Debt and Disability

The impact of debt on families with disabled children

contact a family
for families with disabled children

Family Fund

Contents

Debt and Disability: The impact of debt on families with disabled children.

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Section 1 - Introduction

It is estimated that there are 700,000 disabled children living in the UK. The figure is based on returns from the Family Resources Survey[1] which collects information on adults and children with limiting long-standing illness. The 700,000 figure includes all children under 16 years old and 'dependent children', that is young people aged 16-18 years who are unmarried, in full time non-advanced education and living at home.

Evidence suggests that families with disabled children are more likely than other families to experience social exclusion and to live in poverty. The government recently published the Children's National Service Framework, setting out a challenging agenda for the well-being and health of the nation's children and young people. The relevant service standard states that disabled children and children with complex health needs should,

> "...receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives".

Contact a Family and the Family Fund are aware of the extra costs for families with disabled children and are concerned that they may be forced into debt to bridge the gap between their income and their family living expenses. Both organisations wanted to know how families with severely disabled children manage and whether families with disabled children were more likely to struggle with credit commitments and debt than other households. This report summarises the findings from our survey about debt amongst families with disabled children.

1.1 – Putting Child Poverty in Context

The rapid rise in relative child poverty through the 1980s and '90s has become a central policy concern for government. Tony Blair's historic announcement that the government was going to eliminate child poverty in a generation represents a seismic policy shift, which has required, and will continue to require, a substantial shift in resources.

[1] DWP (2003) Family Resources Survey 2002/03. ONS.

The 2004 Child Poverty Review[2] states,

> `In 1997, one in every three babies born in Britain were born into low-income households – born not into opportunity but into poverty. And we know that an infant who then grows up in a poor family is less likely to stay on at school, or even to attend school regularly, less likely to get qualifications and go to college, more likely to be trapped in the worst job or no job at all, more likely to be trapped in a cycle of deprivation that is lifelong, unable to reach their full potential – a young child's chances crippled even before their life's journey has barely begun. So action to eradicate child poverty is the obligation this generation owes the next'.

In the mid to late 1990s, the UK suffered higher child poverty than nearly all other industrialised nations. Over a period of 20 years, the proportion of children in relative low income households had more than doubled.

The government therefore set an ambitious long-term goal to halve child poverty by 2010 and eradicate it by 2020. As a first step, the government has sought to reduce the number of children in low-income households by at least a quarter by 2004-05.

Many government initiatives have started to make an impact on child poverty. Recent announcements in the 2004 Spending Review have provided for additional investment in childcare places and services for disadvantaged children of £669 million by 2007-08 compared to 2004-05 and 1,700 Children's Centres, by 2007-08. The Children's National Service Framework sets the standard by which children's services can be judged. These initiatives will also have a positive impact on the life experience of Britain's children.

However, the picture for families with disabled children may be very different. The Cabinet Office review in 2004 acknowledges that 55% of families with disabled children live in, or at, the margins of poverty. Recent research by the Family Fund[3] found that of such families,

- 73.3% have an income below the UK mean income
- 63.4% have an income below the UK median income
- 21.8% have an income below 50% of the UK mean income
- 21.8% have an income below 60% of the UK median income

[2] HM Treasury (2004) Child Poverty Review.
[3] Woolley, M (2004) How do They Manage: Income and expenditure of families with severely disabled children. York: Family Fund

What does it mean to live in poverty? End Child Poverty say that,

- 1 in 3 poor children do not have three meals a day
- 1 in 3 poor children miss out on toys, school trips and out of school activities
- 1 in 3 poor children lack adequate clothing, particularly shoes and winter coats

For many families with disabled children, the poverty is absolute and hard to imagine for those whose lives are comfortable.

`My son spent many months on and off in hospital having various operations. My husband was self employed at the time and had to take many hours off work to care for the two at home. We received no financial help in any way shape or form for anything. The upshot was inevitable and his business went down the pan and we were practically penniless. I never wish to open the cupboard doors and be faced with emptiness again.'

Evidence shows that families with disabled children tend to be concentrated in the bottom two fifths of income distribution[4] and have costs up to three times higher than other families[5]. It should be no surprise therefore to find that over half of disabled children grow up in real poverty.

Poverty is not only about a lack of income and material deprivation. There is much evidence to suggest that disabled children and their families routinely face isolation and exclusion from all aspects of ordinary life. We know that three quarters of disabled children live in poor or unsuitable housing[6]. We know that they experience childhoods that are impoverished of access to leisure and play[7]. Families from black and minority ethnic (BME) communities face even greater exclusion than their non-BME counterparts[8].

Working towards the elimination of child poverty is a major aim for the present government and one which the Family Fund and Contact a Family fully endorse. We welcome the many initiatives which the government have brought in to try to address child poverty, both income poverty and poverty of experience. Since 1999, when the current Government pledged to end child poverty,

[4] DWP, (2004) Households Below Average Income 2002/03.
[5] Dobson, B. & Middleton, S. (1998) Paying to Care: The cost of childhood disability. York: YPS. Also Doson, Middleto & Beardsworth (2001) The Impact of Childhood Disability on Family Life. York: YPS
[6] Oldman, C. & Beresford, B. (1998) Homes Unfit For Children: Housing, disabled children and their families. Bristol: Policy Press.
[7] Shelley, (2002) Everybody Here? London: Contact a Family.
[8] Chamba, R. et al (1999) On the edge: minority ethnic families caring for a severely disabled child. Cambridge: Polity Press/JRF.

600,000 children have been lifted out of poverty and this is most welcome.

The government also wants to encourage a responsible attitude to saving. Again, this is an aim that we endorse. If families can build up a cushion of savings, this may help to protect them against some of the financial ups and downs that all families experience. For those with a disabled child, where paid employment may have to take second place to caring for their child, where periods of hospitalisation may be common and outgoings are high, this is even more important. However, most of the families in this research cannot afford to save.

`Many like me in a caring situation are forced to reduce hours or stop work completely which may have a long term impact on your future financial security. This is significant if you are a woman and you may have already had some time away from the workplace'.

Recent government initiatives have actively encouraged saving.

The Saving Gateway initiative encourages families earning less than £15,000 a year, and single people earning less than £11,000 per year, to begin or continue saving by doubling the amount saved within the scheme limits.

Account holders can save from as little as £1 per week to a maximum of £25 per month, up to an overall maximum of £375 in 18 months. Money can be withdrawn at any time throughout the savings period, and at the end of the 18 months the Government will match the highest balance in the account during the savings period, up to £375. This means that by the end of the savings period some account holders can have as much as £750 saved under the scheme.

Launched in August 2002, the five Saving Gateway pilot schemes are run in conjunction with the DfES Community Finance and Learning Initiative.

The Chancellor announced his intention to introduce the Child Trust Fund (CTF) in the April 2003 Budget. The CTF is part of the Government's strategy for saving and asset ownership.

The CTF is a savings and investment account for children. The Government will make payments to children through this account to help build up a useful stock of assets for when they reach the age of 18. The CTF accounts will help to strengthen the savings habit of future generations, spread the benefits of assets ownership to all, educate people in the need for savings and give young people a basic understanding of financial products.

The government is also rightly concerned about the cost of over-indebtedness, both to individual borrowers and to financial institutions and to society as a whole and has recognised the need for cross-government action to tackle the problem.

1.2 - The features of debt in the UK

In 2002 the Minister for Consumer Affairs established the Task Force on Over-indebtedness in the wake of concerns about the increasing levels of consumer borrowing. One of the first actions of the Task Force was to commission a study into over-indebtedness, the first such research for over ten years.

The study found that living on credit was very much a part of everyday life for people in the UK and that, "Three quarters of all households had current consumer credit facilities of some kind, with one in six having five or more"[9]. However, many of those in Kempson's study did not actually use the facilities that they had, with 53.0% of households having either no credit facilities or unused credit facilities[10]. The study highlighted that credit usage was higher amongst families with children and households where there was 'income instability'[11], and that,

- 19% of families had credit card commitments,
- 17% had mail order commitment,
- 15% had outstanding loans,
- 13% had hire purchase agreements,
- 9% used an overdraft and 8% used a store card or account,
- 12% of households were found to be in arrears with Council Tax or utility bills,
- 2% had mortgage or rent payments[12].

Excluding mortgage repayments, the majority of households in the 2002 study owed nothing (53%) and 4% owed in excess of £10,000. Those who owed larger amounts tended to be those with higher incomes. When adjusted to represent a percentage of monthly income, 15% of households paid up to 10% of their monthly income servicing debts, 31% paid between 10% and 25%, 18% paid between 25% and 50% and 14% paid in excess of 50%[13].

80% of the households in Kempson's study reported that they had no financial difficulties at the time of the survey[14]. Furthermore, 60% reported that they were keeping up with their commitments. There was concern that both having a new baby and relationship breakdown were "...strongly associated with financial difficulties"[15].

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[9] Kempson, E. (2002) Over-indebtedness in Britain. DTI. pp9
[10] Ibid pp12
[11] Ibid pp10
[12] Ibid pp28
[13] Ibid pp15
[14] Ibid pp24
[15] Ibid pp25

Where households were in financial difficulty, 34% reported stress or anxiety as a consequence of their financial situation, 25% reported a lack of money or inability to afford non-essentials, 8% reported an adverse effect on their relationship, 8% reported adverse effects on their mental health, and 7% could not afford essential items.

A more recent study, carried out for the Department for Work and Pensions[16], was aimed at uncovering the nature and extent of debt. Based on an analysis of four datasets constructed between 1999 and 2002, this research found that 38% of families with children reported that they were in financial difficulty[17].

Overall, 68% of families with children owed money and were more likely to be using a wider variety of consumer credit[18]. Amongst these families, 34% had credit card debt, 31% a personal loan, 4% used an overdraft and 26% owed money for mail order purchases.

Neither of these previous studies investigated the nature and extent of indebtedness amongst families with disabled children. We know that they are more likely to grow up in poverty[19]. Although there is substantial evidence about low incomes and high expenditure amongst families with disabled children, there is little evidence about the extent and nature of their indebtedness - indebtedness that can be both a cause and effect of poverty.

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[16] Kempson et al (2004) Characteristics of Families in Debt and the Nature of Indebtedness. DWP
[17] Ibid pp13
[18] Ibid pp41
[19] Beresford, B. (1995) Expert Opinions: A national survey of parents caring for a severely disabled child. Bristol: Policy Press.

Section 2 - Summary of findings

This research employed two methods of data collection: completion of a 'pop-up' questionnaire by families visiting the Contact a Family website; and response to the same questionnaire administered by interviewers to families applying to the Family Fund and visited at home. The questionnaires were completed in early summer 2004. 1,843 families participated in the survey: 1,007 families were drawn from the Family Fund and 836 completed the questionnaire on the Contact a Family web-site.

The one thousand families who provided information at a Family Fund visit are a complete data-set (there are no non-responses) and relate to a cohort of low-income families with seriously disabled children. Families responding to the Contact a Family website can be families of any income, with children having a greater range of disabling conditions with varying levels of severity. This gives the total sample a depth and richness that would not be possible from one source alone.

A copy of the questions asked can be found in the appendix. This first section outlines the main characteristics of the respondent families.

2.1 - Age group of child

The largest group of respondents have children aged under 6, representing 49.1% of the entire sample. The second largest group has children aged between 6 and 11 (32.8%).

Child age group	n	%
Under 6	904	49.1%
6-11	605	32.8%
12-17	315	17.1%
Not stated	19	1.0%
	1,843	

2.2 - Ethnicity

Ethnic group	n	%
Asian	103	5.6%
Black African	66	3.6%
Black Caribbean	32	1.7%
White	1,559	84.6%
Other	61	3.3%
Not stated	22	1.2%
	1,843	

14.2% of respondents are from a BME group. The largest such group is Asian (5.6%). These proportions are comparable to levels found in the Family Fund database (15.2%) and are above Census 2001 levels (7.9%).

2.3 - Employment status

The majority of families have main carers who are not in paid employment (65.2%). Just 14.1% have main carers employed full-time and 16.7% are employed part-time.

Employment status	n	%
Full-time	260	14.1%
Part-time	307	16.7%
Self-employed	49	2.7%
Not in paid work	1,201	65.2%
Not stated	26	1.4%
	1,843	

2.4 - Family finances

Families were asked to indicate which of the following statements most closely described their family finances –

Financial situation	Count	%
We are comfortably off & can afford to save for the future	110	6.0%
We manage OK but don't have much left for treats or saving for the future	730	39.6%
We are scraping by and rob Peter to pay Paul	510	27.7%
We are struggling financially and have debts that are beginning to worry us	322	17.5%
We are in very serious financial difficulty	149	8.1%
No response	22	1.2%
	1,843	

Only 6.0% of families reported that they were 'comfortably off' with, 92.8% reporting some form of financial difficulty.

2.5 - Debt levels

Most families owed between £500 and £10,000 (51.7%), with the largest group of families owing between £1,500 and £5,000 (22.6%). 15.7% said that they had no debt. However, an equal proportion reported debts in excess of £10,000 (excluding mortgage payments). Compared to Kempson's 2002 study[20], families with disabled children are four times as likely to owe in excess of £10,000 (15.7% as compared to 4.0%). Conversely, 53.0% of those in Kempson's study reported that they owed nothing – only 15.7% of families with disabled children said that they had no debt.

Debt amount	Count	%
No debt	289	15.7%
Owe under £500	214	11.6%
Owe between £500 and £1500	357	19.4%
Owe between £1500 and £5000	416	22.6%
Owe between £5000 and £10000	235	12.8%
Owe over £10000	289	15.7%
No response	43	2.3%
	1,843	

[20] The categories used by Kempson and those used in this report are not directly comparable except in terms of those owing in excess of £10,000, those owing nothing and those owing up to £500. Other categories must be aggregated for comparison.

2.6 - Types of debt

The most common form of debt is credit card debt, with 4 in ten families reporting this. 599 families (32.5%) had a loan from somewhere other than a bank or building society (family or friends, a student loan or Social Fund are examples). 14.0% had mortgage or rent arrears, and 15.7% had Council Tax or utility bill arrears.

Type of debt	Count	%
Bank/Building society loan	492	26.7%
Loan from elsewhere	599	32.5%
Overdraft	370	20.1%
Credit card	741	40.2%
Mortgage/rent arrears	258	14.0%
Catalogue shopping	434	23.5%
Council tax or utility arrears	289	15.7%
Other form of debt	368	20.0%

Compared to Kempson's 2004 study, debt on all types of credit facility is higher amongst our sample. Credit card debt is double (40.2% of our families in credit card debt, as compared to 19.0%) as is use of an overdraft(20.1% compared to 9.0%). Nearly a quarter of the families, 23.5%, are in debt to catalogues/mail order, as compared to 17.0% in Kempson's study. 26.7% have a bank or building society loan – nearly double the 15% in Kempson's sample.

2.7 - Number of credit facilities used

The majority of families use at least one credit facility (82.9%),such as bank loans, credit cards, catalogues and HP, with most using two or more (55.0%). Two of the families serviced all eight of the credit facilities listed in the questionnaire. On average, our families were using 1.92 credit facilities each.

Number of facilities used	Count	%
0	315	17.1%
1	514	27.9%
2	443	24.0%
3	302	16.4%
4	155	8.4%
5	71	3.9%
6	33	1.8%
7	8	0.4%
8	2	0.1%
	1,843	

Our families tend to use more credit facilities than those in Kempson's research. Those having no current credit commitments account for 17.1% of the sample, compared to 53.0% in Kempson's sample. However, 55% had multiple credit commitments, as compared to 25.0% in Kempson's[21] study.

2.8 - Additional expenses

	Count	%
Agree	1,123	60.9%
Disagree	242	13.1%
Does not apply	478	25.9%
	1,843	

We asked families whether they agreed or disagreed with the statement *'Some of my debts are due to having additional expenses arising from my disabled child'*. The majority of families (60.9%) agreed with this

[21] See table 2.1 Kempson 2002 pp9

statement. This is unsurprising given that Dobson and Middleton in their 'Paying to Care'[22] study concluded that it cost over three times more to raise a disabled child as compared to raising a child without a disability. Just 13.1% disagreed. For about a quarter of the families this question did not apply, possibly because they were in debt prior to the birth of their disabled child.

2.9 - Dealing with debt

Families were asked whether they agreed or disagreed with the statement, *'It is hard to get advice about dealing with debt in my area'*. The responses indicate that about 45.0% of families have possibly sought advice or considered doing so. Only one in five families disagreed with this statement. Possibly the most disturbing feature of these responses is that 54.6% of families don't know whether it is hard to get advice in their area, indicating that they either they feel that they do not need advice, or that they haven't sought advice. This is significant, given that 84.3% of the sample reported being in debt and 52.3% describe their family financial situation as on one of the following - 'Scraping by and robbing Peter to pay Paul', 'Struggling and having debts that are beginning to worry them', or as having 'very serious financial difficulties'.

	Count	%
Agree	483	26.2%
Disagree	353	19.2%
Don't know	1,007	54.6%
	1,843	

2.10 - Benefits and tax

Families were asked whether they agreed or disagreed with the statement, *'Families with disabled children should get increased benefits even if tax has to go up to pay for it'*. Only 4.8% of families disagreed outright with this statement, with 47.2% in agreement. 48.0% were not sure of their response.

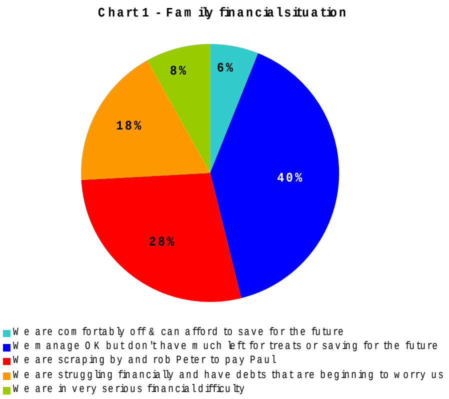
	Count	%
Agree	870	47.2%
Disagree	88	4.8%
Not sure	885	48.0%
	1,843	

[22] Dobson, B. & Middleton, S. (1998) Paying to Care: The cost of childhood disability. York: YPS.

Section 3 - Findings in detail

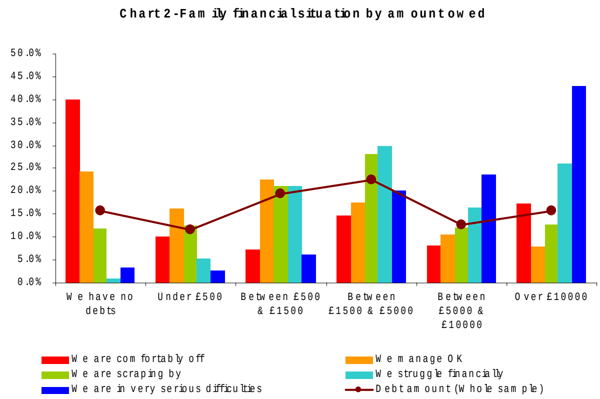
3.1 – Families' financial situation

Families were asked to identify which of the statements given in the chart best describe their family finances. Of the 1,843 responses, only 22 families did not provide a response to this question.



Just 6.0% of families stated that they were 'comfortably off and could afford to save for the future'. If the dual government aims of eradicating child poverty and promoting the social inclusion of families with disabled children are to be considered met, then the number of positive responses must increase dramatically and soon! In the context of government aims, the other categories all indicate some level of financial difficulty.

Families were split into five cohorts according to their response to this set of questions. This was done to establish the different patterns and types of debt and borrowing between them. The proportions of families owing different levels of debt by their description of their financial situation are shown in Chart 2. The chart shows that, unsurprisingly, families owing more are more likely to be in financial difficulties. The main features of each cohort are discussed below.



3.1.1 - We are comfortably off and can afford to save for the future.

	Count	%
We have no debts	44	40.0%
Under £500	11	10.0%
Between £500 & £1500	8	7.3%
Between £1500 & £5000	16	14.5%
Between £5000 & £10000	9	8.2%
Over £10000	19	17.3%
Not stated	3	2.7%
Total	**110**	

Only 6% (110 families) agreed that that this statement described their financial situation. 40% of these families had no debt at all, however, 17.3% (19 families) had debts in excess of £10,000.

The vast majority of families in this

cohort were of white ethnic origin (89.1%). In total, ten black and minority ethnic families(BME) described themselves as being comfortably off, with four of these families having debt. BME families are under-represented within this cohort. 14.2% of the whole sample are from a BME group, yet BME families account for just 9.1% of those describing themselves as 'comfortably off'.

44 of the cohort were employed full-time, 27 part-time, 9 were self-employed and 30 were not in paid work. Hence, the majority had some form of earned income with which to service any debts. Of those families not in paid work, two owed in excess of £10,000, four owed between £5,000 and £10,000, two owed between £1,500 and £5,000, four owed between £500 and £1,500, and three owed less than £500. Fifteen of those not in paid work stated that they had no debt.

24.5% (27) of the cohort were servicing more than one debt. Most of these families serviced just two or three types of debt. One family, however, serviced six types of debt. The most common form of debt for these families is credit card debt at 29.1%. Even amongst a cohort describing themselves as 'comfortably off' credit card debt is much higher than the 19% reported in Kempson's 2002 study. Furthermore, these families are more likely to have a loan (either from a bank or elsewhere) and/or an overdraft when compared to the general population.

The most disturbing aspect of the nature of debt owed by this cohort is that 14.5% have mortgage or rent arrears. This is much higher than the general population of families with children. Kempson et al estimate that 4% of families with children have housing arrears[23]. Furthermore, 2.7% of the cohort owed money due to either Council Tax or utility arrears.

It would seem that, whilst this group of respondents could by no means be described as affluent, those that have debt do have the means to service it. Employment levels are higher amongst this group than any of the others. Across the whole sample, only 2.5% of those families not in paid work reported that they were 'comfortably off and could afford to save for the future', as compared to 13.0% for those in some form of employment. However, amongst the 'comfortably off' families' employment status seems to have little effect on indebtedness. 56.3% of those with some form of employment reported some level of debt as compared to 50.0% of those not in paid employment.

[23] Based on their analysis of the FACS 2002

These families are in a reasonable financial situation now, but this may not be sustainable. Contact a Family reviewed all calls to its national helpline on financial problems. A common reason for getting into financial difficulty involves a life-changing event. For example,

"Father was a self employed lorry driver, with wife working part time. He became ill, was hospitalised and not earning. Family now in mortgage arrears"

"Mother now bringing up her child alone while partner is in prison, has got into debt"

"Daughter is autistic. Family have got into debt after having to move to a new home – paying for removal expenses, items needed for new home etc"

Sometimes it seems as though what would be a small problem for many families is enough to push a family from just about coping to not coping,

"Child has arthritis. Family were managing OK, with outstanding budgeting loan. Son's bed has just broken. Parents have no way to finance a new one, and yet son must have one if his back problems are not to become worse"

Similarly, the Family Fund responds to many families who need financial assistance because of partnership breakdown and consequent dramatic drop in income. Debts that were previously serviceable from earned income now threaten the family's future. If those who described themselves as comfortably off were to experience an adverse life event, their financial situation could rapidly deteriorate and they may not be able to continue to service the levels of debt that they currently manage with relative ease.

3.1.2 - We manage OK but don't have much left for treats or saving for the future.

39.6% (730) of families reported this statement as the one most closely describing their family finances. Proportionately, about half as many of this cohort had no debts as compared to those describing themselves as comfortably off (24.2% as compared to 40.0%).

Levels of debt are more evenly spread than with the 'comfortably off' families. For example, 7.8% of this cohort had debts in excess of £10,000 as compared to 17.3% of those describing themselves as 'comfortably off'.

	Count	%
We have no debts	177	24.2%
Under £500	118	16.2%
Between £500 & £1500	164	22.5%
Between £1500 & £5000	128	17.5%
Between £5000 & £10000	76	10.4%
Over £10000	57	7.8%
Not stated	10	1.4%
Total	**730**	

13.0% (95) of the cohort are from BME groups of which 64.2% (61 families) had some form of debt. Families from BME groups are under-represented amongst this cohort at 13.0%.

When compared to the ‘comfortably off’ cohort, this group tend to be servicing more types of debt, an average of 1.43 per family. 41.6% have more than one debt, with the most common debt being credit cards (34.1%). Fewer families have rent or mortgage arrears than those ‘comfortably off’, however the level is still higher than that identified by Kempson at 6.6%. Council Tax and utility arrears are higher than the ‘comfortably off’ cohort, at 7.5%.

35.1% of families in this group were in some form of paid employment, whilst 64.2% were not in paid employment. Of those families in paid employment, 77.7% had debt. Most employed families had debt of between £1,500 and £5,000 (28.1%). Where families were not in paid employment, most owed between £500 and £1,500 (35.8%). 16.6% (33) of the employed families owed in excess of £10,000, so did 7.0% (24) of those not in paid employment.

It might be expected that those not in paid employment would a) be more likely to describe themselves as ‘scraping by’, and, b) be more likely to owe more money. However, those in paid employment describing themselves as either ‘comfortably off’ or as ‘managing OK’ tend to owe more. This possibly reflects their greater access to credit. If these families were to experience an adverse life event, such as loss of employment, they might easily fall out of the `managing OK’ category. This is especially true as many families with disabled children find themselves losing their employment or changing their employment patterns. Research into employment issues `Flexible Enough?’[24] found that parents who were employed were fearful of losing their jobs if they had to take time off.

“My husband works full time and because he has been there a number of years they allow him to take time off for emergencies, visits and meetings associated with our child. However, he always makes up the time or has it as holiday. He feels if he were to make special requests it could help them to decide that his services may no longer be required. They have him over a barrel.”

“My employer has already had me disciplined for taking my son to hospital appointments; I was on a two written warnings for a year”

“There are more ways of getting you out of a job within the law than there are to skin a cat”

[24] Contact a Family. Flexible Enough.

3.1.3 - We are scraping by and rob Peter to pay Paul

27.7% (510 families) described this as the statement best describing their family's financial situation. Just 60 of the cohort had no debt. Most (28.2%) owed between £1,500 and £5,000. 12.7% owed in excess of £10,000.

	Count	%
We have no debts	60	11.8%
Under £500	64	12.5%
Between £500 & £1500	108	21.2%
Between £1500 & £5000	144	28.2%
Between £5000 & £10000	61	12.0%
Over £10000	65	12.7%
Not stated	8	1.6%
Total	**510**	

BME families are slightly under-represented in this group at 13.3% (68 families). BME families are less likely to have debt than non-BME families. 27.9% of BME families have no debt as compared to just 9.3% of non-BME families. 8.8% of BME families and 13.2% of non-BME families owed over £10,000.

Unsurprisingly, this cohort of families services higher levels of debt as compared to those 'comfortably off' and those that 'manage OK'. On average, these families service 2.07 lines of debt. The most common form of debt is credit cards, with 41.6% of families servicing credit card debt, double the level identified by Kempson (2002). Levels of mortgage and rents arrears and Council Tax or utility arrears are much higher for this cohort than in the previous two at 15.3% and 18.2% respectively. Both of these levels are much higher than UK-wide incidence for these types of debt.

86.7% of this cohort are in debt. Of those in debt, the largest proportion (32.6%) owe between £1,500 and £5,000. 14.7% (65 families) owe in excess of £10,000. Those families in employment are slightly more likely to have debt, 92.5% as compared to 83.9% for families not in employment. Families in employment are also more likely to owe more, with 24.8% owing in excess of £10,000 as compared to 9.6% of those not in paid employment.

It is of great concern that 9.6% of those not in employment owe such a large amount, as they have little income to be able to service such huge debts. For this cohort, the prospect of losing their home is becoming a real and immediate danger, especially given that the proportion of families with building society or bank loans is higher than the previous two cohorts, as is the proportion of those with other loans. It is possible that the 'loan from elsewhere' category contains loans from family and friends and loans from the Social Fund. It is equally possible that this category contains loans from unlicensed money-lenders, given that usage of such 'loan sharks' is higher amongst the more vulnerable low income groups.
The type of credit used by those on low incomes differs from that of 'better off' households, with greater use of moneylenders,

pawnbrokers, the Social Fund and friends and family. The Performance and Innovation Unit report 'Lending Support'[25] provides some detail about the types of credit used by households on different incomes,

Income type	High street credit	Low income credit	Non commercial credit	No credit
	Percentages			
All households	66	2	5	27
Very low income	25	5	15	53
Low income	32	3	8	55
Not low income	82	1	3	15
Volatile income - rise	84	2	8	9
Volatile income - fall	75	2	7	19
Volatile income - rise and fall	86	2	-	-

Adapted from Table A4.1(a) p 139

Low income credit includes credit weekly from the home, pawnbrokers and other credit eg. Loan sharks

3.1.4 - We are struggling financially and have debts that are beginning to worry us.

17.5% (322 families) said that this statement best describes their family finances. Only three families in this cohort had no debts. 96 families (29.8%) had debts of between £1,500 and £5,000, with 26.1% (84 families) reporting debts in excess of £10,000. Those in this cohort owing over £10,000 account for almost 30% of all those owing over £10,000.

	Count	%
We have no debts	3	0.9%
Under £500	17	5.3%
Between £500 & £1500	68	21.1%
Between £1500 & £5000	96	29.8%
Between £5000 & £10000	53	16.5%
Over £10000	84	26.1%
Not stated	1	0.3%
Total	**322**	

BME families are slightly over-represented in this cohort, at 14.6% of all families describing themselves as 'struggling financially'. The BME families in this cohort are less likely to owe in excess of £10,000. 19.1% reported owing in excess of £10,000 as compared to 27.3% of non-BME families. BME families in this cohort are more likely to owe between £500 and £1,500 indicating that a relatively small amount of debt can cause an uncomfortable level of financial difficulty.

As compared to those either 'comfortably off', 'managing OK' or 'scraping by', this cohort service even more lines of debt, on average 2.63. Over half service credit card debts, over a third service a bank or building society loan and 46.9% have a loan from elsewhere. On each debt type, the families who 'struggle financially' are more likely than the previous cohorts to be servicing debt. Families in this cohort are five times more likely to have mortgage or rent arrears than those in Kempson's 2004 study, with 20.8% of

[25] Performance and Innovation Unit (2004) Lending Support. pp139

the cohort having such arrears. Furthermore, levels of Council Tax and utility arrears stand at 26.7% for this cohort.

For this group, employment status seems to have little bearing upon the likelihood of a family being in debt. The proportion of families in paid employment and in debt is the same as that for those not in paid employment - at 98.8%. Families not in paid employment are more likely to owe between £1,500 and £5,000, 30.8% as compared to 27.5% of those in employment. Of real concern is that 24.1% (57 families) of those who are unemployed owe over £10,000. Realistically, these families have little prospect of re-paying their debts without a drastic change of circumstances which increases their income substantially.

As with those families ‘scraping by’, this cohort is in serious danger. The levels of ‘unsecured debt’, and number of debts serviced, are unacceptably high when compared to the general population. It seems that levels of debt, which for other families are acceptable and manageable, can cause families with disabled children a great deal of financial worry particularly if they are not in paid employment or are from a BME community.

3.1.5 - We are in very serious financial difficulties.

149 families, 8.1% of the sample, reported that they were in ‘very serious financial difficulties’. Just 3.4% (5) of these families stated that they had no debt. The largest proportion of families (43.0%) however, reported debt in excess of £10,000. Furthermore it is disturbing that 86.6% owe £1,500 or more.

	Count	%
We have no debts	5	3.4%
Under £500	4	2.7%
Between £500 & £1500	9	6.0%
Between £1500 & £5000	30	20.1%
Between £5000 & £10000	35	23.5%
Over £10000	64	43.0%
Not stated	2	1.3%
Total	**149**	

BME families are over-represented in this cohort, accounting for 26.8% of families in ‘very serious financial difficulties’. This compares with just 9.1% of those describing themselves as ‘comfortably off’ and 14.2% of the sample as a whole. Of the BME families within this cohort, 10.0% stated that they had no debt. However, 80.0% reported debt in excess of £1,500 with 17.5% (7 families) of the BME families in this cohort having debt in excess of £10,000.

Of the five cohorts, this group services the most lines of debt with each family servicing 3.18 debts on average. Chart 3 indicates how many percentage points above the sample this cohort are for each type of debt and Chart 4 shows the percentage of each cohort that has outstanding debt by the type of debt.

Chart 3 - Families in 'very serious financial difficulties' by type of debt (variation from whole sample)

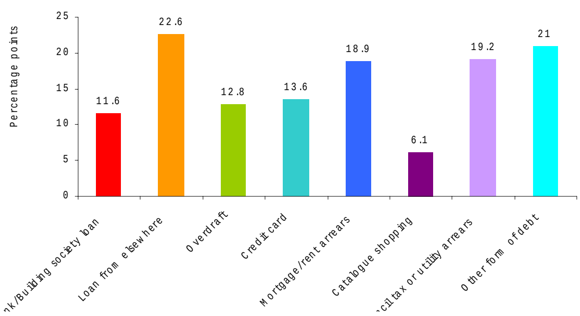
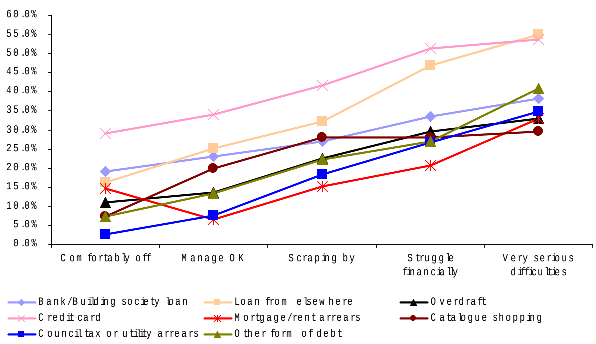


Chart 4 - Percentage of each cohort having outstanding debt by type of debt



53.7% have credit card debt, 38.3% have a bank or building society loan, 55.0% have a loan from elsewhere and 32.9% have an overdraft. This cohort reports the highest levels of mortgage or rent arrears, at 32.9%. It also has the highest incidence of Council Tax or utility arrears at 34.9%. 40.9% of this cohort have debts that are not amongst the main categories listed.

For this group, employment status seems to have little effect upon the likelihood of being in debt. 94.6% of those in paid employment are in debt, as compared to 95.5% of those not in paid employment. Those in paid employment tend to have debt at a slightly higher level, with 74.3% of those in employment owing over £5,000, as compared to 68.2% of those not in paid employment. However, it should be noted that 47.7% (51 families) of those not in paid employment owe in excess of £10,000. As with families in the general population, lack of paid employment makes it very difficult to pay back substantial debts.

For this cohort, day-to-day life is harsh. Many families without disabled children would struggle to service such high levels of debt at such low levels of income[26]. Levels of mortgage or rent arrears and Council Tax or utility arrears are unacceptably high, as is the level of credit card debt at almost three times the level identified by Kempson. For these families each day must represent an 'uphill battle' against debt. As families from Contact a Family's helpline reported,

[26] The survey did not collect income data. However, of those from the Family Fund portion of the sample 89.1% are in receipt of Income Support and the average annual income from employment (all Family Fund families in the sample) is £4,899.85. Family Fund families account for 54.6% (1,007) of the entire sample.

"Money is a continuous worry and this puts us under added strain"

"You can't sleep. It's not because the child is disturbing you, but what goes on inside your head. You worry about the future"

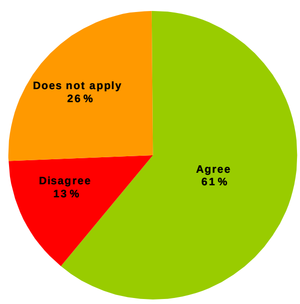
"I have been pressured to make an agreement with the bailiffs for more than I can afford. I have to pay in 12 days and I can't"

3.2 - Attitudes to debt

3.2.1 – Some of my debts are due to having additional expenses arising from my disabled child.

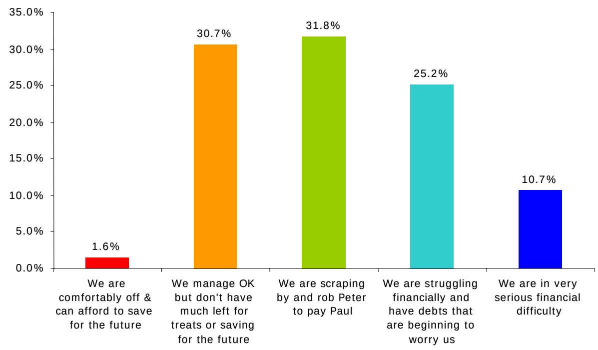
When asked if they agreed or disagreed with the statement *'some of my debts are due to having additional expenses arising from my disabled child'* the majority (60.9%) of families agreed. Just 13.1% disagreed, with the remaining 25.9% stating that the question did not apply to them. Where families stated that the question did not apply it is possible that they were in debt prior to the birth of their disabled child.

Chart 5-Some of my debts are due to having additional expenses arising from my disabled

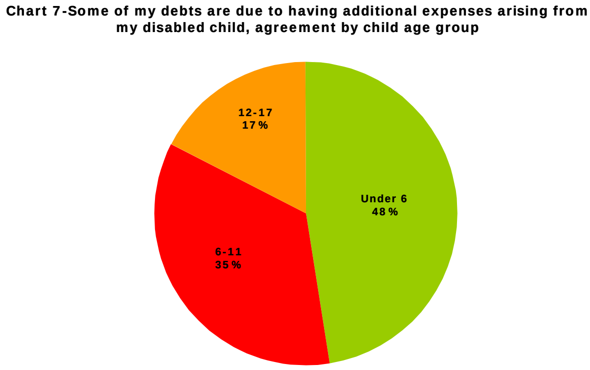


Only 1.6% of those agreeing with this statement fell into the cohort that described their financial situation as 'comfortably off'. 62.4% either 'managed OK', or were 'scraping by'. The remaining families fell into the 'struggling financially' (25.2%) or 'in very serious financial difficulties' (10.7%) cohorts. The 10.7% who agreed with the statement, and also described their situation as 'very serious', account for 40.1% of all families describing their situation as 'very serious'.

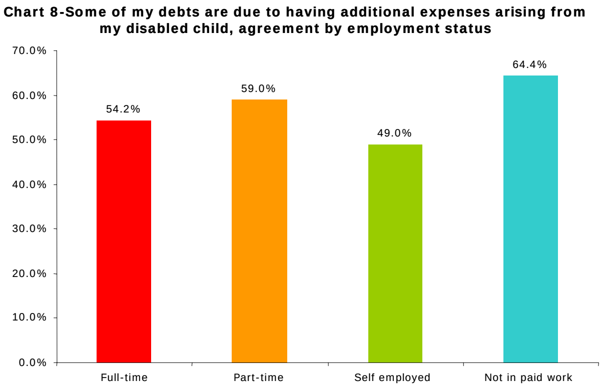
Chart 6-Some of my debts are due to having additional expenses arising from my disabled child, agreement by family financial situation



Most of those in agreement owed upwards of £1,500 (63.5%). Indeed, 20.6% owed in excess of £10,000 - accounting for 77.2% of all families owing over £10,000. Only 13.0% owed less than £500. Families with children aged under 6 make up 47.5% of those in agreement. Most of those with children under 6 owed between £500 and £5,000 (53.1%). However, 18.1% with children aged under 6 owed in excess of £10,000. This is of concern because these families are already in serious debt and face the prospect of raising a disabled child within the context of continuing long-term financial insecurity and stress. These are factors that can lead to relationship breakdown. These families face more expense related to their child's needs in future years and may have little opportunity to clear their debts[27].

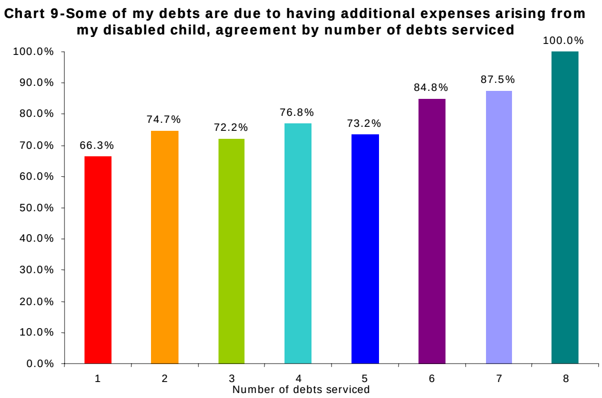


56.2% of those in some form of employment agreed with the statement. Rates of agreement varied according to employment status: 54.2% of those employed full-time, 59.0% of those employed part-time and 49.0% of those self employed. It seems that a regular income does not compensate fully for the extra costs involved in raising a disabled child. Iif it did, one would expect agreement rates amongst those in paid employment to be much lower. Of those not in paid employment 64.4% agreed.



As the number of debts that the family services increases, the more likely they are to be in agreement with the statement. Where families serviced more than one debt the average agreement rate is 81.3%.

Overall, 74.7% of families servicing more than one debt agreed that their debt was due, in part, to the extra expenses relating to the needs of their disabled child.



[27] As previously stated it cost at least 3 times more to raise a disabled child than a child without a disability.

There are certainly some situations where government policy encourages and in some cases forces a family to go into debt. Most notably the Disabled Facilities Grant is a case in point. This is a grant for adapting the home of a disabled person, where the means test calculates how much of a loan the applicant could afford to borrow and then asks them to contribute this sum, thus forcing many to borrow to pay for essential works.

The second example would be the Social Fund. This allows families on Income Support to borrow money for essential items and repay each week out of their benefit. The Family Fund provides washing machines, clothing and bedding grants to hundreds of families who are eligible for loans from the Social Fund but are unwilling to take them because they cannot afford to pay them back. Quotes from Contact a Family's help-line include -

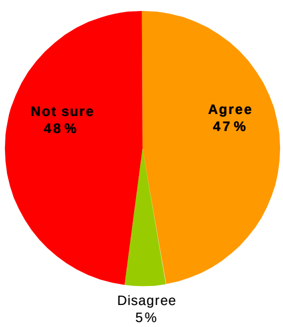
"I have lost all the extra I got on the tax credit through having to take a loan from a loan shark after I was burgled. The Social Fund said they couldn't help at all"

"My son has ADHD and wets the bed each night. The mattress and bedding are unusable. Social Fund cannot help as we had a grant for same thing within the last 6 months.

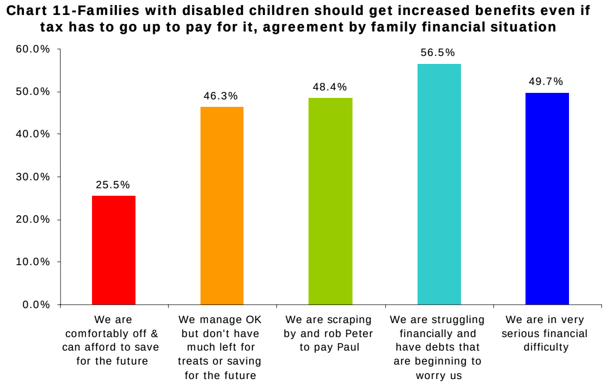
3.2.2 – Families with disabled children should get increased benefits even if tax has to go up to pay for it.

We wanted to know whether families thought that the income they received through benefits was sufficient to live on; and whether they wished to see them increased, even if there was a price to be paid for this in the form of higher taxation. We asked families whether they agreed or disagreed with the statement '*Families with disabled children should get increased benefits even if tax has to go up to pay for it*'. A large proportion of families were 'not sure' (48.0%). However, only 4.8% disagreed outright with this statement. The remaining families were in agreement (47.2%).

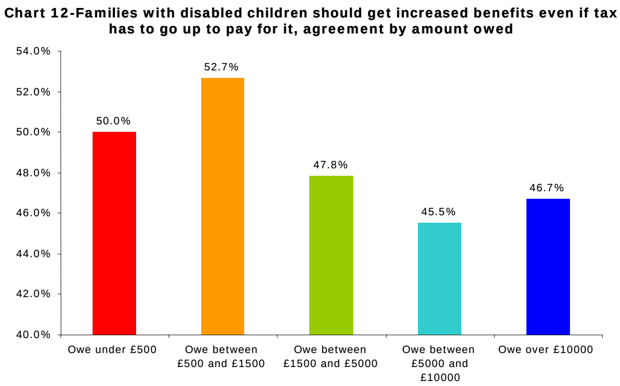
Chart 10-Families with disabled children should get benefits even if tax has to go up to pay for



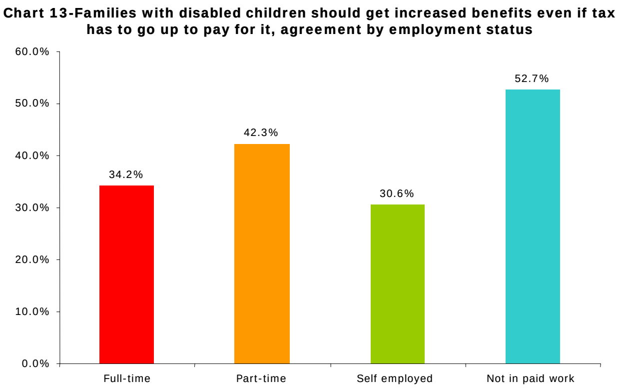
3.2% of those in agreement belonged to the cohort describing their financial situation as 'comfortably off'. The majority of those agreeing fell into either the cohort describing themselves as 'managing OK' or 'scraping by' (67.2%). About a quarter of those describing themselves as 'comfortably off' agreed with the statement. The proportions of those agreeing in each cohort increased as their financial situation worsened. However, as Chart 11 shows just under half of those in 'serious financial difficulties' agreed.

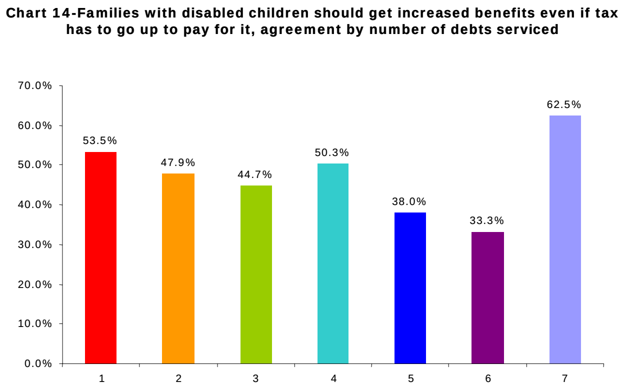


Where families had debt 48.7% agreed with this statement. Those owing relatively smaller amounts had a greater tendency to agree as shown in Chart 12. Surprisingly, those who owed more had lower agreement rates than those owing under £1,500. Of those agreeing with the statement, 47.5% had a child under the age of six, 35.1% had a child aged between six and eleven and the remainder had children aged between twelve and seventeen. The group most likely to agree were those families with a child aged between twelve and seventeen and owing between £1,500 and £5,000.



One would expect agreement with this statement to vary according to employment status. Whilst there was variation it was not as great as expected, with 38.0% of those in some form of employment agreeing, as compared to 52.7% of those not in paid employment. A closer look at employment status shows that those





employed part-time (42.3%) are more likely to agree than those employed full-time (34.2%), who in turn are more likely to agree than those self-employed (30.6%).

As families serviced more debts they were somewhat less inclined to agree with this statement. Where a family serviced just one debt,53.5% were in agreement. Generally, this proportion decreases as the number of debts serviced increases. However, those who service either seven (62.5% in agreement),or four (50.3%) debts, have an increased tendency to agree with this statement.

3.2.3 – It is hard to get advice about debt in my area.

According to Kempson[28], 20.0% of households with current arrears, and 20.0% of those in financial difficulty, had sought some form of advice about their debt. The most common form of advice sought was from free advice agencies. According to Citizens Advice[29], many people try to contact their creditors prior to seeking advice from elsewhere. Unfortunately, even with the 'safeguard' of codes of practice the vast majority were unsuccessful in negotiating manageable repayments. A common practice is for households to approach debt management companies, with little apparent success[30]. Citizens Advice argues that debt advice, particularly for those on low incomes, is a valuable resource for families in financial difficulties. The advice that Citizens Advice provides is free, holistic and enables, '...people to make informed choices about how to deal with their debt and related problems'[31]. With many Citizens Advice Bureaux across the UK offering such advice, Family Fund and Contact a Family decided to assess how accessible such debt advice was for families with disabled children.

Bearing in mind that the sample for this research is composed of one of the most vulnerable sections of society, and, as we have shown, one of the most financially indebted, one would hope that access to quality, free debt advice would be readily available. However, as Kempson[32] points out there are inadequate free advice services to meet need, '...they [free advice services] work to near capacity yet...only assist a small proportion of households facing arrears'.

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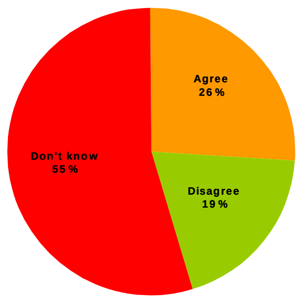
[28] Kempson, E. (2002) Over-indebtedness in Britain. DTI. pp35
[29] Edwards, S. (2003) In Too Deep: CAB client's experience of debt. pp67
[30] Ibid pp70
[31] Ibid pp70
[32] Op.Cit. pp35-38

We asked families whether they agreed or disagreed with the statement *'it is hard to get advice about debt in my area'*. The responses to this question indicate that about 55.0% of families have not sought any formal advice about their debt. This is based upon the number of 'don't know' responses as shown in Chart 15. Furthermore, of those that have sought advice, or at least know that such advice is available (those either agreeing or disagreeing), a large proportion agreed that was hard to get advice. 26.2% of respondents agreed outright with this statement. Implicit within agreement is that the family have tried to seek advice but have been unsuccessful. This may reflect the general access issues that families with disabled children have in relation to local services more generally.

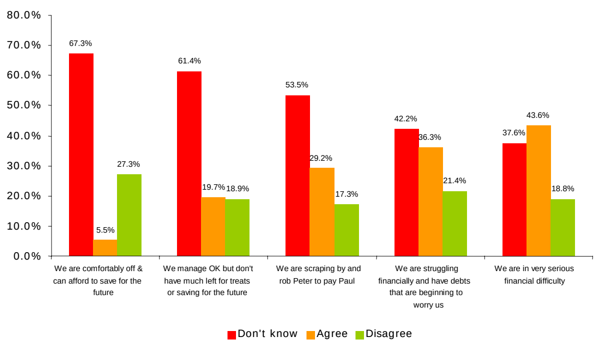
Chart 15-It is hard to get advice about debt in my Agreement rates



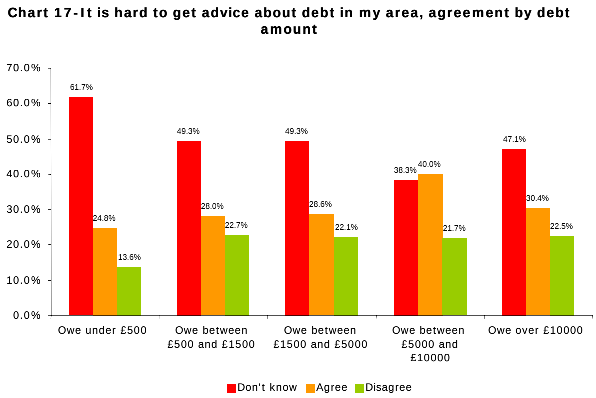
Many families find it hard to get out without their children because of child care problems. Combined with Kempson's assertion that provision of free debt advice is outstripped by need, it appears that families with disabled children face even higher barriers than other families in accessing such services.

Of those families 'comfortably off' the majority (67.3%) didn't know whether it was hard to get advice about debt in their area, 5.5% agreed and 27.3% disagreed. Arguably, those describing themselves as 'comfortably off' do not see a need for debt advice and the 67.3% responding 'don't know' have not sought advice.

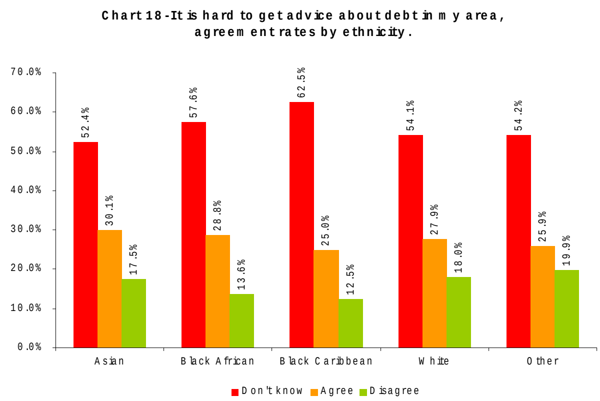
Chart 16-It is hard to get advice about debt in my area, agreement by financial situation



These proportions change dramatically as family financial situations worsen. The proportion of 'don't knows' decreases, although still unacceptably high (37.6%) for those describing themselves as in 'very serious financial difficulty', as financial situation worsens. The proportion of those disagreeing remains fairly stable at between 17.3% and 21.4%. Levels of agreement increase as the financial situation worsens. This is of serious concern, especially in respect of those families in 'very serious financial difficulty', where just 18.8% disagree that it is difficult to get advice about debt. The remaining families in this cohort (81.2%) have either not sought advice, despite the serious nature of their situation, or have tried to seek out advice without success.



61.7% of those owing under £500 did not know whether it was hard to get advice about dealing with debt, similar to those describing themselves as 'comfortably off'. They perhaps saw no need to seek such advice. However, almost a quarter of these families stated that they agreed with the statement. Agreement levels increase steadily as the amount of debt increases, with 40.0% of those owing between £5,000 and £10,000 agreeing that it hard to get advice. Where families owe over £10,000, the agreement rate falls back to 30.4%. However, the 'don't knows' increase to 47.1%, indicating that 77.5% of those families have either not sought advice or tried to seek advice unsuccessfully.



One possible barrier to accessing advice could relate to the language preferred by the family and the availability of services in that language. Data regarding preferred language was not collected. However, ethnicity was recorded. Agreement rates are fairly stable across all ethnic groups. However, those describing themselves as Asian are slightly more inclined to agree (30.1%) than the other groups and those of Black Caribbean origin were more likely to respond 'don't know' (62.5%).

Section 4 examines the nature of debt amongst BME families in more detail.

Section 4 - Ethnicity and debt

Families from BME groups were slightly more likely to report that they were in financial difficulty. As with the whole sample, the BME families were split into 'financial situation' cohorts.

4.1 – We are comfortably off and can afford to save for the future. BME families

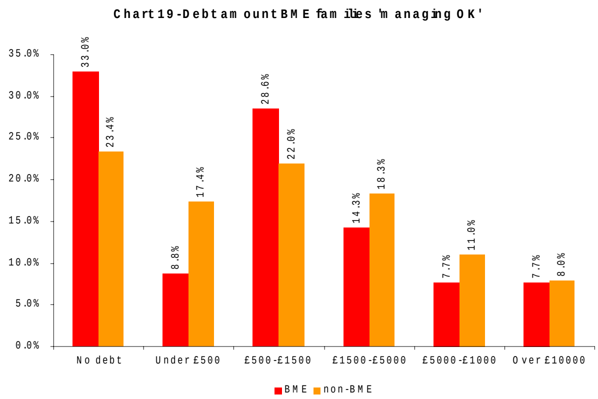
Just ten of the BME families stated that they were 'comfortably off'. This represents just 9.1% of the 'comfortably off' cohort and just 3.8% of the BME families. Hence, 95.4% of the BME sample might be described as being in financial difficulty.

Of the ten families describing themselves as 'comfortably off' six did not have any debt, one owed under £500, one owed between £500 and £1,500, one owed between £1,500 and £5,000, and one owed over £10,000. Amongst the four families owing money one was not in paid employment and owed in excess of £10,000. BME families are under-represented in this cohort.

4.2 – We manage OK but don't have much left for treats or saving for the future. BME families

95 of the BME families reported that this statement best described their family financial situation. This represents 13.0% of the 'manage OK' cohort and 36.3% of BME families, as compared to 40.7% of white families. As with those that are 'comfortably off' BME families are under-represented in this cohort.

These BME families tend to owe lower amounts than the non-BME families in the cohort. Indeed, one third have no debt at all. However, almost the same proportion as for the non-BME families owe over £10,000 (7.7% as compared to 8.0%). This indicates that BME families begin to feel that they are in financial difficulty at a lower level of debt.

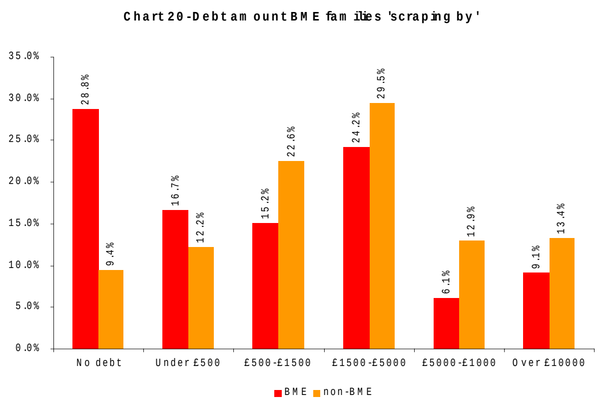


Within this cohort, a larger proportion of BME families were in some form of paid employment, 47.5% as compared to 33.6% of non-BME families. However, all of the BME families not employed had debt, as compared to 65.9% of non-BME families not in employment.

4.3 – We are scraping by and rob Peter to pay Paul. BME families

45 BME families reported their financial situation as 'we are scraping by and rob Peter to pay Paul'. This represents 13.3% of the whole cohort and 26.0% of BME families. BME families are still slightly under-represented in this cohort.

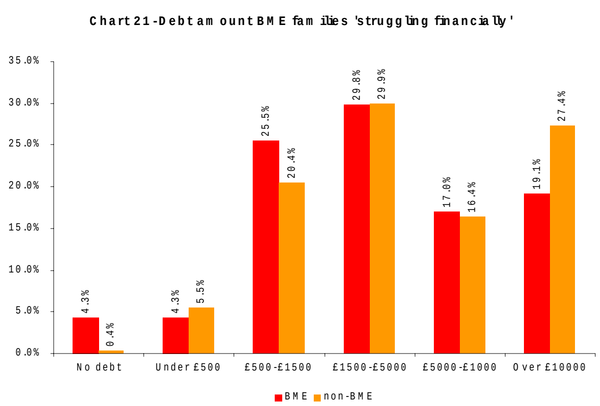
As with the previous cohort, BME families describing themselves as 'scraping by' tend to owe smaller amounts than the white families. For example, 28.8% of the BME families in this cohort have no debt, as compared to 9.4% of the white families.



When looking at employment status, both groups within this cohort have similar levels of paid employment (33.8% of BME families and 31.2% of non-BME families). However, white families are more likely to be employed part time (19.4%) and BME families full time (22.1%). Of those BME families not in paid employment 62.2% have debt, compared to 87.1% of non-BME families.

4.4 – We are struggling financially and have debts that are beginning to worry us. BME families

47 BME families stating that this description best represented their financial situation made up 17.9% of all BME families and 14.6% of the cohort. BME families are therefore over-represented in this cohort.



BME families in this cohort are more likely to have no debt than the non-BME families. However, the levels of debt owed begin to even out. Indeed, a slightly larger proportion of BME families (17.0%) owe between £5,000 and £10,000 as compared to non-BME families (16.4%). White families are still more likely to owe in excess of £10,000.

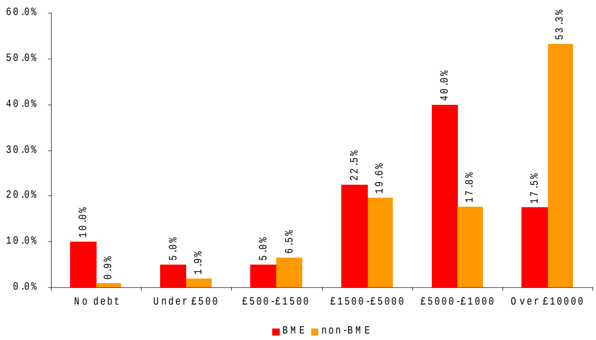
When looking at employment status more white families are in some form of paid employment (36.2% as compared to 23.4%). However, amongst those not in paid employment the likelihood of being in debt is fairly evenly spread, with almost all of those not in employment having debt, regardless of ethnicity.

4.5 – We are in very serious financial difficulty. BME families

40 BME families reported that this statement was the one that best described their family financial situation. This represents 15.3% of the BME families and 26.8% of the cohort describing themselves as 'in very serious financial difficulty'. BME families are very much over-represented within this cohort.

BME families in this cohort are more likely to owe more than their counterparts in the other cohorts, with 80.0% owing in excess of £1,500. On the whole, these BME families also owe money at a greater level than the non-BME families, although a much greater proportion of white families owe in excess of £10,000.

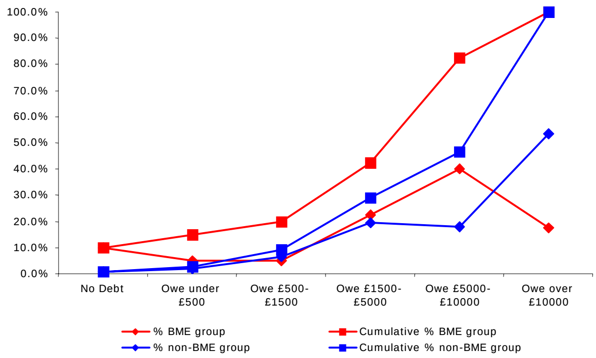
Chart 22 - Debt amount BME families 'in very serious financial difficulty'



Employment levels are much higher for the BME families, as compared to the non-BME families, in this cohort (42.5% as compared to 18.3%). However, when looking at those families not in paid employment likelihood of indebtedness is fairly even for both BME families and non-BME families. 91.3% of BME families not in paid employment have debt as compared to 96.6% of unemployed white families.

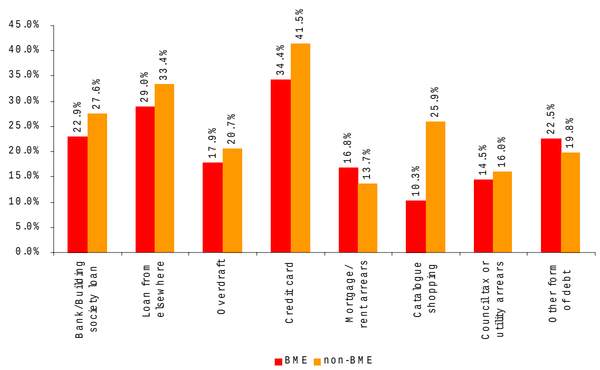
Whilst the BME families are more likely to report that they are in very serious financial difficulty, the proportion of non-BME families reporting very serious financial difficulties and owing in excess of £10,000 was significantly higher. Indeed, 17.5% of BME families in 'very serious financial difficulty' owed over £10,000, for the non-BME group this increases to 53.3%. However, those from a BME background are more likely to report 'very serious financial difficulties' at a lower level of debt. For example, 42.5% of the BME group describing themselves as being in very serious financial difficulties owed between £0 and £5,000, as compared to 29.0% for the non-BME families (see Chart 23). This is possibly due to lower incomes amongst BME communities. Data regarding pay differentials based on ethnicity are difficult to find. However, the Commission for Racial Equality[33] estimates that the hourly earnings of full-time employees from BME groups is about 92% of their non-BME counterparts. For example, 49.0% of Pakistani and Bangladeshi workers earned less than £4.50 per hour as compared 31.0% of white workers[34].

Chart 23-BME groups and likelihood of reporting 'very serious financial difficulties'



The type of debt that BME families have varies slightly from that of the non-BME families. The debt types that stand out most are mortgage or rent arrears, catalogue shopping, and other forms of debt. BME families are much less likely to owe money for catalogue shopping (10.3% as compared to 25.9%). Disturbingly, as these could be considered 'high risk' debts, BME families are more likely to have debt relating to both 'other' forms of debt (22.5% as compared to 19.8%) and mortgage or rent arrears (16.8% as compared to 13.7%).

Chart 24-Type of debt owed by BME and non-BME families



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[33] CRE factsheet – Employment and Unemployment (1997).
[34] Survey by Birmingham Low Pay Unit (1995) cited in CRE factsheet – Employment and Unemployment (1997).

Section 5 - Summary

This research shows that families with disabled children are more indebted than the general population. On all indicators of debt they fare worse than families that do not have disabled children.

- Fewer of them are 'comfortably off'
- more of them are in some form of financial difficulty
- they owe greater amounts
- they have more credit commitments
- their average income is much lower
- they cannot afford to save
- they are less likely to access free debt advice.

BME families are likely to report 'serious financial difficulties' at a lower level of debt than their non-BME counterparts, possibly due to pay differentials or a less accepting attitude to debt.

Levels of housing arrears are extremely worrying, with many families in real danger of losing their homes. Similarly, levels of arrears on Council Tax and/or utility bills are unacceptably high. 'High risk' borrowing over and above bank or building society loans is a common feature of these families. A large proportion of the sample stated that they 'robbed Peter to pay Paul', a short-term solution to a long term problem and one which is likely to increase the risk of arrears. However, due to their low incomes and, for many, the lack of paid employment because of caring commitments, there is often no option but to borrow and juggle bills.

Many families link their debt directly with the added expenses that their disabled child generates. As previous research shows these expenses relate mainly to essential items:

- transport costs for getting to hospital appointments;
- bedding or laundry equipment for an incontinent child;
- replacement furniture for a child with a serious behavioural condition;
- mobility equipment or necessary adaptations to housing for a severely physically disabled child[35].

These additional expenses are unavoidable and totally necessary in order to fully meet the needs of the child and family. It seems that a regular income from employment does not compensate fully for

[35] Woolley, M. (2004) How do They Manage: Income and expenditure of families with severely disabled children. York: Family Fund.

these additional expenses. Where families do not have the money to fulfil these needs they borrow it.

There are circumstances where the government encourages families to get into debt, the Disabled Facilities Grant and the Social Fund being the two prime examples. The Family Fund has noticed a large increase in applications from families requesting help towards necessary adaptations to their homes. These families seek help towards their assessed contribution which is often well above their financial means. Such grants are outside of the Fund's remit and many families must either borrow money from elsewhere or raise funds via individual fundraising activities. Similarly, the Fund receives anecdotal evidence that the Social Fund are unwilling to provide grants or interest free loans for many essential items, especially if a family already have a Social Fund loan.

The consequences of such serious debt for any household has been documented by previous research[36]. Many families report stress, mental health problems, inability to afford essential items, relationship breakdown and fear of facing an uncertain future. Some families are able to move out of debt. However, for families with disabled children this is difficult given that in many cases they face many years of providing unpaid care and support to their disabled child.

Recent government initiatives have improved levels of poverty generally and this is welcomed. The 2004 Spending Review provides much needed investment in childcare and services for disadvantaged children. The Saving Gateway initiative and Child Trust Fund encourages saving. It is estimated that 600,000 families have been lifted out of poverty by such initiatives.

However, there is still a long way to go, especially in respect of the estimated 700,000 disabled children and their families living in the United Kingdom today. If these families are to have the same life chances, the same standard of living and the same quality of life as other families with non-disabled children then urgent action on over-indebtedness is required.

[36] CAB (2003) In Too Deep.
Kempson (2002) Over-indebtedness in Britain, Kempson et al (2004) Characteristics of Debt and the Nature of Indebtedness.

Section 6 - Recommendations

It is our strong view that concerted action is required to address the specific needs of disabled children and their families. The Green Paper, `Every Child Matters' together with the work already done for the National Service Framework for Children, the SEN Action Programme and specific action to address child poverty, could form the basis of a strategy for disabled children. This would be an overarching strategy across government and contain specific and measurable targets for supporting disabled children and their families.

Why might it be politic for the government to provide more support for families with disabled children?

- They are a group who can be targeted through their receipt of DLA or Family Fund application
- They are a relatively small group – some 700,000 across the UK although only around half get DLA
- They are a group of children who are subject to long term poverty, they are 'persistently poor'
- They are a group of children which society will see as 'deserving poor' and therefore government measures for change would be popular.

The government is committed to the abolition of child poverty and has introduced a number of measures to bring this about. Certainly, the introduction of tax credits has helped to lift a number of families out of poverty. It is widely believed that policies for all children will also help disabled children. In some cases, this is so. However, disabled children do not always benefit from the `trickle down effect'. Specific targeted support is also necessary which directly addresses the needs and challenges of disabled children and their families. In the context of financial exclusion and debt, we outline below a number of macro and micro level policy interventions that would provide such targeted support.

Macro level changes

1) Launch benefit take-up campaign for families with disabled children

We believe there is significant under claiming of benefits such as Carers Allowance and Disability Living Allowance. Much progress has been made to publicise Tax Credits and the provision of funding to the voluntary sector by the Inland Revenue to promote take up for hard to reach groups.

The Department for Work and Pensions needs to publicise disability and carer benefits in a similar way and offer funding to voluntary and community sector groups to do this, in the same way. Parents often report that they do not find out about what they should be claiming for many years.

There is also still a stigma attached to claiming benefits that needs to be tackled. There are considerable benefits stemming from take up work to help families claim what they are due. The Acheson Report[37] referred to benefit take up work as a beneficial health intervention. Subsequently, a growing body of research shows a range of direct and indirect positive effects of benefit take up work. There are also benefits to the local economy, as increased benefit income is usually spent in the local community.

2) Review the level of benefits and tax credits available to families with disabled children, with the aim of raising disabled children out of poverty by 2010.

We believe that the time is right for an overarching review of the support offered to families with disabled children. The nature of the disabled child population is changing. We know that more children are born with profound and multiple disabilities because of advances in medical knowledge and treatments and more are surviving, sometimes into adulthood. Numbers of children dependent on technology such as long term ventilation are increasing. When Disability Living Allowance was introduced for disabled children in the early 1990's, such children probably would not have survived and would almost certainly not have been cared for at home. An urgent review of the financial support offered to the most severely disabled children and young people is needed.

3) Review the provision of money advice services

We would like to see a review of the provision of money advice services within the community, in particular, the needs of families who cannot travel to seek advice because of the needs of their disabled child. A home visiting service should be developed wherever possible and access to telephone advice services including casework for those families who need advocacy help should be more widely established.

4) Review the funding offered via the Family Fund

We believe that the Family Fund should be allowed greater flexibility to help families beyond arbitrary income cut off points. At present,

[37] See: http://www.archive.official-documents.co.uk/document/doh/ih/ih.htm

families with incomes over £23,000 gross per annum cannot be helped. For families with a mortgage, particularly in areas of high housing costs, this may exclude many whose real incomes after housing costs are at or below current poverty levels.

Families with two earners may have taken on debt and mortgage commitments that they could sensibly manage. However, the birth of a disabled child and the inability of both parents to subsequently work full time may leave them at serious risk of poverty, debt and even homelessness. This may be the case where one partner earns substantially in excess of £23,000.

The Fund's upper age limit should also be urgently reviewed upwards. The current cut-off, at fifteen, is out-moded and leaves families without a source of help at a critical transitional period in their and their young person's life.

Micro level changes

On a more micro level there are some immediate, interim measures that could be taken. These could help to ameliorate some of the more extreme examples of indebtedness highlighted by this research.

These include a number of anti-poverty measures relating to families with disabled children that could be implemented swiftly and easily and without exorbitant cost and which may help to prevent the spiral into serious debt.

We would suggest that the following measures would have an immediate impact on these families.

1) Help parents to work

Mothers of disabled children are much less likely to be able to work than other mothers. The Child Poverty Review[38] recognised that only 3% work full time (compared to 22% of others) and only 13% work part time (compared to 39% of others).

Recent research[39] found that there were significant challenges combining work and caring, most notably, childcare, taking time off for appointments, financial problems in the benefits system and lack of understanding from employers.

[38] See: http://www.hm-treasury.gov.uk/spending_review/spend_sr04/associated_documents/spending_sr04_childpoverty.cfm
[39] Contact a Family (2004) Flexible enough.

It would help parents to return to work if the amounts allowable for childcare through Tax Credits were increased in the case of a disabled child in order to provide a sum that covers the real costs of providing care for a disabled child. Furthermore, the rule that means less money is paid toward second and subsequent children exacerbates the problem as the care needs of one sibling may differ significantly from other siblings. The Child and Working Tax Credit Quarterly Statistics[40] show that there is inequality in take-up of the childcare element between families with a disabled child and those where there is no disabled child.

If this recommendation was followed more families could enter the world of work. Any provision that helped people either retain or gain employment would be welcome.

2) Direct fiscal measures

Council Tax - Consideration could be given to extending the discount provisions in the Council Tax to those caring for a child under 18. At present, regulations discriminate against those who care for a younger person. For example, two parents caring for a child under 18 who has severe learning difficulties will receive no discount on their Council tax. If the child is 18 or over, as long as he/she gets the higher rate of DLA care component, the parents will receive a discount of between 25-50% on their bill, depending on whether one or both parents care for over 35 hours a week. This would benefit a small number of families caring for the most severely disabled children.

Hospital visits – Our organisations have long asked for financial assistance for parents with the costs of visiting a sick child in hospital. This was also recommended in the report of the Bristol Royal Infirmary inquiry[41]. Unfortunately, the government rejected this recommendation.

The difficulty is that help with the costs of travelling to hospital for *treatment* are met through a statutory scheme for low income families. However the costs of travelling to hospital for *visiting* are not included within the scheme. The only way of having these costs met is through the discretionary Social Fund, or via help from the Family Fund. Low income families who are working or on benefits other than Income Support (e.g. Tax Credits) receive no help at all. Contact a Family and Family Fund suggest that the government introduce statutory help for all low-income families to cover the costs of hospital visiting. Furthermore, those parents whose children

[40] See: http://www.inlandrevenue.gov.uk/stats/personal-tax-credits/child-working-tcs-quarterly.pdf
[41] See: http://www.bristol-inquiry.org.uk/about/background/

are receiving care in a hospital some way from their homes should receive help towards visiting costs, regardless of their means. The Family Fund are asked for help towards such costs by some 2,200 families a year at a cost of £670,000. The Family Fund believe that their own funding would be better used to assist families to purchase items needed to improve the quality of the child's life at home, or to help with holidays for example.

Social Fund - The Social Fund is not able to meet the demands placed on it. Grants need to be extended beyond families on Income Support and Income Based Job Seekers Allowance to those who are in receipt of benefits such as the new Child Tax Credits and Working Tax Credits for low income earners. We believe that new grants should be made at particular trigger points such as a child starting school. The Family Fund believes that their grants are frequently used in cases where the Social Fund could help.

Winter fuel payments - Consideration should be given to extending winter fuel grants and Warm Front central heating grants to parents of disabled children on benefits. This kind of targeted support would be of relatively modest cost and would bring enormous benefits to the poorest families. These benefits would be seen in terms of both lower fuel bills and possibly, health benefits from vulnerable children not living in cold, under-heated homes.

Adaptations -The means test for Disabled Facilities Grants is assessed on the parents' ability to borrow money. Many parents of disabled children cannot afford to borrow money. If they are employed, they may feel concerned that they will have to reduce their hours at any moment, or give up work if their child becomes seriously ill. Some refuse a grant because they cannot afford to raise their contribution. Children's needs therefore go unmet.

The Family Fund report that they are frequently approached by Social Services to fund shortfalls in parental contributions. This is also the experience of staff on Contact a Family's helpline.

Final word

The government's commitment to end child poverty is not in question. However, disabled children and their families need specific actions, over and above generic policies for all children, in order to give them equal life chances. Only then will they stand any real chance of living an ordinary life which is not blighted by poverty and debt.

Section 7 – Appendices

Appendix 1 – Questions asked

Both the Family Fund face-to-face interviews and the Contact a Family website pop-up questionnaire asked identical questions.

How old is your child?

Under 6
6-11
12-17

How would you describe yourself?

Asian male
Asian female
Black African male
Black African female
Black Caribbean male
Black Caribbean female
White male
White female
Other Male
Other female

Are you currently…?

Employed full-time
Employed part-time
Self employed
Not in paid work

Which of the following statements most closely describes your family finances?

We are comfortably off and can afford to save for the future.
We manage OK but don't have much left for treats or saving for the future.
We are scraping by and robbing Peter to pay Paul.
We are struggling financially and have debt that is beginning to worry us.
We are in very serious financial difficulties.

Could you tell us roughly how much you owe in total (not including your ordinary mortgage but including any arrears and second loan)

I do not have any debts and clear any credit cards in full each month.
I owe under £500
I owe between £500 and £1500

I owe between £1500 and £5000
I owe between £5000 and £10000
I owe over £10000

What kind of debt do you have?

None
Bank/building society loan
Loan from elsewhere
Overdraft
Credit card
Mortgage/rent arrears
Catalogues
Council tax, water or fuel arrears
Other

Do you agree or disagree with the following statements:

Some of my debts are due to having additional costs arising from my disabled child.

Agree
Disagree
Does not apply

It is hard to get advice about debt in my area.

Agree
Disagree
Don't know

Families with disabled children should get increased benefits even if tax has to go up to pay for it.

Agree
Disagree
Not sure

Families in the Family Fund section of the sample were also asked an additional question.

Would the family be interested in taking part in further research about debt?

contact a family
for families with disabled children

Getting in contact with us

Freephone helpline for parents and carers

0808 808 3555

Access to over 170 languages

www.cafamily.org.uk

www.makingcontact.org