

The impact of childhood disability on family life

A 1998 study brought together parents to establish minimum budget standards of bringing up a severely disabled child, based on what parents deemed necessary to achieve a reasonable standard of living. This second report describes the actual spending patterns of parents and also considers some of the adjustments families make because they are bringing up a severely disabled child. All figures have been updated by the Retail Price Index to 2000. The research, conducted by Barbara Dobson, Sue Middleton and Alan Beardsworth at the Centre for Research in Social Policy, found that:

- f** All parents strived to spend enough to meet the needs of their children. To achieve this they spent less on themselves and made other savings wherever they could. Excluding spending on food, parents spent on average £65.51 per week on items and services for their disabled child. As more than 80 per cent of families had an income of £300 or less per week, this accounted for almost a fifth of the total family income.
- f** Parents of disabled children spent almost twice as much on comparable items (£65.51) as parents of non-disabled children (£31.22).
- f** Parents were only able to spend half of what they felt was required to ensure a reasonable standard of living. The biggest shortfall between actual spending and the budget standards was for children aged up to five years.
- f** Parents spoke about the love and joy they received from their child but also discussed the emotional costs and how they and their families adjusted to the needs of their child. The study suggests that as well as struggling to cope with the additional financial costs, parents must also confront new and unexpected experiences.
- f** Parents of disabled children often have two roles - parent and carer. The researchers conclude that the challenge for policy and indeed for medical and social services is to recognise these dual roles and to accord each one the respect they deserve.

Background

This is the second report of a study conducted in 1997/98 that explored the additional financial costs to parents of bringing up a child with a severe disability. The first report, **Paying to care**, described the minimum essential budgets developed by parents which represented the amount that they agreed was required to bring up a severely disabled child. This report examines these budgets alongside data on parents' actual spending in order to explore whether or not parents are able to meet the costs. (All of the figures have been updated by the Retail Price Index to 2000.)

During the course of the research, it became clear that the financial aspects were only one element of bringing up a disabled child: parents also experienced other challenges that affected all aspects of family life. The study describes some of these.

Parental spending

A total of 182 parents recorded their spending on goods and services for their child over a seven-day period. Parents spent on average £65.51 per week. As 80 per cent of families had an income of £300 or less per week, spending this amount on their disabled child accounted for at least one-fifth of their total family income. Food has been excluded from this figure as parents were unable to record accurately the quantities of food consumed by their children; this is therefore an underestimate of weekly spending.

Two-thirds of parental spending on their child went on everyday items, including activities, clothes, toiletries, medical items and children's possessions. All parents regarded these items as essential and shared the experience of this mother who said:

"I'm careful with money, I know I don't waste it. I only buy what we need but Helen [disabled child] needs more than her sister, more nappies, more clothes, more creams, more things to occupy her because she is stuck in here with me all the time. I have two children and I know it costs more, a lot more for Helen and there is nothing you can do. You just have to pay it."

In order to allow for this level of spending, parents developed ways of coping financially. These included: parents going without; relying on help from families when it was available; going into debt; and economising whenever and wherever possible. While the majority of parents were creative and

careful money managers, achieving the required results took time and energy - two things that for many parents were in even shorter supply than money.

Comparison of spending on disabled and non-disabled children

Relatively little is known about the nature of the added financial costs that parents incur in bringing up a severely disabled child compared with a non-disabled child. In order to explore this, spending data from this study was examined alongside data from **Small fortunes**, the first national survey of spending on children.

Parents of a disabled child spent on average twice as much on comparable items - £65.51 per week - as those whose child was not disabled - £31.22 per week. Previous research has shown that parents of disabled children have incomes well below the national average.

Parents of disabled children spent considerably more on everyday items, spending more than four times as much on the category 'other regular spending', which includes children's possessions, medical items and toiletries. In group discussions, parents described a need for more items to amuse, occupy and stimulate their children. Many of these items were more expensive than those used by non-disabled children.

Spending and the budget standards

The budget standards represented what parents agreed was the minimum essential amount a severely disabled child needed in order to achieve a reasonable quality of living. The budget standards have been amended so that they can be compared with the amounts parents actually spent. Once again food has been dropped completely because parents were unable to record accurately quantities of food.

Parents were unable to meet the budget standards and spent considerably less on their child than they felt was required. The budget standard suggests that parents needed to spend £120.67 per week on clothes, laundry, toiletries, medical items, activities, transport and occasions. In reality, they were only able to spend £65.51 and were therefore able to provide their children with only half the items they regarded as essential. One parent said:

"It's hard because you want to do more ... I spend what I have, sometimes I spend more than that. Me

and her dad do without and we manage, but it's not easy for me or her. She knows we worry all the time about money and bills, so she doesn't ask for things. What a way to live! She has to put up with all that's wrong with her and then to have us worrying about whether we can pay the electric bill because she has to have the heater on."

The biggest shortfall between spending and the budget standards were for clothes, children's possessions, activities, transport and occasions. Parents came closest to meeting the budget standard with their spending on medical items.

Benefits for disabled children

The benefits system recognises the fact that bringing up a severely disabled child costs more and provides financial help through entitlement to particular benefits. Since the original study, **Paying to care**, was conducted in 1997/8, the benefits for disabled children have increased: the maximum amount a severely disabled child was entitled to in 2000/2001 was £124.80. This figure assumes that a child is receiving all the additional premiums at the highest level.

However, benefit income for parents can vary considerably. Many parents of disabled children do not receive the maximum amount of benefit income because they are unaware of their entitlement. For example, if parents received the middle rate of Disability Living Allowance (DLA) care component and the lower rate of the mobility component of this benefit, their benefit income would drop to £83.85 per week. This has serious financial implications for families.

The effects on family life

The financial costs experienced by parents represent only one element of bringing up a disabled child. Throughout this study, parents spoke about the love and joy they received from their child but they also discussed the emotional costs and described the processes by which they and their families adjusted to the needs of their child. The findings from this study suggest that as parents struggle to cope with the additional financial costs they must also confront new and unexpected experiences.

Parents acknowledged that the process of transition and adjustment for all new parents was difficult but suggested for them it was especially overwhelming:

"You never expect this and you're never prepared."
 "For a brief moment your hopes vanish and you're left holding your fears literally ... But then all you feel is love: the worry, the guilt comes later but so does the joy and the pride - all you really have is a child, not a child who is this or that but a child."

Central to this process of adjustment was the way in which parents received a diagnosis of their child's disability. The diagnosis was important to parents for many reasons. It was often the point from which parents could begin to contemplate their futures and to understand the nature of their child's disability. For this to happen, parents needed information which they could understand and relate to. This process did not happen instantly but for many parents the diagnosis represented a turning point from which they started to regain some control over both their own and their child's lives. Diagnosis was also crucially important because it was often the gateway to services, including the entitlement to financial benefits.

A particular difficulty for parents was that they were suddenly exposed to the attitudes that many disabled people experience all the time: they were marginalised and ignored by some friends and family. As a result many parents became very isolated. It was only as parents grew in confidence that they were able to challenge the way in which they and their children were treated by society.

Many parents of disabled children become used to being stared at in public or the topic of other people's or professionals' conversations. Yet despite this public profile, parents reported how as a family they remained invisible. They were not regarded as an 'ordinary' family, with the same aspirations and rights as families who did not have a disabled child. While families reported that the physical exclusion was hard to deal with, it was the change in attitudes by society, including professionals, that devastated them. Their experience was that they as a family no longer evoked positive feelings but were instead pitied. By being treated as a 'matter of regret' they were stripped of their family status and denied the same emotional and social worth as 'normal' families.

"When I went into a room people would stop talking. No one asked about Tom. It was as if he didn't exist. When I mentioned him they all looked uncomfortable. Nobody knew what to say. None of them ever asked to hold him, they wouldn't go near him. Were they frightened they'd catch something?"

Parent or carer?

Parents of disabled children often have two roles: parent and carer. Many parents did not differentiate between their role as parent and the tasks they performed to care for their child. In their experience, they did whatever was necessary to look after their child and the only difference was that their child had specialised health needs. However, parents described how often their parental or caring roles were denied. In some instances, the specialised knowledge that they had acquired about their child's condition was ignored: in others, their role as parents was overlooked as professionals discussed their child with them in cold clinical terms.

Conclusion

As well as worrying about money, parents of disabled children have other things to worry about. A lack of practical and emotional support was compounded by the lack of money and produced particular difficulties for all involved. The reality for parents was that - while struggling to reconcile the additional financial costs with the needs of their child - they also had to confront new and unexpected experiences.

The researchers conclude that the challenge for policy, and indeed for medical and social services, is to provide parents with the help and support they require so that they can meet the needs of their children. Harnessing parents' expertise and knowledge and working with them can only enhance the effective use of resources to the benefit of all involved.

About the study

Approximately 300 families with severely disabled children took part in this study. Of these, 182 parents returned completed diaries and questionnaires which form the basis of this report. The families were identified through the Family Fund Trust Database and lived in four areas of the country: Leicestershire, Birmingham, Derbyshire and Nottinghamshire.

How to get further information

The full report, **The impact of childhood disability on family life** by Barbara Dobson, Sue Middleton and Alan Beardsworth, is published for the Foundation by YPS (ISBN 1 84263 029 6, price £10.95).

A summary of the earlier minimum budget standards study is available in 'The cost of childhood disability', Findings (Ref: 748). **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). **Small fortunes: Spending on children, childhood poverty and parental sacrifice** by Sue Middleton, Karl Ashworth and Ian Braithwaite