Supporting South Asian families with a child with severe disabilities: A report to the Department of Health

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Executive Summary

Background

The prevalence of severe learning disabilities amongst UK South Asian communities\(^1\) may be up to three times higher than the general population. Combined with general epidemiological trends, projections suggest that the number of UK South Asian people with severe learning disabilities will increase substantially over the next 20 years, with big increases in the number of school-age children and young adults.

South Asian communities in the UK, compared to their White peers, experience pervasive disadvantage and discrimination in terms of housing, education, employment, physical and mental health and access to services, with Pakistani and Bangladeshi populations particularly disadvantaged.

Limited research with South Asian families with a person with learning disabilities indicates that they experience similar material disadvantage in terms of housing, employment, transport, income and benefits.

Despite these high support needs, South Asian families with a person with learning disabilities receive little informal support from family or friends outside the household, largely due to extended family members living too far away.

South Asian families with a person with learning disabilities also report low awareness and uptake of specialist disability support services. Language barriers hinder parental awareness and uptake of services, and services rarely meet the language, cultural and religious needs of South Asian service users.

Finally, limited evidence suggests that South Asian parents of a person with learning disabilities experience very poor physical and mental health.

The Research Project

The Department of Health Supporting Parents Initiative funded this project, which aimed to provide a comprehensive picture of the lives of UK South Asian families with a child with severe disabilities.

The project included semi-structured interviews conducted at two time points with 26 parents, designed to yield in-depth qualitative information on the lives of families.

The project also included structured interviews conducted with 136 parents, sampled across five local authority areas. The sample included substantial numbers

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\(^1\) In this report, ‘South Asian’ is used to refer to populations originating from India, Pakistan, Bangladesh, and families largely originating from India who had lived in Africa for a substantial period of time.
of Indian (16.9%), Pakistani (69.9%) and Bangladeshi (11.0%) families to allow comparisons to be made across these groups.

Structured interviews were translated into four languages, back-translated, and extensively piloted with parents, and covered:

- the personal, material, financial and informational resources available to families;
- the characteristics of the child with disabilities;
- parental perceptions of the process of diagnosis and disclosure of their child’s condition;
- the extent and helpfulness of informal and formal supports received by families;
- the social life of children and parents;
- the physical and mental health of parents.

Where possible, the structured interviews included measures used in previous research to enable comparisons with other South Asian families with a person with disabilities, the UK South Asian population generally, or White families with a person with disabilities.

Qualitative and quantitative data were combined to build a comprehensive picture of the lives of South Asian families with a child with severe disabilities. The lives of families were described and comparisons were made between ethnic groups in the study and with comparative samples from previous research. Finally, factors associated with positive and negative outcomes for families were investigated.

**Findings**

**Financial resources.** As with previous research, parents in this study reported a pattern of pervasive material disadvantage. Household income was low (median £100–£199 weekly), unemployment was high (54.5% of households had no-one in full-time employment), and the patchy uptake of benefits was insufficient to meet the extra costs of caring for the child with disabilities.

**Housing.** Housing was generally rated as unsuitable for the needs of the child, particularly in terms of lack of space and safety issues. Adaptations to housing were rare, often delayed, and sometimes insensitive to the cultural needs of the family.

**Main carer.** Most main carers were mothers born outside the UK, but who had spent many years in the UK and cared for the family full-time. Substantial numbers of families had a lone parent (12%) or were caring for more than one person with disabilities (21%), more than UK families in previous research. Only a minority of main carers could speak, read or write English, with parents reporting a wide variety of spoken and written languages. Almost all main carers were Muslim (93.4%).

**The child with disabilities.** Children in the sample covered a wide age range, with a slight majority of boys. Most parents described their child as having unspecified learning disabilities, with rare reporting of specific conditions. Most children needed substantial support across a range of self-care skills, household tasks and spoken communication skills. Most parents described their children as fairly happy, sociable and affectionate, but over 80% of parents also reported problems associated with eating, toileting and bedtime routines, and their child throwing things, yelling, screaming and throwing tantrums. Around half of parents felt their child had made progress in the past six months, with most parents appearing to calibrate their expectations to the skills and progress for the child, enabling the family to recognise and celebrate the child’s achievements.

**Disclosure.** Most children were diagnosed as having a disability by four years of age. Disclosure was mostly conducted by a medical professional in English. Around
half of parents reported understanding what was told to them at disclosure, with most receiving good support from partners and the disclosing professional. Post-disclosure support was, however, lacking. Parents reported the following factors as essential for parental satisfaction with disclosure: prompt disclosure in the appropriate language with the partner present; emotional support; and clear and practical information linked to action to gain service supports. For parents, a well-conducted disclosure process could have long-term positive consequences, such as increased parental understanding and acceptance of the child, and the mobilising of informal and formal supports.

Information. Most parents reported having enough information about the child’s disability, although fewer parents had enough information about services for the child or for themselves as parents. Parents using the English language were more likely to report having enough information. Parents also reported preferring to receive information in the appropriate language from a professional face-to-face.

Informal support. The most common source of informal support for parents was within the household. Partners usually provided both practical and emotional support, and absent or unsupportive partners could result in practical difficulties and emotional distress. Practical support from other children in the household was also seen as helpful by most parents, although parents reported concerns about the impact of caring responsibilities on these children. Few parents reported receiving support from extended families or religious organisations. This was partly due to extended family members living too far away or being unable to provide support, although even when received this support was often rated as unhelpful.

Formal support: awareness and uptake. As with previous research, parents generally reported high awareness of generic health and welfare services and special education services, but low awareness of other specialist disability services. Uptake of specialist services, with the exception of GP and school services, was generally low. Indian parents and parents who used English reported greater awareness and uptake of services.

Formal support: relationships with professionals. Less than half of parents reported collaborative relationships with professionals. Problems with services experienced by most parents included communication barriers and constant fighting to gain service support, resulting in parental frustration and lack of confidence in services. Bangladeshi parents reported fewer problems with services, possibly due to lower expectations of services, and Indian parents reported more problems with services. English language use was associated with less fighting to get services.

Formal support: schools. Almost all children were in special schools, which were generally very highly rated by parents. Parents reported that special schools were good for the child, gave parents a break, were responsive to their concerns, and were often the only reliable point of contact with services to gain information and support. However, very few schools were reported to provide for the language, cultural or religious needs of the children, and parents were also concerned about the availability and quality of speech therapy and physiotherapy. A small minority of parents reported dissatisfaction with special schools in terms of poor standards of care and lack of parental choice.

Formal support: respite services. Few parents reported awareness and uptake of respite care services for their child. Almost all respite care received was in respite units managed by social services. These services were generally highly valued and responsive to the child’s cultural needs, but insufficient for parental needs.

Formal support: interpreters. Although most parents reported needing an interpreter, less than half had been provided with one. Where used, interpreters were
highly valued, with parents particularly appreciating being able to say what they wanted confidentially without having to rely on family or friends for interpretation. Parents who had not used an interpreter reported most commonly relying on their partner or another child in the family for help with interpreting.

**Formal support: family support groups.** Few parents reported being aware of or participating in family support groups. Parents valued the informational function of these groups and the chance to meet other parents to gain emotional support. However, the helpfulness of these groups to parents was limited, possibly because attendance did not result in increased service support.

**Formal support: keyworker.** A minority of parents (28%) reported having a keyworker, with social workers and health visitors often taking on a keyworker role. Where provided, keyworkers were almost always viewed as invaluable, in terms of raising parental awareness of benefits and services, organising integrated packages of care, and providing ongoing emotional support.

**Formal support: unmet needs.** The range of unmet needs reported by parents was extremely high, substantially higher than those reported in comparable UK research. Bangladeshis parents reported lower unmet needs in a range of areas, and Pakistani parents reported greater unmet needs in emergency health and child care.

**The relationship between formal and informal support.** For most parents formal support services were needed to compensate for a lack of informal supports. Few parents reported complementary or collaborative relationships between informal and formal supports, with some parents reporting no emotional support from any source.

**Social life of parents.** Parents reported wide ranging restrictions on their social and leisure activities, including nights out and weekends away, restrictions reported by a greater number of Pakistani families. These restrictions were exacerbated if the child required constant supervision and if the family was headed by a single parent. Reliable informal and formal supports outside school hours helped parents to have an active social life.

**Social life of the child.** The social life of the child with disabilities was similarly restricted, with the vast majority of children having no social involvement with friends or organised activities. Most parents were unhappy with their child’s social life, which was particularly restricted if the extended family and the general public held negative attitudes towards the child.

**Parental health.** Compared to national data, parents in this study were much more likely to report poor physical health across a whole range of physical health problems. This poor health was reflected by increased use of GP and hospital services. Rates of distress (74% of Phase 2 parents), depression (40.4%) and anxiety (26.5%) were extremely high amongst the parents in the study, up to ten times higher than comparative UK populations. Pakistani parents were more likely to report both anxiety and depression. Despite these high rates of mental health problems, no parents reported using any kind of psychotherapy service in the past year. Parents made explicit links between caring for their child with disabilities, particularly without support, and physical and mental health problems.

**Future plans for the child.** Few parents had considered or discussed future plans for the child. Parents with a child about to leave school reported considerable uncertainty and confusion about the post-education service supports available. Parents who had been in contact with adult services reported concerns about the cultural and religious appropriateness of the services offered.

**Factors associated with positive family outcomes.** Several factors emerged as central in promoting positive outcomes for families.
First, the disclosure process, itself influenced by the time of diagnosis and parental concerns about the child, is crucial for parents. A well-conducted disclosure process facilitates parental acceptance of the child’s disability and helps to mobilise formal support services and the uptake of benefits. Parental acceptance also facilitates acceptance by extended family and friends which, if extended families are able to help, is likely to lead to informal support for parents. More able and socially responsive children with disabilities, with fewer problem behaviours, are also likely to facilitate more informal support.

Second, informal support, together with information from parent support groups and greater parental acceptance and understanding of the child’s disability, helps parents to become aware of and mobilise formal service supports. The cultural identity of parents may also play a role in the mobilisation of formal service supports. This mobilisation also requires language support (e.g. interpreters), a trusted keyworker and a collaborative relationship between parents and professionals to translate parental awareness of services into the uptake of benefits and services.

Third, culturally sensitive service supports reinforce collaborative relationships between parents and professionals, put parents in contact with support groups, reduce the unmet needs of families and help to improve the physical health of parents. Informal supports and parent support groups help to improve the social life of the child and the family, especially when the child is socially responsive and more family needs are being met.

Finally, informal supports, along with formal service supports and an active family social life, also help to reduce parental depression. Parental distress and anxiety are more likely to be relieved if the family’s needs are being met, the child is less of a problem to supervise, and the parent has fewer physical health problems.

Policy Implications

Three current policy initiatives are relevant to South Asian families with a child with severe disabilities: the National Carers Strategy; the Quality Protects Initiative; and Valuing People. These policy initiatives have consistent aims, including improving services for people with disabilities and their carers from minority ethnic groups. Priorities for current policy initiatives are:

**Improving the material circumstances of families.** A striking feature of this study is the material disadvantage experienced by families. Although improving the uptake of benefits would assist many South Asian families, many families reported that benefits were not enough to cover the extra costs of caring for a child with severe disabilities, particularly in the context of high unemployment. Charging for services is likely to have a disproportionate impact on uptake amongst South Asian families. In addition to increasing financial support, an additional priority should be the speedy provision of material aids and adaptations, from specialist nappies through to wheelchairs and housing adaptations, based on a thorough assessment of family needs, including cultural and religious needs.

**Improving information given to families.** Although current policy initiatives emphasise the importance of information, strategic recommendations such as a charter, NHS Direct helplines or websites are unlikely to be used by South Asian families with a child with severe disabilities. These families reported wanting to receive information face-to-face in their preferred language. A well-conducted disclosure process, co-ordinated with on-going keyworker support and the encouragement of family support groups, would appear to be necessary for increasing parental acceptance and understanding of their child’s condition, with the consequent
mobilisation of informal and formal supports. For families already in the system, ongoing informational support from a keyworker is a priority.

Assessments of family needs. All the current policy initiatives emphasise the importance of fast, comprehensive and regular assessments of family needs. The parents in this study rarely reported receiving such assessments, with consequent service supports being absent, patchy, uncoordinated or unhelpful. For assessments to be helpful to South Asian families, they must be conducted in the preferred language of the parent, be relevant to the parents’ circumstances, be quickly followed by concrete action, and be regularly updated. Again, a trusted keyworker would be in a good position to perform assessments. Both ‘colour-blindness’ and stereotyping on the basis of parental ethnicity or religion are detrimental to the identification of individual needs and should be avoided.

Co-ordinated packages of care. In common with previous research, this study has demonstrated an often desperate need for formal supports amongst South Asian families with a child with severe disabilities, especially as informal supports are infrequent. However, it is clear from this study that comprehensive and co-ordinated packages of care for South Asian families are extremely rare. With the exception of special education, family support services are rarely received and are often viewed as so unhelpful that they are discontinued. Again a keyworker would be invaluable to co-ordinate service delivery. To provide co-ordinated packages of care that genuinely meet the needs of families will require a substantial increase in resources and much greater creativity on the part of agencies to provide ‘person-centred’ supports rather than fitting families into pre-existing and unhelpful service slots.

Meeting language, cultural and religious needs. Again in common with previous research, this study has demonstrated that few services meet the language, cultural and religious needs of South Asian families. The recruitment and retention of South Asian staff throughout mainstream services should be a priority, as should the expansion of specialist interpreting services trained to deal with disability issues. Greater priority should be given to meeting the cultural and religious needs of all service users, including appropriate diet, celebration of religious festivals and same-sex carers for intimate personal care tasks. Finally, it should be noted that parents in this study would prefer ethnically integrated services that routinely meet users’ cultural and religious needs, rather than ethnically separate services.

Choice, control and consultation. While this is emphasised in current policy initiatives, there was very little evidence of families being consulted about service provision, or of parents having substantial choice or control over the service supports provided. On a service planning level, meaningful consultation would involve encouraging the formation of parent support groups, and demonstrating responsiveness to parental suggestions. ‘Person-centred’ planning assessment processes, along with greater flexibility and creativity in developing packages of care, could help families to gain more control over family support services.

Meeting the needs of the child with disabilities. Objectives of current policy initiatives include maximising the achievements of the child through education, encouraging children to be fit and healthy, and ensuring that children lead a normal life. Parents in this study highly valued special education services and mostly felt that their child was making progress, despite substantial support needs and high levels of problem behaviour. As these characteristics of the child influence levels of informal support and parental mental health, more intensive early intervention could have a broader impact upon the family system. The provision of some teaching in the family language of the child, together with more reliable and helpful speech therapy and
physiotherapy, were also indicated as priorities by parents. Finally, the extreme social isolation of the children in this study is worth noting as a priority for service supports.

**Meeting the needs of parents.** The National Carers Strategy emphasises the importance of ensuring that service supports enable parents to live a full life, maintain paid employment if desired, maintain their physical and mental health, and integrate into local communities. The parents in this study are clearly a priority group for all these objectives. Parents reported their lives revolving around caring for their child with disabilities, extremely restricted social lives and extremely poor physical and mental health. Although most main carers in this study did not report a wish to go into paid employment, high rates of household unemployment suggest that this could be a priority for their partners. Clearly, the provision of flexible, reliable, sufficient and culturally appropriate short-term care services is crucial here. Many parents also suggested the idea of drop-in centres, where children could be left out of school hours. The provision of reliable schemes during school holidays is also vital for parents, as current support is absent or largely unhelpful. For the parents in this study, improving their physical and mental health was closely tied to improving supports for the whole family. However, despite parents’ high use of GP and hospital services, no parents reported receiving help for mental health problems. Given the extremely high rates of distress, anxiety and depression, this issue should be addressed urgently.

**Inclusion.** Current policy stresses the importance of inclusion philosophies for families with a child with disabilities. Reforming education services are an important part of inclusion ideologies, with services shifting from special schools to children with disabilities being educated in mainstream education services with support. While parents in this study were broadly supportive of integrated services, they were also highly appreciative of special schools. These provided a reliable, high quality service, and also often served as the parent’s only point of access to other parents and information about other services. Any moves towards mainstreaming children with severe disabilities need to ensure that educational standards are maintained. Furthermore, effective alternatives in terms of supporting and providing information to parents need to be in place before mainstreaming occurs.

**Transition.** While transition plans are a current policy, no parent in this study reported being aware of a transition plan for their adolescent. However, transition plans are urgently required, as parents reported great uncertainty and anxiety about post-education services for their child. Greater consistency between child and adult services is also required, as some parents reported that adult services offered did not meet the cultural or religious needs of their child.

**Joined-up thinking.** Although specific policy areas have been outlined here, it is important to note that the parents in this study consistently reported that support services should meet the needs of the whole family, with child supports having a positive impact on parents and vice versa. Furthermore, the circumstances of the families in this study have wider implications for broader policy initiatives. For example, these families would appear to be priorities for the Children’s National Service Framework, the National Service Framework for Mental Health, and the Children’s Fund dedicated to eliminating child poverty. Policy-makers and commissioners need to harness and co-ordinate resources from this array of policy initiatives to meet the needs of families. Such ‘joined-up thinking’ is necessary if the often desperate circumstances and lives of South Asian families with a child with severe disabilities are to be transformed.