










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

This study investigated the experiences and needs of black young people caring for disabled or ill family members and their access to services. A joint research team from Manchester Metropolitan University and the Bibini Centre for Young People interviewed young people and adults from 20 families and also sought the views of professionals from relevant social care agencies. The study found:

-  **The work that children and young people were doing was largely invisible to agencies but was essential to maintaining family life.**
-  **Young people's work ranged from household chores to helping with personal and medical care, and interpreting. Some responsibilities affected their health, education and well-being.**
-  **Young people did not identify with the term 'carer'. This categorisation made no positive difference to the support they or their families received, and it made them feel different from other young people.**
-  **Agencies did not routinely gather information on young people with caring responsibilities and professionals' awareness of the issues was very low.**
-  **There was a high level of unmet social, personal and - in some cases - medical care needs among black parents who were disabled or experiencing ill health.**
-  **None of the families or young people received regular, adequate or appropriate support services. Experiences of social services, health services and schools showed a lack of understanding of the problems families faced and there were examples of discrimination by race and/or disability.**
-  **While children and adults valued caring and household responsibilities as a reciprocal part of family life, the lack of effective and accessible services meant some parents were forced to be dependent on their children and children often had to undertake inappropriate work.**
-  **There was a lack of coherence between children's and adult services particularly in relation to the assessment of needs.**
-  **Families demonstrated strengths, skills and diverse and creative ways of managing their lives and parenting.**

## The significance of caring

While parents appreciated the focus on the needs of their children that services set up for 'young carers' provided, they did not regard their children as carers but as children who were involved in providing support to people in the family. This distinction suggests that being a young carer is a role *not* an identity. Young people saw terms such as 'carer' and 'coping' as unhelpful: these terms carried connotations and expectations that placed pressures on young people and adults to continue caring without adequate support regardless of the effects upon them. These terms were also seen as minimising the contributions of disabled people to family life.

Young people's caring activities had different purposes and meanings and their caring roles had developed in relation to a range of different influences within and outside families. Young people wanted recognition for looking after others; they also found it hard to separate out their own needs from the needs of family members who were important to them.

Specific impairments or actual tasks were not indicative of the impact of caring on the young person. While these were important, their significance was linked to other factors such as relationships in the family, skills and strengths, other sources of stress and kinds of support available. (This raises questions about the provision of services on the basis of criteria such as 'significant caring responsibilities', since externally determined definitions of what is 'significant' tend to be fixed and do not usually take into account contexts specific to families and individuals.)

## Young people's work

The chores, tasks and responsibilities taken on by children and young people varied greatly in terms of the nature of tasks, levels of skill and physical strength required and time commitment. Gender, age, ability, the levels of support being provided by other adults and professionals, and the particular expectations and dynamics of individual families were also important factors. Although not a specific focus of the study, there was no evidence that children and young people's caring roles were determined on the basis of cultural expectations.

Where young people were in situations and undertaking tasks that they found difficult or overly demanding, this affected education, relationships with peers and social life. Some young people had developed ways of dealing with these stresses, such as working extra hard with schoolwork so that they would not fall behind. There was a tendency by some adults to see children's caring role only in positive terms whereas some young people clearly felt that

some of their caring responsibilities had a negative impact upon them. Parents were particularly aware of the impact of stress and anxiety caused by the situation, both on themselves and their children.

The work that children and young people were doing included: cleaning; ironing; gardening; cooking and preparing meals and drinks; shopping; dealing with finances; assisting people with mobility; helping with personal care; medical care; helping people to dress; encouraging people to exercise and to socialise; supervising and playing with children; taking children to and from school; being available in case people need assistance; translating and interpreting; helping people to learn English; building people's confidence.

## Responses of social care agencies

Social care agencies did not gather information about black young people with caring responsibilities and it was therefore impossible to determine the numbers of black children and young people providing support to disabled parents and other relatives. Other studies indicate, however, that black young people are more likely to be involved in informal caring arrangements than other young people.

The kinds of services that would have made a difference to families' lives were health-based services (e.g. accessible facilities in their homes, support with administering medication, information and advice on dealing with illnesses, interpreters), good quality home care services, counselling and social activity services for children and also for families, social work support geared to empowering all members of families and appropriate educational support and increased understanding among schools.

While young people identified these services as appropriate, no families in the study were actually receiving such support. For example, where young black boys had caring responsibilities that affected their behaviour and progress at school, this was more likely to result in their exclusion from school rather than any other response.

The study pointed up a number of specific reasons for the lack of appropriate responses by social care agencies:

- **Invisibility** - among professional workers (social services, health-based staff and workers from voluntary organisations), young people with caring responsibilities seemed to be invisible. There was no acknowledgement of the support that they provided and, even in cases in which a young person was clearly the sole carer for a disabled parent, questions were not asked about their needs or about the needs of their parent (or other disabled/ill family member) for support with

- personal assistance, parenting tasks etc.
- **Record-keeping and monitoring** - both statutory and generic voluntary agencies did not systematically record and monitor the ethnicity of service users even where they had a policy requiring them to do so. There were indications of a continuing sense of unease in recording information about ethnicity, race, religion and language, despite the fact that without such information it was impossible for service providers to see if black people were under-represented within an agency's client base and to plan for appropriate services. In contrast, however, black organisations were routinely recording and monitoring ethnicity even if they did not have a policy requiring them to do so. This was despite the fact that they were less likely to have the infrastructure and resources to undertake systematic monitoring. The study suggests there is a need for a more flexible and participative approach to recording ethnicity and for providing clear evidence to communities about the use of such information.
  - **Parental fears** - parents were often reluctant to approach the local authority, fearing that children would be assessed as 'in need' with connotations of inadequate parenting. In some families, needs and hardship were significantly under-reported to agencies, such as the concern that children might be removed from families.
  - **Inadequate responses** - where families did ask for help this was not always provided and sometimes there was no response at all from the local authority. In families where an element of risk had been identified for children, the social services department *did* become involved; however, the focus was around child protection and did not result in the provision of services to support parenting or reduce children's caring responsibilities.
  - **Inappropriate responses** - families sometimes preferred their own children to provide care because services from the local authority and voluntary organisations did not take into account the significance of cultural and religious needs. Other families had concerns about mainstream young carers' services because they felt these negated the importance of their children's racial identity or operated criteria that excluded members of the family. In contrast, families were very positive about the services provided by the Black Young Carers' Project (although this service had been discontinued).
  - **Poor quality services** - in all but one case, families that had been provided with home care services reported negative experiences. This was both because services were discontinued despite ongoing need and also because of the standard of services, which in all cases were described as very poor. Home care services had been contracted out to private agencies and families felt that the standards were not monitored. In the one case where a family had benefited from good quality home care support, this was because the disabled mother had arranged it herself using direct payments.
  - **Lack of assessment** - there was a failing on the part of local authorities to undertake assessments both of the support needs (including parenting support needs) of disabled parents and also of the needs of young people in relation to their caring responsibilities. None of the parents and young people had been comprehensively assessed for their support needs by statutory agencies offering support.
  - **Lack of coherence at policy level** - the study pointed up the need for greater coherence between children's and adult services, particularly in relation to the assessment of needs. For some families assessments using **The framework for the assessment of children in need** (DoH 2000) seemed appropriate (although the study also highlighted some concerns about this approach). For others, it seemed more relevant to use procedures developed out of policy and legislation on carers. Young people and their families saw a flexible approach as being more likely to meet diverse needs and respect individual family wishes.

### Identities, family life and communities

The study also examined how families felt their experiences were affected by their ethnic and cultural identity:

- **Religion** - this was a significant aspect of most family's lives. Religious communities often provided practical support and helped to keep families together. However, some people's opportunities to practice religion were restricted by discrimination against disabled people, most notably inaccessible places of worship and the attitudes of other people.
- **Language** - most of the families were fluent in English as well as other languages. Where parents did not speak English, children were often required to act as interpreters. Some young people were skilled in this role, however, there were examples in which it was inappropriate and created difficulties, particularly if the child was very young or if the information was of a complex or sensitive nature.
- **Ethnicity** - 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 was that it was often distorted or reduced to fit in with the requirements of service providers.

- **Families** - families were diverse and reflected a broad and inclusive concept of family, based on kinship networks of reciprocal care, support and responsibility, including both biological and non-biological relationships and encompassing families whose members lived apart but carried out these functions, as well as households in which people lived together. The extent to which extended family members provided support to households where there was a disabled parent (where this was preferred), poverty and other social problems facing some black families undermined their attempts to do so.
- **Parenting** - while there were similarities between current social work notions of parenting, there were also significant differences. Families' understandings of parenting were broad and creative. Some parents met their children's emotional, physical, educational and other needs directly themselves; sometimes these responsibilities were shared between different adults. Decisions about children's and young people's involvement in caring were based on the adult's ability to exercise parenting responsibilities, by negotiation within the family, rather than being due to an absence of parenting.
- **Community** - the way in which people experienced their local community was likely to be refracted through experiences of discrimination against disabled people and other forms of social exclusion. In each of the main neighbourhoods where participants lived some felt unsafe in the area, while others found their local community supportive. A range of external stresses affected family life. These included poverty, racial harassment, religious bigotry, isolation from support services, inappropriate or oppressive services, anxiety about the involvement of social 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.

over 12 months and involved consultation events with 13 young people; training of three 'young carers' as peer researchers; interviews with 17 young people and 15 family members from 20 families (the families were diverse in terms of ethnicity and religion); questionnaires from 40 agencies and discussions with 15 practitioners and managers from particular organisations (e.g. young carers projects, social services teams, voluntary organisations and health-based organisations).

### How to get further information

Further information about the study is available from The Bibini Centre for Young People, 60A Wood Road, Whalley Range, Manchester M16 8BL, Tel: 0161 881 8558, Fax: 0161 882 0420, email: [information@bibinicentre.fsnet.co.uk](mailto:information@bibinicentre.fsnet.co.uk).

The full report, **Invisible families: The strengths and needs of Black families in which young people have caring responsibilities** by Adele Jones, Dharman Jeyasingham and Sita Rajasooriya, is published for the Foundation by The Policy Press (ISBN 1 86134 388 4, price £12.95).

### About the project

This was a study by the Bibini Centre for Young People in collaboration with the Manchester Metropolitan University. The study was carried out