61% of families with disabled children struggle to pay their monthly bills.
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AS A SINGLE MOTHER WITH TWO AUTISTIC CHILDREN I STRUGGLE TO MAINTAIN A DECENT STANDARD OF LIVING... I FIND IT VERY DIFFICULT TO COPE NOT BEING ABLE TO BUY THE BASIC NECESSITIES THAT MY CHILDREN AND [I] NEED.

Respondant to a Social Finance survey, 2009
PURPOSE

Over the last two years, Social Finance worked with the Family Fund, Council for Disabled Children, Barnardo’s, Action for Children, KIDS, and others, to understand the financial needs of families with disabled children in the UK.

We undertook two in-depth surveys and analysed the responses of over 6,000 families with disabled children. This report presents a detailed picture of the financial challenges and barriers that they face. It forms part of Social Finance’s work on financial inclusion.

Our research revealed that families with disabled children disproportionately struggle to access appropriate financial advice and credit, have very low levels of savings to protect them against financial shocks and struggle to access appropriate benefits.

This paper presents our results in two ways: the first section describes key findings from our research, followed by a technical appendix with detailed survey data. It recommends steps to increase access to benefits, and the design and supply of financial services. Our survey responses have been weighted to be reflective of families with disabled children across the UK as a whole.

We hope that this report will encourage Government and the financial services industry to act to address their needs.
FOREWORD

I am delighted to be asked to write the foreword to this report. Poverty is a key issue in the lives of any families with disabled children. It is seen as an inevitable consequence for many families. This report highlights real opportunities to change this. The concept of early intervention and prevention in services is well established; translating that into financial planning is crucial. Maximising family income through benefits and ensuring appropriate financial products are available could make a real difference to families and make sure that at least this area of stress is alleviated.

This report is the product of two comprehensive surveys and collaboration between the Family Fund and Social Finance, whose purpose has been to chart families’ financial stability and attitudes towards financial services. Each section deals with a particular issue, building up a detailed understanding of the financial needs of families – from access to benefits, affordable credit to debt advice – tracing the difficulties and describing the impact on families. This report is an important contribution to the debate at a time when we are seeing significant change to family support. The survey brings out an important paradox – that fewer low income families claimed Disability Living Allowance (DLA) care and mobility components than higher income families. The changes to welfare reform and to the DLA in particular could provide a helpful vehicle to address long standing concerns to the low take up rates of DLA, particularly amongst those families on the lowest incomes.

This report should become a valuable reference point for the sector. It bears testimony to the fact that many families with disabled children excluded from mainstream financial services are entitled to better access to financial advice and tailored financial products.

Christine Lenehan
Director, Council for Disabled Children
Understanding the needs of families with disabled children

Families with disabled children face enormous challenges. Pressures are considerable and varied, but include fatigue, strain on relationships, limitations on mobility and consequent feelings of isolation. Over and above these emotional strains, families with disabled children face real financial challenges. These include:

- Meeting the additional cost of care for disabled children; and
- Overcoming the barriers to finding, and maintaining, employment.

Parents of disabled children face a higher cost of living due to the additional expense of providing specialist care. It is estimated that parents will spend three times as much raising a disabled child as it costs for non-disabled children. The extra spend includes items such as home adaptions, childcare, household bills, transport costs and medical bills.

The challenge of managing additional costs is exacerbated by the constraints on the parents’ ability to work full or even part time. Social Finance’s survey revealed that 37% of families with disabled children in the UK had no adult in full time employment, compared to a national average of 17%. Insufficient flexibility in working hours and the heavy time commitment of caring for a disabled child make it difficult to hold down employment. For example, one study suggests that parents of severely disabled children do 14 weekly loads of washing, compared with only two for non-disabled children.

As a result of additional costs and lower income, families with disabled children are more likely to be living in poverty. There are around three times the number of families with disabled children in the lowest income quintile as are in the top quintile. Many families experience significant financial distress. Research suggests that the birth or diagnosis of a disabled child can act as a ‘trigger event’ for poverty, as families face difficulties with employment, extra costs and family breakdown.

Raising a disabled child can increase pressure on parental relationships and make family life harder. A “Contact a Family” survey found
widespread ‘stress/depression’ (76%) and ‘tiredness/lack of sleep’ (72%) amongst parents of disabled children.\(^\text{12}\)

Despite the increased financial strain involved in caring for disabled children, families have little time to engage in financial planning.

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**Looking after a disabled child is time consuming and tiring, not leaving us much time to research [financial products].**\(^\text{13}\)

Responses to the Social Finance survey indicate that 69% of families with disabled children are worried about their financial situation and 61% struggle to pay their monthly bills. Nearly three quarters believe that the high costs of caring for a disabled child are the cause of their financial situation.\(^\text{14}\)

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**2 Access to benefits**

Given the barriers to finding and maintaining employment, it is unsurprising that many families with disabled children are highly reliant on benefit income. Our survey results indicated that the average household receives 36% of their income from benefits.\(^\text{15}\) Despite high levels of benefits take-up, 39% believe that their benefit income is insufficient\(^\text{16}\) and 44% of families are unsure about whether their household is accessing all the benefits that they are entitled to.\(^\text{17}\)

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**Having never had to claim benefits before I have found it very complicated and have often struggled to find comprehensive information.**\(^\text{18}\)

Families have little time to devote to financial planning and complex benefits forms – particularly around child Disability Living Allowances (DLA) – add to the difficulty.\(^\text{19}\) This leaves many families with a deficit in household income. A recent survey by Contact a Family indicated that almost a quarter (23%) of families with disabled children have gone without heating at some point in the last year whilst nearly three
quarters (73%) have gone without leisure and days out in the same period. Social Finance’s survey revealed that 50% of families have had to borrow to cover household bills and daily living expenses – an unsustainable situation.

We have had to borrow from family much to our distress, just to have enough to buy food and get to work.

Our survey also revealed substantial differences in benefit access by higher and lower income groups. Fewer low income families claimed the DLA care component and the DLA mobility component than higher income families. Families in the bottom income quintile received around £800 less per year in benefits than average for families with disabled children in the UK.

These results indicate that lower income families may not be claiming their full entitlement of benefits and could benefit from enhanced support and advice throughout the application process.

3 Access to savings and debt advice

Our survey revealed that 82% of families with disabled children currently have less than £1,000 in savings; 50% have no savings at all. Lack of savings is even more pronounced at the bottom end of the income spectrum, with 93% of respondents in the lowest income bracket having savings under £1,000.

Such low levels of savings mean that the majority of families with disabled children are operating with no financial buffer to carry them through household emergencies like their child going into hospital or replacing a broken washing machine or fridge. Our survey indicates that only 22% save on a regular basis.

The absence of a financial safety net was further reflected in the high levels of debt that our survey revealed. The average family owed over £2,000, primarily on credit cards.
We now find ourselves living off credit cards. To keep ‘afloat’ each month is a struggle to find the money to repay, but we don’t want to go bankrupt, we want help to get out of this nightmare.\(^{29}\)

Our survey revealed high levels of over-indebtedness among low income families. The average income of the lowest income quintile was 3.4 times higher than debt.\(^{30}\) This is substantially lower than the generally accepted threshold of 6.5 as a threshold for sustainable borrowing.

As a result, a disproportionately high number of families with disabled children, around 40%, have experienced some form of financial distress.\(^{31}\) Our survey revealed the rate of bankruptcy among families with disabled children to be five times higher than the UK average with Individual Voluntary Arrangements 20 times higher.\(^{32}\)

These findings suggest that families with disabled children, particularly those on low incomes, may need structured support to enable them to save regularly to reduce their need to borrow for household emergencies. Families with disabled children across the income range may need support to avoid getting trapped in cycles of indebtedness and access to appropriate debt management advice if their debt gets out of control.

### Access to affordable credit

In spite of the issues faced by some families with disabled children around over-indebtedness, lack of access to credit can negatively affect families’ ability to budget and absorb emergency expenditure like repairs to kitchen appliances or even a spike in the price of petrol. Our survey revealed that families with disabled children often struggle to access affordable credit.

Over 40% of families with disabled children applied for and were refused bank credit in the last three years,\(^{33}\) indicating that the supply of appropriate products is inadequate. We estimate that, of the 860,000 families in the UK with disabled children, over 300,000 are shut out of the mainstream (high street bank) lending market.\(^{34}\)
Of families that are borrowing – most often for household bills (49%), emergencies (39%) or holidays (40%) – the most common sources of credit were credit cards (used by 50% of families), loans from friends and family (48%), and overdrafts (42%).

Use of high cost home collected credit or “door step loans” was three times higher among families with disabled children (15%) than the UK family average (5%). 22% of those in the bottom income quintile in our survey had used door step loans. Door step and pay day loans are used by families with disabled children as they are easy to access at home and have reduced credit criteria. However, APRs (annual percentage rates) range from 230% to well in excess of 1,000%.

One explanation for mainstream credit exclusion is that many families receive a high proportion of their income from benefits. Around 230,000 families with disabled children in the UK receive more than three quarters of their income from benefits.

Conversations with high street banks revealed that they are often unwilling to lend against benefit income because many non-disability-related benefits, like job seekers allowance, can be awarded and removed at short notice. As disability benefits often represent a relatively stable income stream, it seems probable that banks are not accurately assessing the risk of lending to many families with disabled children.

It is hard to get credit when you care for a disabled child as you can’t work enough hours to qualify under the usual bank’s criteria. I only earn £62.50 a month and some banks need a minimum of £100 earnings (not benefit) just to open a current account, so no chance of being accepted for a loan!

Encouraging banks to allow disability related benefits to count among stable income streams could potentially transform access to affordable credit by families with disabled children in the UK.
MOST PEOPLE ON LOW INCOME AND DLA FEEL LIKE SCROUNGERS AND GREEDY FOR ASKING FOR ADVICE AND HELP ABOUT FINANCIAL MATTERS AS PEOPLE BELIEVE THAT BECAUSE WE GET BENEFITS FOR DISABLED CHILDREN SHOULD BE GRATEFUL FOR THE HELP WE GET.
Access to appropriate banking

Our research shows that access to a bank account is not, in itself, a problem among families with disabled children. Our survey revealed that 1% of families with disabled children did not have access to a bank account which compares to a figure of 4% for the UK population in general.\(^4\)

Nevertheless, our survey revealed that more than half of families with disabled children had paid penalty fees for missed payments or unauthorised overdrafts in the last six months.\(^1\) More than 30% of families are paying the equivalent of over £100 in penalty fees each year.\(^3\)

I feel ripped off by the high street banks... For example, £2 over an overdrawn limit can cost me £25. Also the bill company will charge me something like £25 to £35 just because the bank refused to pay them. So it cost me about £60 and I still haven’t paid the bill, just charges. It’s like victimisation of the poor.\(^4\)

In light of these fee levels, we believe that many of these families would be better served by Jam Jar Accounts that charge flat monthly fees. These accounts:

- Allow customers to split their account balance into ‘Jam Jars’ for spending, saving and bill payment;
- Support customers to improve their budgeting and bill payment behaviour through low balance alerts and automated transfers of funds between Jam Jars; and
- Give customers access to trained ‘Money Managers’ that can provide budgeting advice and referrals on to specialist consumer services (e.g. debt advice or Citizens Advice Bureau) where necessary.
Designing products and services to meet families’ needs

In addition to developing an understanding of the financial needs of families with disabled children, the surveys undertaken by Social Finance asked families what they would want from financial services providers.

Several key themes from families’ responses in terms of what they want are summarised below:

*Understanding and appreciation of their needs* – families want financial service providers to demonstrate an appreciation of the financial challenges families with disabled children face.

We are too embarrassed to ask for help. If there was an organisation that understood exactly the needs of a family, who have a disabled child, we could go there, knowing we could trust we are getting the best advice and not feeling ashamed of our situation.\(^{45}\)

*Products tailored to their needs* – Families want financial products that are specifically designed to meet their financial needs and lifestyle constraints.

[We need] easier access and people who can tailor or recommend products to suit people’s needs rather than just to meet targets.\(^{46}\)

*Clear Financial Advice* – Families want a trusted advisor who puts the families’ interests first, understands the challenges they face and is not out to make personal profit or serve a profit-making employer.

It would take the worry off our minds to know we have someone we trust to turn to that won’t use us and take advantage.\(^{47}\)
Families like mine often find that although finances are important to them...there is simply no time to do more than the basics.\textsuperscript{48}

*Full service provider* – Families indicated that they would like a one stop shop that could provide advice and access to appropriate financial products so that travelling is reduced to a minimum and families aren’t “given the run-around” when it comes to accessing financial products.

A one stop shop would be invaluable, where you didn’t have to repeat the same information time and time again in order to get advice.\textsuperscript{49}

*Flexibility and transparency* – Families wanted clear and simple structures, no loopholes, fair payment and transparent pricing.

*Accessibility* – The service should focus on physical accessibility by providing easy home access through an online web portal, home visits and mail, coupled with conceptual accessibility by developing simple products that are set out clearly without the use of confusing jargon.

I wouldn’t know who to go to for a loan or might not understand all the jargon that is in the small print and such like.\textsuperscript{50}
7 Recommendations for government and financial services providers

Our survey results clearly showed that families with disabled children have a range of financial needs that are currently not being met. It is clear that these families could benefit from:

- support to maximise their income;
- access to financial advice; and
- tailored financial products.

SUPPORT TO MAXIMISE INCOME

Although benefits seek to reduce financial inequality, our research found that the poorest families with disabled children actually receive less in benefits than many wealthier families. This suggests that lower income groups are encountering obstacles in accessing their full benefit entitlements.

We recommend that Government provides enhanced support and resources to assist families with disabled children, particularly those on low incomes, to navigate the benefits application process. Support should include:

- clear guidance on benefits eligibility;
- simple guides for application forms and assessment processes; and
- telephone and face-to-face support services.

Such assistance must be both physically and conceptually accessible in order to overcome the barriers faced.

ACCESS TO FINANCIAL ADVICE

Our research found high levels of indebtedness, significant incurrence of penalty fees and precariously low levels of savings among families with disabled children. These indicators of financial distress could be markedly improved through early financial advice to prevent financial problems deteriorating into crisis situations.
IT’S REALLY HARD FOR LENDERS TO UNDERSTAND HOW COMPLEX LIVING WITH DISABLED CHILDREN IS, AND ESSENTIALLY HOW DIFFICULT IT IS TO MAINTAIN MONTHLY REPAYMENTS. I FIND IT VERY DIFFICULT AT TIMES AND WOULD LIKE A MORE FLEXIBLE SERVICE.
We recommend that Government, potentially in partnership with financial services providers, make financial advice widely available to families with disabled children. Advice should be affordable, timely, easily accessible and should specifically recognise the unique requirements of these families.

TAILORED FINANCIAL PRODUCTS

Families with disabled children struggle to access appropriate banking and credit services. Our survey confirms that the use of inappropriate financial products exacerbates financial hardship and leaves families financially and emotionally strained.

We recommend that financial services providers consider the unique circumstances of families with disabled children and provide appropriately tailored products. Examples of this should include:

- banking products that promote saving and minimise penalty fees;
- affordable credit that recognises disability related benefits as a stable income stream; and
- insurance products (including travel and carer insurance) that are appropriately priced based on individual circumstances.
Conclusion

Financial difficulties exacerbate other social problems such as unemployment, social exclusion and long-term illness. Families with disabled children represent a group with specific financial needs that differ from those of the UK population as a whole and which mainstream services are not currently meeting. Addressing this gap requires positive action from both Government and financial services providers.

Our survey findings also hold lessons for addressing the financial needs of other vulnerable groups such as the elderly, ex-offenders, care leavers and recent migrants. It cannot simply be assumed that services that meet the needs of the mainstream population will necessarily meet the needs of vulnerable groups.

While the current work has been informative as to the needs of families with disabled children, we would encourage further research into the specific financial needs of other disadvantaged groups.
DETAILED SURVEY RESULTS
BACKGROUND

To better understand the financial situation and needs of families with disabled children, Social Finance worked with The Family Fund, Every Disabled Child Matters and Contact a Family to conduct two consumer surveys. The surveys assessed levels of financial exclusion, indebtedness, credit risk, dependence on benefits and financial product demand. Additional questions placed respondents' answers within the context of their income band and household composition. As such, the survey findings go beyond a simple description of financial need, to explore the relationship between families and financial services.

The two surveys were sent out to over 25,000 families with disabled children and more than 6,000 responses were analysed. Responses were received from families across a broad income range. However, responses were heavily skewed to the lower end of the income spectrum (as shown in Table 1.1).

As a result, we have weighted the responses we received according to the Households Below Average Income (HBAI) income quintiles methodology that adjusts for household size and number of dependents to more accurately reflect levels of disposable income. By weighting the responses, the results more accurately represent the overall income distribution of families with disabled children in the UK. Therefore, references to “average” throughout this report refer to a weighted average to reflect the overall UK population of families with disabled children.

58% of the survey respondents were from households in the bottom income quintile which compares to 28% of the UK population with disabled children. This group has between £0 and £244 in weekly disposable income.

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i HBAI Income Quintiles use a process of equivilisation to reflect the fact that larger households require a greater level of income to have the same disposable income as smaller households. Source: http://www.poverty.org.uk/technical/hbai.shtml
### Table 1.1: Income Distribution of Survey Population and UK Population of Families with Disabled Children

<table>
<thead>
<tr>
<th>Income Quintile</th>
<th>Weekly Disposable income*</th>
<th>Survey Population</th>
<th>UK Population of families with disabled children*</th>
<th>UK Population</th>
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</thead>
<tbody>
<tr>
<td>Top</td>
<td>£626+</td>
<td>3%</td>
<td>8%</td>
<td>20%</td>
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<tr>
<td>Second</td>
<td>£452–625</td>
<td>7%</td>
<td>12%</td>
<td>20%</td>
</tr>
<tr>
<td>Mid</td>
<td>£340–451</td>
<td>11%</td>
<td>22%</td>
<td>20%</td>
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<tr>
<td>Fourth</td>
<td>£245–339</td>
<td>22%</td>
<td>30%</td>
<td>20%</td>
</tr>
<tr>
<td>Bottom</td>
<td>£0–244</td>
<td>58%</td>
<td>28%</td>
<td>20%</td>
</tr>
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</table>

SURVEY RESPONDENTS

Our analysis split respondents by household income quintiles. These income quintiles were weighted to take into account household size, including number of dependents, in order to more accurately reflect standards of living. The quintiles relate to earned income only. The majority of responses – 3,675 out of a total of 6,387 – were from the bottom income quintile (see Fig 1.1).

Figures 1.2 to 1.4 illustrate that the respondents to the surveys were predominantly mothers (86% females) in the 31–45 year age range. The respondents tended to be the primary carer of the disabled child (71%) with only a minority being in employment: 16% of respondents worked part-time and 7% worked full-time.
Understanding the financial needs of families with disabled children

Fig 1.3 Respondents by Age

- Under 21: 9%
- 22–30: 11%
- 31–35: 18%
- 36–45: 43%
- 46–55: 18%
- Over 56: 1%

Fig 1.4 Respondent’s Role in Family

- Primary carer: 71%
- Parent: 66%
- Work part-time: 16%
- Work full-time: 7%
- Part-time carer: 2%
- Grandparent: 1%

Note: percentages do not add up to 100 as respondents have more than one role
SECTION 1. DEMOGRAPHIC INFORMATION

1.1 HOUSEHOLD CHARACTERISTICS

Total household size, number of children and number of disabled children did not vary significantly with income, as shown in Figure 1.5. The average household contained around four people, with two children, of which one was disabled. The bottom income quintiles tended to have marginally larger families, with more children and more disabled children.

Figure 1.6 shows an interesting relationship between the age of the disabled child and household income. Low income quintiles have the lowest proportion of disabled children in the 0–11 age brackets and the highest proportion of children in the 12–25 age brackets. In contrast, the higher income quintiles have the highest proportion of disabled children in the 0–11 age bracket and the lowest proportion of older disabled children. This relationship may be driven by the more time consuming care requirement of older disabled children and the limitations this puts on parents’ employment options.
1.2 EMPLOYMENT

In the bottom income quintile, over 60% of households had no adults in full-time employment, compared to an average of 37% for families with disabled children. The majority of families had one adult in full-time employment, with only 5% of families having two parents that work full-time.

Fig 1.6 Percentage of Respondents with Disabled Children of Different Ages

Fig 1.7 Percentage of Adults in Work per Households by Income Quintile
1.3 BENEFITS CLAIMED

The benefit claimed by the highest proportion of families with disabled children is the care component of Disability Living Allowance (DLA) at 88%. Figure 1.8 shows that 85% of the bottom income quintile claimed this benefit which is 5% less than the fourth income quintile and mid income quintile. At an average of 72%, DLA mobility component is claimed by fewer families overall than DLA care component and at a rate of 68% for the lowest income quintile.

A quarter of families in the top income quintile claimed income support which is higher than the second income quintile (18%) and mid income quintile (17%). In addition, a greater percentage of the top income quintile households claimed housing benefit compared to the second income quintile and mid income quintile. These results are counter-intuitive and suggest that families in the top income quintile may simply have been more proficient at claiming benefits than the other quintiles. This indicates that there is a need for better and/or more accessible benefits advice for families with disabled children.

**Fig 1.8 Benefits Claimed by Income Quintile**
1.4 BENEFITS INCOME

The average value of benefits received by households with disabled children was £9,504 per year. Added to the average earned income of £16,753 (see Table 1.2 overleaf), this gives an overall total household income of around £26,000 per year.

Figure 1.9 shows that the bottom income quintile received £8,704 in annual benefits income which is £1,500 per year less than the fourth income quintile. This group received 10% less in benefits than the average which suggests that this group experience challenges in claiming the level of benefits that they are entitled to.

The range in benefit income received within each income quintile is shown in Figure 1.10. 20% of the bottom income quintile claimed above £1,000 per month in benefits compared to 36% of the fourth income quintile and 34% of the mid income quintile. This further supports the notion that the bottom income quintile was not accessing the full amount of benefits to which they were entitled.

Fig 1.9 Families’ Total Annual Benefits Income by Income Quintile

<table>
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<th>Income Quintiles</th>
<th>Benefits Income (£)</th>
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<tr>
<td>Bottom</td>
<td>£8,704</td>
</tr>
<tr>
<td>Fourth</td>
<td>£10,279</td>
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<tr>
<td>Mid</td>
<td>£9,793</td>
</tr>
<tr>
<td>Second</td>
<td>£9,635</td>
</tr>
<tr>
<td>Top</td>
<td>£8,282</td>
</tr>
</tbody>
</table>

Average: £9,504
1.5 BENEFITS AS PERCENTAGE OF INCOME

On average, the bottom income quintile received benefits worth £167 per week which accounted for 62% of total household income. The top income quintile received £159 per week representing 18% of total household income.

Figure 1.11 demonstrates that for every level of income, families with disabled children had a greater proportion of income as benefits than the UK population as a whole.
There was a smaller gap between families with disabled children and the UK averages at the lower end of the income spectrum (shown by the converging lines on Figure 1.11), again suggesting that families at the lower end of the income spectrum may have been encountering obstacles to claiming their full entitlement of benefits in relation to their child's disability.

Table 1.2 shows that the average earned household income of families with disabled children was £16,753 per year although there was a large range between the highest earners and the lowest earners. The top income quintile earned £37,320; more than double the average, whilst a typical household in bottom income quintile earned only £5,252. Of those in top income quintile, 36% were earning over £50,001.

Table 1.2 Families’ Annual Income and Weekly Benefit Income by Income Quintile

<table>
<thead>
<tr>
<th>Income Quintile</th>
<th>Annual earned income</th>
<th>Annual benefit income</th>
<th>Total annual income</th>
<th>Average weekly benefit income</th>
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<tr>
<td>All*</td>
<td>£16,753</td>
<td>£9,504</td>
<td>£26,257</td>
<td>£183</td>
</tr>
<tr>
<td>Top</td>
<td>£37,320</td>
<td>£8,282</td>
<td>£45,602</td>
<td>£159</td>
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<tr>
<td>Second</td>
<td>£28,100</td>
<td>£9,635</td>
<td>£37,735</td>
<td>£185</td>
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<tr>
<td>Mid</td>
<td>£20,875</td>
<td>£9,793</td>
<td>£30,668</td>
<td>£188</td>
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<tr>
<td>Fourth</td>
<td>£13,952</td>
<td>£10,279</td>
<td>£24,231</td>
<td>£198</td>
</tr>
<tr>
<td>Bottom</td>
<td>£5,252</td>
<td>£8,704</td>
<td>£13,956</td>
<td>£167</td>
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</table>

* Weighted to reflect overall UK population of families with disabled children, see explanation in introduction.
SECTION 2. FINANCIAL NEEDS AND ATTITUDES

2.1 CERTAINTY OF BENEFITS SITUATION

Figure 2.1 shows that there was increased uncertainty among the bottom income quintile about whether they were accessing all benefits that they are entitled to (42% uncertain vs. 24% for the top quintile). Families in the lowest income group could have seen an uplift of as much as £100 per week by claiming their full entitlement of benefits.ii

Fig 2.1 Certainty of Benefits Situation by Income Quintile

Response to the question: Do you think that your household receives all of the welfare benefits you are eligible for?

- Yes
- No
- Don’t know
2.2 WHY MORE BENEFITS AREN’T ACCESSED

The most prevalent reason cited for why more benefits were not accessed is that families did not know which benefits their household was eligible for. Most families surveyed ‘strongly agreed’ that benefits application forms were too complicated and ‘agreed’ that they did not fully understand the benefits application process. In contrast, most families disagreed with the statement that applying for benefits is not a priority.

**Fig 2.2 Agreement with Statements about Access to Benefits**

![Bar chart showing responses to statements about access to benefits]

2.3 FINANCIAL ATTITUDES

The majority of families surveyed found it hard to pay monthly bills and were worried about their financial situation. A high proportion of families with disabled children (72%) had to borrow money to cover extras such as holidays or consumer durables. For the bottom income quintile, nearly eight out of ten families had to borrow for these extras. Overall, an average of 62% did no long term financial planning.

Figure 2.3 clearly shows that the bottom income quintile had the most concerns about their financial situation. Three out of ten families within the top earning quintile did not know who to turn to for financial assistance.

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iii Weighted to reflect overall UK population of families with disabled children.
advice or where to go to borrow money; for the lowest earning quintile, around half (48%) did not know who to turn to for financial advice and a similar percentage (43%) did not know where to go to borrow money.

Respondents were asked a series of questions that explored their level of financial knowledge, resilience and concerns with their financial situation. Statements were rated on a five point scale from strongly agree to strongly disagree. Figure 2.3 shows the percentage of respondents who strongly agreed or agreed with statements about their financial need.

**Fig 2.3 Agreement with Financial Statements by Income Quintile**

- **I don’t know who to turn to for advice about our finances**
- **We don’t do any long-term financial planning**
- **We have to borrow money to cover extras (like holidays or a new washing machine)**
- **I am worried about our financial situation**
- **I don’t know where to go to borrow money**
- **We often find it hard to pay our monthly bills**

% of Respondents

**Income Quintiles**

- Top
- Second
- Mid
- Fourth
- Bottom
WE HAVE FOUR DISABLED CHILDREN, SO ME AND MY PARTNER ARE BOTH CARERS. WE LIVE ON INCOME SUPPORT WITH CARERS ALLOWANCE TO TOP IT UP. NO ONE WILL GIVE US LOANS OR A MORTGAGE BECAUSE THEY CLASS US AS NOT WORKING. BUT WE DO WORK 24 HOURS A DAY, 365 DAYS A YEAR, WE DO ALL THE MEDS AND PHYSIO, USE NO HELP FROM ANYWHERE. OUR LIFE IS OUR KIDS.
2.4 SERIOUS FINANCIAL PROBLEMS

43% of families with disabled children had faced financial distress in one of the following four ways:

- County Court Judgement (CCJ), a legal decision forcing an individual to pay creditors, often through the debtor’s employer;
- Debt Management Plan (DMP), an informal repayment alternative for unsecured credit usually brokered by a third party;
- Individual Voluntary Arrangement (IVA), a formal repayment alternative to bankruptcy;
- Bankruptcy.

CCJs are the most prevalent serious financial problem; over a quarter of families had faced such a judgement (33% for the lowest income quintile). The rate of bankruptcy of 5% was five times higher than the UK’s average of 1% whilst the average IVA rate for families with disabled children of 10% was twenty times the UK average of 0.5%.
Understanding the financial needs of families with disabled children

**Fig 2.4 Serious Financial Problems by Income Quintile**

* Weighted to reflect overall UK population of families with disabled children

<table>
<thead>
<tr>
<th>Income Quintiles</th>
<th>CCJs</th>
<th>DMP</th>
<th>IVA</th>
<th>Bankrupt</th>
<th>Any of these</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All</strong>*</td>
<td>27%</td>
<td>21%</td>
<td>10%</td>
<td>5%</td>
<td>43%</td>
</tr>
<tr>
<td>Top</td>
<td>6%</td>
<td>6%</td>
<td>0%</td>
<td>0%</td>
<td>12%</td>
</tr>
<tr>
<td>Second</td>
<td>20%</td>
<td>11%</td>
<td>7%</td>
<td>1%</td>
<td>32%</td>
</tr>
<tr>
<td>Mid</td>
<td>21%</td>
<td>21%</td>
<td>7%</td>
<td>5%</td>
<td>36%</td>
</tr>
<tr>
<td>Fourth</td>
<td>28%</td>
<td>19%</td>
<td>11%</td>
<td>4%</td>
<td>44%</td>
</tr>
<tr>
<td>Bottom</td>
<td>33%</td>
<td>27%</td>
<td>12%</td>
<td>8%</td>
<td>53%</td>
</tr>
</tbody>
</table>
2.5 REASONS FOR FINANCIAL SITUATION

The predominant reason for financial distress, cited across income bands, was the high cost of looking after a disabled child. Figure 2.5 demonstrates that nearly three quarters of families with disabled children (71%) believed that their financial situation was due to the high cost of looking after a disabled child.

The second greatest factor cited as a cause of financial distress was that benefit income was insufficient. Overall, 39% of families believed that benefit income was insufficient, including 48% of the bottom income quintile and 57% of the top income quintile.

Having insufficient time to manage finances was another significant factor for survey respondents including 57% of the top income quintile. This observation highlights the need for affordable and accessible services to assist families with disabled children manage their finances to maximise their income, and make best use of the funds available to them.
Understanding the financial needs of families with disabled children

**Fig 2.5 Reasons for Financial Situation by Income Quintile**

<table>
<thead>
<tr>
<th>Income Quintiles</th>
<th>High cost of looking after disabled child</th>
<th>Loss of income upon birth of child</th>
<th>Loss of job for other reasons</th>
<th>Family split</th>
<th>Struggle to find time to manage finances</th>
<th>Benefit income not sufficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>All*</td>
<td>71%</td>
<td>23%</td>
<td>17%</td>
<td>20%</td>
<td>23%</td>
<td>39%</td>
</tr>
<tr>
<td>Top</td>
<td>71%</td>
<td>43%</td>
<td>14%</td>
<td>0%</td>
<td>57%</td>
<td>57%</td>
</tr>
<tr>
<td>Second</td>
<td>69%</td>
<td>26%</td>
<td>14%</td>
<td>21%</td>
<td>38%</td>
<td>29%</td>
</tr>
<tr>
<td>Mid</td>
<td>75%</td>
<td>33%</td>
<td>13%</td>
<td>19%</td>
<td>22%</td>
<td>33%</td>
</tr>
<tr>
<td>Fourth</td>
<td>70%</td>
<td>23%</td>
<td>17%</td>
<td>19%</td>
<td>25%</td>
<td>34%</td>
</tr>
<tr>
<td>Bottom</td>
<td>69%</td>
<td>16%</td>
<td>21%</td>
<td>21%</td>
<td>18%</td>
<td>48%</td>
</tr>
</tbody>
</table>

*Weighted to reflect overall UK population of families with disabled children.
2.6 REASONS FOR BORROWING

Table 2.1 shows that half of families (49%) who borrowed money did so in order to cover household bills making it the single greatest factor for borrowing. Families also borrowed to pay for holidays (40%) and to cover emergencies (39%). The lowest income quintile were most likely to borrow to cover household bills and to provide emergency money.

### Table 2.1 Reasons for Borrowing by Income Quintile

<table>
<thead>
<tr>
<th></th>
<th>All*</th>
<th>Top</th>
<th>Second</th>
<th>Mid</th>
<th>Fourth</th>
<th>Bottom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household bills</td>
<td>49%</td>
<td>42%</td>
<td>42%</td>
<td>51%</td>
<td>47%</td>
<td>53%</td>
</tr>
<tr>
<td>Holidays</td>
<td>40%</td>
<td>35%</td>
<td>45%</td>
<td>42%</td>
<td>38%</td>
<td>40%</td>
</tr>
<tr>
<td>Emergency money</td>
<td>39%</td>
<td>29%</td>
<td>34%</td>
<td>38%</td>
<td>40%</td>
<td>42%</td>
</tr>
<tr>
<td>Home improvements</td>
<td>38%</td>
<td>40%</td>
<td>40%</td>
<td>37%</td>
<td>39%</td>
<td>38%</td>
</tr>
<tr>
<td>Gifts</td>
<td>24%</td>
<td>18%</td>
<td>22%</td>
<td>24%</td>
<td>25%</td>
<td>27%</td>
</tr>
<tr>
<td>Leisure activities</td>
<td>22%</td>
<td>20%</td>
<td>24%</td>
<td>20%</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Other</td>
<td>18%</td>
<td>18%</td>
<td>23%</td>
<td>16%</td>
<td>18%</td>
<td>16%</td>
</tr>
<tr>
<td>Home adaptations</td>
<td>14%</td>
<td>14%</td>
<td>14%</td>
<td>13%</td>
<td>15%</td>
<td>14%</td>
</tr>
</tbody>
</table>

* Weighted to reflect overall UK population of families with disabled children
2.7 TYPES OF LOAN PRODUCT USED

Credit cards, loans from families and friends and overdrafts were the most frequently used loan products amongst families with disabled children. Credit cards were used by 50% of families with disabled children and were favoured by the higher income quintiles whilst families from the lowest income quintile most frequently used loans from family and friends.

Over 22% of the bottom income quintile had taken out door step loans compared to an average of 15% among families with disabled children.

Fig 2.6 Types of Loan Product by Income Quintile
2.8 FINANCIAL ADVICE

The majority of families (63%) had never received financial advice, despite the expressed financial worries. Figure 2.7 shows the trend for lower income groups to be less likely to seek financial advice, with 71% of the lowest income quintile never having received financial advice.

**Fig 2.7 Receipt of Financial Advice by Income Quintile**

<table>
<thead>
<tr>
<th>Income Quintile</th>
<th>Has Received Financial Advice</th>
<th>Has Not Received Financial Advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bottom</td>
<td>71%</td>
<td>29%</td>
</tr>
<tr>
<td>Fourth</td>
<td>64%</td>
<td>36%</td>
</tr>
<tr>
<td>Mid</td>
<td>58%</td>
<td>42%</td>
</tr>
<tr>
<td>Second</td>
<td>53%</td>
<td>47%</td>
</tr>
<tr>
<td>Top</td>
<td>58%</td>
<td>42%</td>
</tr>
</tbody>
</table>

*iv Weighted to reflect overall UK population of families with disabled children*
WHEN YOU’RE CARING FOR SPECIAL NEEDS CHILDREN YOU CAN’T ALWAYS GO TO WORK, AS YOU ARE ON CALL WHEN THEY ARE AT SCHOOL, AND THEY TEND TO BE OFF SCHOOL MORE THAN NON SPECIAL NEEDS CHILDREN.
SECTION 3. SPECIFIC AREAS OF FINANCIAL VULNERABILITY

3.1 HIGH PENALTY FEES

In comparison to the UK average, access to a bank account was not a problem: over 99% of respondents had access to a bank account, compared to a national figure of 96%. However, half (51%) of families had paid bank penalty fees in the last six months with one in five families (21%) having paid over £100. Figure 3.1 shows that household income did not appear to be a significant predictor of a family’s likelihood of incurring bank penalty fees.

Of note, more than a quarter of respondents paid more in bank penalty fees in the last six months than the cost of a managed or “Jam Jar” bank account, which is £75 for the same period. Jam Jar accounts divide income into different pots or “Jam Jars” to help account holders with their budgeting and prevent them from incurring penalty fees from bounced cheques or late fees for utilities or other regular bills.

A third of respondents claimed to be willing to pay for a managed Jam Jar account.

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Fig 3.1 Penalty Fees paid in the last 6 months by Income Quintile

---


vi Based on a basic account at Secure Trust Bank.
3.2 LOW VALUE OF SAVINGS

Survey respondents tended to have low levels of savings and would therefore have very little capacity to cope with unexpected expenditure without borrowing. Figure 3.3 shows that an average of 51% had no savings whatsoever whilst 82% had less than £1,000 in savings.
This means that accidents and breakages could have had a severe impact on financial stability with a potential consequence being poor borrowing decisions. For the lowest income quintile, 93% had less than £1,000 in savings with two thirds having no savings at all. 78% of respondents did not save regularly, as shown by Figure 3.4.

The vulnerability of low savings can be mitigated to some extent by effective insurance. Two thirds of respondents expressed an interest in purchasing carer accident insurance to cover short term care. Similarly, over half of respondents expressed an interest in purchasing travel insurance that would cover their disabled child.

**Fig 3.4 Responses to the question: Do you Save Regularly?**

Yes 22%
No 78%

### 3.3 HIGH LEVELS OF DEBT

The average family owed over £2,000 in debt which was primarily on credit cards. Figure 3.5 shows that for each income quintile, around £1,000–£1,200 was owed on credit cards with a figure of £1,632 for the highest income quintile. Credit card debt accounted for approximately half of the overall levels of debt. Families in the lowest income quintile displayed the lowest use of credit cards but the highest use of store cards, which are often easier to acquire but have higher interest rates.
3.4 OVER-INDEBTEDNESS

The debt to (disposable) income ratios of respondents illustrated in Figure 3.6 demonstrate that those in the bottom income quintile were over-indebted. The bottom income quintile had annual income only 3.4 x greater than their level of debt, which is substantially lower than the commonly accepted borrowing threshold of 6.5 x.\textsuperscript{vii} The fourth income quintile are also on the threshold of over-indebtedness.

\textbf{Fig 3.5 Levels of Debt by Type and Income Quintile}

\begin{figure}[!h]
\centering
\includegraphics[width=\textwidth]{Fig3.5.png}
\caption{Levels of Debt by Type and Income Quintile}
\end{figure}

\textbf{Fig 3.6 Income to Debt Ratio by Income Quintile}

\begin{figure}[!h]
\centering
\includegraphics[width=\textwidth]{Fig3.6.png}
\caption{Income to Debt Ratio by Income Quintile}
\end{figure}

\textsuperscript{vii} Based on discussions with several banks.
3.5 ACCESS TO CREDIT

In the last three years, 42%\(^{viii}\) of families had been refused credit in the form of a bank account, credit card or loan. Half of the lowest income quintile had been refused credit over the same period compared to 24% of the top income quintile.

**Fig 3.7 Credit Refusal by Income Quintile**

![Bar chart showing credit refusal by income quintile](chart.png)

Response to the question: In the last three years, have you ever applied for and been refused a bank account, credit card or loan?

- Yes
- No

\(^{viii}\) Weighted to reflect overall UK population of families with disabled children
3.6 MISSED LOAN REPAYMENTS

In addition to a lack of access to credit, those that did secure loans had problems making the payments. The average family missed over two loan repayments in the last 12 months, as shown by Figure 3.8. This suggests that the loan terms were not well-suited to the needs of the borrower.

The lowest income quintile had the most problems making loan repayments and missed an average of almost three payments per year. If these repayments were monthly, this would amount to approximately one quarter of a year’s repayments.

These results suggest there is a need for tailored loan products that allow a greater degree of repayment flexibility to accommodate the needs of families with disabled children.

Fig 3.8 Number of Missed Loan Repayments by Debt Type and Income Quintile

<table>
<thead>
<tr>
<th>Income Quintiles</th>
<th>Credit card</th>
<th>Catalogue shopping</th>
<th>Loan from family or friends</th>
<th>Overdraft</th>
<th>Personal loan</th>
<th>Store card</th>
<th>Face to Face</th>
<th>Doorstep loan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bottom</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fourth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mid</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Second</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Top</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
References

1 As noted by the Every Disabled Child Matters campaign in Disabled children & child poverty (2007)
2 Joseph Rowntree Foundation, Paying to Care: the costs of childhood disability (1998)
3 See Detailed survey results, Section 1.2
5 New Philanthropy Capital, Ordinary Lives (June 2005)
8 Ibid.
9 Such as CCJs, IVAs and bankruptcy. See Detailed survey results, Section 2.1.
11 One Plus One, Growing Together, or Drifting Apart? (2007)
12 Contact a Family, No Time For Us (2003)
14 See Detailed survey results, Section 2.5
15 See Detailed survey results, Section 1.5
16 See Detailed survey results, Section 2.5
17 See Detailed survey results, Section 2.2
19 See Detailed survey results, Sections 1.3 and 2.5
20 Contact a Family, Counting the Costs (2010)
21 See Detailed survey results, Section 2.6
23 See Detailed survey results, Section 1.3
24 See Detailed survey results, Section 1.4
25 See Detailed survey results, Section 3.2
26 Research commissioned for the Consumer Credit Counselling Service (CCCS) by the Financial Inclusion Centre identified 4.3 million UK households with no savings and 1.1 million households with savings under £1,000. This equates to 21% of all families with less than £1,000 in savings and 17% with no savings at all.
27 See Detailed survey results, Section 3.2
28 See Detailed survey results, Section 3.3
30 See Detailed survey results, Section 3.4
Such as CCJs, debt management plans, IVAs or Bankruptcy. The rate at which families with disabled children experience bankruptcy was five times higher than the national average and the rate of IVAs was 20 times the national average. For more information, see Detailed survey results, Section 2.4.

See Detailed survey results, Section 2.4

See Detailed survey results, Section 3.4

Social Finance Analysis

See Detailed survey results, Section 2.6

Social Finance Analysis

See Detailed survey results, Section 2.7


See Detailed survey results, Section 2.7


See Detailed survey results, Section 3.1

Ibid.


Ibid.

Ibid.

Ibid.

Ibid.

Ibid.
ACKNOWLEDGEMENTS

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