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# Invisible families

The strengths and needs of black families in which young people have caring responsibilities

Adele Jones, Dharman Jeyasingham and Sita Rajasooriya

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**Adele Jones, Dharman Jeyasingham** and **Sita Rajasooriya** worked at the Bibini Centre for the duration of this project.

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# Reflections

## Young people researching young people's experiences

“I was able to sympathise with the young people because I could reflect on their experiences because I was there myself. Before I knew about the research I did not think it was normal to have so many responsibilities like that. Talking to young people in such depth made me realise I am not alone.” (Khadija)

“What fascinated me most was there was such a big age gap between me and some young people but we had a lot in common. If more time could be spent with young people to find out what their big ambitions in life are, that would be really good because there is a lot of potential there that could come through. What gets me is that the young people I talked to were like a reincarnation of me. As if I was right back there, as if I was put in a time capsule. I think that the views of young adults should be taken more serious because they are the future.” (Taneisha)

“I found that I could relate to what other young people were going through, which helped because I had that bond with them. I hope that some action will be taken and that young people will be listened to.” (Iram)

# Acknowledgements

## Young people and families

The value of the contributions of black young people and their families to this study lay in their willingness to share experiences; their involvement in the research design; a commitment to the dissemination of findings and also, of major importance, in the discussion and development of relevant theoretical perspectives. Historically black people have gained little from research, sometimes they have lost much and often they have been viewed largely as the objects of scrutiny. We are acutely aware that most research studies focusing on issues of inequality claim social change as a motive and yet those who experience inequality may see little evidence of change. Because of this we acknowledge the participation of black families with genuine appreciation. We are aware that their involvement was due in no small part to the high regard that they had of the agencies through which we were able to contact them and thank Delsierene Waul, Leverne Thompson, Shamin Aktar and Dennis Mullings from the Bibini Centre and Lisa Mok and Circle Steele from the Chinese Women Society for their support.

## Peer researchers

Three young women (aged 18–19) were trained as peer researchers. Their commitment to the work was inspirational and their contributions and perspectives provided insights that enriched the project. Special thanks to: Khadija Ahmad, Iram Ahmed and Taneisha Burke.

## Colleagues

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## Advisory Group

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Emma Stone  
Delsierene Waul  
Glen Mason  
Irene Levine  
Vivienne O'Nealle  
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Gill Thompson  
Clem Henricson  
Amber Wardleworth

## Joseph Rowntree Foundation

Many funding bodies in looking to 'traditional' research, in effect if not always in intent, contribute to writing black people's experiences out of the picture. It is important therefore to acknowledge the contribution to emancipatory research of those organisations, such as the Joseph Rowntree Foundation, which are willing to fund studies that seek to address marginalised voices.

# Setting the context: who are black 'young carers'?

**This section outlines the aims and approaches taken, who the participants were, and the social context in which the research is located. The construct 'young carer' is discussed in the light of the research findings.**

This is the report of a collaborative study between the Manchester Metropolitan University and the Bibini Centre for Young People to investigate the experiences, needs and access to services of black 'young carers' and their families. It is important to highlight that this study was situated within the social and political context of inequality, at a time when interest in the root causes of inequality seems to have been lost; instead, the focus is on 'managing diversity' (as if the problem lies in 'difference') and grappling with the consequences, not the causes, of social exclusion.

The experiences of the young people and families who took part in this study need to be understood within this context of poverty, inequality, racism, disablism and other forms of social exclusion and discrimination, such as immigration controls and school exclusion rates for black young people (especially young men). These families are likely to find it particularly difficult to gain access to services and other forms of support that meet the whole family's needs, and that meet them in ways that are culturally appropriate and non-stigmatising.

## The Bibini Centre for Young People

The study arose out of the experiences of the Bibini Centre for Young People in providing services for black families. While the study was

not an evaluation of the organisation's work, it is important to make explicit the organisation's aims and values since these directly informed the methodology. The Bibini Centre also played a key role in facilitating the participation of black families in the study.

The Bibini Centre for Young People was set up in 1993 as a development of the Manchester Black and In Care Group. It seeks to ensure that its work is of national significance, although its services are provided primarily to children and families in and around Greater Manchester and the Northwest. Its aims include:

1. raising awareness of social issues affecting the well-being of black children, young people and families;
2. developing and promoting good practice in working with black children and families;
3. providing holistic, child-centred services for black children, young people and families who have support needs and/or experience social inequality.

Between 1994 and 1999, the Bibini Centre ran the Black Young Carers Project, providing support and opportunities to black young people and families in which children had responsibilities for the care or support of a family member who was disabled or ill. Through this project, the Centre found that:



- Many of the black disabled parents they worked with received no services at all. Through the Bibini project, they were helped to get services or housing adaptations they had previously been denied.
- The project was often the only way for young people, parents and other family members to receive support that was appropriate, empowering and acceptable to them.
- The project workers adopted a holistic approach, centred on children/young people and respecting and working with parents and wider families.
- The project aimed to celebrate and build on the strengths of black families, acknowledging diverse family structures and parenting.

These experiences formed the basis of the research principles for the study. In particular, the Bibini Centre's commitment to *holistic* working provided the opportunity for shifting the debate about children's rights and disabled parents' rights from one of polarisation into one of constructive dialogue, thus contributing to the development of a more inclusive model of rights and support.

## Aims of the research

Who is a 'young carer'? What needs, experiences and views do they and their families have? How might they and their families be better supported? These were some of the questions the study set out to investigate. The specific aims were:

1. to establish the extent and range of needs of black 'young carers' in Manchester;
2. to examine access to services for families;
3. to make recommendations towards equity and adequacy in services based on accessibility, appropriateness and the empowerment of black families;
4. to examine discourses on children's rights and disability;
5. to contribute to the development of a holistic approach to black 'young carers'.

The study was carried out in Manchester over 12 months. It involved consultation events with 13 young people; training three 'young carers' as peer researchers; interviews with 17 young people and 15 family members from 20 families; questionnaires from 40 agencies and discussions

with 15 practitioners and managers (for example, from young carers' projects, social services, voluntary organisations, health).

## The families and young people who participated

All the family members interviewed were female. Of the young people, 11 were female and four were male. Single women headed 13 of the families.

The relationship of family members to young people included 11 parents, two grandparents and one foster carer. Of these, all but one received care support from a child or young person within the family. In half of the families, we interviewed both the family members receiving care support and the young people providing support.

Nine family members described themselves as disabled. Four described themselves as non-disabled but having a major illness. One parent was neither disabled nor ill, but both she and her child provided support to *her* parent who was ill. Of the young people, 12 described themselves as non-disabled and three as disabled. The illnesses and impairments experienced by parents, grandparents and three of the young people included cancer, diabetes, strokes, epilepsy, mobility impairments, kidney failure, mental health problems and multiple sclerosis.

The young people and families were diverse in terms of ethnicity and religion. Fifteen interviewees were African Caribbean, six were South Asian, three were East Asian, one was white English, four were African and three were Chinese. Self-described ethnicity was: mixed race, Asian, black-Westernised, black-coloured, Muslim, black-British, Sikh, Jamaican, African Caribbean, British, Pakistani and Chinese.

## Social exclusion and disadvantage

Manchester is a large densely populated city, with approximately 404,000 inhabitants. In the 1991 Census, 13% of the respondents described themselves as black from African, Asian, Caribbean or Chinese origin. The Census does not reflect the large population of black people

who were born in Great Britain. This has been estimated as nearly 7,000 more residents of Manchester whose parents or grandparents are from India, Pakistan, the Caribbean and Africa. Manchester has a high proportion of unemployed inhabitants: 17% are unemployed and more than 33% of the population are dependent on Income Support. The city has the highest proportion of Housing Benefit recipients in the UK: 46% of households (Jones, 1993).

It is difficult to identify accurately the numbers of black children and families experiencing difficulties arising from poverty and disadvantage in Manchester. However, it is the case that families with children are more likely to experience poverty than families without children, and that black people experience greater levels of poverty than other groups (Oppenheim, 1993). Given that black families are more likely to be families with children, it is reasonable to conclude that black children are more likely than other children to be living in poverty. In addition, they are often subject to racial abuse and the inequities of institutionalised racism. This is evident in all social spheres and was most graphically revealed through the inquiry into the death of Stephen Lawrence. These factors impact on black children in their day-to-day lives, in schools and in communities.

The experience of social exclusion and structural inequalities based on impairment or illness is another key dimension of the experiences of the families in this study. A recent report found that half of all disabled people live on incomes less than half the national average (a level commonly taken to represent the poverty line). This rises to 60% of disabled adults with children (Burchardt, 2000). While not all children whose parents are disabled take on caring responsibilities, and not all children labelled as 'young carers' provide support to disabled parents, the extent of poverty experienced by disabled parents is likely to have a major impact on parenting and on the lives of their families. Families who experience poverty and unemployment are also more likely to suffer stress and problems of ill health, including mental ill health.

It was not possible to determine how many black 'young carers' there are in Manchester. (The agencies approached as part of this study did not routinely gather information on young people with caring responsibilities.) Estimates based on

surveys elsewhere in the UK suggest there are more than 400 black children in Manchester who assist in the care of relatives (Dearden and Becker, 1995). These numbers may be an underestimate given the high levels of deprivation in the city. It cannot be assumed that all children of black parents who are ill or disabled will have caring responsibilities, but, given the inadequate levels of service provision and findings from other research, this is likely to be the case for a considerable number.

## Who is a black 'young carer'?

Although emerging out of the findings, the term 'young carer' is discussed here since the understandings generated by the children and families in this study have influenced and altered our perceptions.

The term 'carer' is now included in the languages of law and policy (for example, the 1995 Carers [Recognition and Services] Act and of social services policy, in which 'young carers' are categorised as children 'in need' under the 1989 Children Act). However, the term 'young carer' was not one that most of the young people in this study identified with. Although they recognised and understood the term, being categorised in this way made no positive difference to the support their families received: it did not make agencies take notice of the work and responsibilities that the young people had, and it was seen as a label that made them feel different from other young people. While parents appreciated the focus on the needs of their children that services set up for 'young carers' provided, they regarded their children not as carers, but as children who were involved in providing support to people in the family. This suggests that being a 'young carer' is a role, *not* an identity.

'Carer' and terms such as 'coping' were seen as unhelpful. They carried connotations and expectations linked to being a 'do-gooder', 'martyr', 'put upon' and 'being strong', which put pressure on young people and adults to continue caring without adequate support, regardless of the effects. These terms seemed also to contribute to disempowering disabled people as they minimised the support and contributions that *they* provided in the lives of their families.

The study included a number of families in which both the children and the parents or extended family members were interviewed. This allowed us to see that a fixed category of ‘young carer’ obscures the complexity of family life and the ways in which care is reciprocated and shared. Children who provided care also received care. A disabled parent was also the foster carer of a young person whose role in the family included some caring responsibilities. Disabled children provided care support for other disabled children or for adults in their family. Young people provided care for wider family members who did not live in the same household, and, in turn, these family members played an important role in supporting the young people.

From our research, we have concluded that the term ‘young carer’ has limited value for children and families. Where it might have had a useful function – through the inclusion of children and young people in the right to have an assessment of their needs within the 1995 Carers (Recognition and Services) Act – this Act does not apply to children whose needs are addressed through the 1989 Children Act. At one level, this is in line with the UN Convention on the Rights of the Child, which requires that children be treated as children first. In actuality, it means that services to support them and their families are framed within a context of ‘needs’ rather than ‘rights’, and accessed through identifying ‘deficiency’ rather than ‘strengths’. Criteria for deciding who gets a service are underpinned by negative determinants: the child must be ‘in need’ or ‘at risk’; ‘parenting capacity’ is assessed but not ‘parenting support needs’.

The categorisation ‘young carer’ may have led to a small number of specific projects being set up for children and young people. However, categorising children and young people as ‘young carers’ ignores the complexity of caring roles within family life, and may simply mask or perpetuate the social inequality experienced by the whole family. At a practical level, the term has not succeeded in making visible children’s needs or the work they do in their families, nor in securing entitlements for parenting support needs. It allows professionals and policy makers to continue to overlook the important links between children’s work and parenting support needs.

## The report

This report is for a wide range of practitioners, including social workers (from both adult services and children and families services), teachers, health and mental health service workers and also policy makers (national and local). It is also for the children and families whose experiences it seeks to encapsulate.

In addition to the main research findings, the report includes:

- implications of the research for policy and practice;
- questions and ideas to stimulate practice change;
- discussions on theoretical perspectives;
- a critical review of current policy and legislation;
- a description of the research methodology (Appendix).

Reports of this kind rarely include discussions of theory; however, it was considered important in this case to make explicit the meanings behind terms such as ‘black perspectives’, and to illustrate that children’s rights can be constructed as complementary (rather than competing) with the rights of disabled or ill parents, and in the context of family life. More generally, the art of producing theory is important because it signifies who and what is held to be important. We have read and heard it said that black people do not produce theory (Boyce Davies, 1994). bell hooks, a black feminist scholar, writes: “many black people are convinced that our lives are not complex, and are therefore unworthy of sophisticated critical analysis and reflection” (hooks, 1992, p 2). We understand the sources of such views, but do not agree.

When researchers and funders present theory as the least important aspect of the process, they must realise that this indicates not that theory is absent – it never is – but that the theoretical positions that underpin the research have been presented as taken-for-granted. In this lies the danger of perpetuating ethnocentric or universalist assumptions.

# Research principles and theoretical perspectives

**In this chapter, we make explicit the principles and theoretical perspectives that guided the project, including those on race, disability and rights, before reviewing the way black families' experiences have been represented in relevant literature. Our aim is to dislodge ethnocentric assumptions that often underpin policy and practice and to encourage more reflective and inclusive approaches to addressing inequality.**

## Principles of the research approach

Empowerment or emancipatory research (Humphries, 1994) must be situated in the social, historical and political context from which it arises. It cannot be anti-oppressive unless it goes beyond scrutiny of the oppressed to the structures and systems which are the source of oppression (Mama, 1989). If it cannot be used to benefit the lives of those who are researched, it serves little purpose.

The specific principles for this project were that it should:

- adopt a 'critical black perspective' which takes into account: the diverse communities and life styles encompassed within the term 'black'; issues that affect black families (such as immigration, racism or school exclusion); specific needs, such as for language interpreters; and the strengths and achievements of black families as well as their problems and difficulties;
- reflect and value the diversity of black family life based on a broad and inclusive definition of family, which defines family as kinship networks of care, support and responsibility (including biological and non-biological relationships) and encompasses families who live apart but are connected to each other, as well as households in which people live together;
- understand caring and household responsibility as a reciprocal function of family life with value to both children and adults, while recognising that, where there is a lack of appropriate and accessible services and adequate income, caring can involve levels of work and responsibility which affect the well-being of family members;
- adopt a social model of disability while promoting theoretical perspectives that are more inclusive of black people's experiences;
- sustain a commitment to children's rights and situate children's rights in the context of family/community; see children's and parents' rights as mutually supportive; and make explicit the systems of structural inequality that affect children, such as racism, disablism, class and gender inequality;
- adopt a critical approach to 'caring' and 'young carers', where these terms are framed within ethnocentric and pathological notions of caring that may lead to disempowerment of black children and their families.

## A critical black perspective

The term ‘black perspective’ does not refer simply to the perspectives of black people – black people are diverse and are no more likely to share a common perspective than white people. Nor is it a prescription for how to be black. It is a political perspective informed by a political definition of the term ‘black’, through which black people deal with and challenge the destructive effects of racism and the normative assumptions of ‘whiteness’. Our use of the term is a means of conceptualising our analysis of experience and of giving authority to our sources of knowledge. The concept is situated in the context of British imperialism, colonialism and racist oppression; as such, it may not travel well to other societies, even though there may be points of connection with struggles elsewhere. The term ‘critical black perspective’ reflects our concern to address the connections between different forms of oppression, such as sexism and disablism, and to reflect on oppressive behaviours among and between black people.

## Reflecting on the research process

The emphasis in the project was on children and young people’s participation. This came from the experiences of the Bibini Centre’s Black Young Carers Project. These showed that children’s work was not valued, that their voices were not heard, and that the lack of availability and access to services and opportunities had a major impact on their lives. Exploring these issues required an approach that placed children’s voices at the centre. An important aspect of this was to train three young people (who had caring responsibilities) as researchers; these ‘peer researchers’ carried out interviews with some of the young people who participated in the study. We also wanted an approach that was inclusive of parents; hence the decision to undertake interviews with parents and family members as well as children and young people.

We have reflected on the significance of black researchers, both male and female, and including young people, conducting research with black young people, both male and female, and of the research arising directly out of the experiences of black young people (a participative and child-

centred approach). Our experience was that young people did not find it necessary to focus on themselves as *black* young people — they were not ‘other’ in this setting. There was a shared consensus about the existence of racism that did not require the regurgitation of horror stories, the accommodation of white guilt or defensiveness, and a sophisticated understanding of racism that did not reduce affirmation and acceptance of each other’s experience of racism to shared cultural identity. So, while there was ‘sameness’, in that the researchers and research subjects were black, there was no assumption or expectation of ‘sameness’ in relation to cultural or ethnic background.

## Disablism and racism

The social model of disability is built on a political and analytical distinction between impairment and disability – both of which are shaped by gender, class and specific expectations based on notions of difference that are themselves influenced by cultural, social, economic and other factors.

**Impairment** describes an individual’s physical, sensory, intellectual or behavioural condition.

**Disability** describes the structural inequality and discrimination experienced by people who have impairments. The focus for change is on removing *disabling barriers* and changing social, economic and political arrangements that exclude people with impairments from taking part in society as full citizens.

People who may not define themselves as disabled may yet be subject to the inequalities arising out of disablism policies, structures and behaviours. This was the case for a number of black parents in this study who experienced ill health but did not identify with the term ‘disabled’.

This research is rooted in the social model of disability, but we question the limitations of this model as evidenced in its failure to address its own assumptions and power relations. The social model has inadequately addressed the specific circumstances of black disabled people, through making invisible the experience of racism, and thereby minimising the possibility that social, economic and environmental barriers may be a



consequence of both disablism and racism. Black people's perceptions have been largely excluded from the development of the social model and disability movement. An inclusive social model of disability would be one whose analysis simultaneously addressed other sources of inequality such as racism and would therefore be rooted in the economic, social and political context of black people's experiences.

## Simultaneous oppression

Our lives as Black Disabled people are comprised of many different facets and encompass a range of social divisions. (Begum, 1994, cited in Butt and Mirza, 1996, p 87)

Concepts of 'double disadvantage' and 'triple jeopardy' to denote the cumulative disadvantages of racism, disablism, sexism and other forms of oppression have been criticised by black disabled people for failing to facilitate an understanding of their experiences, and for compartmentalising people's lives. Begum (cited in Butt and Mirza, 1996) and others argue that multiple and simultaneous oppression is a more complete way of understanding the impact of and relationship between disablism, racism and sexism.

In this study, all the parents interviewed were women; most were the head of a lone parent household. Some described themselves as disabled; others as non-disabled but experiencing ill health. Their experiences are mediated simultaneously through race, gender, disability and class. Their identities are also subject to stereotypes (especially from medical professionals, but also from social care professionals), which may be underpinned by racist, sexist and disablist ideologies leading, for instance, to ideas about the sexuality (non-sexuality and a-sexuality) of disabled women and questions not only about their ability to parent, but also about the social and 'moral' appropriateness of them as parents. The concept of simultaneous oppression is particularly helpful in understanding their experiences.

## A critical view of rights

Framed within universalist notions of humanity, rights discourses have nevertheless placed male constituency at the centre of that universe. Women's claims for human rights have argued for a more inclusive interpretation based on equality. Some feminists have asked whether, in adopting a concept based on male privilege, women have colluded in marginalising aspects of themselves. It has been argued, for instance, that women should not seek to be equal to men or to remove sexual difference from political theory. Instead, they should recognise the gender inequalities within terms like 'humanity', should challenge assumptions of male centrality and should make visible the experiences of women and the perspectives arising out of women's oppression (Kiss, 1997). Black and non-Western feminists have shown that the 'man' in humanity is not only male but most often white and enfranchised through Western privilege. He can further be identified as determinedly heterosexual – if not in actuality, then in aspiration, through the invisibility of sexuality as a legitimate rights issue. When white women have asserted that gender matters, they have found themselves subject to criticism by black women for their assumptions about how gender matters, and for marginalising different aspects of social inequality (Mohanty, 1992).

## Children and rights

Jones (2000) argues that, rather than adopt universalist notions of children's rights, which level out rather than address difference and inequality, what is required is a theorisation of children's *experience* similar to that developed by Mohanty and others in relation to women and including attention at both the discursive and material level to issues of race, gender, disability, sexuality, class and so on. Jones's concern is that approaches that focus in an individualised way on the rights of the child detract attention from and de-politicise wider issues of social injustice which impact in profound ways on the rights of children, both as individuals and as collective groups. Her proposal is for a children's rights agenda in which the rights of the individual child are not regarded as fixed, but rather are negotiated and situated within family and

community and also within a wider social and political context.

Children's rights are important not because children should be regarded as a distinct group separate from adult human beings, but because they experience particular forms of oppression and subjugation. Rights theorists have categorised children's rights in different ways, for example enforceable rights (such as legal representation); neutral rights (the right to have views taken into consideration) and non-specific rights such as the consideration of a child's welfare. The importance of children's rights, however, lies not so much in adults determining and discussing what is best for children, but in effecting real change in addressing the oppression of children.

## An inclusive model of rights

Many black people will identify with this struggle for recognition. It is in this process of 'identification' that lies the potential for an inclusive model of rights. This does not elevate children's rights as more important or distinct from the rights of others, but places them within the context in which children live their lives, and acknowledges that the dynamics of structural inequality and the power differentials between the child and the adult may subjugate the rights of the child to the rights of others.

This research is informed by an approach to children's rights that:

- questions the concepts of childhood;
- privileges children's experiences with authority and status unmediated by adults;
- recognises children as sexual, political and self-determining subjects;
- values children's contributions and work;
- regards rights as negotiated and placed in context rather than fixed;
- situates children's rights as individuals within the context of family;
- is concerned with wider issues of inequality and injustice.

In making children and young people's experiences and perceptions of their caring responsibilities the centre (although not the whole) of our focus, the authority on determining what their role means to them and what their needs are is shifted to the children and young people themselves. Disabled parents and black parents have fought to assert the value of their own perspectives and experiences. In doing so, the spaces they open up in the challenges they put forward can also make it possible for the voices of their children to be heard.

In summary, the principles and theoretical approaches discussed in this section provide a way of making sense of the 'whole', that is, the range of different, often conflicting, perspectives, and the professional and personal agendas that of necessity must trouble a project of this kind. The understandings that we (research team and Advisory Group) arrived at are not those that we started with, but are the result of debate, contention and the learning that took place as we engaged with the research process.

# A review of key studies

**This section explores from a 'critical black perspective' the development of 'young carers' research, the extent to which this body of work has so far been critiqued, and the way that black children's and families' experience has been represented in existing research and critiques.**

There are a number of methodological difficulties in critiquing studies for their implications for work with black children and families, particularly where this was not an aim of those studies; problems arise, for instance, in the differences in terminology and methods used. Nevertheless, the studies we draw on have influence at the level of both policy and practice, and it is important therefore to point up the significance of particular interpretations or omissions.

Becker et al (1998) provide a useful and comprehensive review of the development of research and literature on 'young carers'.

## Research on 'young carers'

In the late 1980s and early 1990s, several studies were published which began to explore how many young people have caring roles and what their experiences might be (Page, 1988; Billsborrow, 1992). *Children who care: Inside the world of young carers* (Aldridge and Becker, 1993) provided the first detailed exploration and the start of a series of influential publications from the Young Carers Research Group at Loughborough University.

The Aldridge–Becker study looked at 15 young people and adults who had significant caring responsibilities for someone else; in particular, it examined the range of tasks carried out, the impact of caring on their lives and relationships, and the young carers' views about support. The

researchers found that young people and their families generally had little or no support from extended family, neighbours or services. When services were involved, they were unlikely to be aimed at supporting the young person and they often excluded young people from information and decision making. Schools were largely unaware of young people's circumstances; even when they were, they were often unsupportive. Most young people wanted practical support and someone to talk to. Isolation and not knowing how to plan for the future were particular problems.

The study was based on a narrow interpretation of children's rights, effectively restricted to children's rights to have their developmental needs met. While Aldridge and Becker discuss the rights of young people as 'carers', they make no reference to young people's other rights, for example as members of families or communities.

*My child, my carer* (Aldridge and Becker, 1994) was based on interviews with the parents of most of the respondents of the original study. Yet, the focus was not on the "personal concerns of the adult care receivers ... but [on] *their experiences as the recipients of their children's care*" (p vii, original emphasis). Little light is shed on families' experiences of disablism, on disabled people's experiences of parenting, or on the experiences of families where young people have caring responsibilities for another family member.

Later studies have paid more attention to the impact of caring responsibilities, including on



family relationships. Even so, studies continue to be based on disablist notions about parenting and families. In *Couldn't care more* (Frank, 1995), the author suggests that there may be aspects of living with a disabled person that are inherently stressful for young people. However, little attention is paid to how disability impacts negatively on families, such as through inappropriate or unavailable services. Discussions of 'false maturity' and family dysfunction that were related to 'loss of parental authority' and the 'transfer' of family roles make uncritical use of the psychiatric and systemic models of family behaviour commonly found in medical and social work literature on disability and parenting. Such models have had negative consequences for the way in which the families of disabled people, and indeed black families, have been understood and approached by medical and social work services.

## Critiques from a disability perspective

Much 'young carers' research has been subject to criticism by a number of writers who approach the subject from the social model of disability (Keith and Morris, 1995; Olsen, 1996; Olsen and Parker, 1997; Morris, 1997).

Keith and Morris (1995) show how academic and journalistic representations of disabled people's children as having to 'parent their parents' have happened *despite* the evidence. They reveal how Aldridge and Becker found that young people did not view their parents as dependent on them, yet still chose to write that children are "becoming their parent's parent" (Aldridge and Becker, 1993, cover note; quoted in Keith and Morris, 1995, p 40). The conflation of 'caring' and 'dependence' in much of the literature is also criticised.

Olsen and Parker explore the development of 'young carers' projects as a result of the literature, and discover how much service provision "involves some kind of substitution of, rather than support for, the parental role" (Olsen and Parker, 1997, p 127). They question the use of a children's rights approach to the issue of 'young caring' when, for instance, children's rights to continue to 'care' conflict with parents' rights to have their parenting support needs met. They point to "a very real danger that providing services which support the child in the role of a

carer will obstruct the development of services aimed at overcoming parental dependence".

More recently, an inspection by the Social Services Inspectorate, *A jigsaw of services* (DoH, 2000), found that the provision of support services for disabled parents is patchy and that disabled parents remain largely excluded from service development in this area.

## Critiques from a black perspective

There are also a number of ethnocentric and racist assumptions in 'young carers' research which critical appraisal by others has failed to identify.

In Aldridge and Becker's 1993 study, young people are said to take on caring roles "often at the expense of their own childhood" (p 76); yet there is no exploration of contemporary representations of young people, childhood, parenting or family roles, and no recognition that this needs to be situated in terms of culture and race.

The study also depicts the methodological dilemma of black families for researchers. While black families' isolation from support services means that black young people who have caring responsibilities may be harder to identify, we question the implication that there are inherent difficulties in including young people from 'minority ethnic communities' in this kind of research. A primary objective of the Aldridge–Becker research was the involvement of black young people; however, the use of a 'mediator' to contact South Asian families suggests that the need for a more inclusive approach was not recognised. The use of a 'black perspective' in the planning and execution of the research might have prevented assumptions of cultural homogeneity among Asian communities (cf "the Asian community often expects family members to care for relatives without external support and intervention"). Their descriptions of young people also point to an over-reliance on cultural explanations for behaviour. For example, they note that the Asian young people interviewed appeared "shy and uncomfortable", and put this down to the "restrictive" presence of family members. They do not say how they came to this conclusion, and neither do they explore the

dynamics of the researcher–researched relationship which might have contributed to this.

Shah and Hatton, in their study on *Caring alone: Young carers in South Asian communities* (1999), found that young people led lives that were structured around their caring responsibilities, and were rarely able to disengage from their caring role. This role had some positive aspects for some of the young people, but significant negative consequences for almost all of them in terms of their education and their ability to make plans for their future. Isolation and cultural stereotyping by professionals was also identified. These findings were broadly similar to those identified by earlier research on white ‘young carers’, yet it is telling that the finding that aroused most interest was that South Asian young people received no support with their caring from extended family members (*Community Care*, 1999) – even though earlier studies had found that white ‘young carers’ too were unsupported by wider family members.

While research has produced some valuable findings about the experiences of white young people with caring responsibilities, statements about black young people’s lives and those of their families are more likely to have been unfounded or based on assumptions. This also applies to critiques of ‘young carers’ research. Keith and Morris (1995) raise questions about the “condemnatory” approach to disabled parents and appear to find great significance in the parenting practices “of other cultural and social groups”. They fail to address the social and political contexts of black family life or to challenge racist assumptions about cultural practices.

It is unhelpful to argue about whether black families experience greater condemnation than disabled people’s families. Many black people have to deal simultaneously with both racist and disablist misrepresentations of their parenting. There are examples of black people being condemned on the basis of fantasies about aspects of their family life. In addition, black young people’s responsibilities in childcare, domestic work and interpreting may have more to do with black families’ strategies for coping with poverty, exclusion from support services, services’ failure to provide interpreters, poor housing, ill health and long working hours than with cultural practices.

Overall, our review revealed that:

- Some approaches privilege ‘white’ with a normative status, in which only the ethnicity and race of the ‘other’ is made explicit.
- Universalising claims made by some researchers and commentators result in or rely on the ‘invisibility’ of race and racism.
- Some studies have failed to reach black young people at all.
- Even where studies have sought to include the experiences of black people, these are often based on an inadequate theorisation of racism, and in some cases on flawed approaches to planning and conducting the research.
- Disablist assumptions about disabled people as parents and their family relationships are evident in many studies, along with a failure to explore professional assumptions and practices in working with these families.

# 4

## Identities, kinship and communities

**This section describes the diversity of the families involved in this study in terms of religion, language, ethnicity and, importantly, family life-styles and access to support from wider family members and local communities.**

### Religion

The religious faiths of the research participants were diverse and included Rastafarian, Muslim, Sikh, Catholic, Pentecostal, Jehovah's Witness, Church of England and Buddhist. Some interviewees had developed or changed their religious beliefs (one person explained that she had been brought up within a Christian tradition but was now more "into being spiritual").

Religion seemed a significant aspect of most families' lives. In these families people talked about gaining spiritual strength from religion, and about religion helping them to feel more in control of their lives or strengthening their family. Faith communities often provided practical help. Some people felt this helped them to parent their children and keep the family together.

"Being part of my religious community is important to me – they knew about my circumstances and were very supportive."

However, it was also the case that some people's opportunities to practice religion were restricted by disability, most notably by inaccessible places of worship and the disability attitudes of other people who attended.

### Language

Most of the families who participated in the study were fluent in English as well as other languages. Some parents, however, did not speak English, and where this was the case young people's roles in their families included acting as an interpreter, writing letters, translating official information and completing forms. Some of these tasks were also undertaken if a parent's impairment or illness affected their communication abilities.

While young people were often skilled in these tasks, there were examples in which this role was inappropriate or created difficulties, particularly if the child was very young or if the information was complex or sensitive. Misunderstandings or difficulties could arise for example when communicating information that a parent might have preferred to have kept confidential, interpreting personal information, being unaware of the seriousness or urgency with which information might be needed, withholding information or translating medical instructions.

### Ethnicity

Young people and adults understood their ethnicity in creative and constructive ways and discussed this issue with confidence and pride. However, participants also talked to us about ways in which their ethnicity was understood or

represented in a distorted or reductive way by service providers, white peers and others. Participants defined their ethnicity using a range of different referents, including their own or their parents' place of birth, religion, nationality and 'race'. For some, race and ethnicity embraced a country they themselves or their parents had been born in, while others felt they were born in Britain and were therefore 'black British' or 'black'.

While many participants talked about the symbolic and personal significance of their ethnic group, they were more likely to point to the local community as a potential source of practical support, particularly to those who had shared similar experiences of racism.

## Kinship networks and family life-styles

Family life-styles were diverse, and kinship networks included both biological and non-biological relationships. Single women headed most of the families who participated in the study, although there were some two-parent families.

In many cases, the support of the family was a shared activity, which drew on wider family members and friends and was not limited to relationships within the same household. Participants were as likely to have caring responsibilities for, and to draw support from, these relationships as from close biological ties.

The contributions of children to everyday life and the effective running of households were acknowledged by most parents as a major factor in keeping the family unit together. This aspect of children and young people's work is often omitted from the literature on 'young carers'.

## Support from the wider family and community

There was little evidence that young people with caring responsibilities and those they cared for were left unsupported by wider family. Often, though, wider families were unable or not expected to provide practical support on a regular basis. Sometimes this was because they were

experiencing difficulties of their own. Sometimes wider family members were supportive but did not live locally, and so were unable to assist on a day-to-day basis, and/or they could provide support only during crises. Where wider family members were involved in day-to-day support, this was likely to be in families where there had been similar levels of contact before a family member came to require support. A few people spoke of increased stress from wider family members.

Some families made their own homes the focus of wider family social life. This may have affected the amount of privacy and control for some parents, but for other families it was an effective way of addressing isolation and the wider exclusion of disabled family members.

Many family groups were managing to support individuals without any support from external agencies, but this was not the case for all the families. Even those family members who appeared to be providing 'seamless' support were not necessarily able to continue doing so, particularly where support needs were likely to change in the future. In some families older siblings had moved out, and in the absence of other forms of support this usually meant that a younger sibling took on a greater level of responsibility. Some young people had had adult support from partners, extended family members or professionals, but others had looked after the needs of their parent alone until they were unable to sustain the pressure and had contacted an adult they trusted.

The way in which people experienced their local community was often refracted through experiences of disablism and other forms of social exclusion, as well as through the effects of social deprivation on the communities themselves. In each of the main neighbourhoods where participants lived, we spoke to people who said they felt unsafe in the area, as well as to families who said they found their local community supportive.

## Conclusion

The diversity of religion, of ethnicity and also of family life-styles raises important questions about dominant concepts of family life in Britain, and the extent to which non-orthodox family forms (in ethnocentric terms) are seen as deficient or inadequate, and negate the role of black women and men in the upbringing of children with whom they may not live.

The findings also suggest that, where families preferred to receive support from extended family members, there seemed to be no coherent way in which the social inequalities that many black families were dealing with, and which undermined their attempts to support one another, were being addressed. Often, wider family members were supportive but were unable to provide practical support on a regular, long-term basis.

# Parenting and the nature of children's and young people's contributions to their families

**This chapter describes the responsibilities and tasks undertaken by children in the study. We discuss parents' and young people's perspectives on the ways in which tasks are taken on, parenting strategies for managing family life, how tasks become defined as appropriate or inappropriate, and the contribution children's work makes to families surviving and thriving together.**

## Children's and young people's responsibilities and tasks

The chores, tasks and responsibilities taken on by children and young people in this study varied greatly in terms of the nature of tasks, levels of skill and physical strength required, and time commitment. They included: household cleaning; ironing; gardening; cooking and preparing meals and drinks; shopping; managing limited finances; assisting with mobility; helping with personal care; applying medical dressings; administering medication and carrying out nursing procedures; helping to dress; encouraging exercise and socialising; coping with distress or depression; building confidence and skills; translating and interpreting; teaching English; supervising and playing with young children; taking children to and from school; being available if assistance is needed; and communicating with and interpreting for health and social services workers. These were all tasks that young people did on a regular basis. Sometimes this involved coordinating different tasks at the same time.

“I wake up in the morning, and my mum and dad will already be awake, so I pray and give them their medicine and their breakfast. Then I'll go and check on my brother, see if he's all right, whether he's fallen out of bed or anything. We don't have the bed supports so sometimes he rolls out of bed and can't feel it. Then I'll go and tidy up my bedroom and tidy up in time to get ready for school. I'll get my brother up and get him ready, give him breakfast and everything, and then I'll prepare food for lunch because I can't come home every day. I put their medicines in these little containers, put them to one side and then I go to school. By the time I come back, my nephews will need collecting, so I collect them, feed them, get them ready to go to the mosque, then when they're at the mosque I give my parents something to eat, give them their medicine again ... by this time it's seven o'clock. I go to pick my nephews and my brother up from the mosque and they will be hungry again, so I make them something to eat.... I'll tidy up and eat with them in the kitchen. And then I'll probably take my nephews

home, see if my brother needs any help and come back again. It usually depends, but if I don't have any other work to do then I do my homework from school."

## Parenting and parents' perspectives

Previous studies have suggested that in families where young people had taken on caring responsibilities, young people had come to 'parent' their own parent, or that the parents' authority had been undermined (Aldridge and Becker, 1993). We explored family routines and parenting strategies with both young people and their families.

We found that most families had clear ideas about how young people should be parented, and that tasks and responsibilities were allocated and carried out in a way that effectively fulfilled many of the young people's needs.

Families made decisions about children's and young people's involvement in caring that were based on the exercise of parenting responsibilities. Children took on the care tasks that met their elders' needs for physical care and supervision; promoted their own self-care skills and confidence; helped them to look after others and act responsibly and gave them opportunities to demonstrate respect, love and commitment. Most parents tried to balance the responsibilities their child had at home with the things the child needed to do for their own development:

"I had to say to them, whatever you do just carry on going to work or to school. But sometimes it disrupts their schoolwork as well."

## Parents' views on their children's work

Parents took pride in their children being able to contribute to their family unit. They viewed their children's abilities compared with those of other young people and were proud that their children were mature and capable of doing tasks other

children were either not interested in doing or were not expected to do.

"So we sat, she washed the chicken, this is the first time. I cooked the rice because nobody can cook the rice, and she shared out the dinner exactly how I share out dinner. Rice on one side, she shared it out really nice...."

Another parent spoke with pride about how her children had supported her in ways that required a high level of skill and understanding. She explained:

"The relationship has not changed. If anything it has made my relationship stronger. They have always been close and we became closer. It was a time when we just had to deal with a crisis."

Parents talked about the importance of young people learning how to care for themselves and to have confidence in their own skills: "I bring them up from a small age to help themselves". This parent and others felt that, although their children carried out a significant number of tasks that other children might not do, they would not want this to be different:

"It was part of our family to do chores and help out – when you live together as a small group that's what you do. Everybody contributed and helped in the house. Just that mine had to do a bit more than usual."

Parents recognised that some of the tasks their children did involved the commitment of more skill and time than might be expected of others of their age group. But for these family units to survive and stay together, both parents and young people were prepared to take on these tasks. Some parents were fully aware that, without the contribution of their children, everyday life as a family unit would not be possible.

## "A different style of looking after"

While it is important not to generalise or homogenise the experiences of black parents, the study found that different, broader and more creative understandings of 'parenting' were used,



raising questions about the narrow ways in which welfare professionals usually apply the term.

What parents described, even regarding the ways in which they arranged the tasks within their homes, was not an *absence* of parenting, but a *different way* of parenting: “a different style of looking after”. This broader concept of parenting seemed to relate to notions of collective or shared responsibility. Thus, parents met their children's emotional, physical, educational and other needs themselves; or sometimes these responsibilities were shared between different adults.

## Services that supported parents in their parenting

Where families found services that reflected their own understandings (as was the case with the Bibini Centre's project), they made use of them and valued them. This was both because they received practical support and guidance in caring for their children, and because they did not feel labelled as deficient or inadequate:

“Bibini was good for the children. I got support and advice from them too and it helped me how to respond to my children. I needed a lot of advice and they helped me through it.”

Several other parents also said they felt supported in their parenting by the same organisation, and this enabled them to continue to parent their children. They received advice and support for themselves as well as encouragement to parent to the best of their abilities. Parents also valued support that focused on their children – enabling children to have fun and giving them an opportunity to express themselves away from their caring role.

“To me they knew the kids, they knew their ways.... No don't help me out, help the children. I could go anywhere and get help if I wanted to. They helped the children; no I shouldn't say that – guide the children – explore the world, express themselves.”

Parents expressed frustration and disappointment that schools and other services were unable to take this approach and support their parenting in more direct, flexible and constructive ways.

## Parents' fears about approaching services

Parents felt that the ways in which they were likely to be perceived and judged by social care agencies, in particular social services, would be negative. This concern was a major barrier to families seeking support. It also meant that, where social services became involved with a family, this created a high level of anxiety and additional stress, even when individual social workers were found to be supportive and helpful, as was the case in several examples given.

One parent told us that keeping the house clean was one way to prove to social services that their family unit, while going through traumatic external pressures, was able to live together, and to provide evidence of good parenting. Here, domestic tasks were seen as a survival strategy to prevent family break-up:

“I had to prove to myself that nobody from Social Services was going to walk through that door and say, that's wrong, so's that, and that. So the house was spotless...”

Another parent expressed her fears in these terms:

“[child] was my strength, no nobody could take my kids. To this day nobody take my kids.”

## Young people's perspectives on having caring responsibilities

For many young people, caring responsibilities were inseparable from feeling part of a loving and caring relationship. Rather than having been chosen to do certain tasks, young people were themselves choosing to take on these commitments, whether they were minor or had a significant impact on their life-styles:



“It wasn’t like I had to do it. It was me sort of thinking ‘What do I need to do?’ I mean, it would be very inconsiderate of me – when I know my mum is ill and she can’t do it – it would be very hard for me to leave them without food and go off to school. It’s something that you would do anyway, if someone is not well.”

Young people may make such decisions because there seem to be no alternatives for their family. Indeed, most of the families who talked to us did not receive support services. Additionally, young people made decisions in the context of the power relations within their families, particularly those of age and gender, and these affected the range of choices they were able to make.

Young people recalled how the process of taking on caring responsibilities had been a complex one; some found it impossible to articulate completely. One young person described helping her mother through a serious illness:

“Close friends and family knew what was happening but they couldn’t say, well, she was feeling like this or anything like that. They wouldn’t really know. You don’t really know how she feels unless you actually experience it yourself, so with me being in the house I had the experience, and I’ve seen what is going on and the pain that she was in and all the rest of it.... So with me looking after my mum – it’s not a fact of having to do it: it’s just something that I do.”

For this young person, ‘becoming a carer’ was an inadequate way to express her response to her mother’s illness. She felt that the role that she had taken on in supporting her mother – providing emotional support and encouragement through hard times – existed before she ever had to help her through the illness.

Young people were responsive to the needs of parents and often would take on tasks to relieve or support parents without being asked:

“I don’t really need to interpret ... but he gets tired, so it would be easier if I just do it.”

Young people recognised the diversity of their skills and tasks, and how these changed as they

became older and more able, or as circumstances altered. They had their own expectations about “helping out”, and thought that young people doing domestic chores in the home was a “normal”, “reasonable” part of life – their contribution to the smooth running of their family.

Domestic tasks that were seen as contributing to general family life included tidying up rooms such as kitchens, living rooms and own bedrooms; taking out bins; painting and decorating; making cups of tea; filling hot water bottles; and going to the shops to fetch small items such as newspapers, matches or milk.

Tasks like shopping, cooking and cleaning were seen as more demanding and requiring skill and/or physical strength. The age at which some young people began doing this work affected the extent to which this was seen as a “usual” household task.

Some young people were in charge of managing budgets and supporting their parents in day-to-day administrative tasks such as paying bills, answering phone calls and reading out letters. Other young people helped their parents with medical care or were solely responsible for supporting parents with mental health problems.

We talked to a small number of young people who felt that their caring responsibilities (rather than other aspects of their lives) made them feel unhappy, angry, undervalued or isolated, or who felt that having such responsibilities had led them to be less interesting or appealing people. These young people were managing their responsibilities effectively, but clearly should not have had to continue in their caring role in such situations.

Some young people felt that they had been isolated within their caring responsibilities and that this had affected their development in significant ways:

“I think it has affected me mentally ... even now I find it hard to talk to people because I am used to being on my own.”

“I don’t think I should be doing that. I think parents should be showing examples, you know, being a good role model, but I never had that. I just had to

do all these things, so I find it hard to try and ... be how my friends are. My friend has got a really good personality. I sort of wish that I had that personality, but because I had no one to teach me it is kind of hard to make my own personality.”

A number of young people felt their responsibilities meant that they missed out on having fun. This seemed to be a particular issue when young people felt resentful about continuing to care, where young people had no regular opportunities for positive experiences, and where they felt they were taking on inappropriate caring responsibilities:

“As a teenager I don't think I should do any of it [regular medical care] 'cos teenagers are supposed to have fun....”

It is important to stress that specific impairment or the actual task undertaken was *not* indicative of the impact on the young person; while these factors were important, their significance was linked to other factors, such as relationships in the family, individual skills and strengths, other sources of stresses and other supports available.

## Young people, information and professionals

For some young people, their difficulties were exacerbated because they were not given information about family members' health problems and the treatment that they needed.

When one young person's mother became seriously ill, she was given no information about the illness, her mother's treatment, or the possibility that the young person herself might develop the problem in the future, either by health professionals or by her mother, who did not know how to speak to her about the situation. This daughter clearly wanted information. She found out more by contacting a survivors' group and doing her own research.

Most young people said that they were given very little information either about services available or about their parents' needs, and yet it was assumed that they would be able to cope. While

very few professionals actually talked to young people about their parents' circumstances, they still expected to be briefed by them. Nor did the professionals ever enquire about the young person or their needs in their caring role:

“When people ask, it's always how's your dad, how's your mum – never how are you.”

“They were really concentrating on my mum.”

## How tasks are taken on and negotiated

Young people were most likely to come to have caring responsibilities through families having to find ways of coping with crises and being isolated from support services. In these situations, family members, including young people, had little choice in terms of the commitments they took on. Where young people's caring responsibilities were the result of a clear agreement, the responsibilities were likely to be shared fairly or equally between different family members.

While some young people felt proud to do such tasks, because it made them feel good about themselves and close to their parents, others had conflicts with their parent as a result of different expectations when tasks were supposed to be completed. One parent talked about how tasks were negotiated:

“With a lot of arguing, get this done, get that done, ‘oh I will just do it when I have got the energy to do it’.... She will do it eventually, she will leave the dishes there maybe until whenever she felt like washing them, even if it was like two days later.”

Culture was important in that it shaped the way young people understood their relationship with those whom they supported. We did not explore young people's views of cultural expectations specifically, but in our attempts to understand the significance of culture (and other factors) it did not seem to us that young people were ‘elected’ to be carers, or came to have the significant caring roles that they did, because of cultural

expectations. Instead, power relationships concerning disability, age and gender were the main factors that contributed to young people taking on responsibilities. Where cultural expectations were evident, this related to general assumptions about gender and young people's, particularly girls', involvement in household tasks. In some families, girls and boys had different relationships within families, and this led to them taking on different tasks. Overall, decisions about caring responsibilities were made privately and were understood as measures to cope with exceptional circumstances.

Young women and young men in the study faced different dilemmas when changing or ending their caring roles. In one family the young man had left home and was no longer involved in supporting his parent. For young women, leaving home was more difficult. This was largely because of social pressures rather than family values, for example poverty and inadequate housing for single young women.

## Determining what is appropriate or inappropriate

Some of the tasks children did were within the boundaries of what families considered appropriate for their children; for example, young children might be responsible for their own pets and tidying up their own toys. Other young people undertook responsibilities and levels of care that had major implications for their own health and development, or that they and/or family members experienced as upsetting or difficult.

A number of young people frequently helped family members with washing, dressing and using the toilet. For some families, this was appropriate. One young person said,

“I just think it's normal. When you've got a kid you're going to take all their clothes off and give them a bath, so that's what you do with adults too.”

We also talked to families in which young people provided help with intimate personal care tasks but where this was distressing or difficult. One parent had to use a commode in an alcove of the living room, where she spent most of her waking

time, and where she always slept. Her children would have to support her to sit on the commode, and she told us how they often had to assist her when she fell when trying to get off. This was clearly distressing and frustrating for both parent and children.

One young person lived on his own with his parent who has mental health problems. For nearly five years, he had been solely responsible for his parent's well-being, even though the parent's mental health problem was something he found hard to understand. Little family support meant he took on many responsibilities, including domestic tasks, budgeting and monitoring his parent's health.

Another young person's responsibilities involved changing the water of a dialysis system:

“I don't think any kid or any young person would want that kind of responsibility. One wrong move and it could be fatal.... I don't think I should do it but I am.... As a kid I would not understand half of the stuff.... I am supposed to be a lot more educated for this stuff....”

Many parents stated that they thought certain tasks would be inappropriate for young people in their families. One parent told us how the young people in the household did not administer medication: this was a decision she had made, based on her children's lack of awareness of the risks involved in making a mistake or themselves misusing the tablets. This parent was able to take on this responsibility herself. However, other families had no such alternative, and young people were doing similar kinds of tasks and negotiating the risks involved.

Some children and young people were using kettles and cookers from a young age. Although we did not find situations where this appeared to put young people or their families at risk, a number of parents said clearly that they wanted to have more support with domestic tasks that might present difficulties for children. Children as well as parents were conscious of the dangers associated with some tasks. One child who was responsible for preparing meals asked whether someone would be able to come “to boil the eggs”. Several parents were concerned that social services might perceive circumstances like this as

a risk to their children, resulting in the break-up of their family unit.

There was little evidence that adults had access to home support services on the basis of their needs, and no circumstances where the support needs of young people with caring responsibilities had been assessed on the basis of a 'carer' needing support.

## Conclusion

While both children and family members cited the benefits for families of young people having caring roles, it is clear that for some young people the isolation, the lack of choice and control and the failure on the part of professionals to consult with them left them with a deep sense of dissatisfaction. While young people talked of wanting their families to have support that would relieve them of tasks they found difficult or stressful, they also wanted services that would focus on their own needs. It would have made a significant difference had social workers, health professionals and teachers actually talked to the young people themselves, and given them the information they needed:

"There was nobody who gave me information; they just said you are doing well, you just keep trying your best and you will get there and I had to try more ... but I couldn't do that."

The work that black children do in support of disabled parents and relatives ranges from minimal work and responsibility to demanding, complex or very stressful tasks.

The appropriateness or inappropriateness of tasks depended on the social and personal contexts within which the young person had responsibilities, and the impact that these had on their lives, as much as on any intrinsic aspect of the task. For example, where the young people had some degree of choice about who should be involved, where homes had the appropriate adaptations and offered some privacy, and where the young people were comfortable and understood how to maintain their own and other people's dignity in these situations, helping with personal care was not necessarily an inappropriate task. However, these were not

generally the circumstances in which young people were providing this kind of support to family members.

As in most families, parents who receive care support from their children are the best people to determine what is an appropriate task or responsibility for their child to take on. Parents develop strategies and skills in parenting for managing their family life in ways that make the most appropriate use of individual abilities. However, our findings show that children and young people are more likely to undertake tasks that are overly demanding or stressful where support services are inadequate or inappropriate, where there are concerns that services would ignore requirements relating to religion, culture or gender, and where parents are reluctant to approach social care agencies for fear of how they may be judged by professionals and the risk that this will lead to the break-up of their family.

# 6

## Families' experiences of impairment, disabling environments and structural inequalities

**This section discusses the impact of stresses other than those linked to young people's caring role, in particular the impact of disabling environments and disablist attitudes on children, young people and family members.**

Virtually all the families who participated in the survey were dealing with stresses other than those linked to young people's caring role. These included poverty, racial harassment, religious bigotry, isolation from support services, inappropriate or oppressive services, anxiety about the involvement of services, serious long-term illness, and stress linked to living with one's own or a family member's long-term mental health problems. There were also problems dealing with the effects of domestic violence, school exclusion, crime and violence.

Several parents lived in neighbourhoods that they experienced as unsafe, both in terms of crimes against their property and possessions and in terms of the personal safety of themselves and their children. Where these conditions existed, families used their personal resources to try to make things safe and to improve the environment. This high level of attention in terms of personal safety, as well as making their own housing secure, had financial implications which meant that parents could not afford to offer their children the degree of entertainment, relaxation or recreation facilities they would have wished for. Parents were aware of the effects this had in terms of increased stress and anxiety for themselves and their children.

### What impairment and illness mean for families

This was not a study concerned with examining the implications of specific impairments; however, it was important for most of the families and young people who participated that their experiences of impairment in the context of disabling environments should be discussed and not hidden. The impact on families differed in terms of medical, physical and emotional support and in terms of the range of strategies and strengths within families.

We spoke to a number of people whose impairment led to them having complex support needs. In these circumstances, young people were carrying out tasks such as helping family members to relearn their environment and daily life skills, and had to be sensitive and flexible in responding to needs relating to specific impairments:

"The kids, they're wonderful. They fix their time around me."

Many young people had developed a high level of skill and knowledge in dealing with crises.

One young person (aged 16) said their parent had been disabled for 12 years. Over this time the siblings had shared responsibilities between them, with one person being responsible primarily for care and another being responsible for their parent's safety. These responsibilities had shifted from older to younger siblings as the skills and knowledge needed had been acquired and in acknowledgement within the family that, as young people reached the age where they wanted to live more independently of the family, this should be supported and some responsibilities should be taken from them.

Knowing what to do in an emergency was common, even among very young children. This was more than having specific health and safety knowledge: it was also about not losing control. This seemed to be an important strategy for parents as well as for young people. As one parent said,

“Well, if I've got an epileptic fit they've got to make sure I'm okay.”

One parent, who had young children at the time, had had several strokes. Her mobility was partially impaired and she also experienced loss of memory. She recalls the impact this had on family relationships, both because the children had difficulty understanding the changes in their mother, and because she suddenly needed to rely on them for things like the washing, cooking and cleaning. She described the strengths, patience and skills shown by her children in supporting her recovery over 18 months, and helping her to relearn everyday tasks and recognise people:

“They had to write me instructions, break down the process of how to fill the washing machine into small parts. They had to teach me, and as much as I learned from them, they learned from the situation.”

The emotional impact of adjusting to living with impairment or illness was often significant. This was expressed in terms of both change and loss. Some families talked openly about the fears and uncertainties surrounding particular illnesses. Parents and their children faced the prospect of the parent's deterioration or death – a prospect made more immediate by some illnesses. One parent talked about the difficulties her family had in communicating with each other when her

illness was diagnosed, and the impact this had on family relationships:

“It was just a matter of her having to come to terms with the fact that I could possibly die.”

The support needed by families was often emotional as well as social or medical. One parent who cares for her own mother has grown to understand and adjust to her mother's mental health problems. While the family has made physical adjustments to their living space in order for the grandmother to be able to live with them, there were also emotional adjustments to be made:

“If I can get 25% of my mum, that is all right. My son is in the living room with her ... talks with her and if she does get out of hand, like for instance she starts talking to herself again ... and she hears me saying ‘Come on mum’, then she realises.”

There were times when individual family members were dealing with the impact of diagnosis on themselves, and were not always able to provide support for each other.

## Dealing with disablist attitudes

Young people who discussed the impairments of people in their families showed no feelings of stigma or embarrassment regarding impairment, nor did we find any views that impairment was a ‘judgement’ or ‘trial’ for families to endure.

Participants gave many examples of young people challenging disablist attitudes and disrespectful comments relating to impairment. This seemed an important skill to have, in terms of managing caring responsibilities with less stress.

One young person was very protective of his mother and tried hard to ‘cover’ for her behaviour. This appeared to be a way of avoiding the kind of disablist harassment that other participants also discussed:

“When my mum started getting ill I did not realise what the illness was, I thought



it was just her going mad. I did not know why she was like that. People outside like friends and neighbours, they were thinking that she was crazy and that she was not normal. They kept asking me why is she like that, so it is hard for me to try to cover it. That is what I had to do, just try and cover because I don't want people to know."

Maintaining such a degree of privacy was a stressful experience for this young person.

Young people and family members commented on the use of humour as a coping mechanism in dealing with some experiences of impairment. However, there were boundaries in family units about what was acceptable, and when respect and dignity might be compromised by humour. There was a clear distinction between respectful humour and offensive and disablist attitudes which young people themselves would challenge:

"They had to tell off my niece and nephew. Had to say, we have been with this all our lives, we can't laugh, you can't laugh at it because you don't know somebody outside might have it, and you're laughing and its not funny."

## Young people's strategies for support outside the family

Young people were likely to be selective about whom they told about their caring responsibilities, and about whom they became close to. This was partly about the impact of caring responsibilities on their free time, but also because it was important for most young people that their home circumstances remained private. They knew that their peers might not always understand:

"It's common sense who you let in and who you don't."

"It depends who I am inviting round, like R – she can come around anytime. But some people I just don't invite."

"It's sad. That someone can come to your home and ... and your mate just starts laughing."

Young people were protective of their family, but also did not want perceptions of themselves as 'young carers' to affect their friendships. They had developed strategies in order not to mention why they were not able to see their friends or spend more time with them outside school:

"Lots of people call, but I say well I can't come out, but I don't talk about why I have to stay at home and look after my dad. I say I have something else to do. So it's a matter of how I tell them that I have other priorities in my life other than you. So they can't give me stick for having something else to do in my life."

A number of young people found it difficult making friends, and some related this to other people's disablist views:

"I would not talk to anyone else because I find it really hard to trust people. Most of the people I try speaking to about this think this really gets heavy, just really find it too deep and don't really want to go into it."

## Conclusion

Almost all of the families in this study had to deal with a range of stresses, arising from racism, disablism, social inequality, unsafe neighbourhoods and so on. Young people challenged disablist attitudes from family and friends, and they were selective about who they told about their home circumstances or invited into their home. For some families, the impact of adjusting to a family member's impairment or illness required emotional as well as medical or social support. But again, it was often down to family members to provide this for each other.

# Families' experiences of 'young carers' services

**The response of a number of local authorities and voluntary agencies to meeting the needs of young people with caring responsibilities has been to establish 'young carers' projects. This section describes the ways in which these were experienced by young people and families.**

There was a great deal of variation in terms of the kinds of support provided by the young carers projects that families had used. This ranged from individual work and group activities with young people, to group activities and group work involving the whole family, including support to sort out problems and practical and financial assistance. For many families, their only source of support had been one of these young carers projects, and in these situations it was crucial that the project was flexible in the kinds of support it provided.

Parents and family members valued a wide range of supports; time to themselves (to go to the gym, have an undisturbed bath, or catch up on sleep); the chance for their children to have free time without commitments, participate more in community events and meet other young people with similar experiences. Parents felt the involvement of their children in social activities made a big difference. Importantly, many felt their children were being denied opportunities to socialise – not because of caring commitments or because their parents were unwell or disabled, but because of poor facilities or racial harassment in the area in which they lived. Young people wanted the opportunity to spend time in a safe space with other young people who had similar experiences – a separate space, but one that did not exclude parents and those whom young people supported.

## The Black Young Carers Project

All parents and young people who had used the service spoke highly of the Black Young Carers Project (the service provided by the Bibini Centre) and of the advantages of a separate project for black young people and their families. In particular, they cited:

- a safe space where young people were not subjected to racism;
- workers and peers who had insight into young people's experiences of racism and family lifestyles, and did not judge them;
- opportunities for young people to develop their own sense of cultural identity, and to have their cultural and racial identities affirmed;
- diverse and flexible services around each family's particular circumstances;
- looking at the needs of each individual child in their own context (in some cases this meant that siblings were taken on outings and day trips separately so they were able to have time on their own);
- support to family members to understand pressures on young people and whole families;



- inclusive definitions that enabled children with diverse care responsibilities and ages to access their services;
- approaches to providing and delivering services that helped to strengthen relationships between parents and their children, not undermine them.

One parent said this service had helped her children more than anything her extended family was able to offer:

“Oh, gosh, it did help them more than my mother, my sister, my brothers. They’ve been more helpful.”

## Negative aspects of young carers projects

Both young people and parents were critical of services limited to one-to-one support.

A number of young people suggested that they had felt under some pressure from ‘young carers’ workers to continue their caring role, or to express dissatisfaction with their home life. It was not clear whether this was in fact the intention of workers.

Projects operated significantly different criteria for entitlement to a service. Where projects offered a service only to young people who had a certain level of caring commitments, this seemed to leave a number of children, particularly younger ones, isolated and less well supported than they had been in the past.

Some projects were not physically accessible, and workers did not always understand disabled parents’ situations with regard to transport. This was particularly worrying, in the light of the large numbers of young people using these services who have disabled parents.

## Conclusion

There is a risk that parents may have felt obliged to say positive things about the Bibini Centre, or felt inhibited in offering criticism because of the links between the Bibini Centre and this research. Even so, the views of parents and young people pinpoint clear differences in the philosophy and practice of a service provided by a black organisation as opposed to a generic organisation, and the positive impact of this service on supporting family life for both parents and children.

Experiences of social, health and educational services and professionals are explored in a subsequent chapter.

# Responses from social care agencies

**In this section we discuss the results obtained from questionnaires sent to various organisations to ascertain their contact with and awareness of black 'young carers' or their families.**

## Background to the questionnaire

The original intention of this part of the project was to establish how many black young people in Manchester have regular caring responsibilities for family members, and to learn what support systems are available to them and their families. A total of 220 questionnaires were sent to statutory and non-statutory organisations covering a wide range of services catering for many different health and social needs. Questions concerned the numbers of service users who had contacted their team over the previous 12 months, what kinds of services they offered, the ethnicity of service users, information about the numbers of service users receiving support from young family members, and the kinds of support young black family members were giving to service users. Agencies were invited to add any other comments or raise issues concerning their experiences with 'young carers' and their families.

Out of the initial 220 questionnaires sent out, only 38 usable ones were returned. Many of these contained very little statistical data. Therefore any results generated from these figures cannot claim to be statistically significant. The information that was received allowed us to draw some conclusions about the factors affecting an organisation's awareness of young people, specifically black young people, with caring responsibilities for a parent or family member.

The low response rate and lack of data are themselves significant. In some cases, the lack of data provision was attributed to the centralisation of information gathering. In other cases, it was stated that no data could be provided because the service had no contact with young people with caring responsibilities or their families. Overall, though, there was a high incidence of 'don't know' responses by organisations that should have been able to provide some information, not least on the ethnicity of their clients.

## Ethnic monitoring

Although increasingly there are requirements for statutory organisations to monitor ethnicity, this was found not to be happening. One statutory agency claimed to have no policy in place at all and so was unable to give any statistics related to clients' ethnicity. Three out of four that did claim to have a policy were unable to provide the statistics that should have been available. Out of the 10 statutory agencies that did not specify whether they had a policy, four were unable to provide relevant statistics.

The overall picture for generic organisations (statutory and voluntary) was that only three of the 29 said they had a policy and were also able to produce statistics; five had no policy in place and could not give any statistics on the ethnicity of their clients; four claimed to have a policy but were unable to produce evidence of this; of the 17 who did not specify whether they had a

policy, only nine provided the relevant information.

Organisations run by and for black people, or for a particular minority ethnic group, were much more efficient about collecting data on the ethnicity of their clients. Only one of nine black organisations that replied failed to produce relevant statistics.

Some generic agencies seemed unaware of why it was important to monitor ethnicity. One agency stated that it treated everyone equally and therefore did not need to monitor the ethnicity of its clients.

## Awareness of 'young carers'

Out of the 30 agencies who gave information on the clients they had dealt with over the previous 12 months (12,700 in total, including telephone enquiries), only nine knew of service users who were being supported by a young family member (158 such users); 48 of these were black young people. Black agencies were proportionately more aware of young people who have caring responsibilities: four of the nine black agencies claimed awareness, compared with eight out of 29 generic agencies. Overall, 19 agencies gave statistics that confirmed contact with black clients. Two generic organisations knew of parents supported by young black family members.

It seems that few organisations are in contact with black young people who have caring responsibilities, even though some may be aware of their existence. Responses suggested that those who are known to agencies provide care for more than one family member. Only one black organisation had direct contact with 'young carers', but its level of contact (with 39 young people) was greater than any other agency.

There were clear differences in the level of awareness of 'young carers' between statutory and voluntary/non-statutory organisations. The low level of awareness or vague awareness by statutory services is particularly evident.

There were also differences in the way statutory and non-statutory organisations delivered their services. Where work was primarily in-house, there seemed to be a greater awareness of young

people with caring responsibilities for family members: 14 non-statutory organisations delivered their services in-house, compared with only three statutory organisations. Non-statutory organisations, including black agencies, tended to provide a combination of services, including giving advice and psychological support, primarily to adults and families. These organisations could have learned about young people taking on caring responsibilities through discussions with their clients. It may also be that sharing information between colleagues is easier in these organisations because of the nature of the office environment.

In contrast, work by statutory services tended to be on an outreach basis, and this correlated with lower levels of awareness about young people with caring roles. Statutory services dealt with twice as many children as non-statutory services. Yet dealing with children clearly did not make these organisations any more sensitive to the general needs of young people. Most of the work by statutory agencies was carried out in an outreach or health-related capacity. Their work with children was therefore invariably carried out in the child's own home, where the child either was the patient or was undergoing some sort of assessment. Despite the fact that outreach health workers visited clients in their own homes, they seemed unaware of the care being provided by young family members.

## Conclusion

Statutory organisations seemed less informed than voluntary organisations about the existence of young people who have caring responsibilities for a family member. This may reflect differences in the services provided and the way these were delivered.

Outreach workers, usually providing health-related services, seemed the least aware of the existence of 'young carers', even though they visited the homes of clients and seem ideally placed to identify young people who have caring responsibilities and to act as a link between them and other services that could offer appropriate support, thereby fulfilling the obligations of statutory services under the 1989 Children Act.

Overall, few organisations had any active contact with young people with caring responsibilities, whether black or white. Even when there was contact, the numbers involved were very small.

Lack of data made it impossible to explore any differences in characteristics between black young carers and white young carers. The lack of attention to monitoring ethnicity is cause for serious concern. Half of the organisations that responded were unable to provide data on the ethnicity of their clients, and it appeared to be only black organisations that really treated this issue seriously. Some agencies stated that asking questions about ethnicity was racist, or that all clients were treated equally and therefore ethnic monitoring was unnecessary. There is clearly a need to address this confusion about the purpose of ethnic monitoring.

# Policy, planning and practice: national context

**This chapter offers a short and critical overview of the current legislative and policy framework, and considers how national policy and legislation impact on services and support to black families experiencing disability or disadvantages arising from illness or mental health difficulties.**

## Policy and legislative frameworks

All legislation, policy and guidance concerning welfare provision, human rights and the upbringing of children has a bearing on the lives of families in which children have caring roles for parents or other family members who are disabled or ill.

Legislation has different levels of significance for different groups of people, depending on its particular functions. For example, the 1989 Children Act is the primary legislation in which duties of local authorities for children are made explicit. The Act and related guidance are therefore particularly useful in helping us to assess the effectiveness of local authority services. Other legislation, such as the 2000 Race Relations (Amendment) Act, is designed to prevent discrimination, and its provisions may be less immediate. Legislation and policy with particular relevance for services for disabled parents and young people with caring responsibilities are:

- 1989 Children Act
- 1990 NHS and Community Care Act
- 1995 Community Care (Direct Payments) Act
- 1995 Disability Discrimination Act
- 1995 Carers (Recognition and Services) Act
- 1998 Human Rights Act
- 2000 Race Relations (Amendment) Act
- 2000 Carers and Disabled Children Act

- 2001 Health and Social Care Act
- National Carers' Strategy
- Quality Protects

## Fragmentation and confusion

Many commentators have highlighted the confusion and contradiction in policy concerning young people and families, as well as at the organisational level. Such confusion has made it difficult for local authorities to achieve “coherent, integrated and competent practice” even though government requires them to develop policies and protocols on inter-agency working (NISW, 2000).

At the local level, the division of local authority social services into adult and children's services, and the further division of adult services into providers and purchasers, and of children's services into specialist areas (disability, child protection, looked after children, and so on), make little sense for families whose needs cut across these different spheres of responsibility.

For disabled parents, there are often fundamental tensions between social workers whose work is informed by the Children Act and those who work within the context of the NHS and Community Care Act. In most local authorities,

eligibility criteria for community care services do not include parenting support needs.

Furthermore, the stringent approach to assessments for benefits such as Disability Living Allowance often results in the negation of parenting responsibilities, while childcare tasks are specifically excluded when considering eligibility for the Independent Living Fund.

At a wider level, changes in local government management structures and funding arrangements have created tensions between departments and further confusion for the public and practitioners.

In theory, multi-professional or joint working arrangements offer a model for meeting complex social, health or family support needs. However, the notion of a coherent approach to supporting children and families is not borne out in practice or by the experiences of the families involved in this study.

## **Exclusion from policy, planning and services**

There are many ways in which policy, practice and planning fail to recognise and include black families and families in which a parent or other family member is disabled, experiencing illness or mental health difficulties, or where national practice guidance risks disempowering the children and families it should help to support. Some of these are discussed below.

### *Planning based on overall population counts*

Demographic changes may account for the lower level of spending on children's services than for other groups (especially older people). However, although the overall proportion of 0-16 year olds in the UK has been falling, this is not reflected in black communities, which have a higher proportion of children and young people than white communities. In Manchester, the 1991 Census recorded 17,858 black young people under 16; Pakistani and Bangladeshi families were found to have a very large proportion of under-16s at 45% and 46% respectively (Jones, 1993). Failure to make black families explicit in planning budgets and services based on overall demographic data will do little to address social exclusion.

### *Immigration controls and black families*

Welfare provision does not routinely take into account issues that impact negatively on black communities. For example, black families are disproportionately affected by immigration controls (Jones, 1998). Yet, for children subject to immigration controls, the Children Act's protections and provisions are undermined by reservations in respect of immigration law (there are also other reservations) entered on ratification in the UK of the UN Convention on the Rights of the Child. More recently, the 1999 Asylum and Immigration Act has curtailed the use of the welfare provisions of the 1989 Children Act available to children and families who are refugees or asylum seekers, while other welfare and health services may be denied or severely restricted.

A number of the young people known to the Bibini Centre became 'carers' for a parent as a result of immigration decisions which prevented the other parent from entering the country. Although limited, the literature on disability and ill health among refugee and asylum seeking families points to considerable unmet need among disabled people with implications both for them and for those providing care support (Roberts, 2001).

### *Supporting disabled adults in their parenting role*

Approaches based on unexplored assumptions that the children of disabled parents are always 'children in need' or at risk can lead to disempowering outcomes for both parents and children. When racism and disablism position black parents, disabled parents, and black disabled parents as 'deficient', this will directly affect the relevance, take-up, quality and effectiveness of services. This is borne out by the findings from the present study, and is also discussed below with reference to the Framework for the Assessment of Children in Need and their Families.

### *Black children and families' access to appropriate services*

For the black families in this study, the lack of take-up of services and related experiences

indicate that services provided by the statutory and mainstream voluntary sector remain largely inappropriate and inaccessible. This has also been the finding of other studies, which have shown that services have not been able to cater for minority ethnic communities because of a failure to address cultural, religious and linguistic needs, and also because services (particularly those from statutory agencies) have been seen as authoritative, disempowering and in some instances punitive (Butt and Mirza, 1996).

## Framework for the Assessment of Children in Need and their Families

The Framework for the Assessment of Children in Need and their Families (established in 2000) was designed as a mechanism to help local authorities improve support to children 'in need' and their families. It is underpinned by the 1989 Children Act. It requires local authorities to apply a systematic approach to the assessment of children in need as the basis of the provision of family support services, with the overall objective of improving standards and consistency in practice.

The Framework recommends the assessment of parenting capacity. The experience of some disabled parents is that the assessment of capacity is stigmatising and is based on assumptions that the children of disabled adults necessarily receive deficient parenting and/or that they have to 'parent' themselves. As with any other group of children, young people with caring responsibilities *may* be subject to poor care and parenting. However, one is not synonymous with the other.

Parents in our study overwhelmingly expressed a mistrust of social services departments, even where they had had positive relationships with individual social workers. This may relate to automatic assumptions that children of disabled or ill parents, including those who take on caring responsibilities, are inevitably children 'in need' and therefore potentially 'at risk'. The perceptions and experiences of parents in this study were that social workers might judge the tasks that their children were undertaking as placing them 'at risk'. Many worried that the involvement of social services undermined the chances of the family unit to stay together.

There is evidence that the parents of black children (Butt and Mirza, 1996) and disabled parents (DoH, 2000) are more likely to have their children placed in care than other parents. It is understandable, therefore, that parents may be reluctant to contact social services, even where there is extensive need.

## Conclusion

This review raises concerns that legislation, policies and planning mechanisms may fail to take proper account of, or promote appropriate support to, black families and families where there is a disabled parent or other family member.

Specific concerns were also raised by the findings from this and other studies relevant to the use of the Framework for the Assessment of Children in Need and their Families:

- There is a reluctance on the part of families to seek support, even where the lack of support has major consequences for them and their children, because of their fears of the negative implications for their family of seeking support from social services.
- Assessments focusing on children 'in need' rather than on parental support may be counter-productive for both the children and the parents.
- Concepts such as 'parenting capacity', which are presented in the Framework for the Assessment as uncontentious and universal, are actually subjective and should be carefully scrutinised and practitioner assumptions about black parents and disabled parents as 'incapable' or 'deficient' should be challenged.



# Policy, planning and practice: local experiences and ideas to improve support to families

**This section sets out what the research found about families' experiences of education and children's services. Some ideas are put forward on how to use local planning mechanisms (specifically, local education authority Behaviour Support Plans and Children's Services Plans) to better support black children and families.**

The families that took part in this study had had experience of social care services, including home care, health services and education. Some of the views of parents and young people on social services, and on specific projects for 'young carers', have been discussed in previous chapters. In this chapter families' experiences are outlined in the context of local frameworks for providing services to children and families, in particular the Framework for the Assessment of Children in Need and their Families, Children's Services Plans, and Behaviour Support Plans (in schools).

## Families' experiences of social care services

Few of the families that participated in the study were receiving support from social services. This appeared to be because family members lacked information about what services might be available, thought that such services would be ineffective, or believed that such services would not be available to them.

Parents' accounts of their experiences of social services suggested that families had not received support from children's services unless there were

child protection concerns. These services were likely to be time limited, and offered families less control over how they were provided.

### *Home care services*

There was little evidence that people had access to home support services on the basis of their needs, and there were no circumstances in which the needs of young carers had been assessed, or support services provided, on the basis of a carer needing support. Carers' assessments were largely thought to be linked to community care assessments. There was no statutory requirement in any case to apply these to young people.

Responses from agencies suggested that the local authority at best adopted a passive approach to undertaking community care assessments, and at worst was actively resistant to carrying them out. If this is the case, it will impact on white families as well as black ones. Given other factors identified in this study, this failure may be a major reason why the social care needs of black communities are neglected.

Those families that had used home support services generally found workers to be



ineffective, inflexible, inconsistent, overloaded, lacking in initiative, untrustworthy and occasionally extremely abusive and threatening. It is important to point out that most home care services were contracted out by social services to private agencies. Despite this alarming finding on the quality of services, it was clear from the accounts of most young people that these were the kinds of services that *could* have been most helpful to them and their families. A small number of young people had had positive experiences of home care workers, but had since seen this service removed.

Where children and families had good experiences of home care services, this was usually because of the effectiveness and competence of individual care managers. Only in one case did we find a parent who was using direct payments to pay for home care services. While there had been problems with a social worker who expected these payments to cover childcare costs, the parent seemed to have a higher level of satisfaction with the services she received through recruiting her own carers.

### Health services

Most parents said that they were happy with the health services they received; but they also had very low expectations about what support health services would provide. People were more likely to complain about health visitors or health services that provided everyday social support or visited their homes than other health workers and services that intruded less on family privacy, or which they used less frequently.

Several young people and family members talked about experiencing both overt racism and covert racism from health services:

“When I was in labour with my youngest son, that was at [...] hospital, a nurse actually looked at me, I was in pain and I was shouting, and she said ‘Why are you screaming like that? Black people don’t feel the same pain as white people’ and that’s honest to God’s truth. How does she know the pain black people feel?”

## The Children’s Services Plan

Local authorities are required to produce plans to show how they will deliver services to children ‘in need’ and their families. The Children’s Services Plan is a multi-agency plan developed by the local authority, health authority and the voluntary sector. It outlines the framework for the development and delivery of services for children and specifically for children in need. It aims to bring together all plans relevant to vulnerable children to demonstrate shared aims and the ways in which different plans and services should work together.

There are serious concerns about an approach that requires the children of disabled or ill parents to take on the label and even role of ‘young carer’ to access support, and that automatically defines young people who have caring responsibilities for a family member as ‘in need’ or ‘vulnerable’. This ignores the distinction between having needs and being characterised as ‘in need’, and it is disempowering to both children and parents. In the current climate, in theory, having this label may be one of the main ways in which children and families can be provided with services – although it must be stressed that, at the time of the study, none of the families that took part were receiving support services under the 1989 Children Act, even though there was considerable evidence of the need for services.

The Children’s Services Plan provides an important mechanism for monitoring the delivery of services to families in which there are children with caring responsibilities. For Children’s Services Plans to fulfil their objectives, the issues discussed above will need to be addressed; however, in bringing together social services, health and voluntary agencies, there is clearly the potential within joint planning arrangements to develop a more cohesive and comprehensive response.

Although identified from this study as being specific to black families, the challenge for local authorities in providing services to *all* families in which there are disabled or ill family members and children with caring responsibilities is to:

- deliver effective and relevant services;
- prevent disadvantage;
- ensure equity in service provision;

- make sure that parents can approach service providers in the confidence that services will support and not undermine their family life;
- make sure that children and young people do not take on or continue doing tasks or having responsibilities that they and/or their parents feel are inappropriate.

## Improving support to disabled or ill parents

Local authorities are not under a statutory duty to produce plans for the support of disabled parents.

In order to increase access to, and take-up of, services by black disabled parents (and with benefits to all disabled parents), local authorities should consider how they can promote joint working across children's and adult services and the inclusion of parenting tasks as part of standard community care assessments for adults with physical or sensory impairments, learning difficulties or mental health difficulties.

The Children's Services Plan can also be used to support parents in this regard, since the Children Act makes provision for the cooperation of other departments in helping local authorities to meet their duties under the Act.

## Education

Black families have always regarded education as extremely important. While some black children have successfully negotiated their pathway through an education system marked by inequality, others – particularly black boys of African Caribbean descent – have been subject to alarming rates of school exclusion and under-acknowledgement of achievement. Despite concerns about the extent of institutional racism, black workers and parents have urged their children to adopt a more positive approach to education and have regarded education as a means out of poverty and disadvantage. They have set up supplementary schools and homework clubs, challenged the lack of black teachers and curricula that negate black histories, and remained resilient and constant in their commitment to their children's education.

## How to ensure Children's Services Plans help

- Do Children's Services Plans link up with Community Care Plans in the identification of parenting support needs for parents who are disabled and/or experience ill health or mental health difficulties?
- What action is needed to ensure an integrated approach, not only *within* children's services, but between children's services and adult services, for the support of family life for disabled parents and their families?
- What factors have hampered the development of an integrated approach to planning and service provision? What action is needed?
- Children who have caring responsibilities may benefit from having access to assessments of their needs as carers in the context of their family life as of right, and not necessarily on the basis of identification of 'need' through the Framework for the Assessment of Children in Need and their Families. How might the Children's Services Plan work together with the National Strategy for Carers to achieve this?
- What action is needed to ensure that assessments of the needs of young people with caring responsibilities and assessments of the parenting support needs of black disabled parents are empowering to both children and parents and that they fulfil the commitment to holistic approaches?
- What action is needed to ensure that ill or disabled parents and other family members are supported adequately and appropriately, so that children and young people do not have to take on tasks or responsibilities that they or their parents feel are inappropriate?
- Are there measures identified in Children's Services Plans for dealing with racism and disability?
- How does the Children's Services Plan ensure the involvement of black parents, including those who are disabled and experience ill health, in planning and developing appropriate services?

The families and young people who participated in this study similarly demonstrated a high level of commitment to educational achievement. However, there were concerns from both parents and young people about the failure of schools to appreciate the difficulties arising in family life that included, but were not solely to do with, caring responsibilities. This failure led to inappropriate responses from schools which increased stress on children and families.

### *Schools and 'young carers'*

Previous research on 'young carers' has found that schools made allowances with respect to punctuality, attendance and academic performance. In contrast, we found that black young people with caring responsibilities, particularly black young men, were not afforded these allowances and were more likely to be excluded.

One parent told us how, when her son was 10 years old, she became ill and he often had to stay at home to look after her. His behaviour at school became difficult and he was permanently excluded. The school did not know about his mother's illness, or his responsibilities at home. Because this parent did not speak English and was not provided with the means to get to school, school staff failed to take into account the significance of this young person's caring role on his difficulties at school, or to refer the family to services that could support them. Instead, they excluded the child.

Staff in schools and colleges were unlikely to know the full extent of young people's caring commitments and to be unwilling to consider how family circumstances impacted on children's attendance and behaviour.

Some young people did not feel that their domestic tasks affected their schoolwork; others felt that it did affect their ability to concentrate or complete schoolwork. Most young people did not want teachers to know about their home circumstances. They felt it could compromise their privacy unnecessarily. Where illness caused stress or anxiety in families, the fact that school staff knew but had no actual supportive role seemed to add to young people's anxieties and make them feel that they lacked control over their situation.

Although young people talked about not wanting 'special' treatment, where they had major caring responsibilities they usually experienced more stress about their school or college work than about any commitments within their family. While young people with caring responsibilities should have the same educational opportunities as other young people, it may be that they and their peers are under unreasonable pressures at school, regardless of the extent or impact of those responsibilities. This pressured environment may also make it difficult for young people to imagine the kind of flexibility and support they require.

Young people were clear that they did not want to be given less schoolwork than their peers, but there might be other ways in which schools could support them. One young woman had used a school counselling service, and said she benefited from talking to someone in school who knew "what I had been through". The counsellor gave her choices about whether any action should be taken.

When appropriate, supportive services were put in place, young people clearly benefited and felt they were able to focus on their education.

### *Schools and parents*

Many of the parents in this study experienced disablist attitudes and behaviour from schools. This made them feel excluded, and actively excluded them, from their children's education and prevented their involvement in addressing any difficulties their child might experience at school.

Parents were told, for instance, that they would need to attend school before a child would be allowed to return, even though schools were often physically inaccessible. They also found that teachers made negative assumptions about the level of interest they had in their children's progress because they were not always able to attend parents' evenings and so on.

## **The Behaviour Support Plan**

Local education authorities are required to publish their plans for support to children who have

difficulty over attendance or whose behaviour in schools causes concern.

While there are concerns about including ‘young carers’ in an approach, which may result in the problematising of children and families whose difficulties may stem from racism, disablism or lack of appropriate school support, the Behaviour Support Plan nevertheless provides a means for monitoring the implementation of support to young people with caring responsibilities. The inclusion of this group of young people is encouraged under government guidance.

### How to ensure Behaviour Support Plans help

- Does the support plan refer to the fact that some children may have caring responsibilities at home which may affect their schoolwork and attendance?
- Is it recognised that such roles may be taken on by boys as well as by girls, including in black families?
- Are schools encouraged to work with children and their parents in these circumstances, without being punitive and without being permissive, in ways that may not be in the child’s long-term interests? Are specific suggestions for appropriate action made?
- Are schools encouraged to take active steps to make and sustain contact with parents, who may be disabled, or have ill health or mental health difficulties? Are specific suggestions for action made, for example to enable access to parents’ evenings and other meetings at school?
- In what ways might the stresses that individual children face at school be a consequence of racism, disablism or both? What action is suggested, and how will its outcomes be evaluated?
- When schools seek to determine whether a child is ‘legitimately’ absent, have they taken into account the child and family’s perspective?

## Summary

Families want services that:

- offer families a choice;
- provide families with control over how services are provided;
- do not require evidence of ‘deficiency’ to access support;
- do not require children and young people to take on caring responsibilities or be labelled ‘in need’ or ‘at risk’ before the family can access support.

Children’s Services Plans and Behaviour Support Plans can be used to improve support to black children and young people who have caring responsibilities for a family member. The plans may also be used to ensure that appropriate and non-stigmatising links are made with adult services to improve support to disabled or ill parents or family members.

Until local authorities have statutory duties to develop coherent and comprehensive plans to support disabled parents, and ensure that parenting support needs are routinely included within community care assessments, the reliance on planning mechanisms located primarily within children’s services or schools to address the whole family’s support needs is likely to have limited effect, and may continue to undermine rather than support family life.

# Summary and conclusions

**Key findings and conclusions from the study are brought together in this final chapter, which cover: children's and young people's caring responsibilities; how services have failed them; and the implications of the research for ethnic monitoring, joint working arrangements, information and service provision.**

## Families' views of children's and young people's caring responsibilities

We found that young people's caring activities have different purposes and meanings; that caring roles develop in relation to a range of different influences within and outside families; that young people need to be recognised as having key roles in meeting their own needs and in looking after others; that children's and young people's needs can rarely be separated completely from the needs of others who are important to them; and that young people's views and wishes are formed within the confines of whatever possibilities and services seem open to them.

We found it was impossible to understand what constituted 'acceptable' and 'inappropriate' caring roles without considering all of these issues.

The chores, tasks and responsibilities taken on by children and young people varied greatly in terms of the nature of tasks, level of skill and physical strength required, and time commitment. In addition, young people often faced other stresses, including dealing with disablist attitudes and racial harassment from people outside the family.

Children's and young people's work was affected by gender, age, ability, level of support being provided by other adults and professionals, and

the particular expectations and dynamics of individual families and the children themselves. Gender shaped the allocation of tasks in some families, but there was no evidence that certain children and young people were nominated to be carers, or came to have significant caring roles, because of cultural expectations.

Generally, families and young people were proud of the achievements and skills that the children and young people acquired through their caring responsibilities. These were direct ways in which families were able to express their interdependence and love for each other. However, despite these benefits, there were many examples of young people being in situations and undertaking tasks that they found difficult or demanding, or that impacted on their well-being in significant ways. Some of these situations were also experienced as distressing by family members who received this support. Such responsibilities affected young people's education, relationships with peers and social life. Young people developed strategies for dealing with these stresses, such as working extra hard at school or managing care responsibilities so that friends did not find out. They did not want to be seen as a 'do-gooder', a 'victim' or 'different'.

The way that families made decisions about young people's self-care responsibilities and the way that young people were consequently more skilled and confident in certain areas seemed to us to be an example of families achieving successful parenting in difficult circumstances.

Parents used a range of creative strategies to try to meet the needs of their children. Where other adults took on specific roles, this was not an abdication of parenting responsibility. As long as parents made the decisions about how best to care for their children and were able to retain control over their family life, they did not necessarily experience support from others as disempowering. This also depended on the ways in which support was provided.

## Where services failed these families

The research highlights the failings of agencies to provide adequate support to young black people with caring responsibilities. It also indicates a high level of unmet social, personal and in some cases medical care needs among black parents (and other family members) who are disabled or experience ill health.

It was evident that agencies that did not have a specific brief to provide support to young people with caring responsibilities did not take into account the work of children and young people in their families, even where young people fulfilled a primary caring role or were the sole carer for a parent or relative.

This invisibility of children's and young people's contributions to their family life and to supporting disabled people within the community stems from a number of sources:

- the low status accorded to children's labour and skills within wider society;
- cultural assumptions made by workers about how black families cope;
- families not wanting to share information about the responsibilities some young people have because of the belief that the parent/s will be viewed as inadequate and that intervention may result in family breakup;
- institutional racism.

Evidence shows that the children of black and disabled parents are more likely to be taken into care than other children. It was therefore not surprising that the families in this study were resistant to approaching social services for assistance. Moreover, when they did seek help, such families rarely received appropriate or adequate support.

The fear that some families have of the likely response of statutory services is perpetuated in approaches which view children as being 'in need' or 'at risk' because they have a disabled parent and/or because they have caring responsibilities for a parent or family member.

Family crises and isolation from support services (rather than cultural expectations) were common features shared by most children and young people taking on caring responsibilities. In these situations, family members often had little choice about what should be done and by whom. Parents were sometimes forced into dependency on their children because there was no alternative source of support. Although young people seemed to manage in these circumstances, it was usually at considerable cost, for example completing homework at 2 am, once all the household tasks were completed.

Young people and parents had their own ideas about what was considered 'normal' or 'reasonable'. However, many young people were undertaking extensive work that was under-acknowledged by professionals (nurses, GPs and social workers) and was often a direct result of the lack of appropriate service provision from these agencies.

Children and young people need to be involved in assessments about support needs and decisions about what tasks and responsibilities they can do or want to continue to do. Parents also need to be involved.

Young people should not be left to provide extensive levels of support or undertake inappropriate tasks because of inappropriate, inadequate or inaccessible services to support a disabled or ill parent or family member.



## Questioning the term 'young carer'

We found that the term 'young carer' had limited value for children and families in this study. It was not a term that most of the children and young people identified with. On a practical level, the term 'young carer' was not translated into specific action to meet the support needs of the children and young people in this study, or to meet their parents' support needs. It may allow professionals to continue to overlook the important links between children's work and parenting support needs.

Categorising children and young people as 'young carers' ignored the complexity of caring roles within family life, and risked masking or perpetuating the social inequality experienced by the whole family.

There were some specific services for children who have caring responsibilities. A small number (especially the service provided for black young people and their families) were valued by young people and parents. However, the services they could provide were often limited. Some projects seemed to use criteria that reflected the narrow 'risk' approach of social services department. This denied some children and families a service, even where there was a clear need for support.

## Recording and monitoring take-up of services

The Race Relations (Amendment) Act which came into force in April 2001 requires councils to ensure that they have due regard to the need to "eliminate unlawful racial discrimination and to promote equality of opportunity and good relations between persons of different groups". The Act allows people to take a local authority to court if they have evidence that they have received poor services on the grounds of race and ethnicity. By May 2002, local authorities must have introduced specific steps to ensure race equality, including ethnic monitoring.

Our findings indicate that both statutory and generic voluntary agencies do not systematically record and monitor the ethnicity of service users even where they have a policy requiring them to

do so. The responses indicate unease with defining and recording ethnicity despite the fact that such information enables providers to see whether groups such as black young people are under-represented or, indeed, totally absent from their client base. One agency reported that they treated all clients equally, so there was no need to monitor ethnicity.

In contrast, black organisations routinely recorded and monitored ethnicity, even if they did not have a policy requiring them to do so. Despite the fact that they are less likely to have the infrastructure and resources to undertake systematic monitoring, these organisations appeared to appreciate the importance of gathering this information and were confident about sharing it.

Black young people and families described their ethnicity in creative and productive ways and discussed this issue with confidence and pride. However, their experiences of the ways in which their ethnicity was understood or represented were that it was often distorted or reduced to fit in with the requirements of service providers.

Addressing this unease about recording information on ethnicity, race, religion and language will require acknowledging the sources of unease in organisations and, where it exists, the reasons for resistance to providing this information in communities. Our findings suggest that black families and communities may be concerned about:

- use of fixed categorisations (solely to comply with agency systems) that may demean or distort individual understandings of ethnicity;
- use of statistics to perpetuate cultural stereotypes;
- use of information about ethnicity for purposes other than was intended;
- failure to use such information to effect real and lasting improvements for black families and communities.

This may help explain why some generic agencies felt it was "racist" to request such information, while black agencies were more confident about doing so.



A more flexible and participative approach to recording ethnicity is needed, alongside systems that can accommodate the creativity and diversity of self-classification. It is vital that communities see the benefits of providing this information in improved and appropriate services.

## Joint working and assessment of needs

The omission of young people with caring responsibilities from the provisions of the 1995 Carers (Recognition and Services) Act, and the difficulties (actual and perceived) for parents of their children being assessed under child care guidance, have led to large-scale failure in the assessment of parenting support needs and the assessment of needs of young people with caring responsibilities. Where a young person has a major role in providing support to a disabled person, an assessment of support needs should be provided as of right for the young person on the same basis as the rights accorded to adult carers.

The lack of coherence between children's and adult services, particularly in relation to the assessment of needs, has to be addressed.

Parenting support needs should be routinely included in community care assessments for parents who are disabled or experience ill health.

Our findings do not suggest that further legislation and guidance is required, but that *existing* legislation and guidance needs to be used more effectively, flexibly and creatively, and that practitioners carrying out assessments with families need to be provided with the appropriate skills and knowledge. This will be crucial if assessments of 'parenting capacity' are to assist in the identification of parenting support needs as well as in the support of children and young people in the family, and if families are to be supported in seeking assistance from social care agencies.

The key elements of valued services are: flexibility, choice, respect for the family's wishes, a range of support options (for children, parents and whole families), an appreciation of different ways of family life and parenting; and an approach that does not undermine the family unit.

Family groups (whether this included a number of people or just one adult and one young person) made decisions about how family members could be supported in ways that assumed young people's involvement, in whatever capacity. Most young people participated in negotiating care arrangements in meaningful ways within the family. Yet professionals regularly failed to consult or include young people, even when the young person clearly had a major role in providing support to a family member.

Not all families will operate in this way. It is therefore important that parents and young people are given opportunities for sharing information and concerns separately. Parents often have information that they feel should be withheld from their children; it is also the case that young people may find it difficult to express their views in front of the person they provide care support to. Difficulties arise where family members feel excluded, exploited or disempowered, and where expectations result from lack of services rather than choice.

The assessment process should attend to potential sources of tension to ensure children's rights are supported in the context of family rights.

## Information

Studies on services for black people consistently point to the need for information in forms that are accessible and easily understood. This was also a finding of the present study. In addition to improving information for families, it was evident that specific information for young people was required – for example, advice and guidance on what to do in a crisis, relevant contact numbers, information on services and assessment of needs. In addition, black young people should be more visible as service users and as participants in the planning of services.

Although confidentiality must be maintained, health workers should acknowledge the importance of information for carers (including young people) about specific illnesses that families are dealing with, to ensure that the person providing care support is able to respond

appropriately to needs arising from particular illnesses.

Local authorities will need to work together with the education department and the health authority to develop creative ways of getting information across to black young people and their families in a form that they can clearly understand and make use of.

It is important that black parents and families are able to exercise choice as to how their support needs should be met. Statutory agencies will therefore also need to develop services and work in ways that are more sensitive to cultural, linguistic and religious needs.

## Services

The extent of dissatisfaction and the low levels of support provided to black families indicate major deficiencies within the current system.

Services that are contracted out to external agencies need to be the focus of a more rigorous and effective monitoring and review process. Care managers should have an enhanced role in the review of these services.

Local authorities should find ways of targeting and promoting the use of direct payments within black communities, providing assistance where necessary to support black disabled people in making the most effective use of these.

Support with home care tasks should be provided to all disabled parents who have need of such a service. There should be flexibility and choice in the way home care is provided, who provides it, and how it is funded.

Local authorities should also consider what specific action is needed to promote the use of direct payments by black families, including for use with parenting tasks.

Where community and religious organisations provide support that is valued by black parents who are disabled or ill, and where that support does not undermine the rights of individuals (including children) and families, statutory bodies (social services, health authorities and schools) should work together with them to strengthen their role in supporting family members with caring responsibilities. This will require the development of non-exploitative, inclusive partnership arrangements.

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# Appendix: Research methods

## Methods for collecting information

Several methods were developed to involve young people and families:

1. They were approached directly to participate in a focus group discussion as part of a wider consultation process during a three-day event.
2. Young people were trained as peer researchers.
3. Interviews were carried out with young people and with parents and other family members.

Questions covered aspects about their experiences and perceptions of family members' involvement in care responsibilities, their experiences of services, and whether the family circumstances had an impact on their children's education.

## Recruiting young people/parents

Involving young people at every stage of the research process required considerable planning and involved an element of uncertainty in terms of how and whether young people and their families would respond. The research team felt the research process had to be made transparent in order for families and young people to understand how their contribution and participation fitted into the bigger picture. We wanted to ensure that young people and families retained complete control over how much of their life experiences and current circumstances they wanted to share.

An initial three-day consultation event was developed. This introduced the research team to

young people and, more importantly, familiarised young people and their parents with a participative research process where young people could inform the researchers about the areas of questions necessary to reflect their experiences. The event had three main objectives:

1. to introduce young people to the two researchers;
2. to give young people an idea about what the 'research' would involve;
3. to find out how and if young people wanted to participate in the process.

Thirteen young people (aged 5–16) took part in the event. These were young people who had previously attended the Black Young Carers Project. Beyond this and the fact that they identified themselves, or were identified by their families, as 'young carers', no selection criteria were applied. Participation was on the basis of self-selection, with the agreement and support of parents or other family members.

Providing transport was a major factor to ensure young people's participation. It was also important to acknowledge the particular dynamics of 'meeting up' and 'playing' while gradually establishing a focus on the research project.

Ground rules were introduced which would remind and reassure young people that the researchers were there to learn from them. These were left up throughout the event:

- We are here to learn from you.
- We want to listen to you.
- We want everyone to be able to say something.

- We will wait/try not to interrupt when people talk.
- Being angry is OK.
- Talk to someone you feel will listen to you.
- Not knowing the answer is OK.
- We want to get your words right! If we get it wrong tell us.

Young people added:

- Play catching ball.
- Move chairs [to speed up warm-up games].

A considerable amount of time was spent 'playing' with the group; the young people needed to experience the researchers as approachable, flexible and respectful to their needs. Playing games that were appropriate to the ages and interests of the young people gave both young people and researchers an opportunity to observe each other on a different level, without the researchers being figures of authority. The researchers were aware that 'playtime' and 'socialising' provided a space and experience that was precious for young people who have caring responsibilities.

## Research exercises

The researchers devised a survey that asked young people whether they liked particular food, pop stars, football stars and activities. The young people got into teams of two and were given their own surveys to carry out. The exercise involved people considering and giving their own views, and hearing and recording other people's views. Young people had an opportunity to experience an aspect of information gathering which involved them as 'holders of information'.

### *Gathering information on tasks*

Young people were asked to summarise what kind of tasks they tend to do during a typical week in their lives. Materials provided were flip chart paper and crayons, felt pens and pencils. Although young people were willing to share their experiences, there was some uncertainty about how to sketch, paint or write. Most needed some support, encouragement and reassurance. The researchers ensured them that the games

were not about doing things right, but about telling someone about their life.

Drawing exercises meant that young people could choose which aspects of their lives to document. Also, the researchers were not briefed by workers from the Black Young Carers Project about the particular circumstances of the young people. This meant young people could choose the extent to which they wanted to talk about their home lives without adults passing information on which they may not have wanted to share.

### *Gathering information for interview schedules*

How tasks impacted on their relationships within family and friends, how young people felt doing these tasks, and how they experienced support from services were all aspects that were to be explored through one-to-one interviews with peer researchers. The consultation days sparked a lot of enthusiasm for the research project, and young people suggested interviewing each other about their experiences at home. The group brainstormed together on the kind of questions that would enable them to find out more about each other and, where relevant, their home lives.

- What's it like at home?
- What's it like always being told to do things?
- How do you feel about doing things at home?
- How do you feel about having/not having a bedroom to yourself?
- How do you feel about missing out on things other young people can do?
- Do you get fed up sometimes doing all the things that you do?
- How do you feel knowing that any moment something bad could happen/that there might be an accident? About there being nobody to help them?
- How do you feel about always helping out?
- Do you feel depressed because you cannot go out or stay in touch with your mates?
- Do you feel disappointed or left out?
- How do you feel about other people knowing about your parents?
- Do you feel proud doing all the things that you do at home?

With support from the researchers, the young people recognised that some of the information was sensitive and that they might feel vulnerable and exposed if they were to share some of their

experiences and feelings about their home life. The group agreed to go through each question and identify those they would answer in a group and those they would prefer to answer on their own. Nine young people took part in an exercise they called 'Interviewing each other'. These exercises and discussions led to young people being active informants about their home life, and produced early findings.

The research team emphasised and maintained an open dialogue with interested parents. Throughout the consultation event, parents had opportunities to ask the research team questions, clarify the purpose of the research and make suggestions about how the research should be carried out and what contributions they might make.

## Training young people as peer researchers

The research team looked at different ways to ensure the meaningful involvement of young people, acknowledging their experience without putting pressure on them, raising expectations or setting them up to fail.

In training young people to become peer researchers, we acknowledged that there was a group of young people who had first-hand experience of what it was like to provide support to a family member, and who could relate to the experiences young people were likely to talk about.

Developing a peer research training package meant that young people interviewing each other would have to acknowledge to each other that they had demanding responsibilities at home. The researchers needed to be aware of the possibility that the peer researchers, who were also carers in their own lives, would experience various emotions while being involved in the project. The team was aware that the experiences shared might have an impact, resonating with their own experiences and leaving them vulnerable. A support system was put in place to ensure that young people had space to talk about their own experiences as and when they wanted to.

Young people were invited to a four-day training event where they had an opportunity to learn about research methods and get involved in interviewing other young people. The aims were to raise their understanding of face-to-face interviews, develop their own skills, and enable them to interview each other without an adult researcher. It was important for the researchers to assess how skilled and confident the young people were to ensure that the research tasks would not add pressure or stress on them and that they would not feel they had been 'set up'.

Training took place over three consecutive weeks. The peer researchers met in the afternoon after school or college and were introduced to listening and recording skills using role play.

The research team invited the group to the university because they felt it was important for the young people to get a sense of where the so-called adult work took place. Coming to the university triggered curiosity by all young people who attended the course, as they wanted to know what the lecture rooms looked like, where seminars took place and what university life looked like. Although the university was not a young-person-friendly venue, it gave the young people an insight into an adult arena that they were likely to and keen to enter as part of their own further education.

The researchers wanted to ensure that the young people who had volunteered their time and commitment would not be set to fail in tasks or responsibilities they had agreed to undertake. The focus was on having positive experiences which would give them a sense of achievement and the ability and confidence to set up and run interviews. Role play was used to explore appropriate ways of sharing life experiences. The practical and emotional support systems involved ensuring that issues like personal safety, personal boundaries, confidentiality and anonymity, child protection and disclosure were fully explored. Researchers were made aware of whom to contact if they were not happy about an interview. The peer researchers were made aware of their professional boundaries and understood that at no point were they obliged to complete an interview if they found the experience distressing.

An interview feedback form was devised in order to ensure that, in the periods where young people



would be interviewing other young people, they would have an opportunity to reflect on this experience briefly. The forms ensured that formal reflection would also provide a starting point for supervision. This enabled the researchers to monitor whether the peer researchers enjoyed the interview, what issues young people thought were important, and whether any emotional issues came up that needed to be addressed by the peer researchers. Given that the peer researchers themselves were experts in managing care responsibilities in their lives, the researchers wanted to ensure that they would not miss out on issues they identified as important. Regular contact was maintained, and the young people were informed about each step of the research process either directly or through letters.

“I think the young person was nervous, but gradually spoke more and more as she knew who I was.”

“Yes ... we share a lot of views. I understood everything that she said. I thought I was talking to myself.”

“... I know what he is going through, because of the caring roles like me.”

“... what she was saying was exactly what I do so I could relate to that.”

The schedules were framed in language that was accessible to the families and young people who were interviewed, and the process provided an opportunity for participants to reflect on what it felt like to be part of the study and how they felt research could be a part of bringing about change. Interviews were carried out over one to two hours and sometimes involved going back a second time. In families that were more comfortable communicating in languages other than English, workers with skills in both interviewing techniques and languages carried out the interviews.

## Dissemination

Virtually all of the families and young people who participated in the research project attended a dissemination event to receive the findings and hear from workers, managers and policy makers from key agencies (social services, health and education) what action would be taken as a result of the research.

The event was also a celebration event, to celebrate the strengths of black families and to acknowledge the work and contributions that black children make.

## Interview schedules

Two different interview schedules were devised, one for parents and other family members and one for children and young people. The interview schedules were informed directly by young people and families through the consultation process, by the review of literature and by questions raised from our evaluation of other studies. The schedules were comprehensive and comprised questions about identity, religion and ethnicity, experience of family life, the work children do to support disabled family members, the impact of tasks, the division and allocation of work, and other factors affecting children and family life, experiences of services, wishes and aspirations.