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findings

The number and characteristics of families with more than one disabled child

Analysis of the Family Fund Trust database, which records grant applications to the government-funded Trust from families with severely disabled children, has provided the first estimates of the number of families in the United Kingdom who have more than one disabled child. The analysis has also provided evidence that these families have additional disadvantages compared with families with one disabled child. Secondary analysis of data from a national survey of over 1,000 families with one or two severely disabled children confirms and adds to that evidence.

- About 17,000 families in the UK have more than one disabled child.
- About 6,500 families are caring for two or more severely disabled children. This represents well over 10,000 severely disabled children living in a family where there is another severely disabled child.
- Families with more than one disabled child are:
  - more likely to be single parents;
  - less likely to be in work;
  - more likely to be in semi-skilled or unskilled manual jobs;
  - more likely to be dependent on income support;
  - less likely to own their own home.
- Mothers are more likely to have a disability themselves and fathers are more likely not to be working because of illness or disability.
- Families applying to the Family Fund Trust from Black minority ethnic backgrounds are less likely to have more than one disabled child than white families or Asian families.
- Families with more than one disabled child have more extra costs and more of them say that their home is in some way unsuitable for a disabled child than families with one disabled child.
- Some combinations of different conditions are more prevalent than might be expected by chance: asthma in one child was found to be associated with skin conditions in another; non-specific learning disability in one child was found to be associated with cerebral palsy in another, with speech disorders in another and also with autism or other challenging behaviour in another.

JR

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How many families?

Family Fund Trust figures, based on applications for grants, show that approximately 17,000 families in the United Kingdom have more than one disabled child; approximately 6,500 of these families are caring for two or more severely disabled children. This represents over 10,000 severely disabled children living in a family where there is another severely disabled child.

Family profile

Single parents

Families with disabled children are known to be more likely to be single parents; figures from the Family Fund Trust show that there is a higher proportion of single parents, particularly mothers who are separated or divorced and lone fathers, among families with more than one disabled child (28 per cent compared with 22 per cent in this sample). This suggests a greater strain on marriage when parents are caring for two or more disabled children.

Employment

Figures from the Family Fund Trust indicate that parents of disabled children, and particularly mothers, are less likely to be in work than in families without a disabled child (Table 1).

Where there are two parents in a household with two or more disabled children, fewer fathers work than in families with one disabled child, suggesting a negative impact on the father's working patterns. In addition, of those who do work, more are in semi-skilled and unskilled jobs.

Table 1 shows that very few mothers with one disabled child work outside the home - about two per cent work full-time and about ten per cent part-time. These are well below the figures for the general population of families with children. In addition, mothers with more than one disabled child are slightly less likely to work outside the home.

Benefits

The higher incidence of lone parenthood and unemployment among families with more than one disabled child leads to greater dependence on benefit. Almost two-thirds of families with more than one disabled child were dependent on income support compared with just over half of those with one disabled child.

Tenure

Families with more than one disabled child were also less likely to own their own home than families with one disabled child.

Comparative information from the national survey of 1,000 families adds to this picture. Mothers of two severely disabled children and their partners were more likely to be at home caring for family full-time. They were more likely to be unhappy with their employment situation whether they worked or not. The analysis suggests that many parents feel they have little choice about whether to work, and that both parents are often needed at home to care for the children.

Ethnicity and geographical distribution

About 10 per cent of families who apply to the Family Fund Trust are from minority ethnic groups, predominantly Asian or Black. The recently introduced Family Fund Trust ethnic monitoring programme indicates that a smaller proportion of Black applicants are caring for more than one disabled child - 5 per cent, compared with 12 per cent of white or Asian applicants.

There is a higher proportion of families with more than one disabled child in the Northern region (Cumbria, Northumberland, Durham, Cleveland and Tyne & Wear) and in the South West region (Avon, Gloucestershire, Somerset, Devon and Cornwall). There is also a higher proportion of families with more than one disabled child in Northern Ireland, where there appears to be a correlation with larger

Table 1 **Percentage of parents in work**

	Families with one disabled child	Families with more than one disabled child	General population of families with children[1]
Mothers full-time[2]	**2**	**1**	**23**
Mothers part-time[2]	**10**	**6**	**37**
Fathers with a partner (working full- and part-time)[2]	**63**	**51**	**86**

Notes: 1 1994 General Household Survey
2 'All mothers' includes single mothers and mothers with a partner. 'Fathers with a partner' excludes single fathers

family sizes. In this sample, 14 per cent of families from Northern Ireland have four or more children, compared with 6 per cent across the rest of the UK.

Within this sample two regions, Wales and the East Midlands, have a relatively lower prevalence of families with more than one disabled child.

Access to support

It may be particularly complicated or difficult for families with two or more disabled children to access the support they need. In the national survey of over 1,000 families, one-fifth of parents with two disabled children said they had no-one to look after their disabled children if they were unable to care for their child due to an illness. They were more likely to use respite care for emergencies rather than on a regular basis.

Fewer of the families with two disabled children had relatives living nearby than families with one disabled child and they generally received less help, emotional or practical, from the extended family.

In families with two disabled children, compared with families with one disabled child, mothers were more likely to have a disability themselves. Among Family Fund Trust applicants, fathers of more than one disabled child were more likely to be sick or disabled than fathers of one disabled child.

Services

Families with two disabled children who took part in the national survey generally found professionals, particularly the family doctor, less helpful than did families with one disabled child. They were also marginally less likely to have a key worker or single contact point. Both groups reported similar problems with services and were equally well, but not very, satisfied with services.

Family Fund Trust applicants with more than one disabled child were slightly more likely to be known to the local authority social services than families with only one disabled child (74 per cent and 70 per cent respectively).

The same or different diagnoses

Among the families who apply to the Family Fund Trust who have more than one disabled child, half contain siblings with the same disabling condition. For children with genetically determined conditions such as cystic fibrosis, haemophilia or muscular dystrophy, more than 80 per cent of disabled siblings have the same condition. Where there is no genetic component, such as with head injury or meningitis, less than five per cent of disabled siblings have the same condition.

Other conditions which show some predisposition to run in families are asthma and non-specific learning disability, named syndromes, metabolic conditions and chromosome disorders. There is some suggestion of a genetic component in sensory impairments, with two-thirds of families where there is one blind or deaf child having another with the same rather than a different impairment.

There would not appear to be a significant familial element in cerebral palsy or epilepsy, in childhood cancer or leukaemia or in most of the non-genetically determined conditions leading to physical limitation such as scoliosis, spina bifida, Perthes' disease, Still's disease and congenital dislocation of the hip. Nor do diseases of the major organs, the heart, the kidneys, the lungs and the digestive system show a predisposition to run in families.

Among families in the analysis who have two children with different diagnoses, four combinations are more prevalent than might be expected by chance. Asthma in one child is associated with skin conditions in another. Non-specific learning disability in one child is associated with cerebral palsy in another, with speech disorders in another and also with autism or other challenging behaviour in another. There may be a genetic component in these conditions which is not yet understood.

In the smaller sample of 1,000 families, which contained three sets of adopted children, 29 of 39 pairs of children had the same diagnosis. There were four pairs of deaf children and four pairs of children with non-specific learning disabilities, supporting the view that there may be a genetic predisposition to these conditions.

In conclusion: supporting families

Families with more than one disabled child are given special consideration by the Family Fund Trust, which takes account of the extra care and stress imposed by having more than one disabled child. However, although they may receive more in total from disability benefits, the benefit system does not allow for the cumulative effects of care. For example, where two children in one family both fall outside the criteria for the care component of disability living allowance, the family will receive no award, despite the overall burden of care.

Previous research has shown that families with a disabled child can be extremely positive in their everyday lives. Parents can be active and creative in the ways they manage the stresses and strains of caring and their situation is helped when formal services seek to support the family in ways that

nurture a positive and rewarding parent-child relationship. How much more important must it be for families who have more than one disabled child for services to take account of their individual circumstances and the sometimes very differing needs of each disabled child.

About the study

The Family Fund Trust was established in 1973 and provides grants and information to families with severely disabled children in the UK. (A disabled child may have a physical impairment, a sensory impairment, a mental impairment, or complex and multiple impairments.) For this study, their records of over 100,000 families with one or more disabled child under the age of 19 were analysed. More than 10,000 of the families, about eleven in every hundred, had two or more children with a disability. Material from a national survey of over 1,000 families with one or two severely disabled children was used to provide a broader picture. This survey included 39 families with two severely disabled children.

For further information about this work, or about using the Family Fund Trust database as a research resource, contact Dot Lawton, Research Fellow, Social Policy Research Unit, University of York, Heslington, York YO1 SDD (tel: 01904 433608; fax: 01904 433618; minicom: 01904 432626; e-mail DL1 @york.ac.uk).

A two-year programme of qualitative research which will more fully investigate the circumstances and needs of families with more than one disabled child is now in progress. For further information contact Rosemary Tozer, Research Fellow, at the above address.

How to get further information

The full report, **Complex numbers: Families with more than one disabled child** by Dot Lawton, will be published later in the spring by the Social Policy Research Unit as part of its Social Policy Report series. It can be ordered from Social Policy Research Unit, University of York, Heslington, York YO1 5DD, Tel: 01904 433608 (ISBN 1 871713 92 7, price £5.00 including postage and packing).

The following *Findings* look at related issues:

- **The needs of disabled children and their families,** Dec 95 *(SC76)*
- **Trends in applications to the Family Fund,** Jun 94 *(SC53)*

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