Other:
Beresford, B (1995) The needs of disabled children and their families. Joseph Rowntree Foundation, York.

findings
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The needs of disabled children and their families

A national survey of over a thousand parents has explored the needs and circumstances of families caring for a severely disabled child. The research, carried out by Bryony Beresford at the Social Policy Research Unit, University of York, sought parents' views of their and their child's needs as well as their experiences as service users. Parents also reported the care demands and impact on living circumstances brought about by having a disabled child. Comparisons with data collected twenty years ago indicate little improvement in the circumstances in which families are caring for their severely disabled child. The researchers found:

- **Severely disabled children of all ages are highly dependent on their parents to meet their basic care and treatment needs. In addition, older children are likely to have social, communication and behavioural problems.**
- **One in two of the children under 2 years was dependent on at least one item of medical equipment.**
- **On average, household incomes were lower among these families compared with families with non-disabled children. Nine out of ten lone parents, and over a third of two parent families, had no income other than benefits.**
- **Over four out of ten families said their housing was unsuitable for caring for a disabled child; difficult stairs, lack of space, and cold and damp were common problems.**
- **Only half the sample described their relationship with professionals as positive and supportive.**
- **The most common unmet needs of the child related to learning skills, meeting physical needs, and having someone to discuss their disability with.**
- **The most common unmet needs of the parents were financial resources, help in planning the child's future, help with care, and knowledge of available services.**
- **Certain groups were particularly vulnerable to high levels of unmet need and poor living circumstances. They included families from minority ethnic groups, lone parent families and those caring for the most severely impaired children.**

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Background

In an earlier study the researchers described how most parents caring for a disabled child actively seek to manage their day-to-day lives, and that a happy and loving relationship between parent and child is vital to such a positive approach (see *Social Care Findings 54*). That research also showed how services can both support and hinder the ways families choose to cope. The survey reported here complements that research by identifying areas of unmet need, and providing insight into the ways services can better support disabled children and their families.

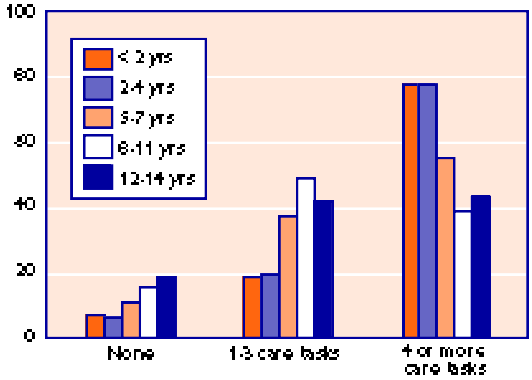
Looking after a disabled child

The demands placed on parents attempting to meet the child's care needs are high, and they face the additional pressure of dealing with behaviour problems and mobility dependency.

Self-care

Any young child needs help with self-care tasks such as dressing, toileting, washing, feeding and moving about. Many parents of severely disabled children find the demands for help with self-care do not diminish as the child grows older; more than 40% of 12 to 14 year olds needed a lot of help with at least four self-care tasks (see Figure 1).

Figure 1 **Number of self-care tasks with which child needs a lot of help (n=1,061)**



Special care needs

Disabled children have special care needs such as physiotherapy, special food requirements and drug regimes. It takes time to meet many of these needs, which may arise several times a day. It was found that, although younger children had most special care needs, many parents of older children still carried out at least one special care task (see Table 1).

Extreme cases of special care were found among very young children. Half the parents of children under 2 years of age said their child was dependent on at least one item of medical equipment (such as feeding tubes, pumps and suction equipment).

Behaviour problems

Behaviour, communication and social difficulties put additional strains on parents. It was found that these problems increase, both in prevalence and severity, as children grow older.

Table 1 **Special care needs of younger and older children**

Special care task	**< 5 yrs %**	**> 5 yrs %**
Giving medicines by mouth	**63**	**47**
Physiotherapy	**63**	**40**
Preparing food in a special way	**48**	**28**
Turning child at night	**35**	**25**
Special diet	**25**	**18**
Changing dressings	**19**	**15**
Injecting drugs	**8**	**6**
	n=436	***n=716***

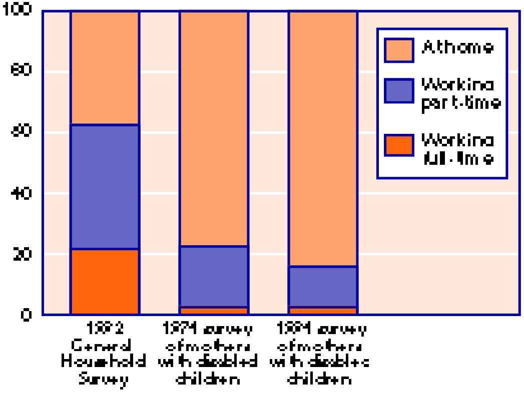
Mobility

Almost none of the children under 5 years, and less than half of the older children, were independently mobile. Lack of access to a car, reported by half the sample, made getting out even more difficult. Many parents experienced problems using public transport, especially getting on and off buses.

Employment and income

Almost none of the parents with main caring responsibility worked full-time. Levels of employment for mothers in the study, who made up 96% of the respondents, were much lower than mothers with non-disabled children as identified in the General Household Survey of 1992 (see Figure 2). In addition, fewer mothers with disabled children were working in 1994 than in 1974. Among two parent families, however, half the partners did have full-time jobs.

Figure 2 **Employment among mothers (n=1,073)**

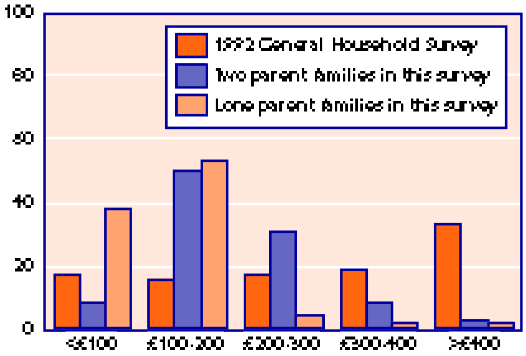


It was found that nine out of ten lone parent families, and a third of two parent families, had no income other than benefits. Families in this survey had substantially lower incomes than the general population (see Figure 3).

Extra costs

Families with a disabled child face extra demands on the household purse. All the parents reported at least one extra cost related to the care of their child. Most said there were five or more different sources of

Figure 3 **Household Income (n=1,116)**



additional expenditure. Laundry, clothing, heating, bedding and transport were the most common extra costs of care. If further financial assistance was to be provided, most parents said they would prefer it to be as high weekly benefits as opposed to an annual grant.

Housing

Four out of ten parents said their homes were unsuitable, often in a number of ways, for the care of their child. A similar figure was obtained from a study of families with disabled children conducted twenty years ago. Typical housing problems were difficult stairs, lack of space or downstairs facilities, and cold and damp.

Almost half the families had moved due to the needs of their child. Unsuitable housing was the most common reason for changing home. For many families, however, moving did not solve their housing problems: 40% said their new home was still unsuitable.

One in five families made adaptations to their homes. Those who applied for a disabled facilities grant typically had to wait more than six months to hear the local authority's decision. One in three families had waited longer than a year.

Sharing the load

The survey found low levels of support from members of the extended family, such as grandparents, aunts and uncles. Four out of ten parents said they received no help from their extended family. Parents from minority ethnic groups, and those with older children, were less likely to be helped by their families.

Support groups

Only one in three parents belonged to a support group. Those who were members said their group was a valuable source of information and emotional support. A third of the sample had chosen not to join a group. Almost 1 in 5 parents did not know what a support group was, whilst the remaining respondents reported there was no local group.

Using services

Of the range of professionals with whom parents had contact, the most frequent was with those from the fields of health or education. Less than half the sample had seen a social worker in the past twelve months. Two out of three parents did not have a key worker. Virtually all contact with practitioners concerned the child's, as opposed to the parent's, needs.

Half the parents said their relationship with professionals was collaborative (see Table 2). Most of the rest of the sample felt unsupported.

Table 2 **Relationships with professionals (n=1,050)**

Type of relationship	**%**
Collaborative: parent and professional respect each other, recognise their respective contribution and act as equals	**51**
Co-existence: do not interfere with each other	**29**
Confusion: relative roles unclear	**5**
Colonisation: professionals take over	**3**
Conflict: for example, over contrasting objectives	**5**

Factors which parents said promoted positive relationships between themselves and professionals included having a key worker, good communication skills, adequate levels of information, responsive services, and sensitivity to the parent's situation and needs.

Problems with services

Virtually all parents experienced at least one problem with the services they used (Table 3). A lack of empathy, having to fight for services, and experiencing delays - both in terms of a service being provided, and waiting at appointments - were reported by half the respondents. A third felt poorly informed about services, and one in five said they did not always understand what was being said to them. Finally, a quarter of parents surveyed said they had experienced a reduction or withdrawal of services.

Table 3 **Range and frequency of problems with services (n=1,152)**

Type of problem with service	**%**
They do not understand what it is like to look after my child	**50**
I have to fight for everything my child needs	**47**
Everything takes so long to be sorted out	**46**
I do not know what services are available to help me	**32**
I have to wait a long time at hospital	**30**
Services have been reduced or withdrawn	**24**
I do not always understand what they tell me	**21**
I do not know where to go for information	**20**
I have to wait a long time between visits or appointments	**19**
I have difficulty making myself understood	**17**
Appointments are not organised so that only one visit is needed	**16**
I see a different person every time	**13**
It is not possible to have appointments when my partner can attend	**16**
They put pressure on me to carry out treatment and therapies with my child by myself	**11**
I do not feel they are interested in helping me or my child	**11**
I do not like so many professionals visiting my home	**10**

Needs

The children's needs

While less than a quarter of parents (23%) said their child had no unmet needs, one in two parents felt their child had at least four unmet needs.

The most common unmet needs concerned learning skills for future independence and meeting the physical and learning needs caused by the impairment. In addition, four out of five parents said their child needed to talk to someone about being disabled. Over a third identified unmet need relating to social or relationship skills.

The parents' needs

Nine out of ten respondents reported at least one unmet need, and over half said they had five or more unmet needs.

There was considerable consensus about the main areas of unmet need. First, most parents felt they had insufficient financial resources to care for their child. Second, two out of three parents needed help planning their child's future. Needs for help with the care of the child, both short-term breaks and during the school holidays, were identified by one in two parents. Half the sample said they needed someone to show them the services that were available.

In addition, a third of parents had unmet needs related to learning skills which would encourage their child's development, as well as those which would resolve or ease sleep and behaviour problems. Many had social and emotional needs. One in three respondents said they needed to talk to someone about their child. Four out of ten said they simply needed more time to spend with their other children and their partner.

Vulnerable families

Families from minority ethnic groups, and very severely impaired children and their parents, were most vulnerable to high levels of unmet need. Older children also had more unmet needs than younger children, as did their parents.

About the study

Over 1,100 parents caring for a severely disabled child completed a questionnaire about their needs and circumstances. This represented a response rate of over 80% from a sample drawn from the database of the Family Fund (a government funded body allocating modest grants to families of severely disabled children) - arguably, the most representative database of families with severely disabled children in the United Kingdom. The questionnaire was developed in consultation with parents and professionals. The sample included parents caring for children with a range of impairments. Minority ethnic groups were well represented. Where appropriate, the findings from the survey were compared with research carried out on similar populations in the 1970s and with data from the 1992 General Household Survey.

Further information

For further information about this project, contact Bryony Beresford at the Social Policy Research Unit, University of York, Heslington, York YO1 5DD (Tel: 01904 433608).

A full report, **Expert opinions: a national survey of parents caring for a severely disabled child**, is published by The Policy Press in association with **Community Care** magazine, as part of the Community Care into Practice series (price £10.50).

The earlier work by Bryony Beresford is published as **Positively parents: caring for a severely disabled child** (1994). It is available from HMSO Publications priced £12.50 (Tel: 0171 873 9090).

Related *Findings*

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Housing

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