches by service organisations may in fact be no more than an attempt to delegate responsibility or tick off a task that has not really been addressed.

We suggest that the lack of established and well-organised groups for South Asian disabled people and their carers may make contact through traditional means almost impossible. The needs of such individuals may be marginalised both within disability groups and within minority ethnic voluntary organisations (*ibid*). Where, as in Bradford, a voluntary group with this specific focus does exist it can become a key actor in the process of establishing links between service providers and South Asian families. The Asian Disability Network was, until recently, run on a voluntary basis without funding and relied on the commitment of group members to become established. We suggest that the group is unusual in this respect: the lack of support available for such organisations may explain the absence of other similar groups. An overall strategy may therefore need to include community development work to enable the formation of South Asian carers' groups through whom effective consultation can take place.

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- *Professionals must be motivated to take the courses of action that are being promoted.*

Harrison (1994) suggests that motivation may take the form of material benefits or the threat of resources being withdrawn. Intrinsic motivation may further arise from strong agreement with the kinds of action being advocated. Motivation is thus linked to resources and organisational culture and implies the absence of any substantial disincentives. The greater availability of funding for research rather than for service development has already been highlighted as a disincentive to channelling resources of time and skill into meeting the more immediate needs of South Asian families, such as communication and access. Specific funding does not appear to be available to ensure that service developments are able to address these needs. A further consequence of this situation is that a medical model of inequalities in health is promoted through a research focus on genetic causes of cerebral palsy in South Asian communities. The explanation for higher incidence is, as a result, shifted away from poor medical care, which many carers believe to have played a significant part in the cause of their son's or daughter's condition (see Mir et al 2000).

Our findings further highlight the effects of organisational culture on motivation. Where organisations fail to prioritise the needs of South Asian service users, the intrinsic motivation of individual staff may be hampered by a lack of management focus or encouragement. This lack of pressure is a disincentive to individual effort and communicates discouragement to those who may attempt to address the needs of South Asian families. Systems of accountability may effectively only exist towards provision for the ethnic majority population thus sustaining current inequalities in levels of service delivery.

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## **Conclusion**

The previous section highlights the relationship of service development to the dynamics between individuals, the organisations in which they work and external factors such as community activity and political direction. It is suggested that 'cultural competence' requires awareness and motivation at all three levels if improved service delivery to South Asian people is to be achieved. Our findings have relevance not only to services relating to cerebral palsy nor only to services for South Asian communities but to all organisations that have yet to develop their services to adequately meet the needs of minority ethnic communities.

Individuals acting within their own sphere of influence can significantly improve access and support for South Asian individuals and families. However they will require organisational approval for their activities if these are to contribute to wider organisational change. Priority status for service development in this area, along with adequate resources and incentives to achieve improvements are vital to the success of individual efforts. It is suggested that such initiatives may create a culture that encourages and indeed requires such efforts, providing a necessary incentive to individuals who, the data suggests, currently do little within their own sphere of influence.

In terms of external triggers to change, our findings suggest that political direction is a more realistic trigger than carer lobbying groups. The recognition of unmet need amongst certain South Asian communities highlighted in the recent 'Independent Inquiry into Inequalities in Health' (Acheson 1998) requires consequent action if it is to be of any

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practical value. Unless local and national bodies take action on the findings of such reports, the growing body of studies which highlight these needs as recurring themes are in danger of becoming an end in themselves.

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## **Appendix: Service Provider Profiles**

Andrew Ellis and Bill Jones are leading authorities on paediatric care and are involved in research on cerebral palsy.

Carole Smith and Diane Baker work in multidisciplinary health care teams and have a specific remit to support the parents of children with impairments.

Ellen Martin is the manager of a residential home for women with cerebral palsy.

Gail Norton and Harold Watson are Social Services officers with specific responsibilities towards disabled people and their carers.



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