



The cost of childhood disability

This study of the financial costs of bringing up a child with a severe disability brought together groups of parents to establish the minimum essential costs. Parents acted as their own 'budget standards committees', negotiating and agreeing the goods and services that they deemed to be necessary for a disabled child to participate as fully as possible in the world around them. The research, conducted by Barbara Dobson and Sue Middleton at the Centre for Research in Social Policy, found that:

- f** The budget standards estimated an average cost of £7,355 a year to bring up a child with a severe disability. This is at least three times more than the amount required to bring up a child without a disability established in a study using a similar methodology.
- f** Benefits for severely disabled children would need to be increased by between 20 and 50 per cent, depending on the child's age and type of impairment, to meet the costs of the minimum essential budgets.
- f** The shortfalls in benefits are based on figures that assume families are receiving the maximum benefits available. This is not always the case; parents participating in the study stressed the difficulties of finding out about and claiming benefits.
- f** Younger children with a severe disability are especially disadvantaged in benefit calculations. In particular the ineligibility of children under five for the mobility component of Disability Living Allowance causes parents real financial difficulties.
- f** Most of these families are unable to increase their income through paid employment because of the demands of caring as well as the lack of suitable childcare.
- f** The ambition of a 'seamless service' for children with disabilities has failed to be realised. Parents report constant battles with the range of service providers who are there to support them. Services varied from area to area and this lack of consistency increased the frustration and difficulties of parents.

Background

The benefits system acknowledges that disabled people incur additional financial costs as a result of their disabilities. While previous research has confirmed that these costs exist, estimates have varied in size and focused mostly on adults. To date there has been comparatively little research on the additional financial amounts needed to allow severely disabled children to lead as full a life as possible.

The aim of this study was to work with parents of severely disabled children to establish minimum essential needs and then to use these as the basis for developing estimates of additional costs. This study is unique in three ways. First, it recognises the expert and detailed knowledge of parents in knowing what a severely disabled child needs. Secondly, it uses need as the starting point rather than what can be afforded. Finally, because the budgets are negotiated and agreed by parents there is a strong sense of consensus.

The minimum essential cost

The minimum essential budgets produced by parents suggest that, at 1997 prices, it costs on average £125,000 to bring up a child with a severe disability from birth to 17 years of age. This is equivalent to £7,355 per year. Earlier research (*Family Fortunes*) which used similar methods, found the cost of bringing up a child without a disability was £37,394 or £2,100 a year. In other words, a severely disabled child would cost parents at least three times as much as a child without a disability, if the goods and services regarded as essential were all being purchased.

Comparing the minimum essential budgets for disabled children with those for children without a disability suggests that the average *additional* cost is £99.15 per week.

“It’s all the little things, the extra clothes, sheets, even food that you’re buying every week and you don’t realise what it costs or rather it would scare you if you

sat and worked it out so you don’t. Every now and again I’ll think I’ll get myself some new clothes because mine are almost in holes but I come home with things for Erin, because she needs it more than me. And just when you think that you might be getting straight it all falls apart, she’ll have a bad patch and maybe she’ll need a new bed or she’s back in hospital and that costs ... The thing you have to realise is that everything like this is a disaster for us.”

Benefits

By using case studies of severely disabled children it was possible to calculate the maximum benefits that children with three different conditions might be entitled to (see Table 1). The conditions were mobility disability, sensory impairment and traumatic or intermittent conditions. The calculations assume that the family is in receipt of Income Support. As Child Benefit is claimed back pound for pound from Income Support, it has not been included as part of the benefit income.

Comparing maximum benefit income with the minimum essential budgets for the three types of disability shows that benefits fall far short of what parents believe to be the minimum essential costs for severely disabled children. The shortfall varies between 20 per cent for a child aged between 6 and 10 years who cannot walk and almost 50 per cent for children aged 5 years or less regardless of their disability. Even if children were receiving their maximum entitlement, benefits would need to be increased by between £30 and £80 per week in order to meet the minimum essential costs identified by parents.

Benefits and age

In addition to the overall shortfall in benefits these findings suggest that the relativities in benefit calculations for children of different ages do not reflect the patterns of spending which parents believe

Table 1: Budget standards and benefit income*

Age group	Mobility disability	Maximum benefit income ¹	Sensory impairment	Maximum benefit income ²	Traumatic/ intermittent conditions	Maximum benefit income ²
0 – 5 years	170.68	87.35	143.20	70.95	134.45	70.95
6 – 10 years	151.08	121.95	131.23	84.10	117.95	84.10
11– 16 years	169.61	129.80	126.63	91.95	128.01	91.95

* The benefit rates included in the Table are for 1997/98 when the budget standards were constructed, for comparability.

1. Assumes the highest rate of Disability Living Allowance. Children less than 5 years of age are not eligible for the mobility component. It is assumed that those in the older age groups receive the higher rate of the mobility component of this benefit.

2. This assumes the middle rate of Disability Living Allowance. Children less than 5 years of age are not eligible for the mobility component. It is assumed that those in the older age groups receive the lower rate of the mobility component of this benefit.

are necessary. Benefits for all children, not only those with a severe disability, assume that younger children cost much less than older children. The findings of this study indicate that this is not so – the essential minimum cost of children in the oldest age group is lower than for the youngest children, whatever the disability.

The parents in this study were aware that the costs involved in bringing up a severely disabled child do not necessarily increase with age. Rather, their experience was that the costs start from a much higher level and remain fairly constant over the lifetime of the child. The difficulty for parents is that many disability and associated benefits are age-related. Two examples of this are the mobility component of the Disability Living Allowance and the entitlement to free nappies:

“You think it gets easier as they get older but it doesn’t, the money still isn’t there, and the debts are bigger. I don’t worry about the bills now, that’s the only difference. What are they going to do to me, put me in prison? Great, a room to myself and a night’s sleep. That would be the first in nearly 15 years.”

Applying for benefits

Parents of disabled children can apply for a confusing array of benefits. Some parents are not aware of their own and, indeed, their child’s entitlement to benefit and find the system bewildering.

“I’m sitting here listening [in the focus group] and I never knew you could get these benefits, nobody told me. I just thought they knew Mark was disabled and we don’t work so we got what we got.”

Parents were keen to stress the difficulty they experienced in: finding out which benefits they and their child were entitled to; in filling in the forms; being assessed; and in appealing against the benefit decision.

Budgets

All areas of the minimum essential budget for a disabled child were higher than those for a child without a disability. Spending priorities, as well as spending levels, differ between parents of children with and without a disability. Whereas parents of children without a disability allocated 60 per cent of their budget to clothe and feed the child, these items account for less than a third of the budget for parents of disabled children. Instead the largest proportion of the minimum essential budget for disabled children goes on transport costs. Priorities are also much more evenly spread across the budget areas for children with a severe disability.

Whilst the detail of the budget standards varies for children of differing ages and with different combinations of disabilities, the overall differences are not enormous. All severely disabled children need

extra clothes and bedding, money for trips to hospital, extra possessions and activities to enable them to develop to their potential. They also need equipment to make both the child’s and the parent’s life possible within a normal home environment. All of these things require additional expenditure.

In constructing the budgets, none of the parents thought that they had been over-generous and none were prepared to amend the budgets in order to reduce the costs. In their experience, these budgets are a true reflection of the minimum essential costs of bringing up a disabled child with a reasonable quality of life.

Failing to meet the budgets

The central difficulty for parents of severely disabled children is that these minimum essential budgets represent what parents consider to be necessary and not what their children actually receive. Most parents cannot meet the levels of spending implied and for many the gap between the budgets and their weekly income is insurmountable.

Parents attempt to minimise the gap between their income and the levels of spending that they believe are needed by going into debt, spending less on themselves and on other family members, and completely altering their lifestyles and aspirations.

One of the biggest problems faced by parents in trying to juggle their budgets is that the need for extra spending often comes suddenly and unpredictably. Parents identified cycles in their budgets linked to their child’s health. When their child is comparatively well and settled they manage better. However, when the child is ill they spend considerably more money and it is at this point that many go into debt, as they often have no savings or flexibility within their budgets.

Financial difficulties are compounded by the limitations on parents’ options to increase the family income through work. Childcare is often simply not available beyond the limited hours offered by school. On the rare occasions when it can be found, it is usually substantially more expensive than for children without a disability.

Sometimes having an income from work can create more problems than it solves, as the upper income threshold for the granting of additional financial help is set too low and excludes many families who are just above these limits. The dilemma is that if they work they may miss out on formal statutory help. But the alternative of not working means that they are destined always to be poor.

Strength of consensus

The consensus which parents reached in agreeing the budget standards was extremely strong. In addition to pointing out the savings to the Exchequer which accrue from their commitment to caring for their severely disabled children, they stressed that:

“he [Chancellor] has a responsibility to maintain all

children in this country, and that's his job to do that. You know there are acts, such as the Children Act, she [daughter] has rights to services and rights to a basic standard of living to increase her well being and all that bumph. ... So I would say, so here you are, you have her in care and then see how much that would cost you."

The parents were adamant that the additional financial costs of bringing up a child with a severe disability which they had identified were not excessive. The budget standards demonstrate the real financial costs to parents. They emphasised that extra amounts in the budgets for items such as transport, clothing and adaptations are necessary for both parents and children. Without them, parents simply do not have enough time to care for the child as they would wish.

However, parents emphasised that there were also costs other than the purely financial. For many, having a disabled child resulted in them *'being a disabled family'*. All said that they had no social life and only a limited family life, however hard they tried to protect and compensate their other non-disabled children. The sense of guilt was enormous.

"I've got a six-year-old [non-disabled] child who is like going on 40, you know he's like a little old man and sometimes you think, that's awful because they don't get a childhood. And some of the things he comes out with I think, oh dear. And they have all their worries and all their problems and they'll be upset one day and you ask, 'What's the matter?' And I'll say, 'Why didn't you tell me?' and he says 'Because you've got too much else to do'."

Service provision

Legislation has attempted to provide a framework for improvement in services for disabled children and their families. One of the main aims of this is to improve access to services for families through better co-ordination. The experiences of families in this study suggest that, whatever institutional arrangements may have been put in place to encourage joint planning and delivery of services, few improvements have reached families.

Conclusion

What parents of severely disabled children want remains the same as in all previous research, services which are appropriate, that they have some degree of control over, that are reliable, responsive and work together. In addition they want adequate financial resources to allow them to bring up their children to the minimum standards to which they aspire. The

average cost of this is £141 per week, or three times the amount needed for a child who is not severely disabled. The maximum amounts available in benefits would have to be increased by between £30 and £80 per week to meet the essential minimum needs identified by parents. It seems that, in 1998, parents are still 'paying to care'.

About the study

Approximately 300 families with severely disabled children took part in this study. The families were identified through the Family Fund Trust Database and lived in four areas of the country, Leicestershire, Birmingham, Derbyshire and Nottinghamshire. For the purposes of this research families were asked to participate if their child had one of three conditions, restrictions in movement, sensory impairment, or a traumatic or intermittent condition. A total of 36 focus groups were held with parents.

How to get further information

The full report, *Paying to care: The cost of childhood disability* by Barbara Dobson and Sue Middleton, is published for the Foundation by YPS (ISBN 1 899987 75 4, price £11.95 plus £1.50 p&p). It is available from York Publishing Services Ltd, 64 Hallfield Road, Layerthorpe, York YO31 7ZX, Tel: 01904 430033, Fax: 01904 430868. The earlier research referred to, *Family Fortunes: pressures on parents and children in the 1990s*, was published by CPAG in 1994.

The following *Findings* look at related issues:

- Attitudes to spending on children, Dec 94 (*SP67*)
- The needs of disabled children and their families, Dec 95 (*SC76*)
- Independent Visitors and disabled children, Feb 98 (*F138*)
- The number and characteristics of families with more than one disabled child, Feb 98 (*F238*)
- Disabled children and the Children Act, Mar 98 (*F378*)
- Combining work and care: working parents of disabled children, Apr 98 (*F538*)

Full details of all JRF *Findings* and other publications can be found on our website: <http://www.jrf.org.uk>. If you do not have access to the Internet or have any further queries on publications, contact the Publications Office on 01904 615905 (direct line/answerphone for publications queries only).