








## Providing better access to short breaks for black disabled children and their parents

Short breaks for disabled children are a popular service with families and one supported by central government, local authorities and the voluntary sector. However, black families do not have equal access to this service. A team based in the School of Health and Social Welfare at the Open University reviewed literature on access to short breaks by black families, and carried out interviews with children and young people, parents, short break carers and scheme organisers. Two main aims were to examine the barriers to access and what works to overcome these. The study found:

-  **Over ten years, the overall take-up of short breaks by black families has not significantly improved. There is still unmet need and a disproportionate number of families using institutional rather than family-based provision compared with white families. There is a known high level of unmet need among South Asian families, in particular.**
-  **Disabled children's services do not adequately cater for black children, and services for black and minority ethnic groups do not adequately cater for disabled children. This means that black disabled children 'fall through the net'.**
-  **Home-based services such as sitting and befriending are very popular with black families, particularly South Asian ones.**
-  **Lack of effective information and communication about services is a major barrier to access for families.**
-  **There are misconceptions about the role of social services and social work. Parents also express anxiety about whether their child's culture, religion and language will be respected and whether ethnic matching with short break carers and sitters is possible.**
-  **Disabled children want to do the range of things other children do. Lack of support for this is a significant barrier for all disabled children but for black disabled children the barriers are higher.**
-  **A shortage of black social workers and short-break carers means that services cannot adequately represent the communities they serve.**

## Background

Family-based short breaks have been available since 1976. Usually, non-related people are approved as foster carers to have a disabled child in their own home for one weekend a month. In some schemes, family and friends can be approved as short-break carers. The model has now broadened to include daytime services in children's own homes such as sitting and befriending, and other flexible provision.

This research consisted of a review of UK literature that aimed to highlight strengths and weaknesses in access to short breaks. There was also a postal survey of 24 short break schemes in England and visits to six of these schemes. Information received back from 13 schemes highlighted examples of good practice. Interviews with nine children and young people in Scotland, and short-break carers and parents in England were carried out, for firsthand accounts of service use.

## Barriers to access

Although there are gaps in information about use of short breaks by some black communities, the overall picture is clear. Many families do not know about short breaks and there are a number of reasons for this:

- Information does not appear to get to families either through word of mouth or printed literature. There is evidence that white workers still hold notions of South Asian families in particular 'looking after their own' and may not offer them short breaks, whereas in reality these families report little help from relatives.
- Families may not actually understand what 'short breaks' are, whereas what schools, doctors and hospitals offer is familiar to them.
- Families may have misconceptions about the role of social services: for example, families may believe that if a child stays away overnight, she or he will be removed permanently, or that to accept help is to be accepting 'charity'.
- Social workers may not do enough to engage with families in order to address these misconceptions and encourage them to apply to use a service; they may just take a 'no' at face value. If there is no worker available to speak with people in a first

language other than English, or if an interpreter is not provided, communicating the complexities of services, assessment and referral can be difficult.

- When printed information is provided, it may not reach the families or be in a language that is easily understood.
- There is a lack of co-ordination between disabled children's services and services for black children (for example, black-run nurseries, parent groups and initiatives such as Sure Start and Connexions).

Another set of barriers concerns the appropriateness of services. Like all parents, black parents are anxious that their children will be well cared for by trained and supervised carers who will respect their family values and preferences. White parents can almost always be offered an ethnically matched placement. But a shortage of black carers and sitters means this is not the case for black parents. This can be off-putting for parents who want to feel their language, culture and religion will be respected. Parents, particularly those from South Asian communities, do not want their children to stay away regularly overnight. But at the same time, some would like their child to be cared for competently whilst they, for example, visit family abroad for a few weeks a year. Schemes are just beginning to look at accommodating what they would see as 'non-traditional' needs.

The group of black disabled children and young people interviewed in Scotland generally seemed to enjoy their school experiences, but were isolated from friends and leisure activities after school, at weekends and in the holidays. Short break provision could open out services to all these children who seemed to want nothing more than to have equal access to leisure with non-disabled children.

## What works in successful schemes?

Short-break schemes that include black families successfully demonstrate a number of key principles.

### *Community relations*

Short breaks are part of the services provided to disabled children and families in a local community. But they are often designed with only some communities in mind. To ensure that everyone benefits, good community relations are essential.

This means consulting and building trust between services and black communities, ensuring representation and cultural competence in service delivery, and dispelling myths and stigma.

Successful schemes had:

- Good knowledge of the communities they aim to serve and consulted widely about the service.
- Visibility as a service provider amongst black families and organisations.
- Knowledge of the ethnic make-up of the population. The need to keep accurate statistics of users and non-users of the services on waiting lists so comparisons can be made is also important. This information needs to be updated regularly.

Some of the most successful schemes had specific equal opportunities and anti-oppressive practice statements for their service. These supplemented the general ones provided by the local authority or voluntary agency, but set out in detail what users and carers could expect and how the scheme aimed to promote inclusion. The process of developing such a statement of inclusion can be an empowering experience for service users and providers alike.

### ***Commitment***

Schemes that set out to include black families from the outset - rather than as an add-on - send messages that this is a service for these families. To achieve this, all staff need to take their responsibility for inclusion seriously, and not see it as a chore, or a part of the job that they don't have time to develop the skills for. Schemes that operate in areas with relatively small black populations can find it useful to network amongst themselves and pool what works well for them. Frequently schemes with an all-white staff group move their services along through the appointment of a black worker. The evidence suggests that before appointing such a worker, the existing staff team benefit from discussing the implications of change that widening the staff group will bring. All the team need to be clear that working with black families is everyone's responsibility, though the new worker will have skills the existing staff group don't have. This worker may need support

to avoid marginalisation, and may need to network with other black workers in similar positions.

### ***Leadership***

The quality of leadership seems crucial in order to:

- Set an inclusive culture;
- Remind people regularly of how black families can be excluded from services, whilst not casting them in the role of victims;
- Support and encourage self-help initiatives such as parent groups, which can be a way of promoting equality;
- Regularly review the make-up of the staff and short break carer groups in relation to local need;
- Value critical and reflective practice;
- Be open to new ideas and flexible to change.

Being able to accommodate changing demand is important. For example, the popularity of daytime and sitting services may have to involve planning to expand these while cutting down on overnight care.

### ***Resources***

Resources need building in from the start. Many initiatives aimed at increasing access by black families are marginal, insecure and short term, resulting in lack of continuity of services and disappointment for users.

### ***Conclusion***

At a time when services are being encouraged to be inclusive, it is clear that they still have major challenges to meet in relation to access by black families.

- Schemes in areas with 'low' black populations are not proactive enough in making their services culturally competent. There is a lack of clear policy, strategy and management in this service aspect, and a need to recruit black workers and black short break carers to provide the necessary expertise.
- Successful schemes are finding it hard to meet demand and are continually looking at ways of funding growth in their services.
- There are great possibilities for short breaks. If used flexibly they can provide a lifeline of support. But

no scheme can be complacent about its service. Even schemes that are successful find there are some groups that need better access.

- Black communities are tired of taking part in research that asks them what they want from services, only to find nothing happens until five years later when they are asked the same questions over again.
- There is therefore no real need for more research on access, but a need for action. Community development and outreach work carried out by people who are trusted and credible should have some priority. People need to know about the services and believe they have something to offer. This could be achieved by long-term planning and resourcing to boost service provision to underrepresented groups.
- An organisation briefed and funded to carry out a national coordinating and monitoring role and disseminate good practice could be a valuable resource.

### About the project

A research team based in the School of Health and Social Welfare at the Open University reviewed UK literature going back some 15 years. In addition, the following fieldwork was undertaken to supplement the literature review:

- In Scotland, nine disabled children and young people of Pakistani and Chinese origins were interviewed about their lives and use of services.
- Two parents and three carers involved in family based short break schemes were interviewed in London and Nottingham. Two short break carers from Dudley were also interviewed. Carers and parents were of African Caribbean and South Asian origins.
- A postal survey of twenty-four family-based short-break schemes was undertaken to gather information on policies and practices and 'what works'. Details were obtained from thirteen such schemes.
- From these thirteen, six schemes were either visited by one of the research team, or in-depth telephone interviews were carried out with project managers.

### How to get further information

This *Findings* was written by Ronny Flynn, e-mail R.M.Flynn@open.ac.uk.

The full report, **Short breaks: Providing better access and more choice for Black disabled children and their parents** by Ronny Flynn, is published for the Foundation by The Policy Press (ISBN 1 86134 428 7, price £12.95).