Extending Access to Short Breaks for Disabled Children From Black Families: a Case Study of Research into Practice

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Abstract

In 2001, as part of its programme of work on disability and ethnicity, the Joseph Rowntree Foundation (JRF) commissioned a review of research and practice on access to short breaks by Black disabled children and families. The review showed that there was still much to be done to improve access. True to its commitment to policy and practice relevant research, JRF then funded a development project located at the national organisation for family based short break care Shared Care Network. This project employed two workers who helped implement some of the recommendations from the review in four local authorities. This article outlines the background and findings from the review, and describes the process and outcomes of the development project. As the article focuses on barriers to access and the process of organisational change needed to remove them, its recommendations apply to many other aspects of service provision for Black disabled children and families.

Keywords

Black and minority ethnic people, children with disabilities, ethnicity, access to services, short term care, action research.

Background

> *It is no longer acceptable for agencies to develop services without paying attention to the ethnic composition of the population to be served; or, if particular ethnic groups do not use a service, to conclude that 'they don't need it' or that 'we're here- it's up to them to come and find us'.*
>
> (Flynn, 2002, p. viii)

The self-help/empowerment and service user movements have frequently brought about changes to practice in services. In the early 1980s the development of the social model of disability (Oliver, 1995; Oliver & Sapey, 2006) and the organising of Black workers against the over representation of Black children in care (Association of Black Social Workers and Allied Professionals, 1983) were highly significant in challenging attitudes and practices and laying the foundations of current legislation and policy in the fields of disability and 'race' equality. However, it is only relatively recently that multiple oppressions and identities have been acknowledged, such as being Black, and disabled and a woman (Vernon, 1996) or Black, disabled and a child.

Black disabled children have always been relatively invisible in research and practice literature, but they became a little more visible during the 1990s. Attention was drawn to disabled children in general when they were defined as 'children in need' under the *Children Act 1989* and associated Guidance (Department of Health, 1991b, s17), and were therefore entitled to ask for an assessment for services. The same Act and Guidance also required local authorities to give 'due consideration' to 'race, religion, language and culture' when making child placements, thus

putting race equality on the public children's services agenda in an unprecedented way (Department of Health, 1991a, s22(5)(c)). Many disabled children were in residential care and research had pointed to an over-representation of Black (African, African-Caribbean and 'mixed' heritage) children among them (Gordon *et al.*, 2000). In fostering services, residential care was being replaced by family based foster care as the first option for young children living away from home (Cliffe & Berridge, 1991), and in adult mental health and disabled people's services, residential care was also being phased out in favour of less institutionally based services. In 1990, a report by the King's Fund (Baxter *et al.*) drew attention to how Black children with learning difficulties faced 'double discrimination'. In 1989 and in subsequent years, researchers from the Norah Fry Research Centre had found low take up of short break services by Black families in their regular survey of short break schemes, and an over-representation of these families on waiting lists for placements (Robinson & Stalker, 1989; Stalker & Robinson, 1991). So there were clear signs even then that services were not able to cater for all their communities. However, it took a decade before progress was really visible.

The growth of the disability rights movement and the development of the social model of disability moved the focus away from labelling disabled people and their impairments as 'the problem' and instead located the problem with society and its disabling barriers (Finkelstein, 1980; Morris, 2003; Oliver, 1995). With its focus on rights, self help and empowerment the disabled people's movement agitated for change. Subsequently, enabling legislation in the form of the *Disability Discrimination Act 1995* and the *Human Rights Act 1998* created a climate for more positive action. A more favourable climate for promoting 'race' equality had been slow in coming but gathered momentum following the election of a Labour government in 1997, with action taken after the Macpherson Report (1999) firmly identified institutional racism. The *Race Relations (Amendment) Act 2000* that followed places a duty on public bodies and services to promote 'race' equality. This proactive approach and the location of responsibility with the management of institutions are welcome.

Under the *Quality Protects* (Department for Education and Skills) initiative introduced in 1998, disabled children were allocated a separate 'strand', but Black disabled children still struggled for space within this. The little research there had been to date (Morris, 1995; Shah, 1995; Singh, 1992) had pointed to racism, social exclusion and the identification of great need.

The Joseph Rowntree Foundation (JRF) has as its mission a desire to search for the underlying causes of inequality, so it was appropriate that it funded a programme of research that aimed to highlight the experiences of Black people and include Black disabled people. A summary of findings from the whole programme is available (Chahal, 2004). Research with Black disabled children and young people and their families was part of this programme. Baseline data was needed as an indication of the national picture. In 1995, a survey of some 1,000 families with disabled children (Beresford, 1995) highlighted poverty, stress and unmet need. The sample of Black families was too small for rigorous statistical analysis to be carried out, so an additional study was funded, focusing on the experiences of Black families (Chamba *et al.*, 1999). Data from almost 600 families was

obtained using the Family Fund database. The study replicated the methods used in the earlier study in order to draw comparisons between the two samples.

The study was aptly titled, *On the edge* and painted a depressing picture. Black families were struggling to live their lives the way they wanted to in circumstances that were more difficult in almost all respects compared to white families (whose lives were in turn, more difficult than families without a disabled child). A number of areas stood out as worthy of further investigation, and access to short breaks was one of them. JRF commissioned the review of literature and practice, but at the same time set aside funds for a development project that would disseminate the findings and recommendations from the review, and help agencies put them into practice. The work forms the basis of this article.

The review

The review needed to be completed quickly if its impact was to be timely. The National Service Framework for Children was being developed and it was important that Black disabled children were included. The *Race Relations (Amendment) Act 2000* was also requiring Race Equality Schemes to be developed by public services. The *Special Educational Needs and Disability Act 2001* would have an impact, and various initiatives such as *Quality Protects* (Department of Health, 1998) were keen to make use of lessons learnt. Over an eight-month period, researchers based at the Open University Faculty of Health and Social Care carried out a range of activities. There was a review of UK research and other literature going back 15 years and a survey of short break schemes that Shared Care Network had identified

(through self-report) as having contributed in promoting race equality. Six of these schemes were visited by a researcher, and written up as examples of positive practice.

The parent and carer messages from the review were checked for their current relevance through a series of interviews with carers and parents. At a conference held in London attended by over 60 people, the messages from the draft review were discussed, and suggestions made for follow up and dissemination.

The work aimed to cover all four nations in the United Kingdom but literature from Wales, Northern Ireland and Scotland was scarce. In Northern Ireland, the Chinese community was the largest minority ethnic group, but at that time, disabled children were not featured. In Wales, some early work identified unmet need but neither the time nor resources had been allocated to follow this up. Work in Scotland was at a basic stage as well, though racism awareness was high, and the Black childcare workforce was well organised and visible within government circles. JRF agreed that some of the grant could be spent finding out how some Black disabled children and young people in Scotland viewed the services they received and what might help improve them. Nine young people were interviewed, seven were from Pakistani, and two were from Chinese backgrounds. The findings can be found in detail in Patel (2002).

Key findings

The whole study is written up in book form (Flynn, 2002). More literature was available on families from South Asian backgrounds particularly Pakistani, and much less on African and African Caribbean families. Barriers to access and provision of appropriate services were also different for the different

communities. For example, a child's need for carers who spoke a familiar language or shared the same religion and culture could be more of a challenge to service providers.

The research found that the situation had not changed much over the past 10 years and that despite additional research and attention, there was still much unmet need. Disabled children's services were not generally inclusive of Black disabled children, and services for Black children were not inclusive of Black disabled children. They thus 'fell through the net'. Many families lacked information about services in appropriate formats, languages, and locations. They also seemed 'out of the communication loop' when it came to receiving information, even 'word of mouth' did not reach them.

There were misconceptions and myths on both sides. Families worried that if their child went to stay overnight with a carer, they would not return showing how, in the eyes of the families, social services were associated with child removal. In turn, service providers held the view that extended families provided support and that this was the reason for low take up of short break services.

Yet when asked what they would like from services, parents and young people were clear about what they wanted. In particular, South Asian families preferred their children to be cared for at home, and for their short breaks to be provided through sitting and befriending services. Young people wanted to get 'out and about' and do what their non-disabled peers, sisters and brothers did in their everyday lives.

A number of barriers to access were identified, linked to the findings above. It was clear that agencies were not being proactive in engaging families and encouraging their use of services. The

services themselves were also not sufficiently flexible to accommodate diverse needs. They had been developed with a particular client group, white majority ethnic users, in mind, and needed to adapt to changing populations. Services were not always well co-ordinated, with families not having a clear way of accessing them, and staff not always willing to engage them. Families worried that their children's cultural and religious needs would not be met, and were keen to have carers from their own or similar communities. Terminology taken for granted by professionals was often confusing. Short breaks had replaced 'respite care', but these were unfamiliar concepts and needed explaining. Young people were particularly dependent on adults to take them out, and when this was not possible, were quite isolated.

Significantly, the review found relatively poor representation of staff from Black and minority ethnic backgrounds working in services for disabled children, including short break services. This explained some of the skills and experience shortages illustrated in the section above.

What works?

From the literature, practice survey, and visits to short break schemes, the following were identified as key to good practice in working with Black disabled children:

Having an explicit policy and practice commitment to inclusion, disability, and race equality.

Organisations that have clear policy statements that are visible to staff and service users are more able to demonstrate their commitment to equality and to be able to call upon these policies to back up their practice.

Having leaders who are competent in equalities, managers who can implement equalities strategies and who can demonstrate commitment and shared responsibility.

Where equalities work is seen as a mainstream rather than marginal activity, it is more likely to be part of each team member's responsibility and to be managed as such. Frequently, these initiatives have a 'champion', only to flounder when the individual leaves the job. Often, Black workers are expected to take on disproportionate responsibility for equalities work, which can result in its marginalisation.

Having a diverse workforce and reviewing it regularly as populations change.

Families generally want services from people they can identify with, and who have some understanding of their backgrounds and cultures. Even in authorities with relatively small minority ethnic populations, there will be a pool of people to target for recruitment purposes.

Proactive use of the Race Relations (Amendment) Act 2000 plus other enabling legislation.

Rather than seeing the legislation as an annoying imposition, it can be used to audit services and help them become more inclusive. It can be used to argue for change and resources.

Having detailed knowledge of the ethnic make up of the population served by the scheme or other service.

This information is vital to providing effective support and services. Census information is now easily available and should be routinely used, supplemented by local information.

Being proactive about consulting local groups, and taking time and effort to meet all sections of the community.

Black families need to know that services are there for them, and all staff need to be able to work across difference. Visibility at local events can increase confidence in the service.

Scrutinising all administrative processes for barriers to access.

Getting someone to look at recruitment, outreach, literature production, assessment and other processes with a critical eye can identify what needs to change.

Regularly reviewing, monitoring, and evaluating the service.

A good service is a thoughtful and self-critical one, which is open to user feedback and to change.

Allocating sufficient resources, either by forward planning or by redistributing them.

Agencies worry that increasing access will drain their limited resources. While there may be more needed, sometimes a look at how money is spent is worthwhile. For example, the cost of a regular overnight short break could be used to fund other types of support such as sitting or outings for a child.

A process for change: the development project

The development project was specifically planned to follow on from

the research review and as a way of putting the key recommendations from the review, covered in the previous section, into practice in short break schemes.

Shared Care Network (SCN) is the national organisation for family-based short break care. Its membership includes some 300 short break schemes in the UK. SCN was well placed to carry out the development project associated with the JRF review. The organisation had close links with Norah Fry Research Unit at the University of Bristol, where research on take up and use of short break schemes was regularly carried out. SCN had also convened a Black and Minority Ethnic Inclusion group that was advising the staff and trustees on how to make the organisation more diverse and inclusive and able to support a race equality development project, and model good practice internally.

SCN recruited two development workers from South Asian backgrounds, Shameem Nawaz and Manju Kaushal; one to work in the North of England, one in the South. Short break schemes in SCN's membership were asked to apply to have a development worker attached to them part time, and to make a case for why they should have this resource. There was a formal short-listing and interview process and schemes had to commit to change and demonstrate their commitment to promoting 'race' equality. Two schemes were selected in the North West of England, and two in the South West. As well as their level of commitment, they were also chosen for their different settings and type of minority ethnic populations - urban, rural, local authority and voluntary organisation; a location with many different minority ethnic groups and one with a small minority ethnic population.

The two project staff provided intensive input over a twelve-month period. At the same time, they wrote up the process for a Practice Guide (Nawaz & Kaushal, 2005).

The two workers mentored and coached individual workers in a team, as well as facilitating the whole team's way of thinking about promoting 'race' equality. They encouraged debate about 'race', culture, ethnicity, religion, and difference; they challenged myths and stereotypes about Black families and encouraged integrated ways of thinking about need. For example, that increasing access for some families meant tackling housing, transport, and financial difficulties first. They were able to motivate teams and give them confidence, acting as a critical friend. They were, for some schemes, their Black worker for a time, introducing a different perspective and allowing schemes to see how having a Black worker in the organisation can make a difference.

As well as personal support, the project workers offered very practical advice and the benefits of their physical presence. They acted as a bridge between short break teams and local minority ethnic communities, and also the local community organisations. Both workers spoke more than one language and had experience of working across faith, ethnic and cultural boundaries. They went out with teams on visits, located and identified groups to be worked with and modelled good practice, for example, in running a recruitment campaign to attract more Asian carers. They encouraged short break teams to make links across other departments; for example, one authority had a community social work team made up of Black workers with significant expertise. The two teams had not previously worked together.

Because the two workers were operating nationally and based in a national organisation, they were able to access new information, research, ideas and resources to energise the local schemes and focus their activity. The teams were forced in a positive way, to consider the needs of Black families.

How was the work carried out?

The workers were both experienced in community development and saw their role as facilitating change. They created a climate where people could take risks, express anxieties and not feel judged, whilst still realising that the SCN worker role was to help them change their practice. Using the key recommendations from the Flynn report, the workers audited the service and negotiated priorities. They took the main recommendations and worked with the teams to implement them. Examples of how this was done are given below in Boxes 1-4:

Box 1: Helping to implement culturally sensitive services

Recommendations for implementing culturally sensitive services	How recommendations were implemented
Ensure you have clear equal opportunities policies and procedures that are understood by scheme employees, volunteers and service users alike, and that these cover access to services and user involvement.	*Development workers checked written policies and procedures, facilitated staff to develop them further, or to create new ones. They emphasised that good policy and practice needed to be in place or they would not recruit or retain Black staff.*
Leadership and teamwork are important. All scheme staff should share responsibility for access and the inclusiveness of services. Regular discussion of what this means is crucial. In particular, there is a danger that lone Black workers become responsible for 'minority ethnic' work and can therefore be marginalised.	*The development workers built up trusting relationships so scheme workers could be open about their skills and how they needed to develop them.*
Provide support for all staff whilst recognising that Black staff may have additional support needs.	*They emphasised the need for managers to show leadership in this area. Black workers had an external person they could confide in if needed. Development workers did not do people's jobs for them or encourage dependency. They encouraged white staff to develop and use their skills and work across difference whilst recognising the additional skills of Black workers.*
Consider the balance between women and men. The recruitment of male carers is proving successful in some schemes and can be enabled by recruitment of male project staff.	
Training should draw on the views of service users and under-represented groups. Training for cultural competence should be continuously available.	*Shameem and Manju helped set up appropriate training for teams.*

Box 2: Helping to build community links

Recommendations on building community links	How recommendation were implemented
Keep checking out the assumptions about families and culture upon which your service is based. If in doubt, ask people what is right for them.	*Staff anxiety about 'doing and saying the right thing' was common. Encouraging staff and users to meet with some kind of mediating role broke down barriers.*
Examine the make up of your scheme's workforce and paid carers. Are they representative of the communities being served? If not, how could this be improved?	*Staff were encouraged to take part in community activities where they might recruit new paid carers. Their visibility would help with recruiting future paid carers, and also staff.*
As a way of increasing access, do not underestimate the value of outreach and development work, with clear goals and targets.	*The development workers facilitated local recruitment campaigns and accompanied staff to community events, acting as a bridge.*

Box 3: Achieving greater flexibility

Recommendations on achieving greater flexibility	How recommendation was implemented
Review the referral processes and assessment procedures used, and check they do not discriminate against and exclude Black families. In order to do this well, you may need to take advice from Black people. Can you consider self-referral from families in under-represented groups?	*By shadowing scheme workers, and providing an outside perspective, Shameem and Manju were able to identify where improvements could be made. They could also bring in experiences from their national knowledge and question schemes custom and practice.*
Include sitting services and other home-based provision in your plans, as some Black families prefer them.	*The workers were able to bring examples of different ways of providing short breaks and assist with setting them up.*

Box 4: Reviewing procedures

Recommendations on reviewing procedures	How recommendation was implemented
Prioritise the goal of a diverse group of carers, and check that your recruitment processes do not exclude or disadvantage particular groups; for example, at the panel approval stage	*The importance of ethnicity, religion, culture, and language for each family was continually stressed, and agencies helped to increase their pool of paid carers so they could make good matches.*
Build on your successes. For example, even one Black family using a scheme or one Black paid carer being recruited, can introduce you to others and provide you with a way into a previously excluded community.	*Scheme workers encouraged good relationships and helped scheme workers to see their Black families as a valuable resource.*

Achievements

Practical changes were made to systems and processes in each short break scheme. For example, the way they recruited and assessed short break carers; the literature they produced; the places where they publicised their service; the times they ran carer training. Schemes were helped to obtain and use local information on the ethnic make up of the population, to find out where they were and to meet community members. This helped to build relations with the local minority ethnic communities, and form the basis for a trusting relationship.

As a result of the intervention, schemes reported an increase in referrals of Black children; an increase in Black short break carers and scheme staff better able to work with colleagues across services and also within their own service.

Acknowledgements

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