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The impact of childhood disability on family life

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The impact of childhood disability on family life

Barbara Dobson, Sue Middleton and Alan Beardsworth

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First and foremost, we would like to thank all the parents and children who took part in the original study, *Paying to Care: The Cost of Childhood Disability* (Dobson and Middleton, 1998), as their contributions and diligence in completing the questionnaires and diaries made this report possible. All the families who participated in the project live very pressured lives with constant demands on their limited time and energy. Yet, despite these constraints, all were willing to co-operate and support this study in the hope that it will make a real difference, if not to their lives, to the lives of other parents and children who will inevitably come after them. Parents hope that, if they tell their story, other people will understand the reality of their everyday lives and will work with them to help them care for their children.

Thanks also to the Joseph Rowntree Foundation who funded and supported this study, particularly to Barbara Ballard, Principal Research Officer; our Advisory Group who gave encouragement and words of wisdom; Roger Mattingly, Chief Executive of The Family Fund Trust; and Dot Lawton, at the Social Policy Research Unit, University of York, who provided the sample and made the initial contact with the families who took part in this research. Jean Rushton and Rosie Porter then distributed the necessary questionnaires and diaries to the families as well as arranging our meetings. Finally, thanks to our secretarial support team, our colleagues within the Centre for Research in Social Policy and our families for their help and patience.

1 Introduction

This is the second report of a study funded by the Joseph Rowntree Foundation that explored the costs to parents of bringing up a child with a severe disability. The first report, *Paying to Care* (Dobson and Middleton, 1998), described a minimum budget standard, which is the minimum amount that parents believed to be necessary to bring up a child with severe disabilities. This report describes the actual spending patterns of parents on 182 children with severe disabilities, and presents a detailed examination of how much parents actually spend on bringing up a severely disabled child. Fieldwork was conducted during 1997–98 and so all figures presented have been up-rated to 2000 by the Retail Price Index.

The financial costs experienced by parents are, of course, only one element of bringing up a disabled child. Throughout this study parents spoke about the love and joy they received from their child. They stressed that it was not, as one parent said, 'just doom and gloom', nor was it about only giving. But parents also talked about the emotional costs and described the processes by which they, their families and friends reacted and adjusted to the needs of their child. The data suggests that as parents struggle to reconcile costs with needs they must also confront new and unexpected experiences and in so doing construct a new paradigm of family life. Within this new paradigm, relationships, obligations, aspirations, responsibilities, as well as one's sense of self, have to be redefined.

Chapter 1 provides some background information about the study and the research design. It also contains a brief description of the participants. Chapter 2 describes the actual spending patterns of parents and compares these with the spending of parents whose children did not have a disability. The data on children without disabilities was collected via the Small Fortunes Survey (Middleton *et al.*, 1997). This study, funded by the Joseph Rowntree Foundation, was the first national survey on expenditures on children. Chapter 3 compares spending data with the budget standards to explore whether severely disabled children received what their parents deemed essential for children like them. It also examines the budget standards compared with benefit income. Chapter 4 describes some of the emotional costs of bringing up disabled children, and suggests that parents were often compelled to reconstruct and renegotiate every aspect of their lives.

The aim of the study

In 1997, the Joseph Rowntree Foundation funded a study to explore the additional financial costs of childhood disability, as well as related issues, and to develop minimum budget standards.[1] Budget standards attempt to determine a list of necessities that are essential to maintain a given standard of living. In previous studies, panels of experts produced a budget standard by drawing up lists of necessary items, which were then costed as a weekly basket of goods and services. The price of the basket represents the costs to a family of achieving a pre-determined standard of living (Dowler and Dobson, 1997). This process was modified in the present study, in that the 'experts' were parents of children with severe disabilities as they, better than anyone else, understood both their own and their child's needs and priorities. It was parents who discussed, negotiated and agreed the minimum

essential needs of severely disabled children and drew up the budget standard. This variation of the budget standard approach is referred to as 'consensual budget standards'.

Parents constructed the minimum essential budget standards in a total of 36 focus groups. The focus groups took place in three stages: orientation, task and check back groups (for a detailed description of the research process, see Appendix 1). The main aim of the focus groups was to bring parents together to agree the items that disabled children needed and, during the final stages of the research, to discuss the additional costs. However, the focus groups also allowed other aspects of bringing up a child with a severe disability to be discussed. For this report, transcripts from the group discussions were analysed so as to explore the effect of a child's disability on particular dimensions of family life. For example, parents' discussions provided invaluable insights as to how they negotiated new relationships with health and social professionals and, equally important, how they renegotiated existing relationships with family and friends.

Prior to attending the task and check back groups, parents completed a one-week consumption and expenditure diary about the disabled child, an inventory of the child's possessions, and a self-completion questionnaire about spending on items and activities which are likely to take place less regularly than once a week. This instrumentation is described below. The data from this instrumentation was coded and analysed, and provides the estimates of parental spending used in this report.

Instrumentation used

Recruitment questionnaire

A total of 272 recruitment questionnaires were administered to parents. These questionnaires collected information about the socio-demographic and economic circumstances of the family. The questionnaires collected data on household composition, housing tenure and type, ownership of certain consumer durable items (taken from Smyth and Robus, 1989), household income, benefit receipt, marital status and social class.

Inventories

The inventories were used to record information about items owned by the child or that s/he had access to. As the inventories took some considerable time to do, parents completed either the clothes or the possessions inventory. The inventories were developed from those used in the Small Fortunes project but amended according to the suggestions of parents in the orientation groups. In the inventories, the parent was asked to write in the number of the items their child possessed. They were then asked about the most recent item acquired by their child – whether it was new, second-hand, handed on or on loan and who gave the item to their child.

Diaries and self-completion questionnaires

A total of 182 parents completed a diary for seven consecutive days relating to spending on their child with disabilities. Each diary recorded information about spending on school and non-school activities, medical items, phone calls

made by parent or child and other possessions. Although the diaries also recorded information about the foods eaten by the child, this data has not been included as it was not possible to cost this element of parents' spending.

A self-completion questionnaire was included at the back of the diaries. This collected information about actual spending on the following: outings; day-trips and weekends away; holidays; birthdays; Christmas; respite care; adaptations; car ownership; child's savings; laundry; fuel and heating bills.

Children's questionnaire

A questionnaire was administered whenever possible to children aged over five years and a total of 42 were successfully completed. The questionnaire was an amended version of that used in the Small Fortunes study. It explored whether children received pocket money, if they and their families could afford to buy the items they wanted, what the child did if they were refused items and the reasons for this. It also explored if children did not ask for things because they thought their families could not afford it.

The sample

Parents were identified via the Family Fund Trust (FFT) database. The Family Fund Trust is an independent trust set up by Government in 1973 and entirely funded by them through the Department of Health. It currently allocates approximately 20 million pounds per year in grants to families with children with severe disabilities. The FFT was established to help families with modest means, and applies income and savings guidelines to applications. At the time of this study these guidelines were £18,800 income per year and £8,000 savings.

It is estimated that the FFT has had contact with between 60 and 70 per cent of all families with severely disabled children in Britain and is, therefore, the best available sampling frame. A sample of families in four different areas was drawn from the database and a letter was sent by the FFT to each family asking if they were prepared to participate in the research. A list of names and addresses of those who had agreed was then passed to the researchers and, subsequently, to professional recruiters who contacted parents and distributed the instrumentation.

The basic classification of disabilities used by the FFT recognises over 60 different conditions. It was neither possible nor desirable to establish minimum essential budget standards for each one of these conditions. Furthermore, research on the database showed that the majority of children have multiple disabilities. For example, a child with cerebral palsy, as well as having problems moving, may also be incontinent, have difficulty speaking, etc. Therefore the disability groups were condensed into the following three main disabling conditions:

- restrictions on movement (Mobility Disability: e.g. cerebral palsy, spina bifida)
- sensory disablement (Sensory Impairment: e.g. deaf, blind)
- traumatic intermittent conditions (Traumatic/Intermittent Disability: severe asthma, epilepsy, autism).

The rationale for the separation into different disability categories was to try and contain the

discussion, and to focus on the extra costs related to the type and severity of a particular disability. This approach had limited success as the severity of the children's disabilities was such that the disabilities spanned the three categories and some could have been allocated to any one of the above groups. This was especially true of the children in the older age groups. Parents explained this by saying that the assessment by the FFT was several years old; their children's conditions had changed during this time – some had improved but the majority had developed (or were diagnosed with) more complex health and social care needs. This finding in itself did not have a major impact on the study because of the use of case studies, which are discussed below.

The groups were also divided according to the age group of the child. The age groups chosen were identified in previous work as reflecting the main changes in a child's life around school, which might be anticipated to have a significant effect on parents' expenditure patterns (Middleton *et al*., 1994). The age groups chosen were birth to 5, 6 to 10 and 11 to 16 years. In reality, it was possible to recruit only a few parents who had a child under 2 years of age. The explanation for this, according to parents, is the length of time taken to receive a diagnosis and also to discover organisations such as the FFT.

The groups were mixed according to social class, family composition, gender and birth order of the child. While ethnicity was not included as a specific criterion, slightly less than 10 per cent of families participating in the research came from differing ethnic minorities.

Selection of areas

The four areas chosen were Leicestershire, Derbyshire, Birmingham and Nottinghamshire. The rationale for area selection was twofold. First, areas were needed in which the number of families with severely disabled children was sufficiently large and geographically concentrated to enable groups to be put together. Second, we wished to include areas with differing local government structures, which might have an impact on the experiences in accessing services.

Case study children

Descriptions of three children were developed into case studies to represent each of the main disabling conditions. The case studies were developed by the orientation groups, which consisted of the first nine focus groups. These case studies were then used in the task and check back groups to focus discussion away from the needs of participants' own children and towards the minimum essential extra costs of bringing up a child with a particular combination of disabilities. This was important to ensure standardisation of the budgets throughout the groups and to avoid the temptation for parents to construct individual budgets for their own child. To explore whether costs varied in relation to age, the case studies were 'aged'. For example, the groups where mobility was the main disabling condition discussed Karen aged 4, 9 and 15 years (see Appendix 2 for a detailed description of the case study children).

Profile of the families who participated in the study

Two-hundred-and-seventy-three parents who had responsibility for the day-to-day care of a child with severe disabilities took part in this study. Of these, 200 participated in the task and check back phases, which drew up the budget standards. One-hundred-and-eighty-two of these parents completed the expenditure and consumption diaries, which equates with a 91 per cent response rate.

Analysis of the characteristics of the overall sample showed it to be representative of families registered with the FFT, and there is no reason to suggest that the priorities and concerns of the families in this study are radically different from others registered with the FFT.[2] In brief:

- The participants were mostly women (92 per cent). In other words, 8 per cent of participants were the fathers of children with disabilities. Whilst still very small, the numbers of fathers claiming 'to have the main day-to-day responsibility for the care of the child' was far higher in this study than in earlier work with parents of children without disabilities.
- The average age of participants was 36 years. The youngest was 20 years of age and the oldest parent was 70 years old.
- Three-quarters of participants did not work (75 per cent), 18 per cent worked part time with only 7 per cent in full-time work. In other words, only one-quarter of participants were in some kind of paid employment.
- Seventy-three per cent of participants had a partner. Less than 60 per cent of partners worked on a full-time basis.
- One-fifth of parents had only one child, two-fifths had two children, one-quarter had three children and 16 per cent had four or more children.
- Half of the families rented their accommodation, 40 per cent from their local council. Forty-six per cent of families owned their own homes. The vast majority (93 per cent) lived in houses, rather than flats.
- Approximately half of the families were in receipt of Income Support.
- Nine out of ten families were claiming Disability Living Allowance and four-fifths were in receipt of Invalid Care Allowance. However, 3 per cent of families received no other benefit apart from Child Benefit.
- The majority of participants were in the lower socio-economic groups.
- Approximately half the children had their own savings; a third saved their money in a building society; 27 per cent saved using a piggy bank; 15 per cent had a bank account; and 7 per cent had a post office savings account.
- Almost half of school-aged children attended a special school.

The above findings demonstrate that the families who participated in this study were less affluent than the population as a whole. They

were less likely to own their homes, more likely to be on Income Support and less likely to have at least one adult in full-time work (General Household Survey, 1994). There were more lone parents than in the population as a whole. Two reasons for this lower socio-economic profile are possible. First, the Family Fund Trust applies income and savings guidelines to grant applications. As stated above, in 1997/98 when this study was conducted, these were incomes of below £18,800 per annum and savings of less than £8,000. Whilst the database includes higher-income applicants who were turned down as a result of the income and savings guidelines, it may be that, in general, few affluent families apply to the Trust in the first place and so would be under-represented. Second, the relatively low socio-economic profile may be the result of having a child with a disability. The socio-economic profile of families in the Family Fund Trust database may be genuinely representative of all families of disabled children.

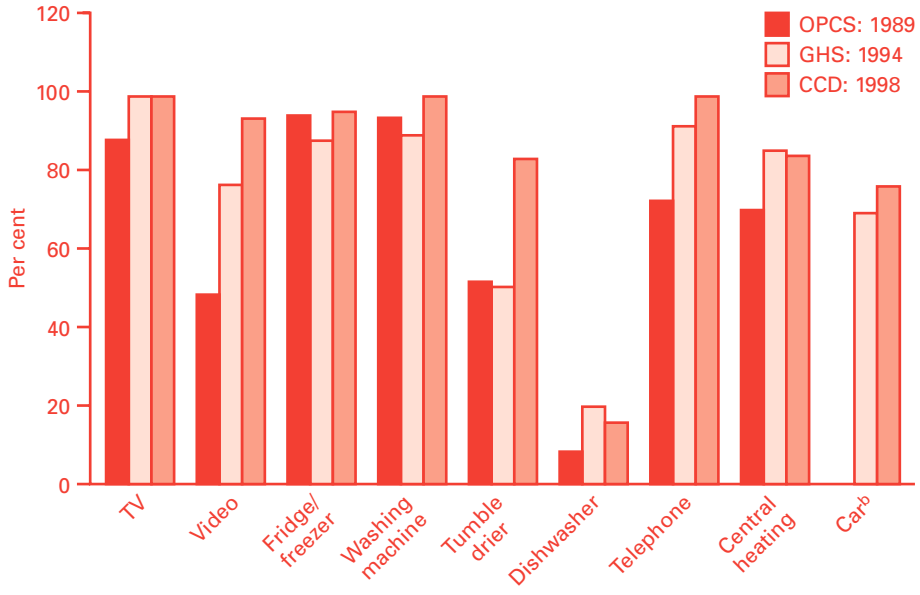
The OPCS (Office of Population Censuses and Surveys) study showed that both mothers and fathers of disabled children were less likely to work and, when they did, their earnings were lower than for parents as a whole (Symth and Robus, 1989). This finding is supported by more recent work which has found that both parents, or even one parent, may find it difficult to take, or sustain, employment given the demands of caring for a child with severe disabilities, particularly when there are other children to be looked after (Kagan *et al*., 1998):

> *You can't work when you've got a child like ours, it's just not possible. I tried and you always need time off when they're ill and they're ill more than normal children, then you've got all the appointments as well, but the killer is the holidays, what do you do with them then. If you can find someone to have them then it costs you more because they can have less of them, kids I mean, because of the ratios and it ends up costing you more so that it's not worth working even if you'd got someone, a boss who'd understand.*
> (Task Group, Sensory Impairment, 11–16 years)[3]

However, although the families in this study were less affluent than the population as a whole as measured by housing tenure, labour market activity and benefit receipt, they were not necessarily less affluent on other measures.

Figure 1 compares patterns of ownership of selected consumer durables by families in this research with those for the population as a whole taken from the General Household Survey (GHS, 1994). Families with disabled children were more likely than the population as a whole to own each of the consumer durables, with the exception of a dishwasher and, although the difference is small, central heating. Evidence from the focus groups confirmed that, with the exception of a dishwasher, these items were regarded as absolutely essential by the parents of children with disabilities. The difference in ownership rates is, therefore, explained not by relative affluence of the families in our study, but by the presence of a disabled child.

Figure 1 Ownership of consumer durable items: OPCS; GHS; and CCD[a]



[a]CCD refers to the original study, *Paying to Care: The Cost of Childhood Disability* (Dobson and Middleton, 1998).
[b]Car not included in the OPCS survey.

Further analysis showed that ownership of some of these items varied among our families. Lone parents were less likely to own a car (53 per cent) than two-parent families (86 per cent) and less likely to live a in a house with central heating (71 per cent compared with 86 per cent). These items were described as vitally important in enabling parents to continue to care for their children with disabilities, yet it seems that significant numbers of lone parents are having to manage without.

2 Spending by parents

On returning the diaries, parents were keen to stress that spending varied according to the health of their child so that during the data collection period some had spent less than usual and some more. For example, some parents reported that their child had been ill and had not been able to go out or to participate in activities. Other parents reported that their spending, especially on activities during the data collection period, was higher as they were taking advantage of the fact that their child was well and able to do things:

> *All children rule the roost but even more if they are like ours* [have a severe disability]. *You have to work with them and change your plans to fit with how they are. If he isn't well you can't go out; we've even missed our holiday because he was ill at the last moment. So, when he is able to do things, we do them and I worry about the money later because I think to myself that you don't know the next time he will be up to it.*
> (Orientation Group, Mobility Disability, 6–11 years)

Throughout this chapter, average spending figures are described. This will help to 'iron out' some of the discrepancies between those parents who had spent more and those who had spent less during the diary week. In addition, all spending data has been carefully examined and a small number of very large items that were significantly distorting the average spending figures have been removed.

Spending[1]

A total of 182 parents recorded their spending on goods and services for their child over a seven-day period; of these, 68 per cent of the children were of school age and 32 per cent were aged under 5 years.

Parents spent on average £65.51 per week. As 85 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 total family income. It should be borne in mind that the average spending figure does not include spending on food for this child and so is an under-estimate of weekly spending.

Spending on everyday items accounted for almost two-thirds of parental spending. Everyday items included activities, clothes, toiletries, medical items and children's possessions. All parents regarded these items as essential and shared the experiences 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.*
> (Task Group, Sensory Impairment, birth to 5 years)

In order to allow for this level of spending, parents developed financial coping strategies. For example, in the group discussions, parents spoke of: going without; relying on help from families when it was available; and going into debt. One mother organised regular car boot sales, as this was the only way she could find to afford the items her child needed. This required a considerable amount of time as she had to collect and sort things to sell, go to the car boot sale and clear up afterwards. 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. Given the high proportion of their income required to meet the needs of their child, it is not surprising that one mother said:

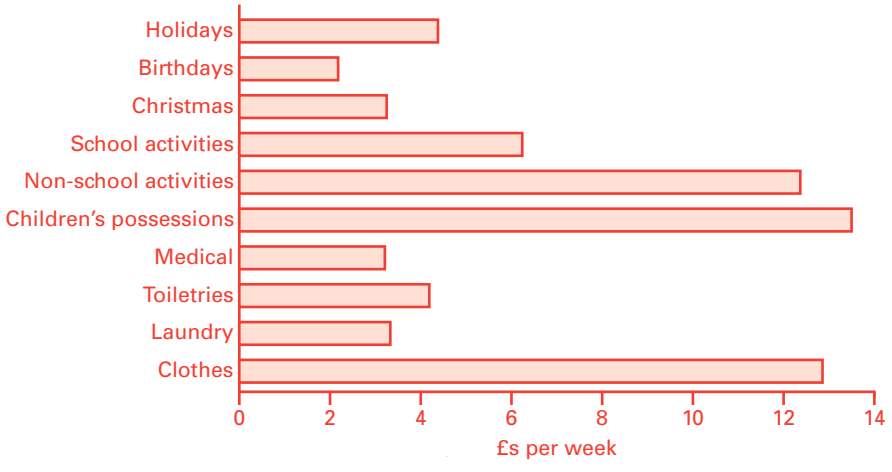
> *When I tell people how much I pay out a week they look at me as if I'm mad. They think we've got loads of money and we're living a life of luxury and go on fancy holidays. Then they come and see where we live and I tell them we haven't had a holiday for almost ten years. I know some don't believe me but it's true. All my money goes on what we need and when it doesn't stretch I get into more debt because there is nothing else I can do.*
> (Orientation Group, Mobility Disability, 11–16 years)

Figure 2 indicates that the three main items of expenditure were children's possessions (an average of £13.50 per week), clothes (an average of £12.86 per week) and non-school activities (£12.37). Parents spent least on birthdays (an average of £2.18 per week) and Christmas (an average of £3.25 per week). Parents were aware that they spent what they regarded as a considerable amount of money on day-to-day items but they insisted that the reasons for this were simple; either their child needed more of a particular item and/or it was expensive. Parents' explanations for their level of spending on possessions, clothes and non-school activities are discussed below.

Children's possessions

Children's possessions include toys, books and games as well as videos, computers and specialist toys and, as mentioned above, parents spent on average £13.50 per week on these items. There were a number of reasons for this. First, especially when the child was diagnosed, parents were desperate to find things that might help their child and they spent more on special toys, games and books. Second, there was an additional cost as parents found things that their child could use and enjoy, and that lasted. For example, learning the type of buttons or switches a child could operate took time and cost money:

Figure 2 Average weekly spending



You have to stop yourself from only buying toys that will help them to do something. They're kids and at the end of the day, they want to play and you want to see them happy.
(Orientation Group, Sensory Impairment, 6–10 years)

Third, parents were often unable to borrow or share toys with family or friends and had to buy more themselves:

It's hard to borrow things from other people because they end up wrecking it, you just can't borrow things.
(Check Back Group, Mobility Disability, birth to 5 years)

Fourth, as a child with a severe disability was less likely to play with friends and more likely to be on their own than a child without a disability, there was a greater need to find something to occupy them. Finally, specialist toys, games and books that were appropriate for disabled children cost more. For example, a single book for a child with a visual impairment costs somewhere in the region of £10.

When the extra time that children with a severe disability spend at home due to illness is added to these other factors, the relatively high level of spending is understandable. For example, some parents rented an extra one or two videos a week, especially when the child was ill and at home. Also, children with behavioural difficulties and autism often watched the same videos over and over again, and parents had no alternative but to buy these outright.

Clothes

Parents spent on average £12.86 per week on clothes. Many disabled children need more clothes to allow for extra changes, whether the result of incontinence, spillages or damage. Parents frequently sent spare sets of clothes to school/nursery/hospital/respite care and, regardless of how carefully the clothes were labelled, they were seldom returned. Also clothes were washed more frequently, often at a higher temperature because of staining, and so did not last as long as they did for children without a disability. Finally, severely disabled children may inflict additional wear and tear on clothes, which means that they have to be replaced more often. This was especially true for older children whose clothes were often not designed to withstand such treatment thereby pushing up the costs.

Non-school activities

An added strain on parents' budgets was paying for non-school activities, such as swimming, attendance at youth clubs or other events. These activities were regarded as essential by parents as they provided children with the opportunity to go out, to make friends and to share the experiences of non-disabled children. Parents spent on average £12.37 per week on a range of activities and, while this is a significant amount of money, often it represented only one activity.

Parents explained that the seemingly high cost of activities arose because the price of participation is higher for disabled than for non-disabled children. Finding safe and suitable activities was often difficult, as these tended to be located further afield and/or were specialist and, therefore, cost more. Also, parents explained how having to participate in activities with their child increased the costs of activities in two ways. First, parents often had to pay for

two tickets, one for the child and another for themselves. Second, as they had to attend the session, they had to pay for childcare for other children, thereby further pushing up the costs:

> *Because there is only me, if Jenny wants to go to her swimming, I have to take her myself and that means I have to pay someone to babysit the others. Sometimes, I put the others in the crèche but that costs as well. You see I have to help Jen get changed because the swimming teacher won't, the pool people aren't allowed. So, it's not just the swimming itself you end up paying for, but you have to let them do it.*
> (Task Groups, Traumatic/Intermittent Condition, 6–11 years)

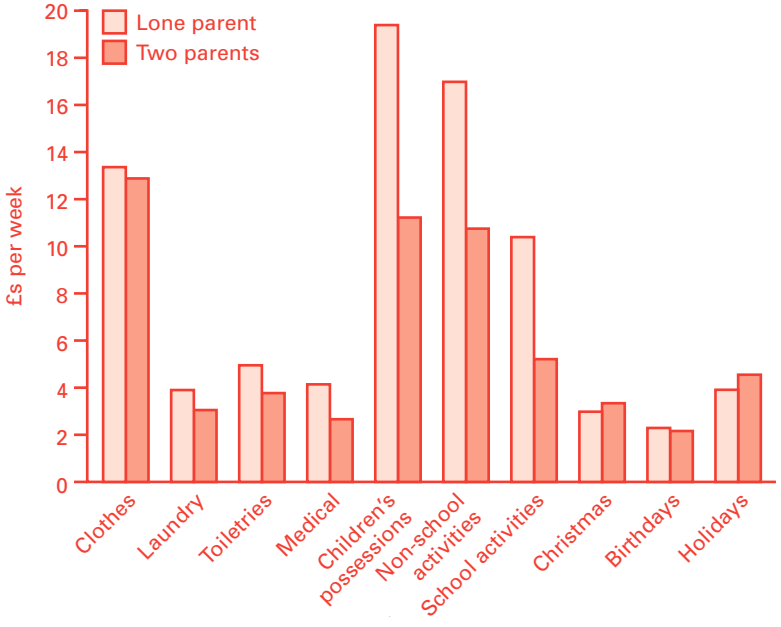
Parents understood and accepted that staff of leisure facilities were not trained or insured to provide the type of help their children needed. However, they resented the fact that they had to pay for tickets for themselves so that they were available to provide the help required. Parents were especially annoyed if their presence was required to overcome inadequate facilities or poor access.

> *I have to go with him because there is no ramp and he can't get into the toilet.*
> (Task Group, Sensory Impairment, 6–11 years)

Spending and lone parents

Lone parents spent substantially more than two-parent families (Figure 3); lone parents spent on average £82.27 per week compared with two-parent families, who spent £59.57 per week. Lone parents spent more on day-to-day items and activities. They spent, on average, approximately twice as much as two-parent families on school activities (£10.39 and £5.21), and over one-and-a-half times as much on non-

Figure 3 Spending and family type



school activities (£16.98 and £10.57). Lone parents spent £7 more than two-parent families on things to amuse and occupy their children, i.e. children's possessions (£19.39 and £11.22). The only two items on which lone parents spent less than two parents were Christmas (£2.98 compared with £3.34) and holidays (£3.91 compared with £4.55).

The explanation for much of this extra spending by lone parents on everyday items can be found in their descriptions in the group discussions of how coping on their own meant simple practical tasks took longer, leaving them less time to do other things. For example, one parent described how she spent money on items so as to free her to do other things such as housework or to spend time with other children:

> *When there is only one of you, you have to be everywhere and do everything. Doing things with James takes longer, getting him dressed, giving him a bath. Everything takes longer so you have less time to do other things. If I want to do the housework, or help the others with their homework, I have to make sure James is all right, and he has something to do so I buy a game, paints or a video. If he gets bored he throws things, or he breaks something and that ends up costing more. It's not his fault.*
> (Check Back groups, Traumatic/Intermittent Condition, 11–16 years)

However, this explanation does not account for the difference in spending on school activities by lone- and two-parent families. Spending on school items and activities included buying books, sports equipment, craft items, parties, trips and sponsorship money. The only item on which two-parent families spent more was school-books; for all other items lone parents spent more. The difference in spending for all items except school trips was small, that is, less than £1. However, the difference in spending on school trips was more substantial in that lone parents spent on average £3.50 per week more than two-parent families. The group discussions do not provide a definitive explanation for this difference in spending.

Severity of disability

It had been anticipated that spending would increase with the severity of the child's disability but the data suggested this was not the case. There was no significant difference in overall spending according to the severity of the children's conditions. Parents of children with the most severe disabilities spent on average £67.44 per week compared with £68 for children whose disabilities were less severe. While parents of children with the most severe disabilities spent slightly more on medical items, toiletries and laundry, they spent less on clothes and on things to amuse and occupy their children. The difference in spending on each budget item was small, less than £1.50. It should also be remembered that all the children who participated in this study had severe disabilities and this may explain why there was so little variation in spending:

> *I have been sitting here listening to the others talking and I'm surprised that even though all our kids have different things wrong with them, it is the same story. We've all got our own way of coping and no matter what the problem is you can't make do, if she needs something then you have to get it.*
> (Task Group, Mobility Disability, 11–16 years)

Income and spending

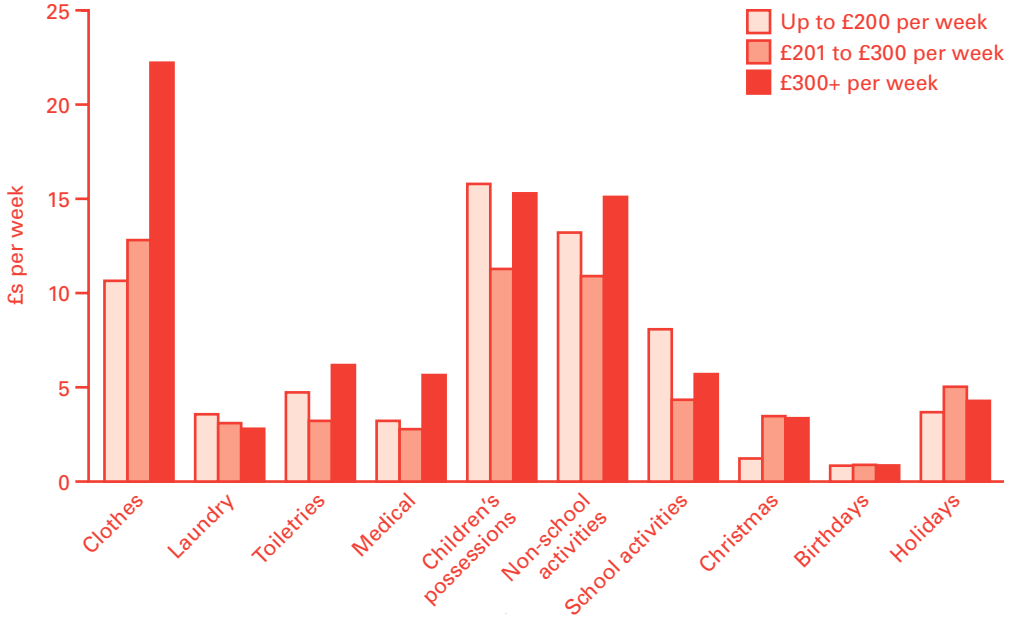
All parents were adamant that they spent the amount necessary to meet the needs of their child, irrespective of income. To achieve this, they spent less on themselves and made other savings to allow for the required level of spending. However, Figure 4 shows that families with the highest income spent most: the 15 per cent of families with incomes greater than £300 per week spent on average £82.70 per week.

While the 47 per cent of families whose weekly income was less than £200 spent on average £68.13 per week, it was families whose income was between £200 and £300 who spent least, on average £59.13 per week. The item of the budget in which there was greatest difference according to parental income was clothes. Parents with the highest incomes spent almost twice as much on clothes as those with the lowest incomes. Although the group discussions provide no exhaustive explanation for this difference in spending, there is a suggestion that parents with higher incomes opted for better quality items of clothing, which cost more.

Spending and age

Spending on disabled children did not necessarily increase with the age of the child. Parents of children aged up to and including 5 years were spending on average £60.18 per week; the average spending for children aged between 6 and 10 years was £68.73, and for the oldest age group it was £67.61 per week. The difference in spending can be accounted for by the amount parents spent on items and activities for school (Figure 5). Parents of school-aged children spent on average an additional £9.35 per week on these items:

Figure 4 Parental spending and income



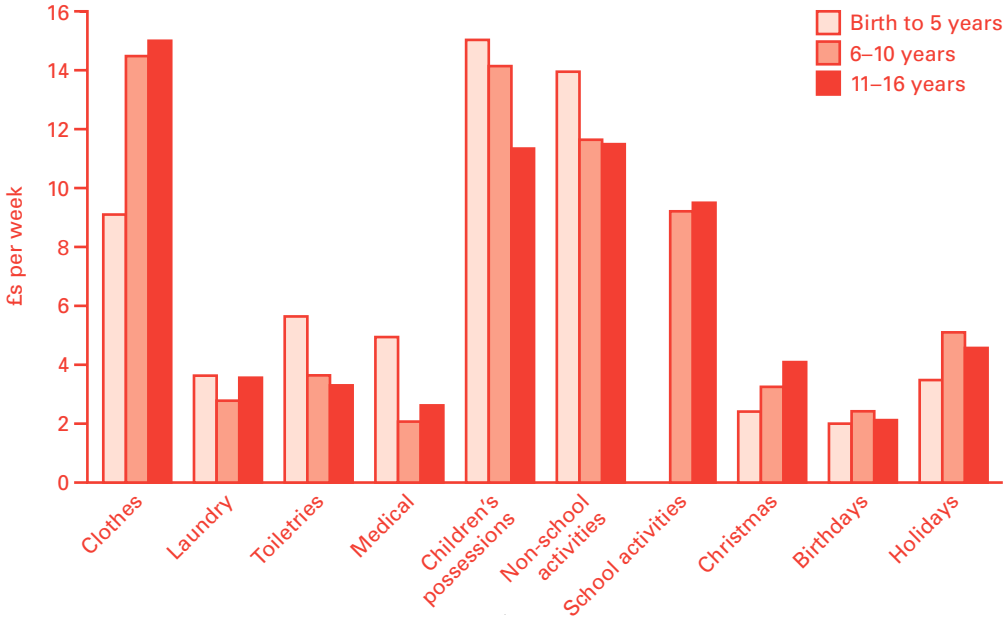
When mine went to school, it cost us more. It was always money for this or that.
You see, because they can't always use the equipment, you end up having to get stuff they can manage … and it's not always sent home, so you need one set for school and another for home.
(Task Groups, Traumatic/Intermittent Conditions, 6–11 years)

Average spending by parents of children aged up to 5 years was higher for laundry, toiletries, medical items, children's possessions and non-school activities. In the group discussions, parents explained that spending on these items was often higher as it was only with time that parents discovered what their child needed, which items they were able to use and which were of most use. These discoveries were usually made only by trial and error, and involved parents buying the items and seeing what worked. This learning curve often meant that parents spent more.

Figure 5 shows that average spending on toiletries and medical items decreased as the child got older. This was not necessarily because parents required fewer of these items, rather, it was only as the child got older that parents had established a routine and knew what worked best for them and their children. Added to this was the fact that it took parents time to find out about the services and statutory provision that were available to them free of charge. While professionals informed some parents about statutory service provision, others relied on informal networks. For example, access to this information usually coincided with the child going to school, as this was when parents met other families who knew the medical and social service system.

Costs for these items were also higher for younger rather than older children because, in

Figure 5 Spending by age groups



order to qualify for services, parents had to have received a diagnosis. For some parents this was problematic as often it took considerable time to get a diagnosis:

> *I don't know if this is standard, but I know I was told that they* [doctors] *don't like to give a diagnosis until she is older. I understand why they do it, but everyone knew that there was something wrong. The waiting just meant that we had to cope on our own and that we couldn't get help. You see, on so many forms you have to be able to say my child has this disease. You need the diagnosis.*
> (Check Back Groups, Traumatic/Intermittent Conditions, 11–16 years)

For many parents, diagnosis acted as a gateway to health and social services as well as financial benefits.

Parents of older children spent more on clothes (the reasons for which have been discussed above), Christmas, birthdays and holidays. Parents of older children explained that they spent less on possessions because their children were now at school. This meant that parents had help to amuse, occupy and stimulate their children.

Comparison of parental 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 child with a severe disability compared to a child who does not have a disability. In order to explore this, spending data from this study was examined alongside that from the first national survey of spending on children, *Small Fortunes* (Middleton *et al.*, 1997). To enable direct comparisons between the two data sets to be made it has been necessary to disaggregate some budget items, for example, nappies now appear as a category on their own; and to aggregate other categories such as 'other regular spending', which includes children's possessions, medical items and toiletries.

Parents of a disabled child spent on average twice as much on comparable categories of expenditure as parents whose child did not have a disability (£65.51 and £31.22 respectively), despite the fact that parents of disabled children have incomes well below the national average. This data suggests that, in order to maintain this level of spending, parents must be making considerable economies in other aspects of their budgets. As mentioned above, discussions with parents indicated that they often went without and/or accrued debts so as to afford essential items.

Figure 6 shows that parents of disabled children spent considerably more on everyday items, spending almost four times as much on the category 'other regular spending' which includes children's possessions, medical items and toiletries. Parents in the group discussions described needing more items to amuse, occupy and stimulate their children, and many of these items were more expensive than those used by children without a disability. Also, many disabled children needed more toiletries and non-prescription medicines which were used for a longer period.

On average, parents of disabled children spent almost two-and-a half times as much on non-school items and activities as parents of non-disabled-children (£12.37 and £5.22 respectively). Activities for disabled children often cost more as they are specialised or need

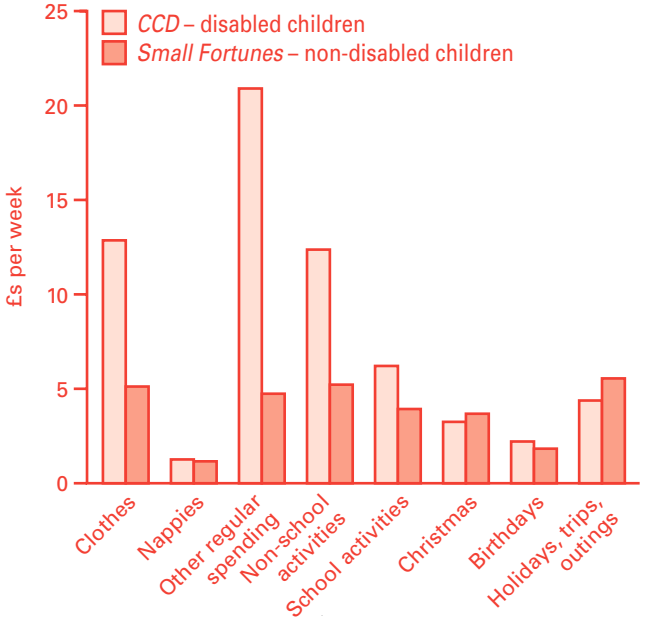
to be on a one-to-one basis. Parents of disabled children spent twice as much on clothes to allow for the additional wear and tear, and to accommodate the extra changes their children required. Finally, parents of disabled children spent more on school activities to compensate for the lack of specialised equipment, especially in mainstream schools. Parents of disabled children insisted that the extra expenditure was related directly to the needs of their child.

There were only two areas of spending on which parents of non-disabled children spent slightly more: Christmas presents and holidays. It may be that, because these parents spent less on the essential everyday items, they had more money available to spend on 'treats'. It should be noted that the majority of parents of disabled children who participated in this research received help from the FFT and most obtained a holiday grant of up to £300, thus restricting their spending on this budget area. The data reveals that the same pattern of spending more on everyday items and less on Christmas and holidays for disabled children holds true irrespective of the age of the child.

New or second-hand

The data from the inventories shows that the majority of items bought by parents were new. There were two main reasons that parents gave for not using second-hand goods. First, most parents were unable to invest in the time needed to look for suitable items since many of the children required very specific items, such as clothes with Velcro rather than buttons, or equipment that was safe to use with a child with a severe impairment. Second, some parents regarded second-hand goods as a false economy since they did not last as long as those bought new.

Figure 6 Comparison of parental spending



Borrowing items from friends or organisations was also not an option for many parents. This was because either the items were unsuitable or parents were concerned they would be damaged by the extra wear and tear.

Support from family, friends and organisations

Examination of the data contained in the inventories highlighted that parents provided the majority of items for their child (Table 1). The main exception to this was the provision of medical equipment, most of which was provided by statutory organisations. Medical equipment included items such as wheelchairs and lifting equipment. Organisations also supplied 15 per cent of the computing equipment for educational use to which children had access, and provided specialised footwear to 16 per cent of children in this study.

Parents were grateful for the help provided by grandparents, other relatives and friends, although it was limited. Relatives and friends bought or handed on clothes, videos, toys and travel items such as car seats and pushchairs. These gifts were important to parents and children because they meant not only that parents did not have to meet the cost but also that, perhaps more importantly, other people treated their child as they did any other.

Summary

Excluding food, the spending data showed that parents of disabled children spent on average £65.51 per week. This was almost twice as much as parents of non-disabled children. The higher level of spending was on day-to-day items rather than on holidays, and on birthday and Christmas presents. All the parents in this study spoke of the financial difficulties they had

Table 1 Who provided the majority of items (row percentages)

Item	Parent	Absent parent	Grand-parent	Other relative	Friend	Organ-isation
Travel equipment	82	–	2.6	5.1	2.6	7.7
Computer and accessories	79.4	–	–	–	5.9	14.7
Bed equipment	95.5	1.5	–	1.5	–	1.5
Audio/visual	88	1.5	3	3	1.5	3
Baby clothes	96.3	–	–	1.9	1.9	–
School clothes	94.4	2.8	–	–	–	2.8
Home clothes	92.6	–	1.9	1.9	3.7	–
Outdoor wear	94	–	4.1	2	–	–
Underwear	98	–	2	–	–	–
Nightwear	90.5	2.4	2.4	2.4	–	2.4
Footwear	81.4	–	2.3	–	–	16.3
Toys and games	98.5	–	1.5	–	–	–
Medical equipment	4.5	–	–	–	–	95.5

experienced in trying to provide their child with the things they needed. The following chapter examines the data on parental spending alongside the budget standards, so as to explore the extent to which parents were able to provide their child with the items they regarded as essential.

3 Spending and the budget standards

The budget standards represented what parents agreed was the minimum essential amount a child with severe disabilities should have to obtain a reasonable quality of living. In this chapter, the budget standards are compared with what parents actually spent on their children. To enable direct comparisons to be made, the budget standards have been adjusted so that they include only items of spending covered by the diaries. Food has been dropped completely as the data collected in the diaries proved impossible to cost reliably. Also the budget standards allowed an amount of money to cover the costs of school and non-school activities, transport, birthdays, Christmas and holidays. Therefore, in the discussion that follows, these items are presented as one category: activities, transport and occasions.

Spending deficit

Examining the budget standards alongside actual spending data revealed the shortfall between minimum essential needs and actual spending.

Parents spent less on their children on average than the budget standards. The budget standard for the six items – clothes; laundry; toiletries; medical items; children's possessions; and activities, transport and occasions – was £120.67 per week. Parental spending for these same items was £65.51 per week. This means that there was a spending deficit of 46 per cent. According to this data, parents were only able to provide children with just over half the items that they regarded as essential. Parents were only too aware that they could not afford to meet the level of spending implied by the budget standards as demonstrated by this parent:

> *I'd love to be able to spend that much every week but no way can I afford it. If I spent that on her there would be nothing left for the rest of us. There would be no money for food or bills, for nothing. I'd like to but no way.*
> (Check Back Groups, Mobility Disability, birth to 5 years)

Figure 7 shows that, for five of the six comparable items, parents spent considerably less than the budget standard.

Parents came closest to meeting the budget standard on medical items; the budget standard allowed for an average of £3.30 and parents spent £3.21 per week. However, for clothes; laundry; toiletries; children's possessions; activities; transport and occasions, parents' spending was approximately half of the budget standard. This means that parents spent only half as much as they had agreed was necessary to provide a disabled child with the minimum essential to achieve a reasonable quality of life:

> *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 had to have the heater on.*
> (Task Groups, Traumatic/Intermittent Conditions, 6–11 years)

Figure 7 Parental spending and budget standard

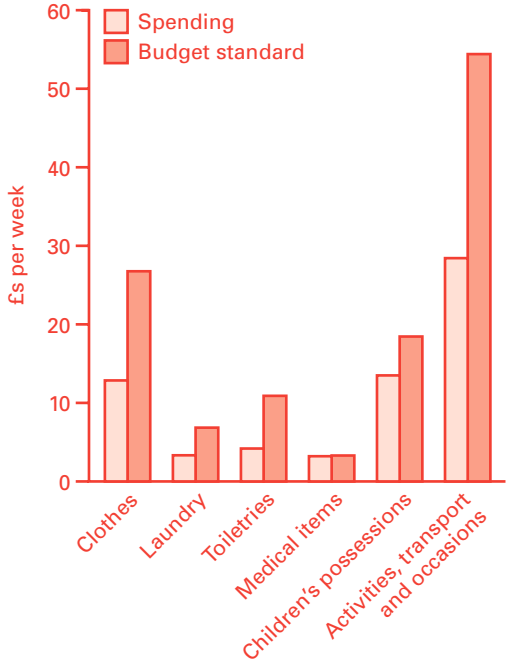
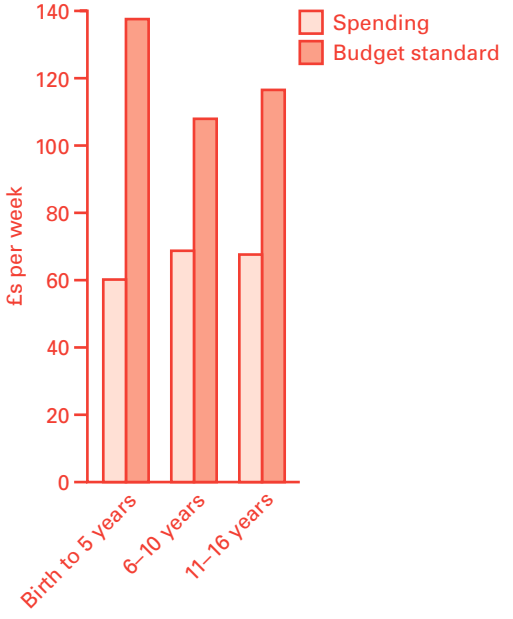


Figure 8 Parental spending and budget standards by age groups



Average spending and the budget standards by age

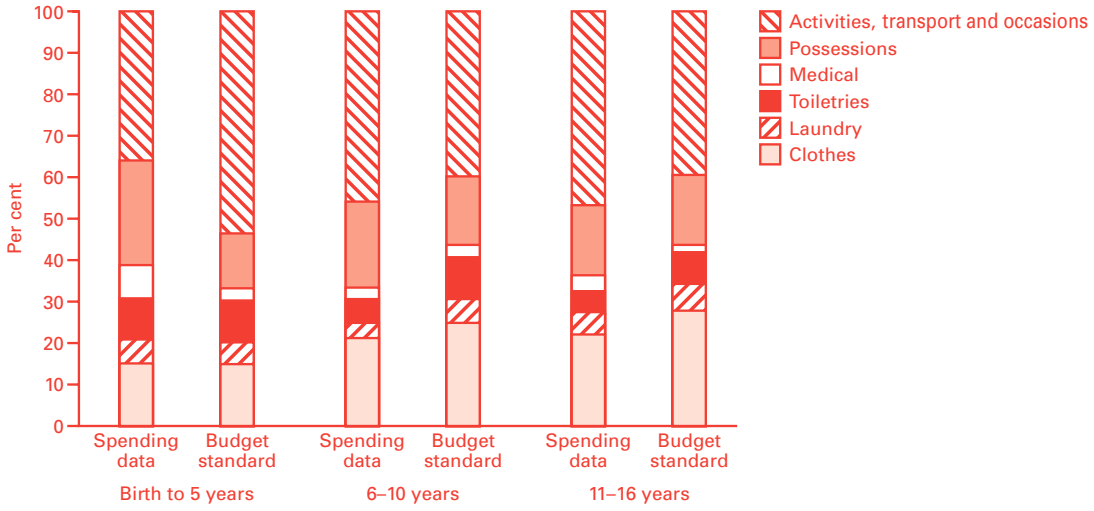
Figure 8 shows that the greatest shortfall between average spending and the budget standards was for the youngest children, that is, those aged less than 5 years. Average spending for this age group was £60.18 per week and the budget standard was £137.57: a spending deficit of 56 per cent. This deficit was reduced to 36 and 42 per cent for children aged 6 to 10 and 11 to 16 years respectively. If this shortfall between spending and the budget standard is taken as an indicator of unmet needs, then this is greatest for children less than 5 years of age.

Parents of the youngest children also had slightly lower incomes and received fewer benefits than those of older children, which meant that they had less money to meet the budget standard. Approximately 53 per cent of parents of the youngest children had incomes of less than £200 per week and the same proportion received a maximum of three benefits. This was compared with 37 per cent of 6 to 10 year olds and 48 per cent of 11 to 16 year olds whose parents had incomes of less than £200 per week. These parents also received more benefits; 66 per cent of parents of 6 to 10 year olds and 54 per cent of 11 to 16 year olds received four or more benefits.

Spending priorities

Despite the differences between the budget standard and actual spending levels, the priorities of parents were similar, regardless of the age of the child. Figure 9 shows that, while

Figure 9 Comparison of spending and budget standard priorities



there were small variations between the percentage of parental spending allocated to each area and the budget standard, in general spending priorities were the same. This confirms that the budget standards reflect parents' actual spending priorities. The highest percentage of both actual spending and the budget standards was allocated to activities, transport and occasions (43 per cent and 45 per cent respectively).

For the youngest children, the biggest differences between the percentage spent on each item and that allocated to the budget standard were for medical items, children's possessions and activities, transport and occasions. Parents of these youngest children spent 18 per cent less than the budget standard on activities, transport and occasions. This pattern changed slightly for 6 to 10 year olds. Parents of these children spent less on laundry and toiletries but more on possessions, and on activities, transport and occasions. For parents of the oldest children, the biggest difference between the percentage spent and the budget standard was for clothes. Parents spent 19 per cent on clothes whereas, in the budget standard, clothes accounted for 28 per cent of the costs.

Benefits for children with disabilities

The fact that children with disabilities cost more than other children is recognised by the benefits system. Parents of children with disabilities can apply for a confusing array of benefits. Some are additional sums within existing benefits (Disabled Child Premium in Income Support); others are benefits specifically for people with disabilities (such as Disability Living Allowance). Some benefits may be available to those whose income falls below a certain level (Disabled Child Premium in Income Support). The sums allowed can be flat rate (Disabled

Child Premium) or can vary according to the age of the child (Disability Living Allowance has different rates for the care and mobility components depending on severity). Eligibility for some benefits is dependent on the claimant meeting certain criteria or already being in receipt of other benefits. The problem for some parents is that they were not aware of their own and, indeed, their child's entitlement to benefit and found the system bewildering:

> *I'm sitting here listening 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.*
>
> *Well I used to work for the Employment Service, so I know about benefits but I still ended up in tears on the phone trying to persuade someone that I was entitled to the higher rates. So knowing doesn't always help.*
>
> (Task Group, Mobility Disability, 6–10 years)

Table 2 shows the range and rates of benefits to which a severely disabled child might be entitled in 2000/01.

Parents might also be entitled to Invalid Care Allowance in recognition that many carers are prevented from entering the labour market. Since Invalid Care Allowance is paid to the carer, or in this case to the parent, rather than to the child, its value has not been included in the calculations below. Also, as Child Benefit is claimed back pound for pound for those in receipt of Income Support, it has not been included as part of benefit income.

Since the original study was completed in 1997/98, the benefit rates for children have increased and the age relativities have altered so that, in 2000/01, the levels of benefit are the same for children aged up to 16 years, In 1997/98, the maximum benefit income for a child with a severe disability was on average £113.03.[1] This assumes that the child was entitled to all additional premiums available.

In 2000/01, this situation has improved and Table 2 shows the maximum benefit income for a child with a severe disability was £124.80 per week. This represents a significant improvement in that, during this period, benefits for children with severe disabilities increased by almost 10

Table 2 Maximum benefits for children with disabilities, 2000/01

Benefit	Amount (£s)
Child disability payments	
Disability Living Allowance higher rate – care component	53.55
Disability Living Allowance higher rate – mobility component	37.40
Income Support, disabled child premium	22.25
Total	**113.20**
General children payments	
Income Support	26.60
Minus Child Benefit	15.50
Total	**11.60**
Total child disability payments + general children payments	**124.80**

per cent. However, £124.80 assumes that the child is receiving their full entitlement at the highest rate. If children receive the middle rate of Disability Living Allowance (DLA) care component and the lower rate of DLA mobility component, their maximum benefit income would drop to £83.85 per week.

Benefit adequacy

This section compares the minimum budget standards with the maximum benefits to which children might be entitled to in 2000/01. The budget standards referred to below include *all* items identified by parents as essential. The items included are: clothes; bedding; laundry; toiletries; food; furniture; equipment; transport; children's possessions; trips, activities and occasions; and adaptations. The amount necessary to meet their children's needs was £152.77 per week.

The difference between the maximum benefit income and the budget standard is £27.97 per week, which means that there is a shortfall of 22 per cent. While this is significant for parents, the situation has improved since 1997/98 because of the increases in benefits for children and the premiums available to children with severe disabilities, and these have helped to reduce the deficit between the budget standard and benefit income.

However, very large assumptions were made in calculating the maximum benefit income. First, it was assumed that children with disabilities receive their maximum benefit entitlement. While nine out of ten children received Disability Living Allowance, this was not always at the maximum rate. Parents were keen to stress the difficulty they experienced in:

- Finding out which benefits they were entitled to:

There is a definite lack of communication concerning what you are entitled to.

And unless you read about it or someone else tells.

Unless somebody tells you because I didn't know how old they had to be for Motability.

I didn't know about Attendance Allowance, Disability Living Allowance.

(Task Group, Traumatic/Intermittent Conditions, 6–10 years)

- Filling in the forms:

They are extremely long-winded.

You're filling out the same questions over and over again.

When you're trying to get into the system first of all, you fill out a form for disability, fill out a form for other benefits that you can get as well, then you're filling out forms for your statementing and the statementing process is horrific, you have to write reports.

(Check Back Group, Mobility Disability birth to 5 years)

- Being assessed:

Everybody you see has to do an assessment, it's all in the files, can't any of them read?
(Orientation Group, Sensory Impairment, 6–10 years)

- Appealing when they were either not awarded the benefit at all or given the incorrect rate:

Just claiming for the benefits that you're entitled to, you have to appeal, the things they send you, they're enough to put anyone off … it takes you a week to fill it in and it's madness.

Further on they'll ask you the same questions in a different way, and I reckon it's to try and catch you out. So I always keep a copy of everything. When I first applied for disability money, it took me nearly two years to get it. I had to constantly fight, appeal it.

(Check Back Group, Traumatic/Intermittent Conditions, birth to 5 years)

Summary

When the data on parental spending is examined alongside the budget standards, the picture that emerges is one of parents who, whilst struggling to do their best, are unable to provide their children with the goods and services they believed to be essential for a reasonable quality of life. On average, parents would require £152.77 per week to enable them to meet the budget standard.

This chapter suggests that, while the financial situation has improved, in that benefits for disabled children have increased, there is still a shortfall between benefits and the budget standards. The difficulty for parents of disabled children is that, as well as worrying about the lack of money, they have other things to 'worry' about. The following chapter considers some of these concerns.

4 A new paradigm of family life

Previous chapters of this report have explored the additional financial costs of bringing up a child with a severe disability and described how spending on essential items accounted for the bulk of parental spending. However, there was a deficit between what parents spent and the things they believed their children needed, even though they spent 'as much as they could'. The focus groups revealed that this deficit was not restricted to spending. Rather, parents reported similar shortfalls between needs and resources in other areas of their lives. For example, many parents felt they needed help and support from professionals and their own families, especially on learning that their child had a particular impairment or condition. In reality, such help and support was not always forthcoming and, when it was available, was often not tailored to their particular needs.

The lack of practical and emotional support produced particular tensions and difficulties for all involved. This chapter describes how, while struggling to reconcile the additional financial costs with the needs of their child, parents also had to confront new and unexpected experiences. In essence, they had to construct a new paradigm of family life so as to accommodate and include all aspects of their 'new' lives. Within this new paradigm, relationships, obligations, aspirations, responsibilities, as well as one's sense of self, had to be redefined and renegotiated.

Reconstructing family life

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

> *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.*
>
> (Orientation Group, Mobility Disability, 11–16 years)

All the parents who participated in this study reacted and responded to the news that their child had a serious medical condition in different ways. Some parents had suspected that 'there was something wrong' and confirmation was in some senses, a relief:

> *I knew there was something wrong. She was so quiet, she didn't cry, but she didn't really respond to other things either. When I said anything to my health visitor or anyone else, they just said I should be grateful she didn't cry all the time. But I knew she wasn't right but nobody would believe me. When they told me I was shocked and angry, they should have listened to me before. This was one time when I wanted to be proved wrong but … now I know, I'm finding out what helps and I'm doing things. I don't just worry and I'm not frightened.*
> (Check Back Group, Sensory Impairment, 6–10 years)

For other parents, it was evident either at the birth or shortly afterwards that their children had a serious condition, although further tests

were often required which delayed diagnosis and prognosis. Parents in this situation were equally devastated that their baby was seriously ill but they spoke about the excellent care they received from the specialist baby units. This did not lessen their shock, but it reassured parents that everything possible had been done and reduced feelings of anger:

> *The pregnancy had been great. All the tests were OK. There was no hint that anything was wrong. The doctors said it was just one of those things. No explanation, so we were shocked. We cried. Seeing something that small fighting with its tiny body to breathe. You don't think beyond the moment. The doctors did everything they could. You can't describe the feelings, of worry, of wanting them to be OK. This little baby that you love more than anything or anyone and all the machines.*
> (Task Group, Mobility Disability, 6–10 years)

Receiving a diagnosis or confirmation that there was something 'wrong' with their child, was very important to parents as it often signified the point at which they were able to begin to contemplate their future and to 'think beyond the moment'. The evidence from this study is that parents need this information to enable them to begin to reconstruct family life and to address fears, worries and feelings that previously had been hidden away. This rebuilding process did not happen instantly; often there was some considerable time between hearing the news, understanding and accepting it. But, on reflection, parents reported that 'being told' represented a turning point in their lives. For many, it was only from this time that they started to regain some control over their own, as well as their child's, lives. This was particularly so for parents who had suspected their child suffered from a particular condition but who experienced a long delay in getting a diagnosis.

All parents emphasised that the process of rebuilding family life was slow and difficult. They had anticipated and hoped to be a typical family: mum, dad and baby. Their reality was somewhat different. By having a child with a severe impairment they were atypical: they were not a 'normal family' and felt excluded:

> *When you have a child like ours, everyone sitting at this table will tell you, you are treated differently. I thought it was me and I imagined it but listening to everyone else, I know it wasn't.*
> (Check Back Group, Traumatic/Intermittent Conditions, 6–10 years)

Parents were suddenly exposed to the attitudes that many disabled people and terminally ill patients encounter everyday: they were marginalised and ignored. The discussions with parents suggested that 'other people' did not want to associate with anyone who was 'less than perfect' or different from everyone else. By deviating from the 'norm' parents and children appeared to threaten the illusion of normal family life:

> *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?*
> (Task Group, Mobility Disability, birth to 5 years)

Many parents said that it took time for them to adjust to their child's condition. During the

initial period, the practicalities of looking after their child and establishing workable routines meant that there was little time for them to confront their own feelings. One parent described this activity as a cocoon in which she wrapped herself so tightly that little if anything could get beyond her hard work or exhaustion. This cocoon enabled her to keep the world at a distance so that she did not have to deal immediately with its harsh stares and unthinking questions and reactions. Even those parents who struggled to obtain a diagnosis had similar experiences in that the 'battle' with professionals, combined with the practicalities of their child's condition, left little time for anything else. With the benefit of hindsight, some parents said that life at this time was 'like living in a blur'.

During this initial period parents said that, whilst some of their families and friends were quite supportive, others were not. Some parents were disowned and others blamed. Parents described how the birth of a child, which should be a happy family occasion, was sometimes transformed into a hostile and loveless event:

> *I come from a big family and I got two cards from them saying congratulations. Most of them wouldn't have anything to do with us. I couldn't believe it. I was heartbroken.*
> (Task Group, Sensory Impairment, birth to 5 years)

Frequently, normal social relationships with family and friends were strained. Parents accepted that the social rules that ordinarily influence our attitudes and suggest patterns of behaviour were inadequate. They were aware that many people simply did not know what to say or do, but many parents stressed that they felt the same. Receiving a diagnosis somehow changed this situation in that it eventually gave parents the confidence to challenge others' behaviour:

> *I doubted everything. The way we were treated, I thought they must be right. It's my fault. I'm a bad mother. When I found out what it was, I thought they're wrong. It's not me. No one's to blame and they have to get used to it.*
> (Check Back Group, Traumatic/Intermittent Conditions, 6–10 years)

This is part of the explanation why getting a diagnosis or formal acknowledgement that something was 'wrong' was so important to parents. While parents were not seeking to have their child labelled, they spoke of the emotional relief on knowing exactly what the child's situation was and of what to expect. It also reassured parents that they were not to blame and that they were good parents.

As parents grew in confidence, they were able to establish new social rules. For example, they challenged behaviour that excluded them and their child; they demanded that their child was treated fairly and had the same rights as other children; and they refused to be pitied and then dismissed from social gatherings. One parent was particularly infuriated and frustrated by how people responded to her autistic son. When he had a temper tantrum and people stopped to look and comment on how he only 'needed a good smack', she would hand out cards suggesting they contact the autistic society for more information. This direct action was at some personal cost and came about after many years of being exposed to such ridicule. Setting the rules for what was acceptable meant she was no longer made to feel inadequate or

apologetic. It was neither she nor her son's behaviour that needed to change; rather it was other people who were in the wrong. This action was unusual, but other parents who listened to this story were impressed by it, and said that they wished they had thought of it and had the courage to do the same.

Public entity and invisible family

The descriptions above of parents' experiences of family life highlight certain contradictions and paradoxes. The parents regarded themselves as a family with a child and expected to be treated accordingly; yet experience taught them that they were treated differently. It appears that the effect of the news that their child had a serious condition, regardless of when it came to light, was to transform them into a family apart. They were no longer 'ordinary'. Few people saw beyond their child's condition, and recognised and accepted them as a family with similar hopes, fears and ambitions as any other.

Parents reported that they stopped being treated as a family and, whereas other 'normal' families participated in everyday events, they were excluded. However, it was not the physical exclusion that parents found most difficult to deal with, rather it was the change in attitudes that devastated them. Their experience was that as a family they no longer evoked positive feelings from people but instead were 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. The discussions with parents suggested that, because they did not function as a 'typical' family, they ceased to be one and became invisible:

> *It was like we didn't exist. Nobody wanted to know us.*
> (Orientation Group, Traumatic/Intermittent Conditions, 11–16 years)

However, the contradiction was that despite their invisibility they were a public entity. The majority of parents in this study reported that when they went out with their child everybody stared at them, but they added that few people looked directly at them and even fewer saw a mum and a child. Parents were also aware that they and their child were often the topic of conversations with friends, neighbours and passers-by. Yet, despite this, parents said few people would talk to them and many had the experience similar to the mother quoted above, of conversations stopping when they entered a room.

Parents reported a similar duality in the way in which health and social professionals treated them. In their experience, they as families were subsumed by their child's condition and were for example, the 'dyspraxia family'. By equating the family with the child's condition, they were disassociated from most of the attributes of family life, leaving the condition as the only thing to treat or assess. Their needs as a family often were not addressed or acknowledged.

Parents in this study were acutely aware of their loss of privacy. In many instances, they and their child were often the topic under discussion:

> *They hold case conferences and have meetings to talk about us or rather what state his lungs are in now.*
> (Task Group, Mobility Disability, 6–10 years)

They reported that they were always being assessed:

> *… everyone who comes through my door does their own assessment. Some prod and poke and don't talk to us, some ask the same questions but hardly anyone will talk to Emily.*
> (Orientation Group, Mobility Disability, birth to 5 years)

They also reported that professionals often asked the same sensitive questions in what was sometimes an insensitive manner:

> *They ask me in front of Jonathan whether he still wets himself, is he dry at night? This is a young man who has nothing wrong with his brain and even the social worker doesn't talk to him.*
> (Task Group, Mobility Disability, 11–16 years)

The majority of parents argued that the intimate details of 'normal' families were not discussed in a similar manner and they failed to see why they should be treated differently. All they wanted was the same respect afforded to other families.

A few parents were aware that they posed a particular dilemma to some health and social professionals in that the condition of their child could not be cured. Doctors and other professionals could only treat the symptoms and so in this way their children represented a 'failure'. One parent spoke about how her son was described as a 'an especially challenging case' and another as 'a very difficult and sad case'. These conversations took place in front of parents and children although they were not part of them. Parents did not want professionals to become emotionally involved with them and all agreed that they needed 'professional detachment'. However, parents were adamant that they deserved and were entitled to respect. They also insisted that their public profile within the world of professionals should not make them invisible as a family.

Parent or carer?

> *I'm not a saint. I'm a mum who has a beautiful little daughter. That's all. I love her and look after her. I do my best for her. She brings us love; she makes us happy. Some things are harder than others, but I'm her mum.*
> (Task Group, Traumatic/Intermittent Conditions, 6–10 years)

The above quote demonstrates that parents did not differentiate between their role as parent and the tasks they performed to care for their child. In their experience, parents did whatever was necessary to look after their child and in this sense they were no different to any other parents. The only difference was that many of the children in this study had specific and specialised needs. In order to meet these needs, parents often performed tasks ordinarily undertaken by professional or formal carers, that is, by individuals specially trained and paid to care for the sick or disabled.

However, to the outside world, there was some ambiguity; were they parents or carers? A large proportion of non-professionals viewed many of the parents in this study as carers first and parents second. By giving primacy to their caring role, it enabled them to focus on the physical and practical tasks performed. Thus, it became possible to ignore the loving relationship between parent and child, and the effect of this division of roles between parent and carer was to depersonalise the relationship.

In this way, it was legitimate to dispense with normal conventions when relating to parents and to justify treating them differently to others.

In contrast, many professionals did not acknowledge the expertise that parents had acquired in looking after their child and the carer element of their role was ignored. Often, the opinions of parents were not sought and, when offered, were dismissed. For example, parents reported that, when changes to medication, treatment or service delivery were discussed, they were not consulted until after the decision had been made. There were numerous examples of how changes to services resulted in chaos or added expense for parents. Changing the type of free nappies provided left some parents with nappies they could not use because they did not fit or were simply inadequate and leaked. Parents resented this cavalier attitude and were angry and frustrated at how professionals ignored their knowledge and the fact that they provided the bulk of the day-to-day care for their child. It seemed to parents that professionals were happy to let them care for their child when it suited them, but would not afford them the same rights as a carer. By being excluded in this way, parents were made passive recipients of services, despite the evidence to the contrary that they also were active providers of care.

To add to the frustrations and difficulties of parents, there were a few instances when professionals even denied them their parenting role. That is, they would fail to realise that they were not talking about a disease or condition but a child and the person to whom they were talking was a parent. Parents accused some professionals of lacking tact and understanding both at the point of diagnosis and in subsequent episodes of treatment, and this is demonstrated by this parent's experience:

> *… you sit around and you're sort of slumping in your chair, and he doesn't do this, and you think, oh, I think I'll just slit my throat now and have done with it and they just don't seem to realise that this is your child that they are talking about, that this child to you is just as important as their children are to them and they wouldn't talk about their children in those terms.*
> (Check Back Group, Traumatic/Intermittent Conditions, 6–10 years)

In the private worlds of the families that took part in this study, there was no division between parent and carer. However, in the public world of the professionals as well as those outside their immediate family, they were often allocated only one role, either parent or carer. A few parents were denied any role. The issue for parents was how to integrate their private reality with public perceptions in such a way as to afford them the same status as any other family. Many parents developed strategies to help them achieve this integration, which involved renegotiating and reconstructing relationships with all involved, including their sense of self. This is explored in the following section.

Reconstructing relationships

Reconstructing the self

The majority of parents had expected that having a child would bring about very fundamental and far-reaching changes in terms both of their lifestyle and for them as individuals. Over half of the parents in this study already had a child and were aware of the

ramifications of having children. Yet, despite their previous experience and knowledge, all parents were equally shocked and upset at finding out that their child had a serious medical condition. Already having a child did not in any way dissipate these emotions.

Resolving the emotional issues and addressing the practical concerns was difficult for parents and changed them as individuals. All parents (both mothers and fathers) spoke about how they had changed as people. The statement that echoed through all 36 of the group discussions was: 'I'm not the same person any more'. Many explained that before their child was born they had been relatively quiet and reserved; they did not challenge authority and accepted what they were told; they were relaxed, had lots of friends and had 'a sense of fun'. Since finding out that their child was severely disabled, their personalities had changed. Some parents described themselves as aggressive, pushy, stressed and obsessive. These changes did not happen instantly and most parents did not welcome them, with some stating they did not like who they had become. But experience had shown parents that these changes were necessary if they were going to do their best for their child.

Parents explained why they had to become someone else:

> *I would say I am much more aggressive now. I don't take no for an answer. I know that if I don't push for something then my daughter won't get what she needs. I don't like doing it and it makes me angry.*
> (Check Back Group, Traumatic/Intermittent Condition, 11–16 years)

One mother explained that she used to be 'well liked' and never made a fuss but now:

> *I can see how people look when they see me coming. I know they're thinking 'not her again, what does she want this time?' I can honestly say that, before Emily, I never made a scene, I never dreamed of shouting at anyone but I've done it. But what else am I to do? I've tried everything else but they won't listen.*
> (Orientation Group, Mobility Disability, birth to 5 years)

Parents said repeatedly that it was those who shouted loudest who got the help they needed and were entitled to. Some of those who had previously lacked confidence became assertive. They acquired new skills and learnt substantial amounts about their child's condition. Some parents became 'experts'; they set up or joined self-help groups and for the first time in their lives were an active part of an organisation. It was not 'all bad'; some parents had benefited from the changes.

However, parents resented their lack of control and argued they had no choice but to change in order to obtain the help their child required. While many were now very driven and determined individuals, all said they were tired and exhausted. Although all the parents loved their children, some were overwhelmed by the responsibility. In their experience, it was up to them, and them alone, to ensure everything possible was done to help. This left some feeling so daunted that as one mum said:

> *I worry all the time. Should I be doing something else? I'm scared all the time. I can't relax.*
> (Task Group, Traumatic/Intermittent Conditions, 6–10 years)

There were other changes that affected parents' sense of identity. Many mothers were unable to return to work. Some were unable to find suitable and/or affordable childcare, some children required 24-hour care but, for most, the practical implications of attending appointments, combined with the unpredictable nature of their child's conditions, made it very difficult to find a job with enough flexibility. For some, this was the first time in their lives that they had not worked or had not intended to return to work. Suddenly and unexpectedly, their social world became the hospital, the waiting room and the home. Their sense of isolation was intense.

Although few fathers gave up jobs to look after their child, most changed their working patterns if not their jobs. Some found employment that offered greater flexibility or that required them to work fewer hours, so as to enable them to help with day-to-day tasks. However, the implication of this was that they missed out on promotions:

> *I know because I can't work the overtime, I've not been promoted. They actually said it to me. They're very good but because I can't be around all the time when they want me to be, that was it. I see their point.*
> (Check Back Group, Mobility Disability, 11–16 years)

The corollary of a world without paid work or with reduced career prospects was altered life plans and aspirations. Parents spoke about how different their futures looked now as opposed to before the news of their child's condition. For example, some parents had planned to move house, go on holidays, retire early or change career. These things were no longer a possibility, given their reduced financial circumstances combined with the additional financial costs described earlier. Most parents were very fatalistic about their changed aspirations, it was 'just the way it was'. A few parents were angry because it was not their child's condition *per se* that brought about these changes but rather the lack of appropriate practical help.

> Parent 1: *It's the way it is and we get on with it, there is no point doing anything else.*
>
> Parent 2: *Well it makes me mad. They have all these services and things to help but we can get none of them. If you could just rely on them [services] then you'd know you'd be able to work, but at the minute it's a miracle if they come on time to take him to school. How could I get to work if I don't know when I've to take him the 12 miles to school? Tell me that.*
>
> (Task Group, Sensory Impairment, 11–16 years)

Parents of older children were worried about what would happen when they retired. Many had given up work to look after their child and had no pension other than that provided by the state. A few parents were especially anxious because their children were soon to move into supported accommodation, that is, leave home. This would mean that they as parents would no longer be entitled to claim benefits in their own right such as Attendance Allowance. The only benefits they would be entitled to claim were state pension and Income Support. Some parents were very concerned how they would manage to live on this reduced amount as none of them had any savings. These fears produced tensions within the family. While parents were pleased that their child was taking a step towards independent living, their pleasure was

tainted by fears for their own financial security and future.

Finally, parents who had been independent, and who had taken pride in managing on their own and not asking for help, talked about how this situation changed when the severity of their children's conditions became apparent. In order to obtain the help their children needed they had to ask for help. Some parents turned to family and friends, and others to formal agencies such as statutory organisations and charities. The majority of parents did not like having to ask for help, as they did not want to feel obligated. Also, in asking for help, they felt as if they had to justify and explain why they needed a particular item. Often they had to provide charities and other agencies with information about their financial and living arrangements in order to qualify. They also had to complete application forms, which took time and effort. These forms usually required detailed information about their child's condition and concentrated on the things their children could not do. For these reasons, applying for help was emotionally draining:

> *I'm always writing 'Ben can't' in forms. He can do such a lot but people only see what he can't do, that's how they think of him.*
> (Orientation Group, Traumatic/Intermittent Conditions, 6–11 years)

Relationships with families and friends

Relationships with family and friends also changed. As mentioned above, some were supportive and helpful while others were unable to accept the emotional and practical implications of the children's conditions. As a result, they had very little contact with either the parents or the child. Some partners and grandparents blamed one parent and the relationship was sullied by recriminations:

> *They* [parents-in-law] *blamed me. They kept telling me how nothing like this had ever happened in their family so it must be my family.* (Task Group, Sensory Impairment, birth to 5 years)

This particular parent explained that their child's condition was caused by a lack of oxygen at birth and was not a genetic disease. The rational explanation did not overcome the emotional and reactive responses because for some families a disabled child was a symbol of shame and/or imperfection. The following extract from one of the group discussions illustrates this point:

> Diane: *Well I don't have parental influence thank goodness, because they couldn't cope with it … My mum found it hard to cope ... and it was like a ghastly secret, couldn't tell anyone who this child was or anything, couldn't say it was her granddaughter, and in the end we walked away from it because the staff had been so supportive, they were like my parents. If I was having a bad day I could go to the hospital, and I did, I lived there, but I never stayed overnight, never, but that's another thing, parents having to cope with it and having to cope with your parents coping with it as well.*
>
> Linda: *No my in-laws didn't accept it … it wasn't mentioned to people particularly, I mean the next-door neighbour knew about it, we still see the next-door neighbour, but a lot of the relatives had not got a clue.*

Wendy: *My mother-in-law just couldn't cope with it. They just couldn't have this associated with them.*

(Orientation Group, Mobility Disability, birth to 5 years)

Parents found these reactions impossible to deal with and, in some families, relationships with grandparents, and even some partners, ended. Parents concluded that there was no relationship to reconstruct because there was no shared understanding. They believed that this action was necessary so as to prevent their family being undermined by people who were ashamed of their child and, by association, of them. The particular relationships disintegrated because they lacked reciprocity and respect.

Yet parents knew that it did not have to be like this. There were many examples of how families and friends responded well:

My parents have been great, they treat Rose the same as all the others. She goes and stays with them and next year they're taking her on holiday.

Mine moved to be closer so that they could help.

(Check Back Group, Traumatic/Intermittent Conditions, 6–10 years)

Parents were aware that families and friends, like themselves, needed time to adjust to the children's conditions. They also recognised that the nature of these relationships changed and some concluded that it was a 'completely different way of life'. For some parents, the renegotiating of relationships and roles with partners, families and friends encompassed only practical tasks; the emotional aspects were left unmentioned. Other families successfully addressed both aspects and their relationships developed and continued to be rewarding.

Never having time together put added strain on relationships, as did the day-to-day practicalities of providing intensive, round-the-clock care. Many parents had not been out with their partners for years as they were unable to get anyone to baby-sit and/or they could not afford to go out. As a mechanism for coping with the demands of life, some became two separate families with mothers providing most of the care for the disabled child and fathers looking after the other children. Parents were unhappy at this division but were unable to do anything to resolve the situation as they had neither the time nor the energy.

In reconstructing their family life, parents were aware of the needs of all their children. They did their best to address these and often found themselves trying to compensate for the difficulties that all encountered. This compensation operated on two levels. First, parents tried to limit the impact of the disabilities on the child so that he or she achieved a reasonable quality of life and, at the same time, they attempted to compensate for the way society treated them. For example, in order to try and prevent people from staring more and reacting badly, parents paid more attention to, and money for, clothes for children with severe disabilities than for other children.

Francis: *Well I think if you don't dress them well, if they don't look really nice, then people are going to stare aren't they, if their clothes look shabby or anything. I mean they stare anyway when they see a child in a wheelchair, or a child with some form of disability. I mean they do stare, but if they look untidy they will stare even more, so I think it's very important that they look really nice all the time.*

Interviewer: *Is it essential?*

Francis: *I would say so.*

Heather: *For their self-esteem and for yours, yes.*

Diane: *Yes, I think it is essential.*

(Check Back Group, Mobility Disability, 6–10 years)

There were other examples of how parents tried to limit the impact of the disability on their child. For example, as disabled children were often unable to go out and play with friends, parents took them out more often and bought them items to entertain and amuse them. As discussed in Chapter 3, this increased the financial costs to parents. Not surprisingly, the majority of parents in this study were worried about not having enough money and how they would manage financially. Most parents tried to protect their children from these concerns and data from the 42 questionnaires administered to children suggest that parents were relatively successful in this. Most children thought that their families had enough money to live on and that they were no worse or better off than other families. This is despite the fact that the majority of the families had incomes below the national average as all but a few qualified for help from the Family Fund Trust.

Almost half of the children (20) said their parents never, or rarely, discussed money with them and one-third received the items they asked for. However, parents were sure that older children knew about their financial difficulties and limited their requests as a result. While there is insufficient data to confirm or refute this belief, the indications are that children did limit their requests to things that they thought parents could afford. Added to this, nearly all children said they believed their parents when they said they could not have an item because their parents could not afford it.

Second, parents tried to compensate their other children for the lack of time they had to spend with them and for the alterations and limitations to their lifestyles, which resulted from having a sibling with a severe impairment:

Sam: *Well, you do* [compensate], *but I think about you saying you compensate the child who has the disability because they can't do things, we, I think, compensate to the one who is not disabled because there is a lot of things we can't do as a family.*
(Task Group, Mobility Disability, 6–10 years)

In compensating for their children's conditions, parents were doing their utmost to reconstruct a normal family life. Life had shown parents that there was considerable discrimination, as well as numerous physical barriers, which prevented their children from achieving their potential. They simply wanted their children, disabled and non-disabled, to have the same opportunities and experiences as others and they were prepared to do whatever was required to achieve this.

5 Conclusions

This report has demonstrated that the financial costs to parents of bringing up a disabled child are significant. Excluding food, parents spent on average £65.51 per week, which is almost twice as much as parents spent on non-disabled children. An examination of parents' spending patterns show that the increased costs were for day-to-day items rather than 'luxuries' such as holidays, and birthday and Christmas presents.

Comparing parents' actual spending with the budget standards revealed a shortfall between what parents spent and the amount they agreed was necessary to meet the needs of their children. While parents did their best, spending an average of £65.51 per week provided disabled children with less than half the goods and services that parents had agreed were essential to achieve a reasonable quality of life. The budget standards suggested that parents actually needed to spend £152.77 per week.

While the financial situation has improved, in that benefits for disabled children have increased, there remains a shortfall between maximum benefit entitlements and the budget standards. Benefits would need to be increased by £27.97 per week so as to meet the budget standards.

The difficulty for parents of disabled children is that, as well as worrying about money, they have other things to 'worry' about as well. The lack of practical and emotional support was compounded by a lack of money, and produced particular tensions and 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 data from the group discussions suggests that it was only by constructing a new paradigm of family life that parents could respond positively to these new experiences, and redefine and renegotiate relationships, obligations, aspirations, responsibilities as well as one's sense of self.

The conclusion of this report remains the same as in *Paying to Care* (Dobson and Middleton, 1998). Bringing up a disabled child costs more money and takes more time. Therefore, parents want and need services that are responsive, sensitive and reliable, and that reflect both their needs and those of their child (Baldwin and Carlisle, 1994). To achieve this, services will have to change. Some of these changes will require more money but they also necessitate a more fundamental overhaul so as to ensure that disabled children and their parents are accorded the same rights and respect as those who are not disabled.

The parents of a severely disabled child are also carers. They have expertise and experience and, therefore, must be involved in planning the care of their child. Harnessing parents' knowledge and working with them can only enhance the effective use of resources that will benefit both parents and professionals; to do otherwise would be to neglect the rights of parents and their children. As one mother said:

> *I don't want any other mother to have to go through what I did. To sit in office after office and listen to doctors, social workers, all of them, talk about me and my child as if we weren't real. We have feelings. They should remember that we are mums, that's all they have to do.*
> (Orientation Group, Mobility disability, 6–10 years)

Notes

Chapter 1

1 The definition used by parents was derived from the United Nations Convention on the Rights of a Child. Article 27 states that parties recognise the rights of every person to a standard of living adequate for their physical, mental, spiritual, moral and social well-being.

2 For a detailed discussion of the sample see *Paying to Care* (Dobson and Middleton, 1998, pp. 50–7).

3 The reference after the quotation refers to the stage of the research at which the quotations were collected. The age and disability group refer to the case study used by that group.

Chapter 2

1 The diaries recorded regular spending and, in order to produce a more complete estimate, this data was supplemented by information from the self-completion questionnaires on less regular spending such as Christmas, birthdays, holidays, etc.

Chapter 3

1 This is taken from the earlier report, *Paying to Care* (Dobson and Middleton, 1998), and refers to the maximum benefit income that children with the severest disabilities were entitled to.

Bibliography

Baldwin, S. and Carlisle, J. (1994) *Social Support for Disabled Children and their Families: A Review of the Literature*. Edinburgh: HMSO

Dobson, B. and Middleton, S. (1998) *Paying to Care: the Cost of Childhood Disability*. York: YPS for the Joseph Rowntree Foundation

Dowler, E.A. and Dobson, B. (1997) 'Nutrition and poverty in Europe: an overview', *Proceedings of the Nutrition Society (1997)*, No. 56, pp. 51–62

Kagan, C., Lewis, S. and Heaton, P. (1998) *Caring to Work: Accounts of Working Parents of Disabled Children*. York: Family Policy Studies Centre in association with the Joseph Rowntree Foundation

Living in Britain: Results from the General Household Survey (1994) London: HMSO

Middleton, S., Ashworth, K. and Braithwaite, I. (1997) *Small Fortunes. Spending on Children, Childhood Poverty and Parental Sacrifice*. York: YPS for the Joseph Rowntree Foundation

Middleton, S., Ashworth, K. and Walker, R. (1994) *Family Fortunes*. London: CPAG Ltd

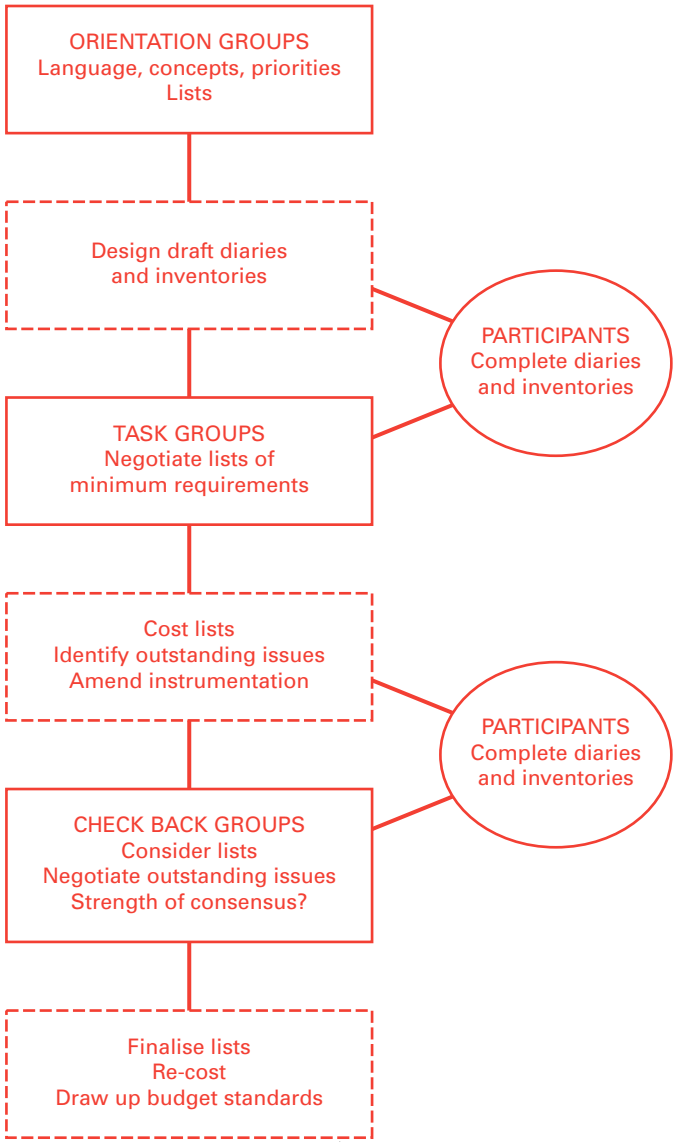
Smyth, M. and Robus, N. (1989) *The Financial Circumstances of Families with Disabled Children Living in Private Households*. OPCS Surveys of Disability in Great Britain. Report 5. London: HMSO

Appendix 1: The research design

The research design was modified from , a study which drew up budget standards for children without a severe disability (Middleton *et al.*, 1994). There were three main stages to this study, which are summarised in Figure A1.1. These were the orientation groups, task groups and check back groups.

The first task for those participating in this study was to agree a definition of essential minimum. The definition which groups were given as a starting point was from the United Nations Convention on the Rights of a Child (to which the United Kingdom is a signatory). Article 27 of the Convention states that 'parties

Figure A1.1 The research process



recognise the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social well-being'. This definition was discussed by parents and was accepted as the basis for drawing up the budget lists. Parents voiced their support for this definition as it recognised that the concept of essential, especially for a child with a severe disability, must go beyond mere subsistence.

Costs were deliberately omitted from the discussions until the final stages, the check back groups, so as to avoid needs being defined by available income. In costing the budget lists, the researchers incorporated criteria specified by parents. For example, parents decided on which retail outlets should be used to price items; they estimated how often to replace items and whether or not they had to be new or second-hand. In general, parents opted for 'middle of the range' outlets which represented a compromise between quality and price.

The budget standard groups

The group discussions took place in three phases between January and October 1997. The first phase, or *orientation* stage, consisted of nine focus groups and aimed to ensure that the ideas and concepts employed in later stages of the research were informed and understood by participants. Participants in these groups also developed pen pictures of three case study children for whom the budget standards were derived (see Appendix 2). The parents in these groups also discussed the instrumentation to be used in the task and check back groups.

During the *task groups* (18 groups), each area of the budget was considered in turn and parents were asked to negotiate and agree lists of minimum essential items. The groups were presented with lists of items and activities for each budget component taken from the earlier budget standard for non-disabled children developed by Middleton *et al*. (1994). Parents were asked to consider whether the case study child would need more, less, the same amount or completely different items and activities. The facilitator intervened in the discussions and negotiations as little as possible: recording decisions reached on a flip chart; moving the negotiations along; and reminding the group when necessary of the definition of essential minimum to which they were working. Once each list was complete, groups were asked to consider whether it was too restrictive or over-generous. Issues such as the proportion of new to second-hand, durability and where items should be costed were all discussed. After this stage, the researchers costed the budget lists at outlets agreed by the groups. Outstanding matters that needed to be resolved in the final phase of the groups were noted.

The final phase or *check back* (nine groups) was in some ways the most important since, as well as resolving outstanding issues, the financial implications of the budgets were considered and the strength of the consensus tested. Parents were given uncosted lists of items compiled by the task groups and asked whether they agreed with them (or not) and if they should be amended in any way. Once changes had been negotiated and agreed, they were incorporated into the budgets by a second researcher present in the groups. Parents were then told how much it would cost to provide the agreed list of items and asked if, in the light of

this, they would change the lists. Any changes were noted and the budgets revised accordingly. Following the check back groups, the budgets were re-costed and finalised, and the essential minimum budget standards were drawn up.

Appendix 2: Case studies

Movement

0–5 years

Karen is 4 years old and has been diagnosed with cerebral palsy. She cannot walk unaided. She has recently started wearing callipers although she still needs a buggy when going outside. Karen also has problems manipulating things with her hands and is particularly small for her age. She is incontinent and does not sleep through at night because of severe spasms. She also has to be turned on a regular basis.

Recently, Karen has started attending a specialist day nursery and receives physiotherapy once a week at the hospital. She also attends the hospital on average about once a month to see other specialists.

6–10 years

Karen is 9 years old and has cerebral palsy. She attends a special school. She uses a wheelchair and her legs are sometimes in callipers. As Karen has problems manipulating things with her hands, she struggles to feed herself and usually needs help. She has access to a computer at school to help with school-work but needs one-to-one tuition.

Karen suffers severe spasms and has to be turned regularly at night. As she is getting older, this is becoming more of a problem as is getting her in and out of the bath. Karen is also incontinent.

Physiotherapy treatment helps with her condition. She attends the hospital regularly but has also needed emergency treatment when her spasms have been severe. Karen has good and bad days. On good days she attends school but on bad days, especially during the cold winter, she is at home most of the time.

11–16 years

Karen has cerebral palsy and is 15 years old. She attends a specialist school. She uses a wheelchair and her legs are sometimes in callipers. As Karen has problems manipulating things with her hands, she struggles to feed herself and usually needs help. She has access to a computer at school to help with school-work but needs one-to-one tuition.

Karen has severe spasms; this has resulted in a number of emergency visits to the hospital. Physiotherapy helps with her condition. Her parents have recently heard about a new treatment to help reduce and control the spasms but this is not available on the NHS.

Karen needs to be turned regularly during the night and has to be lifted in and out of the bath. She is incontinent.

As Karen gets older, she wants more and more to be like the other children, to wear fashionable clothes, etc. However, as she is very small for her age, finding suitable clothes can be problematic.

Sensory disablement

0–5 years

Ben is 2 years old and has been blind from birth. It is thought that he may have learning difficulties caused by brain damage as he has not yet started to talk or crawl. Ben is an anxious child who wakes up several times a night and who needs constant supervision. He is currently at home full time with his mother. Ben attends the hospital for regular assessments.

6–10 years

Ben is 8 years old and attends a special school for children who are blind. He has also been diagnosed as suffering brain damage and his speech has been slow to develop. He is able to walk unaided for short distances. Ben is incontinent and wakes several times during the night. He is a very anxious child and needs help with most daily tasks. Ben is very prone to other illness and is frequently not able to attend school. He is often at home with his mother and needs constant supervision.

11–16 years

Ben is 14 years old and is blind. He was diagnosed as suffering brain damage and his speech is also limited. Ben can walk for short distances unaided and does not need a wheelchair. As he gets older, he gets very frustrated at not being able to do things for himself and regularly has tantrums. He needs constant supervision.

Ben is also very prone to other illnesses and often has to spend time away from school and at home with his mother. The situation at home is sometimes very stressful.

Traumatic and intermittent conditions

0–5 years

Patricia is 5 years old and has started mainstream school. She has severe epilepsy and is diabetic. Her diabetes is controlled by injection, which her mother gives. Patricia does not sleep through at night because of her condition and is frequently off school as a result. She wets the bed at night but is otherwise continent.

6–10 years

Patricia is 11 years old and attends mainstream school. She has severe epilepsy and is diabetic. Her diabetes is controlled by injection, which her mother gives her. Patricia does not sleep through because of her condition and is frequently off school as a result. She occasionally wets the bed.

11–16 years

Patricia is 16 years old and attends a mainstream secondary school. She has severe epilepsy and is diabetic. Her diabetes is controlled by injection, which she administers herself. Patricia has never slept through at night and has missed considerable time from school. She is often at home because of her illness.