



Department
for Education

Review of the Family Fund Trust

Appendix B – Summary Reports from the Main Strands of the Research

Research Report

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Review of the Family Fund Trust

In April 2012, the Department for Education commissioned the Moorhouse Consortium (including Cognizant and OPM) to undertake a rapid review of the Family Fund Trust (FFT). The review, carried out between April 2012 and July 2012, had five main objectives:

1. To compare the efficiency and cost effectiveness of the current Family Fund model with alternative delivery models
2. To assess the process of awareness raising with families and allocation and distribution of funds
3. To identify the short and long term impact of initial and repeat funding on families
4. To measure the qualitative impact of home visits
5. To review the appropriateness of the role of UK Government as a direct grant provider.

Alongside the main report there is a research brief and five supporting appendices. These are:

- Appendix A: Detailed Methodology and Research Tools
- Appendix B: Summary reports from the main strands of research
- Appendix C: Individual Family Case Study Reports
- Appendix D: Alternative models
- Appendix E: Raw survey data by country, first time applicants and multiple applicants

A. Survey of families: Summary Report

Our Sample

In total, 2,848 families submitted responses to the online survey to capture views and experiences of the Family Fund Trust. The survey was intended to target families from the four countries in the UK, and to include first time applicants and families who have applied multiple times. Our achieved sample is set out below:

	Type of applicant (no. of respondents)			Total
	1 st time	Multiple	Not stated	
England	682	1368	185	2235
Scotland	91	173	23	287
Wales	54	105	23	182
Northern Ireland	39	90	15	144
				2848

Reading this Report

Unless specified, all findings are represented as a percentage of the 2,848 responses received. For some questions, less than 2,848 responses were received and so the number of responses received has been stated. Some questions allowed respondents to select multiple answers, so in these cases the total of all responses may exceed 100%. All figures and percentages are rounded to whole numbers.

The findings relate to *all* respondents unless stated. Analyses were conducted by country and by type of applicant (first-time or multiple) however with the former there were no substantial variations to report. Differences in the findings by type of applicant have been reported where relevant and response rates are given as a proportion of the type of respondent (for multiple applicants (1,736 responses) and for first-time applicants (866 respondents)).

We looked for differences across groups and reported any differences greater than 10%-15% as appropriate to the particular question¹. Because the sub-group analysis is based on quite small 'cell' counts, confidence tests were not appropriate as the margin of error would be far too great. For this reason, any sub group differences that are reported are only indicative rather than statistically significant.

Further analyses comparing these survey findings with those from the PWC Review of the Family Fund Survey (2005) and the Family Fund Trust Customer Satisfaction Survey (2010) are provided in section 5 of this chapter.

¹ In most instances the differences reported on are between first-time applicants and multiple applicants.

1. Background Information

Profile of Respondents

Country of Residence

An analysis of the survey respondents by country of residence indicates that:

- 79% live in England (n=2,235)
- 10% live in Scotland (n=287)
- 6% live in Wales (n=182) and;
- 5% in Northern Ireland (n=144)

Caring Responsibilities

When asked about how many disabled children they have in their care:

- The majority of parents/carers (85%) reported that they provide care for one disabled child (n=2,420)
- 13% reported that they care for two disabled children (n=361)
- Less than 3% reported that they care for three or more disabled children (n=66)

Nature of Child's or Children's Disability

Respondents were asked about the nature of the disability of the child/children they care for, and were invited to select multiple responses (many respondents have children with more than one disability).

Disabilities ranged from autistic spectrum disorders, which were the most commonly reported form of disability (55%, n=1,580), to heart disease, the least commonly reported disability (3%, n=84).

Table A1 shows the full list of disabilities that respondent's reported. *Note: as respondents selected multiple answers the number of responses does not add up to the number of respondents (n=7,823 responses).*

Table A1 Nature of children's disabilities

Disability	Percentage	Number of responses
Autistic spectrum disorders	55%	1580
Learning disabilities	51%	1463
Speech and language difficulties	38%	1084
Behaviour disorders	36%	1036
Other (e.g. diabetes, cancer, ADHD, other physical disorders (such as arthritis, CF), mental health problems)	25%	718
Sensory impairments	21%	591
Epilepsy or convulsions	11%	314
Asthma	11%	313
Cerebral palsy	9%	266
Named syndrome	8%	230
Downs syndrome	5%	144
Heart disease	3%	84

Base: 2848

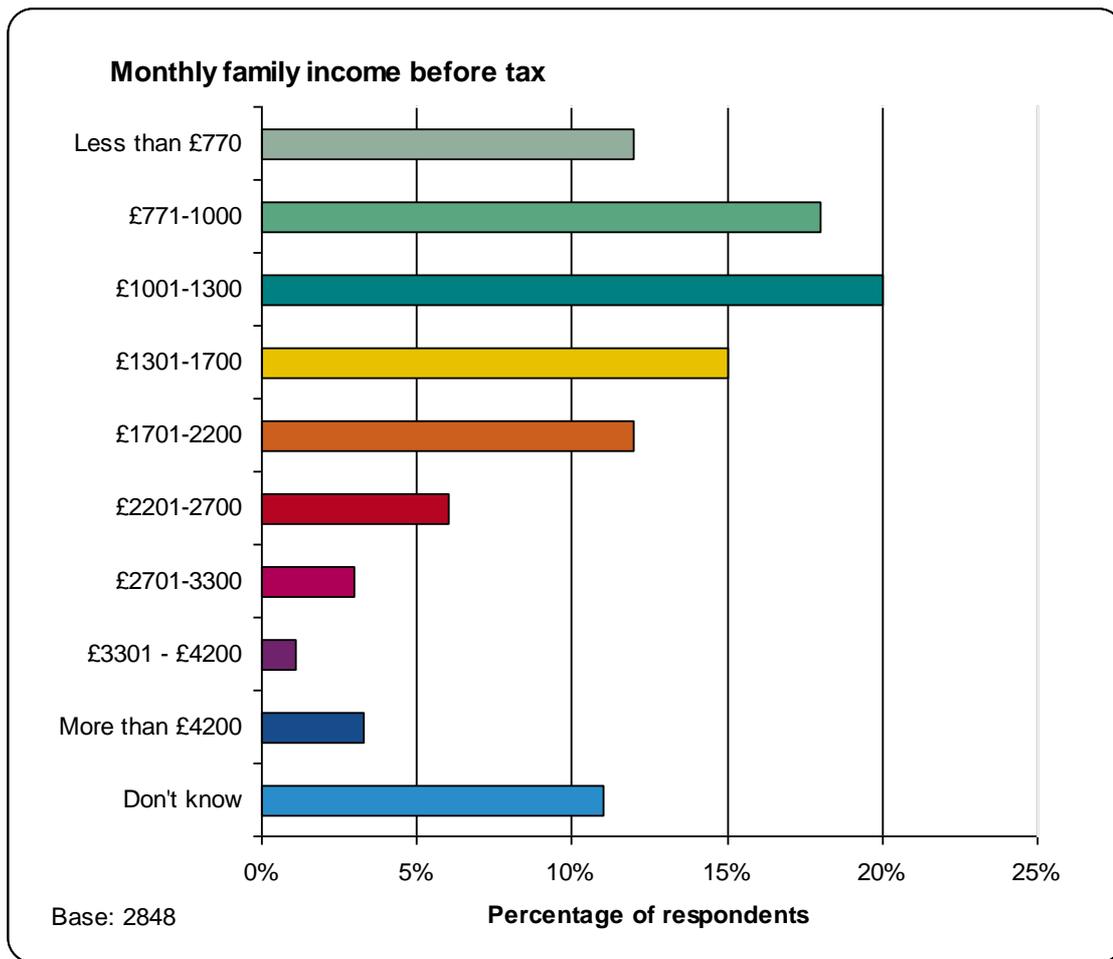
Family Income

Respondents provided information about their monthly family income before tax (to include all sources of income).

- The largest proportion of survey respondents (20%) reported a household income of £1,001 – £1,300 (n=562)
- 18% reported an income of £771 – £1,000 (n=509)
- 15% of respondents reported an income of £1,301 – £1,700 (n=423)
- 12% of respondents reported an income of less than £770 (n=330)
- 12% of respondents reported an income of £1,701 – £2,200 (n=337).

Graph A1 below shows the proportion of respondents within these income bands. Whilst the larger proportions of respondents are on lower incomes (below £1700), it is notable that a high proportion reported that their monthly family income before tax was more than £4200. It is not possible to understand why this may be, although it may be linked to family size or other factors that the survey findings do not capture.

Graph A1 Monthly family income before tax



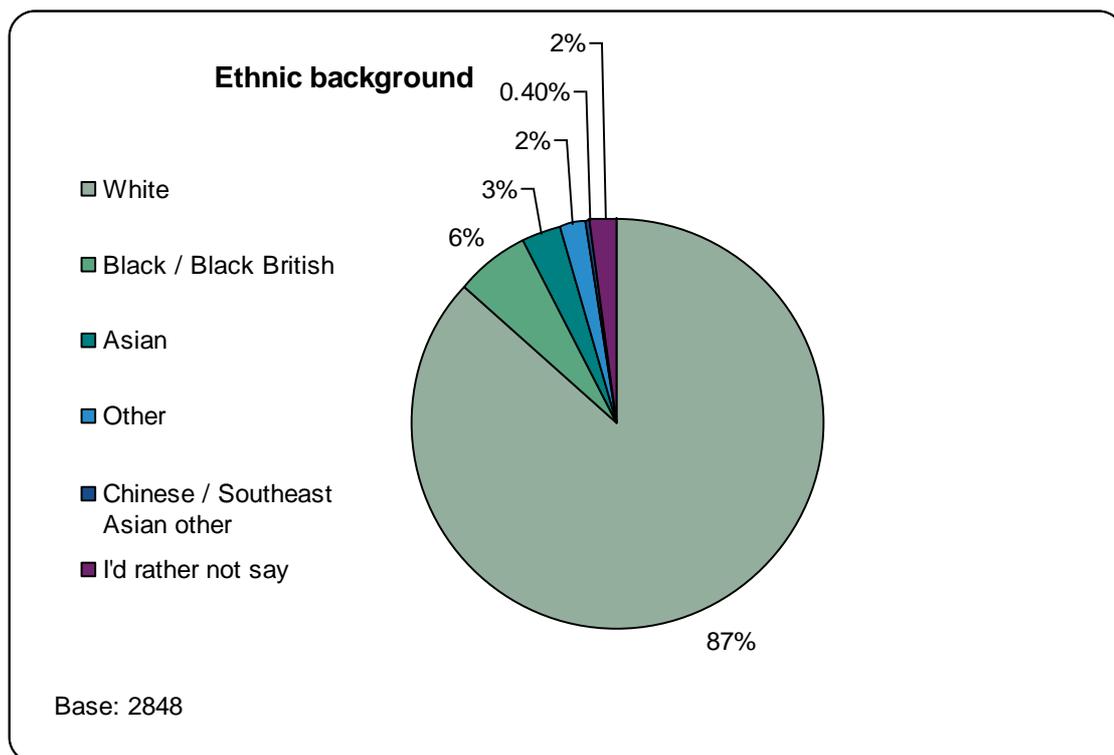
Ethnic Background

An analysis of respondents' ethnic backgrounds shows that:

- The majority of all respondents (87%) reported their ethnic background to be White (British, Irish or Other) (n=2,471)
- 6% of respondents reported their ethnic background to be Black or Black British (n=177)
- 3% of respondents reported their ethnic background to be Asian or Asian British (n=81)
- 2% of respondents selected 'other' to describe their ethnic backgrounds (n=63)
- Less than 1% of respondents reported their ethnic background to be Chinese or other South-East Asian (n=10)
- Less than 2% of respondents preferred not to state their ethnic background (n=46).

Graph A2 provides an overview of the ethnic backgrounds reported by respondents.

Graph A2 Ethnic background



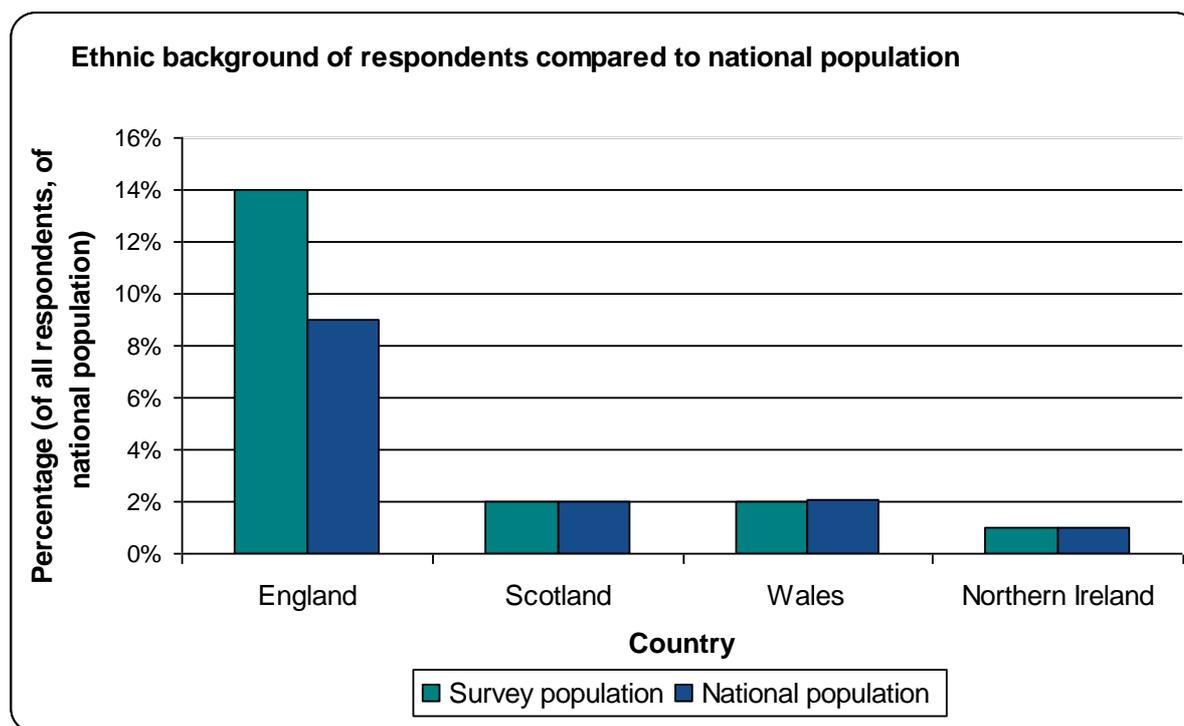
Analysis by country shows that:

- 84% of respondents from England reported their ethnic background to be White British, Irish or Other, 14% of respondents reported a BME background, and 2% did not say.
- 96% of respondents from Scotland reported their ethnic background to be White British, Irish or Other, 2% of respondents reported a BME background, and 2% did not say
- 97% of respondents from Wales reported their ethnic background to be White British, Irish or Other, 2% of respondents reported a BME background, and 1% did not say.
- 99% of respondents from Northern Ireland reported their ethnic background to be White British, Irish or Other, and 1% of respondents reported a BME background

Graph A3 shows how these proportions compare to national figures on the BME population in England, Scotland, Wales and Northern Ireland. It shows that:

- A higher proportion of respondents from England (14% of all respondents) reported a BME background compared to the national BME population (9%)
- The same proportion of survey respondents from Scotland and Wales (2% respectively) reported a BME background compared to the national BME populations (also 2% respectively)
- The same proportion of survey respondents from Northern Ireland (1%) reported a BME background compared to the national BME population (1%)

Graph A3 Ethnic background by country



Pressure and Needs Facing Families

Respondents were asked about the greatest pressures and needs that their families are facing in an open question. 94% of all respondents provided an answer (n=2,670), and the key issues highlighted were:

- **Financial pressures:** lack of income; decrease of income due to cutting work hours to care; cuts to welfare benefits; cuts to specialist services; cost of specialist equipment / help, e.g. to aid mobility, sensory abilities, learning abilities
- **Emotional pressures/stress:** single parenting; lack of shared caring; balancing needs of disabled and non-disabled children; finding time to be together as a family; finding time to spend with non-disabled siblings, and with partner; loneliness and isolation
- **Housing needs:** lack of equipment, unsuitable accommodation, lack of space
- **Transport needs:** cost and access to suitably sized vehicles; expense and time linked to maintenance of family car
- **Education needs:** lack of access to schooling; exclusion; teachers lack of understanding/knowledge of how to deal with conditions
- **Bullying and discrimination:** lack of wider understanding about disabilities
- **Caring:** keeping disabled children motivated, e.g. to attend school; keeping disabled children healthy; dealing with challenging physical behaviour, e.g. violence; dealing with challenging emotional behaviour, e.g. anger, frustration, anxiety; limited time to go out on day trips / holidays as a family; lack of access to respite care; providing stimulating, safe and appropriate activities for all children dependent on their needs; time and access to

attend specialist/hospital appointments; lack of support and information from services e.g. doctors

Personal Budgets

The majority of respondents (72%), reported that they/their child or children **do not** have a personal budget, direct payment, individual payment or personal health budget from their local authority or local NHS for their disabled children (n=2,047).

18% of respondents reported that they do receive one of these budgets, and 10% reported that they did not know (n=285).

It is possible that the high proportion of respondents that are not in receipt of a form of budget could include people that are waiting to receive one but were not at the time of the survey, and include respondents that opted out of direct payments.

Membership of Forums

When asked whether they were part of a local Parent Carer Forum or similar support group with links to their local authority the majority of respondents (76%) reported that they were not (n=2,171). 18% of respondents reported that they were part of such groups (n=518) and 6% did not know (n=159).

Of those respondents that reported being a member of a support group, the majority (97%) specified what type of group (n=505). Responses included:

- Local or national charity support groups, e.g. National Autistic Society, Contact a Family, Carers UK, Rethink, Mencap, Kaleidoscope,
- Local support groups for specific conditions/disabilities, e.g. autism, ADHD, Down's syndrome

An analysis of respondents by membership of Parent Carer Forum or support group by income does not show any trends. It is plausible that those respondents that are involved in groups may find that the support helps to alleviate pressures or meet social needs, but the survey findings do not provide insight into this.

2. Applying for a Family Fund Grant

2.1 Recent Grant History

Respondents were asked in which calendar year they made their most recent grant applications and the findings show that:

- The majority of respondents (60%) reported they made their most recent application in 2011 (n=1,712)
- 34% of respondents reported they made their application in 2012 (n=980)
- 4% of respondents reported they made their application in 2010 (n=118)
- 1% of respondents reported that they could not remember when they made their most recent application (n=38)

When asked about the number of times they have applied for Family Fund grants, the largest proportion of respondents said that they had applied just once (30%, n=866).

Table A2 shows a breakdown of the number of applications for Family Fund grants made by respondents.

Table A2 Number of Family Fund grant applications made

Number of applications	Percentage	Number of respondents
One application	30%	866
Two applications	23%	653
Three applications	16%	463
Four applications	9%	267
Five applications	5%	144
Six applications	3%	74
Seven or more applications	7%	209
Can't remember	6%	172

Base: 2848

When asked how many of their applications had led to a Family Fund grant being awarded, the largest proportion of respondents reported that they had one successful application (31%, n=892). This reflects the large proportion of respondents that had only applied for a grant once.

Table A3 below shows the proportions of respondents by the number of applications that successfully led to a Family Fund grant being awarded.

Table A3 Number of applications leading to grant being awarded

Number of applications leading to award of grant	Percentage	Number of respondents
No successful applications	0.3%	8
One application	31%	892
Two applications	23%	655
Three applications	16%	447
Four applications	9%	261
Five applications	5%	146
Six applications	3%	73
Seven or more applications	8%	214
Can't remember	5%	152

Base: 2848

Challenges When Applying for a Family Fund Grant

The majority of respondents (89%) reported that they did not experience any specific challenges when applying for a Family Fund grant (n=2,544), 9% of respondents reported that they did have some challenges when applying (n=243) and 2% of respondents reported that they did not know (n=61).

Improvements to the Application Process

When asked how they would improve the Family Fund application process in an open question, the majority of survey respondents provided a response (79%, n=2,241). A number of comments were positive (reflected by the lack of challenges faced by the majority of respondents).

Respondents praised the application process and Family Fund staff, with comments such as

- 'Easy-to-use'
- 'Staff were really great at answering questions and offering support'
- 'I wouldn't change anything, I think it's a wonderful thing that they do'
- 'Think the service is great, very helpful, and much needed support'
- 'It is a great benefit for the whole family'

In particular, the online application process was greatly appreciated and seen by respondents to be faster and advantageous through reducing the amount of paper used.

Some respondents made suggestions as to how the application process could be improved, and the main comments were through:

- Being able to make applications online: this comment may have been made by first-time applicants responding to the survey, as they are not able to apply online. It could also imply that respondents are unaware of the website facility and that there may therefore be scope for improving the promotion of the online application process.

- Being able to make applications on a year by year basis without waiting for 12 months exactly
- Receiving a reminder to know when a re-application can be made
- Less cumbersome applications for re-applications, where details can be updated rather than having to complete another lengthy form again
- Faster response to telephone calls, some respondents had to wait a long time (up to half an hour) on hold before being able to talk to someone at Family Fund
- Having another way to access application details when calling up the Family Fund, if an applicant has misplaced their personal application number
- Faster application processing time

2.2 The Application Process

How Applicants First Found Out about the Fund

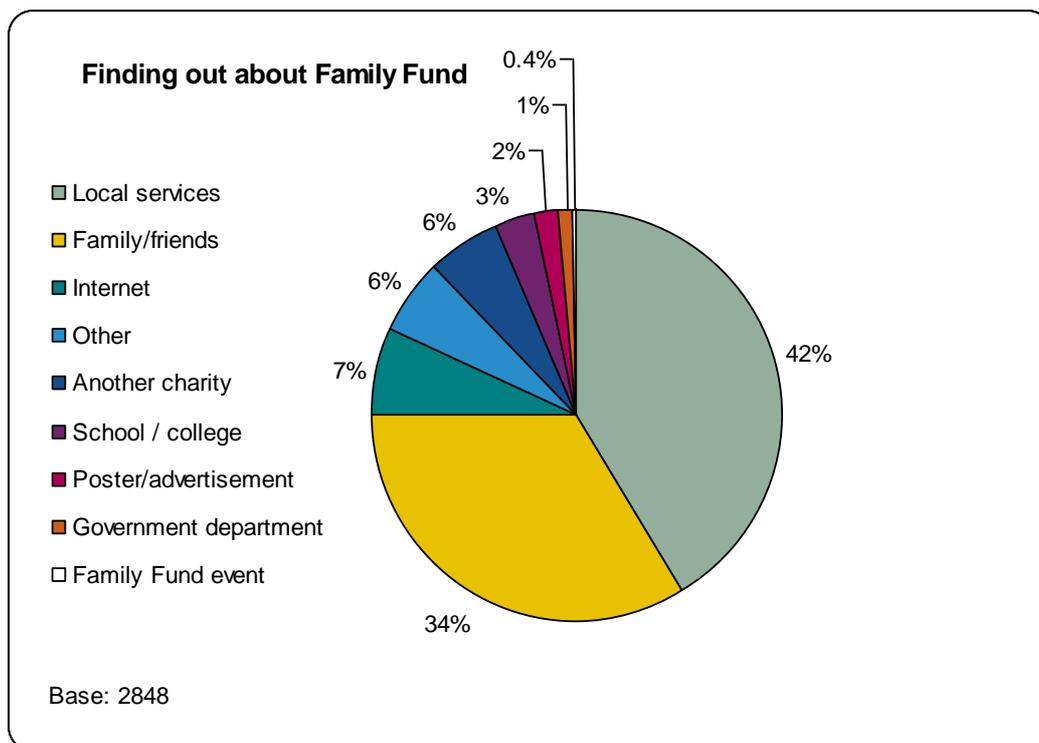
shows the different ways in which respondents first heard about the Family Fund. The largest proportion of respondents (42%) found out about the Family Fund from a local service (e.g. social care worker, health visitor, local authority, school, Citizen's Advice Bureau) (n=1,194), and over a third of respondents heard through a friend or family member (34%, n=962).

Other sources from which respondents heard about the Family Fund include:

- Local charities or local branches of national charities, such as Barnardos, National Autistic Society
- Carer support groups
- Children's Centres, Sure Start centres
- Health or social care services/professionals, e.g. doctors, specialist nurses, physiotherapists, CAMHS, hospital staff, portage workers

It should be noted that a lower proportion of first-time applicants found out about the Family Fund from local services (30%, n=259) compared to multiple applicants (45%, n=782). This could imply that multiple applicants have more contact with local services (possibly because they may have children with complex needs and therefore require multiple grants), or that applicants that find out about the grants through local services are more likely to make multiple applications (possibly due to the level of information and support received). However the survey findings do not provide further insight into this.

Graph A4 Finding out about Family Fund



How Applicants Obtained their Last Application Form

- The majority of survey respondents (63%) obtained their last application form from the Family Fund over the Internet (n=1,781)
- 27% of respondents requested their application directly from Family Fund by telephone or letter (n=781)
- 7% of respondents obtained their last application form from a third party professional (n=204)
- 3% of respondents obtained their last application form from other sources, such as local charities, support groups, friends, or events organised by Family Fund or other organisations (n=82).

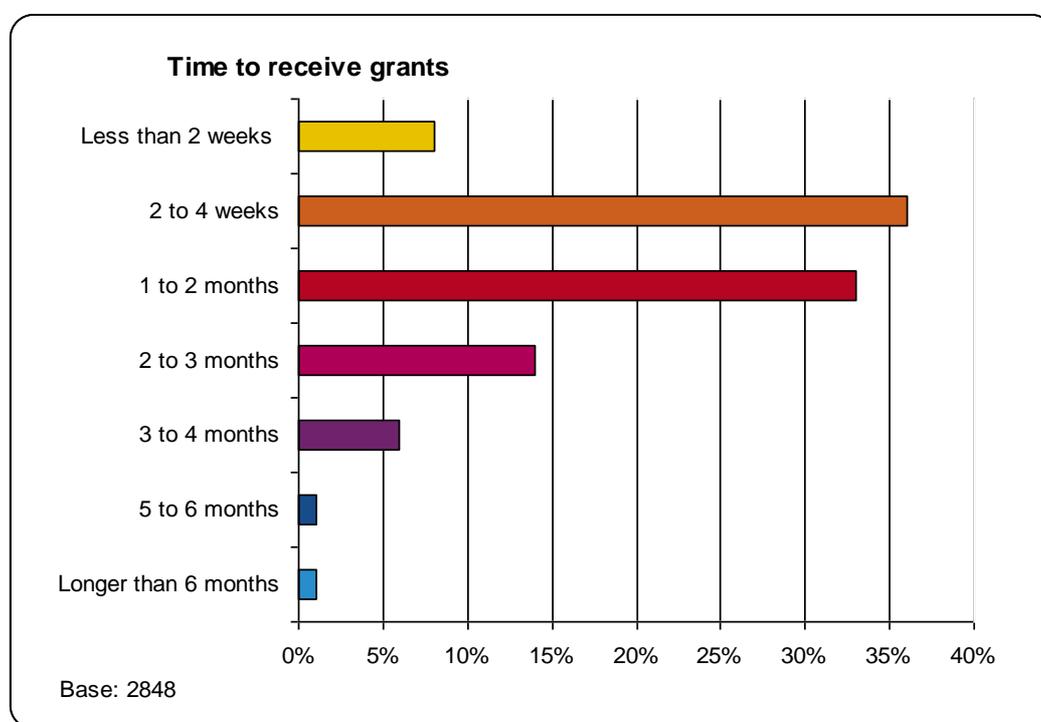
Analysis by type of applicant shows that a lower proportion of first-time applicants (43%, n=369) obtained their application from the Family Fund website, compared to multiple applicants. This could reflect the way in which the process for first-time applicants requires submission in hard copy, or suggest that people are less likely to know about downloadable form if they have never applied for the Family Fund before.

Time Taken from Application Submission to Grant Receipt or Outcome

Error! Reference source not found. shows the breakdown of how long it took for respondents to receive their grants after submitting their application. The majority of respondents (70%) reported that it took between two weeks and two months to receive their grant after submitting their applications (n=1,973).

A higher proportion of first-time applicants (63%, n=540) had to wait between one and three months for their grant after submitting their applications compared to multiple applicants (40%, n=685). This could be as a result of first-time applications taking slightly longer to process, given that more information and documents have to be provided, e.g. proof of receipt of welfare benefits or evidence of Disability Living Allowance award. This could also be related to the fact that some grant applications might be 'pushed through', such as those from families who have applied before.

Graph A5 Time to receive grant after submitting application



Views on the Application Process

Respondents that had submitted multiple responses were asked their views on the application process:

- The largest proportion of respondents felt that the application process had improved through time (38%, n=1,078).
- 28% of respondents felt that the process had stayed the same (n=802)
- 4% of respondents felt that the process has worsened through time (n=114).

It should be noted that 30% of respondents (n=854) have only applied once and therefore could not say whether the application process had improved, worsened or stayed the same.

Respondents were also asked to identify why they felt the application process had improved or worsened. Multiple responses were selected by participants, therefore the total number of responses (n=1,922) was higher than the number of respondents (n=1,192).

Of the respondents who found the application process had improved (n=1,078), most identified that this was due to new ways of applying for the Family Fund, e.g. online applications (n=817). Improvements were also related to:

- Familiarity of the application process (n=343)
- Time taken to be informed of the application decision (n=314)
- General improvements in the application process (n=290)
- Other reasons, such as details of first application being in Family Fund system, and text message reminders (n=26)

Of the respondents who felt the application process had worsened, the majority indicated that they found this was because of the time taken to be informed about decisions (n=62).

2.3 Purpose of Your Most Recent Application for the Grant

When selecting reasons for their most recent applications for the Family Fund grant, respondents were able to select multiple responses, therefore the number of responses to this question (n=4,105) was much higher than the total number of overall responses to the questionnaire (2,848). The largest proportion of respondents (46%) made their most recent application to relieve the stress of caring for a disabled child (n= 1,238). Table A4 below outlines the distribution of the reasons for making the most recent applications to the Family Fund.

Table A4 Reasons for making most recent application to Family Fund

Reasons	Percentage	Number of responses
To relieve stress	43%	1,238
To help cope with my child / children's challenging behaviour	29%	813
To replace household equipment which is old or broken	27%	769
Other (e.g. holidays, day trips, educational/sport equipment)	26%	749
To help with mobility difficulties	7%	204
To help with extra household tasks such as washing	7%	199
To help with shopping difficulties	5%	133

Base: 2848

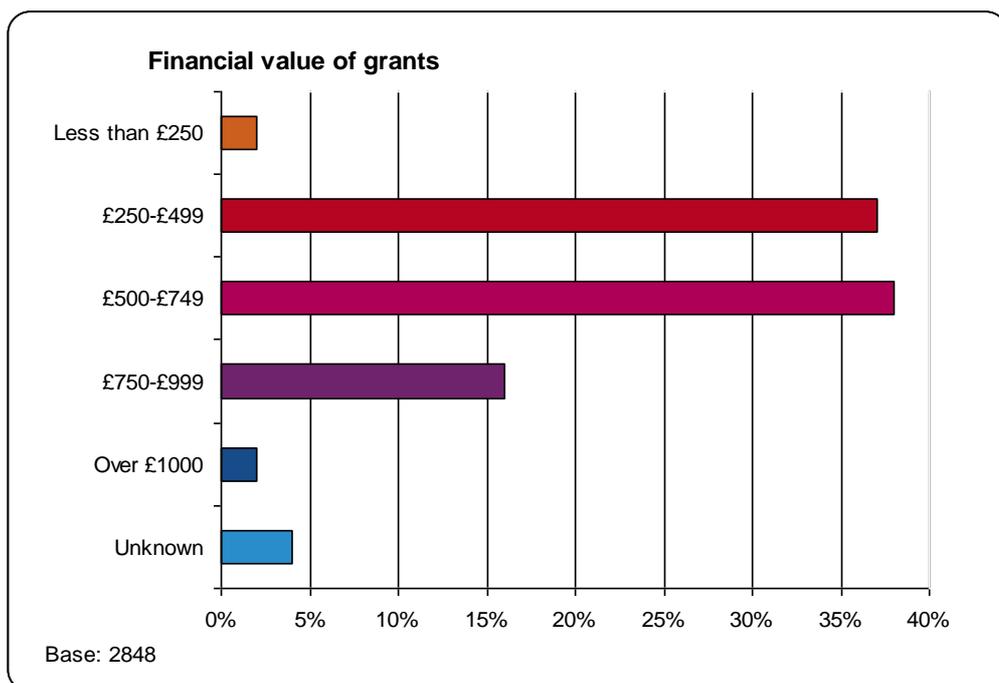
Amounts Received

Error! Reference source not found. shows the reported financial value of the last grant received by respondents.

The largest proportions of respondents received grants of between £500 and £749 (38%, n=1095) and between £250 and £499 (37%, n=1048).

Higher proportions of first-time applicants received higher value grants than multiple applicants. For example 46% of first-time applicants received grants to the financial value of £750 - £999 (n=397), whereas only 4% of multiple applicants received grants of this value (n=66). This could reflect a policy of offering higher value grants to first-time applicants.

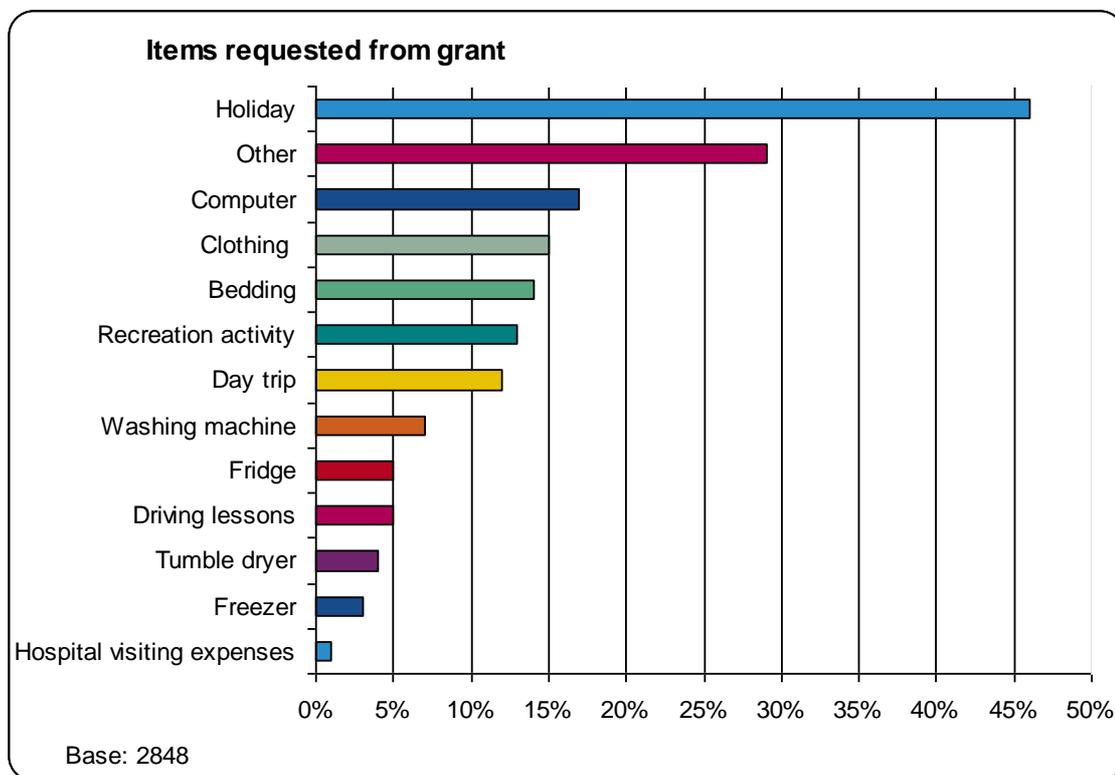
Graph A6 Reasons for making most recent application to Family Fund



Items Requested through the Family Fund

Survey respondents requested a number of different items when applying for a Family Fund grant. Respondents were able to select multiple answers to this question. The most commonly requested item by respondents was a holiday including overnight stays (46%, n=1,294). Graph A7 shows the distribution of items requested by percentage of respondents.

Graph A7 Items requested through grant



2.4 Outcome of Most Recent Application

When asked about the outcome of their most recent application:

- The majority of respondents (55%) received all that they requested (n=1,572)
- 39% of respondents received some of what they requested (n=1,109)
- 4% of respondents were still waiting for the outcome of their application (n=111)
- 2% of respondents received items that were not what they expected (n=43)
- Less than 1% (n=13) had their applications rejected or couldn't remember what the outcome of their last Family Fund application was

A higher proportion of first-time applicants received all that they requested in their grant application (69%, n=599), compared to multiple applicants (49%, n=858). This could be a reflection of only considering the first item requested by multiple applicants.

2.5 Support from an Adviser

Respondents were asked about whether they had received a visit/telephone call from a Family Fund advisers on their first application and were invited to give multiple responses (n=2,923 responses).

- Analysis indicates that approximately 50% of respondents received a home visit (n=1,438) and 26% respondents received a telephone assessment (n=752) from a Family Fund adviser.

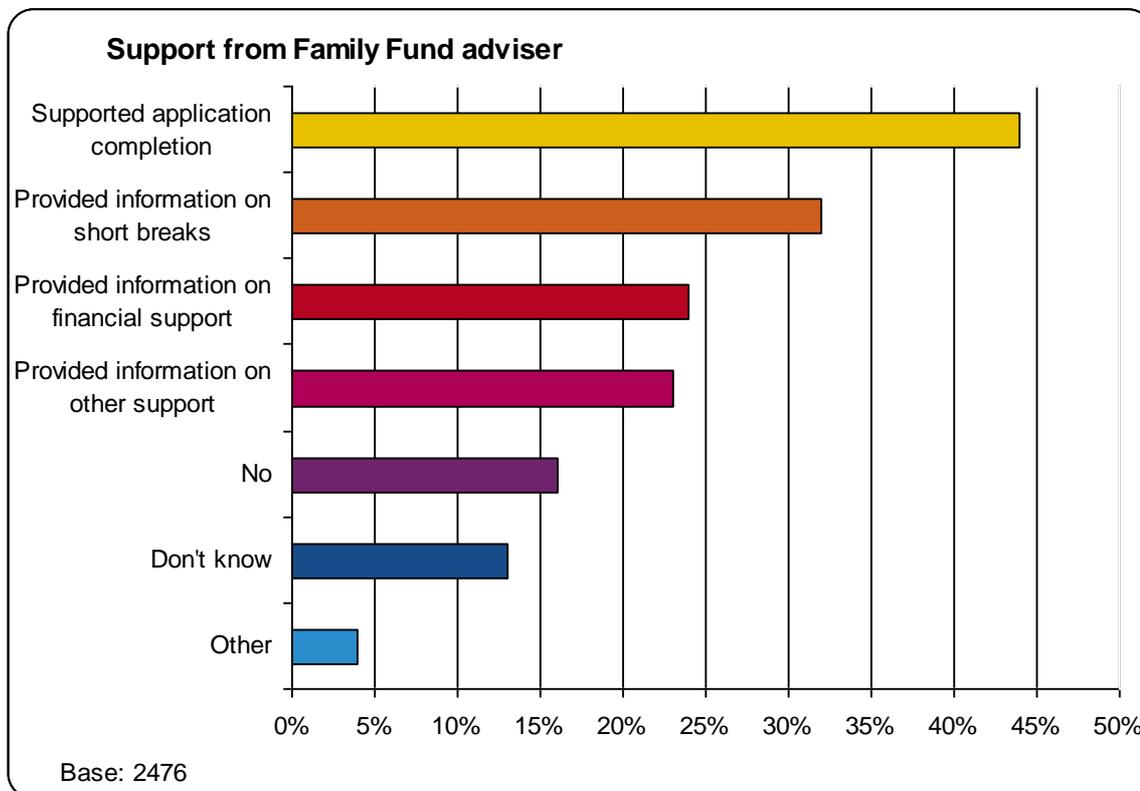
- 13% of respondents did not receive any sort of home visit or telephone call (n=372), 12% could not remember (n=346) and less than 1% were still waiting for a decision on their last application (n=15).

Those respondents that received visits/telephone calls, could not remember, or were still waiting for a decision (n=2,476), were asked about specific types of support received from the advisor. Of these, 44% of respondents received support to complete the grant application (n=1,100); and 28% also received information about short breaks (n=788). Graph 8 presents this information.

Comparison by type of respondents shows that 10% of first-time applicants did not receive a home visit or telephone call from a Family Fund adviser (n=93). It is not clear from the survey data why this may be.

A slightly higher proportion of multiple applicants received home visits (52%, n=903) compared to first-time applicants (46%, n=398). Conversely, a higher proportion of first-time applicants (42%, n=366) received telephone assessments compared to multiple applicants (20%, n=354). Again, it is not clear from the survey data why this may be.

Graph A8 Support received from Family Fund adviser



2.6 Comparing the experience with other organisations

The majority of survey respondents (82%, n=2,032) had not applied for similar grants from other organisations, such as local authorities, local NHS, Social Fund other charities. 15% of respondents had applied for similar grants (n=418) and 1% did not know whether they had applied for similar grants or not (n=26).

Of those who applied for other similar grants (n=418), the majority of respondents had been successful in their applications (61%, n=253). 22% of respondents had been partially successful (n=94) and 13% had not been successful (n=54) whilst 4% did not know the outcome of their application (n=17).

When asked to compare their experiences:

- 58% of those respondents that had made applications to other similar grants confirmed that the Family Fund application experience was better than experiences of other organisations (n=243)
- 35% of respondents reported that they had similar experiences (n=144)
- 5% had experiences that were no different to those of other organisations (n=20)
- 2% had worse experiences with Family Fund than with other organisations (n=10).

Of those who had made applications for similar grants or loans, 355 respondents made comments identifying the key differences between Family Fund and other organisations' application processes. Most comments were positive and focused on the following points:

- Family Fund provides a more caring, supportive, understanding, personal, **compassionate service**, including during telephone calls and home visits
- **Good communication**, faster response rate/decision making process
- **Easy to understand** application process
- No requirement to provide lots of **information** with application
- **Flexible** and **guaranteed** source of funding
- **Other sources of funding** were suggested by the Family Fund if it was deemed unsuitable or insufficient

Negative comments about the Family Fund application process compared to other organisations funding applications included:

- More frequent applications can be made to the Social Fund (DWP fund for welfare benefits recipients)
- Family Fund application can be a longer process, with telephone calls, application forms, and home visits

3. Impact of the Grant

Impact for Respondents, their Children and Families

When asked about the impact they felt the grant had for their child and for themselves:

- A high proportion of survey respondents (80%) felt that the grant made a big difference to their children (n=2,271) and 83% of respondents felt that it made a big difference to themselves (n=2,362)
- 58% of respondents felt the grant made a big difference to their wider families (n=1,654) and 16% of respondents felt that the grant made some difference to their wider families (n=459).

In response to an open question, the majority of respondents commented on what the biggest impact of the grant was for them, their child and their family (93%, n=2,661). Impacts identified by respondents include:

- **Quality time** together for the whole family away from stressful situations, e.g. holidays, day trips, mealtimes
- Parents have **less disruption at night** because children have better sleeping conditions, such as separate rooms or beds, new mattress, more bedding is useful for children suffering from enuresis.
- **Better / easier travel** if parents have used grant to learn how to drive, or if new vehicle has been obtained.
- Parents are better able to deal with **laundry requirements** of children who are prone to vomiting or soiling themselves at night, if they receive a washing machine and/or tumble dryer. This can also save them money if they used to attend the launderette.
- Children improve their **social and learning skills** by using technology obtained through the grant, such as touch-screen computers, laptops, iPads, and games consoles. Children are able to:
 - Participate in social activities with the rest of the family
 - Use technology to aid children's learning and improve communication
- Children have improved their **confidence**, for example through interactions outside of the home funded by the grant (e.g. holidays, swimming lessons and driving lessons)
- Children can have **privacy / their own space** for when they prefer to be on their own or to calm down if they are in getting angry or anxious
- Obtaining **new kitchen appliances and technology** benefits the whole family as appliances are more reliable, and there are less arguments between siblings if more than one TV, games console or laptop is acquired

Items that had an Impact for Respondents, their Children and Families

In response to a further open question, the majority of respondents (92%) commented on which grant items contributed most to making a difference to them, their children and their families (n=2,613), responses included:

- Holidays
- Driving lessons
- Washing machine / tumble dryer / white goods
- Bedding / furniture
- Laptop / iPad
- Exercise equipment, e.g. trampoline, bicycle
- Games consoles/TV
- Day trips/theatre
- Equipment to support disability
- Garden equipment
- Clothing

Financial Impacts

Respondents were asked about whether they had experienced certain financial impacts as a result of applying for the Family Fund grant (in a multiple response question) and overall 39% of respondents provided an answer that they had (n=1,112). The majority of respondents reported that this question was not applicable (57%, n=1,630). Of those that did provide an answer:

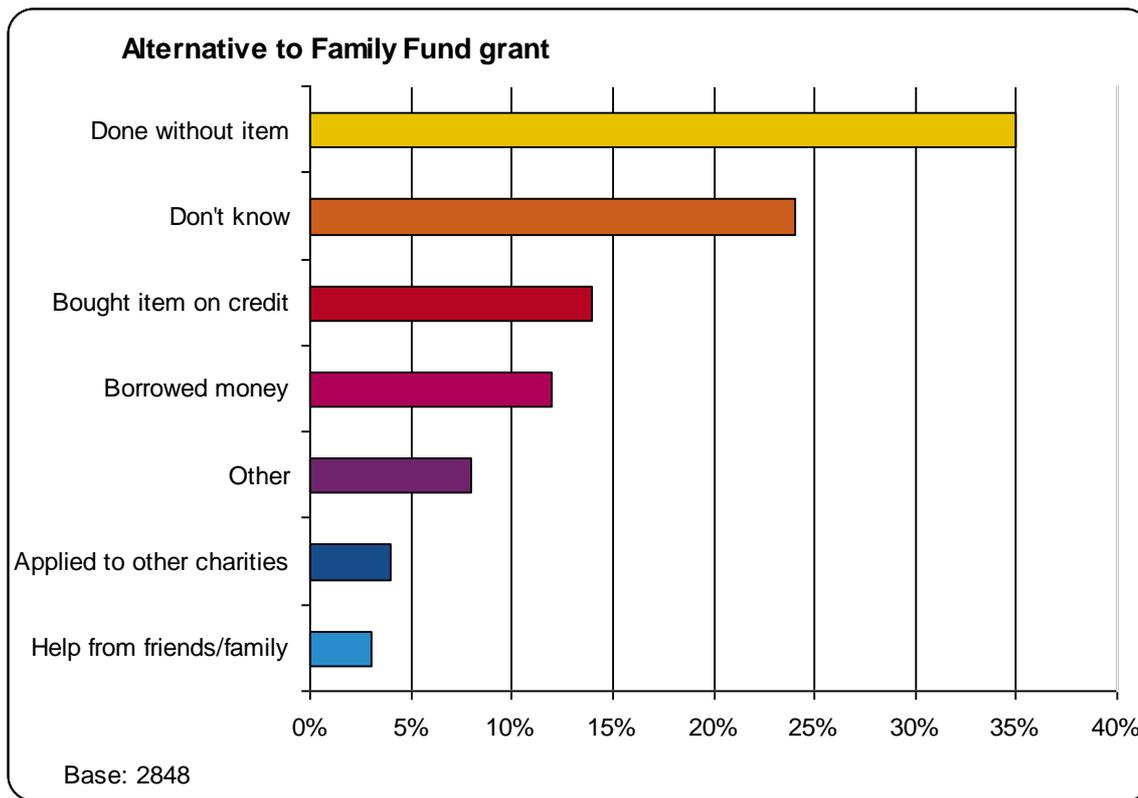
- The largest proportion (35% of all respondents) reported that they received an additional three or five year warranty for grant items (n=1,009)
- 2% of all respondents reported that they received additional savings from a number of retailers (n=69)
- 1% of all respondents reported that they received other kinds of financial support (such as benefits or other types of grants).

Analysis shows that a higher proportion of multiple applicants (39%, n=682) received an additional three or five year warranty for grant items compared to first-time applicants (25%, n=216). It is not clear from the data why this difference may be.

How Applicants would have Met their Needs Without the Grant

When asked how they would have met their need without the grant, the largest proportion (35%) of respondents reported that they would have done without the item (n=1,004) and a high proportion of respondents reported that they did not know what they would have done without the grant (24%, n=681). Graph A9 shows the distribution of this and the other responses.

Graph A9 Alternative to Family Fund grant



4. Additional Comments

How the Family Fund Could Extend Support Offered

Table A5 shows how respondents felt that the Family Fund could extend the support that it offers. Respondents felt that a range of extended support could be offered by the Family Fund, such as summer holiday schemes (33%, n=952) and home decoration and adaptation (31%, n=889). It should also be noted that a high proportion of respondents (43%) reported that they were satisfied with the Family Fund as it is (n=1,213).

Respondents were able to select multiple responses for this question so the number of responses for this question (n=5,919 responses) does not add up to the total number of responses received for the whole survey.

Analysis suggests that multiple applicants felt more strongly that the Family Fund could extend support by increasing the age threshold for applicants (30%, n=519), compared to first-time applicants (14%, n=116). This may be related to the fact that multiple applicants' children may be older than first-time applicants', and therefore the former may have fewer opportunities to apply for the grant in the future.

Table A5 Proposed extended support of Family Fund

Type of support	Percentage	Number of responses
Satisfied with Family Fund as it is	43%	1213
Offer summer holiday schemes	33%	952
Offer home decoration and adaptation	31%	889
Increase age threshold for applications	26%	748
Reduce time taken to process grants	19%	547
Offer play schemes	15%	418
Facilitate support from other local/national services	14%	399
Facilitate peer support from other families	13%	360
Increase income threshold for applicants	12%	334
Other (e.g. offer loans, enable siblings to be included on application)	2%	59

Base: 2848

How Respondents would Change the Family Fund

When asked an open question, the majority of respondents (67%) made recommendations as to how the Family Fund could better meet the needs of their family (n=1913). Suggestions included:

- Wider **range of household items** to be covered by the grant
- Better **communication** with applicants
- Offer **alternative holiday locations** to leisure parks (Haven, Butlins')
- Offer wider range of retailer / travel agent **vouchers**
- Offer **money** so that families can access most appropriate type of holiday for their needs rather than having to book a holiday through Family Fund as caravan or leisure park is not always suitable for the age/disability of child
- **Increase the amount of money** given to recipients and have more **flexible** application criteria, as many families are suffering during the recession and with cuts to benefits, e.g. Working Tax Credit has increased the salary threshold for eligibility
- Offer **more than one item** per grant, e.g. a new cooker and a holiday
- **Better promotion** of the Family Fund grant, as not everyone knows about it. Some applicants found out about it just before their child turned 18, others do not realise it can be used for all sorts of disabilities not just physical

How Respondents would Change Other Services

When asked an open question about how they would change other services to better meet the needs of their families 59% of respondents (n=1677) responded, and they referred to:

- **Better coordination:** Respondents felt that services need to work better with each other to coordinate support and share information about disabled children
- **Accessibility:** Respondents highlighted the importance of services being available and accessible, both practically (through straightforward application processes) and specific programmes of schemes, e.g. the Blue Badge scheme.
- **Communication:** Respondents felt that some services could communicate better and felt that having more face-to-face contact with users was important
- **Information:** Respondents referred to having better access to information as important; for example through enhanced provision of advice about services available (such as personal budgets)
- **Accountability:** Respondents felt that services should be transparent and accountable, particularly local authority services
- **Specific forms of support needed:** Some respondents referred to specific forms of support they felt would be useful and would improve services, including: holiday/respice

care, activities/youth clubs, support from staff in education services, more dedicated support from social workers and counselling support.

5. Comparison to PWC Review (2005) and Customer Satisfaction Survey (2010)

PWC Review of the Family Fund

As part of a review of the Family Fund in 2005, PWC conducted a postal survey of 500 applicants to the Fund and received 152 responses (a response rate of 30%). Respondents to the survey were families who have received grants through the fund and the aim was to find out about experiences of the application process and how grants that had been received made a difference to recipients and their families.

Family Fund Customer Satisfaction Survey (CSS)

In 2010 the Family Fund Trust collected customer satisfaction data via a telephone survey (run by PCP). In total there were surveys of 1,001 recipients of the Fund (a response rate of 86%). The aim of the survey was to establish satisfaction levels and the reasons behind them, as well as opportunities for improvement. The data reported here excludes carers of 16-17 year olds (as the base figure is not available).

The relevant findings from both of these surveys are presented in comparison to the findings from the OPM survey below.

Profile of Respondents

Ethnicity

12% of respondents to the Customer Satisfaction Survey (2010) were from BME groups, compared to 12% of respondents to the OPM survey (all respondents that did not select White British/Irish/Other or did not say).

The PWC report does not state the ethnicity of respondents to the survey.

Country of Residence

Findings from the 2010 Customer Satisfaction Survey show that:

- 80% of respondents were from England, 8% were from Scotland, 8% were from Wales, and 5% were from Northern Ireland.

These proportions are very similar to the OPM survey, for which:

- 79% of respondents were from England, 10% were from Scotland, 6% were from Wales and 5% were from Northern Ireland

The PWC report does not state the country of residence of the respondents to the survey.

Disability Status

When asked about the nature of their child(ren)'s disability, a total of 75 disabilities were mentioned in the PWC survey. As a proportion of the total number of respondents to the survey:

- 17% had autism, compared to 55% of all respondents to the OPM survey
- 12% had learning difficulties, compared to 51% of all respondents to the OPM survey
- 11% had behavioural problems, compared to 35% of all respondents to the OPM survey
- 11% had Cerebral Palsy, compared to 9% of all respondents to the OPM survey
- 11% had ADHD, although there is no comparison available for the OPM survey
- 7% had Epilepsy, compared to 11% of all respondents to the OPM survey

These differences most likely reflect the way the survey was designed. In the PWC survey respondents were invited to openly state their child's disability, whereas the OPM survey provided a list of options, enabling respondents to select multiple responses.

The Customer Satisfaction Survey does not provide information about disability status.

Recent Grant History

Number of Applications to the Family Fund

The table below shows a comparison between the numbers of applications made by respondents in each of the surveys.

Table A1: Number of applications to the Fund

Number of applications	Customer Satisfaction Survey 2010 (Base: 1001)		PWC survey (Base:152)		OPM survey (Base: 2848)	
	No.	%	No.	%	No.	%
One application	420	42%	30	20%	866	30%
Two applications	60	6%	24	16%	653	23%
Three applications	150	15%	20	13%	463	16%
Four or more applications	371	37%	78	51%	694	24%
Can't remember	0	None	0	None	172	6%

The largest proportions of respondents had made one application in the OPM survey and Customer Satisfaction Survey (2010) (30% and 42% respectively) but in the PWC survey the majority of respondents had made four or more applications (51%), compared to 24% in the OPM survey and 37% in the Customer Satisfaction Survey.

This suggests that participants are likely to be either first time applicants, or applicants with complex needs that have needed to use the Fund on multiple occasions.

Number of Successful Applications

Findings from the PWC survey show that 76% of respondents were successful on every application they had made to the Family Fund. This compares to approximately 81% of the respondents to the OPM survey (excluding those that reported they had made '7 or more applications' as it is not possible to calculate a specific success rate).

The PWC survey found that 95% of all respondents would apply to the Family Fund again, compared to 90% of respondents to the OPM survey.

In the PWC survey 75% of those applicants that had been unsuccessful reported that they would not apply to the Family Fund again, this is in contrast to the OPM survey where 75% of unsuccessful applications (those that had not had any successful applications) reported that they would apply again (although this applies to only 0.3% of all respondents).

There is no comparator data within the Customer Satisfaction Survey (2010) on the number of applications.

Items Requested/Received Through the Family Fund

Each of the surveys asked respondents about items requested (PWC and OPM surveys) or received (Customer Satisfaction Survey 2010) through the Family Fund.

When asked about items requested through their most recent application, respondents to the PWC survey (n: 122) referred to:

- Holiday and travel costs (65%), compared to 57% of all respondents the OPM survey (holidays, overnight stays and day trips) and 59% of respondents to the Customer Satisfaction Survey (items received)
- Household items (47%). This does not directly compare to these other surveys as they break down items into specific categories. The OPM survey shows:
 - 5% of all respondents requested a fridge, which compares to 12% of all Customer Satisfaction Survey respondents (items received)
 - 4% of all respondents requested a tumble dryer, which compares to 20% of all Customer Satisfaction Survey respondents (items received)
 - 17% of all respondents requested a computer, which compares to 20% of all Customer Satisfaction Survey respondents (items received)
 - 14% of all respondents requested bedding, which compares to 28% of all Customer Satisfaction Survey respondents (items received)
 - 3% of all respondents requested a freezer, which compares to 9% of all Customer Satisfaction Survey respondents (items received)
- Clothing (22%), compared to 15% of all respondents to the OPM survey and 17% of all respondents to the Customer Satisfaction Survey (items received)
- Leisure items (13%), compared to 13% of all respondents to the OPM survey (recreation activities) and 10% of all respondents to the Customer Satisfaction Survey (items received)

Purpose of Your Most Recent Application to the Fund

When asked about their why they applied to the Fund in relation to their most recent application, respondents to the PWC survey (n: 122) gave the following reasons:

- To break/receive stress (57%), compared to 43% of all respondents to the OPM survey
- For extra washing/wear and tear needs (46%), compared to 7% of all respondents to the OPM survey (that gave the reason “to help with extra household tasks such as washing”)
- To help cope with destructive behaviour (16%), compared to 29% of all respondents to the OPM survey (that gave the reason “to help cope with my child/children’s challenging behaviour”)
- For needs stimulation (16%) – there are no comparator responses to the OPM survey
- To help with mobility/shopping difficulties (13%), compared to 12% of all respondents to the OPM survey
- Other reasons (10%), compared to 26% of all respondents to the OPM survey

The Customer Satisfaction Survey (2010) did not contain information on reasons for recent applications.

Amounts Received

Respondents to the PWC and OPM surveys were asked about the financial value of the grant received from their most recent application to the Fund. The table below shows a comparison between the amounts received by respondents in each survey.

Table A7 Financial value of grants received

Financial value of the grant	PWC survey (Base:122)		OPM survey (Base: 2848)	
	No.	%	No.	%
Less than £250	6	5%	64	2%
£250 to £499	78	64%	1048	37%
£500 to £749	28	23%	1095	38%
£750 to £999	7	6%	468	16%
Over £1000	3	2%	51	2%
Unknown	None	None	122	4%

The Application Process

How Applicants First Found Out about the Fund

The majority of respondents to the PWC survey reported they heard about the Fund through health and social services (70%), and this compares to a smaller proportion (but still the largest proportion) of respondents to the OPM survey (42%) (This relates to OPM survey respondents that selected the option “local services”).

Similarly, the largest proportion of respondents to the Customer Satisfaction Survey (54% in 2010) reported that they first found out about the Fund through a healthcare professional or social services.

28% of respondents to the PWC survey stated that they heard about the Fund through another person that had benefited, which can be compared to 34% of respondents to the OPM survey (that selected “through a friend or family member”) and 31% in the 2010 Customer Satisfaction Survey.

In all three surveys these were the main two ways in which applicants found out about the Fund.

Time Taken from Application Submission to Grant Receipt or Outcome

The surveys asked respondents about the time taken for them to hear the outcome/receive the grant after submitting an application to the Fund.

- In all three surveys, the largest proportion of respondents heard between 1 and 3 months after submitting their application; 43% of all respondents to the PWC survey, compared to 47% of all respondents to the OPM survey and 40% of respondents to the Customer Satisfaction Survey (2010).
- 24% of all respondents to the PWC survey reported that they heard within 2 to 4 weeks, compared to 36% of all respondents to the OPM survey. Similarly 32% of respondents to the Customer Satisfaction Survey (2010) heard within 1 month (but the findings do not distinguish timescales within this).
- Small proportions of respondents to the PWC and OPM surveys reported that they heard within 2 weeks of submitting their application (7% of all respondents to the PWC survey, and 8% of all respondents to the OPM survey).
- 3% of all respondents to the PWC survey reported that they waited longer than 6 months to hear compared to only 1% of respondents to the OPM survey. 10% of respondents to the Customer Satisfaction Survey (2010) heard in more than 4 months (there are no directly comparable findings for those that waited 6 months or more).

These figures show that overall OPM survey respondents reported they heard about the outcome/received the grant sooner compared to PWC and Customer Satisfaction Survey (2010) respondents. This could reflect improvements in the application process in recent years and may be supported by the finding in the OPM survey that 38% of all respondents felt that the application process had improved (which was asked to those respondents that had submitted a grant more than once).

In both the OPM Survey and the Customer Satisfaction Survey (2010) comparisons can be made between first time applicants and those that have applied for multiple grants, and both show that overall multiple applicants receive their grant/outcome quicker (23% of first time applicants responding to the Customer Satisfaction Survey received their grant within one month compared to 38% of multiple applicants, and 23% of first time applicants responding to the OPM survey received their grant within one month compared to 55% of multiple applicants).

Outcome of Most Recent Application

When asked about their last application, the majority of respondents to both the OPM Survey and the Customer Satisfaction Survey (2010) reported that they had received all of the items requested (53% and 59% respectively). 39% of respondents to the OPM Survey and 32% of respondents to the Customer Satisfaction Survey reported that they received some of the items requested.

The PWC report does not provide information about the outcome of the most recent application.

Support from an Advisor

Respondents to the Customer Satisfaction Survey (2010) and the OPM Survey were asked about whether they had received support from an advisor (specifically on their first application in the OPM survey, comparable to data for first time applicants in the CSS).

- 51% of respondents to the OPM Survey reported that they received a home visit from an advisor on their first application, compared to 40% of respondents to the Customer Satisfaction Survey that were first-time applicants (Base: 404).
- 27% of respondents to the OPM Survey reported that they received a telephone assessment from an advisor, compared to 16% of respondents to the Customer Satisfaction Survey that were first-time applicants (Base: 404)..
- 13% of respondents to the OPM Survey reported that they did not receive a visit or telephone assessment from an advisor, compared to 39% of respondents to the Customer Satisfaction Survey that were first-time applicants (Base: 404).

Comparing the Experience to Other Organisations

The PWC and OPM surveys had the same proportion of respondents that had applied to other organisations for grants (15%).

In the PWC survey, of these respondents 83% found that experiences with the Family Fund to be better than their experiences of other organisations, 13% found the experience similar, and 4% found their experiences of the Family Fund to be worse.

In the OPM survey, of these respondents 58% of respondents found that experiences with the Family Fund to be better than their experiences of other organisations, 34% found the experience similar, and 2% found their experiences of the Family Fund to be worse.

Impact of the Grant

Findings from the PWC show that of those respondents that were successful in their most recent application (base: 118), 92% said that the grant had made a 'big difference' to them and their child.

This compares to questions asked of all respondents in the OPM survey, which found that 80% of respondents reported the grant made a big difference to their child and 83% reported it had made a big difference to them.

In the PWC survey, 7% of respondents that were successful in their most recent application said that grant had made 'a little' difference to them and their child. In the OPM survey 18% of respondents reported that the grant had made 'some difference' to their child and 16% reported that it had made 'some difference' to them.

1% of respondents to the PWC survey (that been successful in their most recent grant application) reported it had made no difference at all for them and their child. This figure is similar to the findings from the OPM survey, where 1% of all respondents reported the grant made no difference for their child and 1% reported it made no difference for them.

There was no information reported on the impact of the grant in the Customer Satisfaction Survey (2010) report.

How Applicants would have Met Their Needs Without the Grant

- 41% of respondents to the Customer Satisfaction Survey (2010) reported that they would have "done without the item" if they had not received a grant, compared to 35% of all respondents to the OPM survey.
- A higher proportion of respondents to the OPM Survey reported that they "did not know" how they would have met their needs without the grant (24%), compared to 4% of respondents to the Customer Satisfaction Survey (2010). This may reflect the method used for each survey; being delivered by telephone may have encouraged respondents to specify an answer.
- In both surveys the next response most commonly selected by participants was that they would have "bought the item using credit" (15% of respondents to the Customer Satisfaction Survey and 14% to the OPM Survey).
- A low proportion of respondents to the OPM Survey reported that they would have asked for help from friends and family (3%) compared to the Customer Satisfaction Survey (12%). The reason for this difference is not known.

The PWC report does not provide information about how applicants would have met their needs without the grant.

Additional Comments

The OPM and PWC surveys asked respondents about how the Family Fund could extend the services/support it offers. In response to the PWC survey:

- The largest proportion of respondents said that they were satisfied with the Fund as it is (11%)² compared to 43% of OPM survey respondents (also the largest proportion of respondents).
- 7% of all respondents to the PWC survey suggested by offering play schemes/summer holidays, compared to 48% of all respondents to the OPM survey

² Response rates are as a proportion of the total number of survey responses, but based on an open question

- 4% of all respondents to the PWC survey suggested by offering home decoration and adaptation services, compared to 31% of all respondents to the OPM survey

B. Procurement Analysis and Issues: Summary Report

Introduction

The Family Fund is facing challenging times in terms of the current UK economies, and will need the procurement activity of the Family Fund to continue to deliver savings, so that grants to families can be maintained.

The Family Fund's procurement activities are relatively limited; they must meet their own domestic needs, such as utilities, rent, stationery, IT costs. Additionally they seek out major procurement opportunities in order to move the bulk of their grant-giving onto contractual agreements whereby applicants are obliged to meet their requirements through designated suppliers, rather than issue cash.

The Family Fund has been able to move 75% of the grant total onto contract-based method of delivery.

The Family Fund has created a Trading Company (Family Fund Trading) in order to generate greater income, by providing services to third parties, where the main motive is raising funds for the charity rather than directly meeting the needs of beneficiaries.

As a 'locally-based' organisation with a national 'reach' Family Fund is able to take advantage of local suppliers and therefore able to react quickly to changes – not always possible if there are national contracts in place.

Procurement Issues

Ensure that one member of the finance/procurement staff receives training in procurement to a suitable level of competence, initially to NVQ 3 level.

There are no designated procurement posts within the Family Fund and the staff that do engage in procurement matters are generally described as 'finance/procurement' and have financial responsibilities as well as carrying out procurement commissioning and subsequently monitoring of contracts and maintaining links with suppliers. A 'designated' procurement post is one in which the post holder carried out 75% of their time on procurement issues. The Family Fund should designate one of the operational posts and train the post-holder to NVQ3 minimum.

The post-holder should have the responsibility of providing 'professional' support whenever a procurement activity is carried out. They should be keeping abreast of Government procurement policies and activities in order to ensure that the Family Fund is in a position to take advantage of Government – wide /local authority contracts where applicable. Additionally if the Family Fund grows its trading arm it will need specific procurement skills in place.

Where contracts are awarded by The Trust consider including formal opportunities to extend the contract for a given period, under existing terms and conditions.

The current policy is to award contracts for periods of between three and five years and it is accepted that longer contracts should provide greater value for money. Yet there are risks

associated with longer contracts, for instance, will the supplier still be in existence? Will the supplier be able to sustain the negotiated rates over the whole contract period, given current economic realities? Might Family Fund's requirement change over a longer period? Of course all of these questions can be answered through suitable contract drafting, but given the current climate the Family Fund should consider as a possible alternative perhaps a three-year contract model of a three-year contract, with two one-year extensions built in. This would provide greater flexibility: the market place can change quickly; extensions to contracts can be affected quickly if necessary, perhaps if there are major pressures on resources at the time. Suppliers might initially resist but should recognise the potential of the extra year or two on the contract without further competition.

It should be pointed out that a number of Family Fund's suppliers have suffered some financial difficulties in the recent past: Thomas Cook, British School of Motoring (BSM) and Comet. This is not to criticise the Family Fund because it is difficult to predict the financial future in current circumstances. In each case staff has been adept at identifying and understanding the issues and skilfully maintaining their levels of service and in each case the supplier has moved on from immediate financial difficulties. A dedicated procurement officer may well be better placed to be aware of potential developments through their increased procurement contacts within the Government Procurement Service (GPS).

Consider that any contracts awarded are 'open', in the sense that they allow other relevant contracting entities to join if they have a similar need.

This could enable the throughput of the contracts to be increased and in turn increase the value for money benefits. More emphasis on the continuing procurement role should help identify potential candidates.

Examine other departmental contracts for suitable synergies with Family Fund's activities.

Family Fund is a niche supplier and although there are other grant-awarding Third Sector organisations none quite has the same operational model. As such the wider procurement community might not provide suitable contracts upon which the Family Fund can 'piggy-back' but at the least their staff should be more aware of Government procurement activities and policies and where there is an existing contract that they can join they should be able to be able to achieve better value for money and save time and resourcing costs. Some examples that might prove suitable are: ESPO Dealing Direct and LUPC (London Universities Purchasing Consortium). Another organisation is 'Key Travel' – a travel management company dedicated to the 'Not For Profit' sector.

If Family Fund wishes to expand on the use of its Trading Company then a good knowledge of public procurement legislation is particularly important.

Use of the Business Link 'Contracts Finder' ³ can help identify existing contract activity, together with the host department.

³ www.contractsfinder.businesslink.gov.uk

Future Procurement Direction

The Family Fund is rightly focussed on moving grant-giving from issuing cash to fulfilling the requirement via contracts which can meet the needs of the customers through such devices as charity gift cards, 'flexi cash' (pre-loaded plastic cards) and pre-paid vouchers. The Trust estimates that 75% of their grant-giving is now based upon contracts. Taking cash out of the system will usually provide a solid audit trail and through the use of their suppliers, such as Park Retail, should reduce the pressure on their limited staffing resources.

Reducing their staffing overhead will enable the Family Fund to concentrate more on its own operational needs, although these are limited. In procurement terms and, as an example, their last furniture contract was awarded when they moved to their new premises in Huntington, and it is unlikely they will have another such requirement in the foreseeable future. However, Family Fund recently identified a requirement for interim staff and conducted a suitable competition. They had the advantage of using local firms, but this is an area where there are a number of central Government contracts that could be used and, if suitable, would have saved resources.

C. Case Studies with Families: Summary Report

Overview of Families

A total of twenty case studies of successful applicants were carried out over June 2012. They comprised twelve families in England, four in Scotland, two in Wales and two in Northern Ireland. Some of the most frequently reported conditions for children within these families were Autism, Aspergers, ADHD and learning and behavioural difficulties. Other children had Downs Syndrome, rheumatoid arthritis, hemophilia, communication difficulties, hearing impairment, anxiety problems, epilepsy, spina-bifida, heart condition, gastric reflux, cleft palate, club foot, Smith-Magenis Syndrome, hypermobility, serious phobias and special dietary needs. Many of the disabled children in these families have multiple conditions. The majority of families have just one child with a disability but there were a minority of families where more than one of the children has a disability and in two families all three of their children are affected.

Families' monthly income was between £590 and £2400 and many felt under real financial pressure. Many parents find that the opportunity to work at a level suitable for their family's needs is limited because of the amount of time and energy required to deal with their disabled child/ren. In some families neither parent is working, however in the majority of families where there are two parents, one of the parents has either given up work entirely or reduced their hours to fit in with the needs of their disabled child.

The majority of these families do not receive a personal budget/direct payment/individual budget for their disabled child's needs. The few families who receive direct payments often use it for respite care so that they can spend time with, and give attention to, their other children. A high proportion reported receiving DLA, although the latter was not claimed by all those who were eligible as they thought they would lose out on other benefits.

In addition to financial support the majority of families benefit from the support of one or more professionals, in particular child and adolescent mental health workers, social workers, occupational therapists, physiotherapists, education psychologists and/or a CAF co-ordinator. Other types of support include a designated support worker, hearing clinic, child development worker, speech and language support, health visitor, youth worker, community nurse, Autism Outreach, Surestart, Parent education class, counselling service, volunteer workers, Family Action, and local groups for families with disabled children.

Some of the support from this multitude of providers is managed by visits to the family home, but many involve travelling to appointments. For some families the pressure of managing a busy calendar of appointments can be a struggle. Other families also have to cope with travelling daily to a specialist school which can be some distance away, for example one lone parent spends five hours a day on buses to and from her child's school.

Over-arching the financial and time pressures on these families are the day-to-day struggles they face looking after the needs of their disabled children. "*Tired from coping*" describes many of these families' circumstances. In addition to being under pressure physically (lack of sleep due to broken nights, demands of lifting/hoisting disabled children, restraining/managing children with severe

behavioural difficulties), emotional stress was frequently reported too. Some parents said that their relationship was under strain because of the challenges they face and talked about the difficulties that the siblings of the disabled child experience because they are often forced to 'take a back seat'. Parents frequently reported feeling socially isolated and talked about a lack of understanding from the community. Several reported being 'housebound', sometimes because they cannot afford to take part in activities outside of the home but also often because their disabled child's condition means that they cannot lead a 'normal life'. This includes families where a child is on the autistic spectrum and being away from the home environment can be particularly challenging and stressful for them, as well as children with ADHD where behaviour can be an issue.

All the case study families have had a successful history of applying to the Family Fund. Some families have been applying to the Family Fund for a period of several years and have experienced changes over time in the application process; the move from paper to online applications, with texts for progress updates was particularly welcomed. Although most families agreed that the initial application required the most effort and subsequent applications were much quicker and easier to complete, one family felt very strongly that when the child is profoundly disabled and the level of need is unlikely to change much over time, the requirement to describe and list every impairment for the application is unnecessary and demoralising. This family went on to question why, if a family is in receipt of DLA, and other benefits, all the relevant information could not be collated centrally:

'You still have to put in the same information each time, it's very trying on parents and reduces their capacity to work because it becomes a full time job explaining the level of need to the different agencies you have to engage with.' Family 18, lone parent mum with daughter with 'classic' autism, regular contact with social worker.

There were a few families where not all of the items applied for were granted as part of a single application but families were generally satisfied with the application process itself. It is interesting to note that there were many families who, despite having regular contact with a wide range of professionals, had heard only about the Family Fund in an informal way through a contact who had a child in similar circumstances.

Overview of Grants Received

Families made applications for a wide variety of items, including white goods (washing machine, fridge, dishwasher, tumble drier, cooker), a new boiler, sofa, carpet, bed, bedding, garden play equipment (trampoline, swing, slide, scooter), driving lessons, money towards petrol and parking costs for trips to hospital, insurance and tax for a car, a computer, laptop, mp3 player, games console, clothing, days out and holidays.

Families recognise that a voucher system is an efficient way of ensuring that people use the fund appropriately, however most would prefer more flexibility to shop around for the cheapest deals, in particular to go online and try and make their money go further.

'Over the years they have realised people aren't always using the money in the right ways but it is frustrating for people that aren't abusing the system – we shouldn't all be tarnished with the same brush.' Family 17, mother whose child is autistic

A few families also commented that they would like to be able to access more specialist stores, for example, one family needed a specialist mattress that was not available at Argos.

It would seem that certain vouchers restrict families more than others. Most praised Argos vouchers because they allow them to purchase the intended items and then use any remaining money to buy other things that they need. This was particularly useful when stores have a sale or offer discounts on the price of the required items or the price changes between the application and the grant being given. Although some felt that Comet provides enough choice, most regarded the Comet vouchers as too inflexible⁴. For example, one family said that the voucher obliged them to spend a certain amount on a fridge and a certain amount on a washing machine; in fact they would have preferred to get a slightly more expensive washing machine and a cheaper fridge, which would have totalled the same amount overall.

A couple of families were critical of the BSM vouchers. Both were unhappy with the instruction they had been given by BSM and would have preferred to have used a local, less expensive instructor. In fact neither of these two women had passed their test using the BSM vouchers and are now faced with having to pay for further instruction themselves.

Some families do not feel restricted at all by the level of choice available for holidays, while others regret that they are not able to shop around for the best, and often last minute, deals. However, on balance most feel that this lack of choice is a reasonable compromise in the circumstances. On the other hand, there are a few who have children with very specific needs who felt constrained by the options available. For example, a family with three children, all with severe haemophilia, require a safe and secure space where they are less likely to have accidents and would have preferred to have chosen their own location and go on a private holiday. Another family with a child with Downs Syndrome and many health conditions would have preferred to have gone on a holiday where they could have accessed specialist staff.

All respondents, with the exception of one, were extremely pleased and grateful that purchased items always come with a good warranty.

Home Visits

All of the case study families had a home visit as part of the Family Fund application process. It was usually part of the initial application and was arranged by a phone call in advance. The visit commenced with the checking of financial, medical and other records which was welcomed by families because it meant that their important, original documents did not need to be sent in the post. It then proceeded to a discussion about the needs of the child and their family. Families reported that the visit usually took around 45 minutes to an hour but some lasted up to two hours. Regardless of duration all the families stated that they felt the amount of time spent was appropriate in the context of their situation. All families commented that the Family Fund worker was professional, yet friendly and helpful, and the majority praised their ability to interact with their disabled child.

⁴ These comments were made before Comet went into administration

Many of the families feel that the home visit benefits both the family applying and also the Family Fund itself. One of the perceived benefits to the Family Fund was the prevention of fraudulent or unnecessary applications. One family said that the home visit gave them a sense of relief that the allocation of grants was not 'just a lottery'. Reflecting on the outcome of the home visit, some families noted that it gave justification and dignity to the process of asking for financial support and 'gave them permission' for the whole family to benefit from the money.

'The visit made the fact we were getting the grant feel normal and justified rather than something we were simply lucky to get'. Family 9, lone parent mum with two daughters and autistic son with learning disabilities.

'You think it's your duty to provide things for your child yourself, and it is, but you can't always do that. So to have someone tell us it was OK to ask for things we needed, was so good. I don't know what we would have done without it.' Family 10, couple with two daughters, youngest with Downs Syndrome.

One of the key benefits of the home visit for families was that it gave them the opportunity to improve the quality of their initial written application. Through an exchange of questions and answers with the Family Fund worker they worked out how best to complete their application to a point where the Family Fund did not need to come back with queries, and it was suggested that this would save time for both the applicant and the Family Fund in the long run. In some families, help was given to improve the quality of their responses and this was particularly the case for families where English was their second language. For other families the home visit helped to improve their application in terms of prioritising their needs and checking that the family was applying for the right items.

It was noted that the home visit allows every voice in the family to be heard, including those of siblings of the disabled child, whose needs might not otherwise be heard. The full circumstances of the family are therefore assessed first hand and the Family Fund worker can look at the needs of the entire family.

'She knows families, and she can ask you questions to find out what you need, when you might not have even thought of it yourself.' Family 2, lone parent mum with son with Aspergers, ADHD and anxieties.

Some families talked about the home visit as making the process more personal, as if they were establishing a more meaningful exchange with the Family Fund. There was, for some of the families, a positive benefit of feeling that someone (as opposed to something) was 'on their side', as if they had an advocate. The rapport that existed between the Family Fund worker and the family meant that they felt they were being visited by someone who was part of the disabled community, who understood them and made them feel that they were supported. Some families noted that the empathy displayed by the home worker set the Family Fund apart from other organisations.

Feelings were expressed by many of the families that the home visit allows the Family Fund to gather a full picture of both the physical and emotional needs of families. Families applying to the Family Fund are often under a great deal of strain and find it difficult to communicate all facets of their circumstances via a written application or even via telephone. One parent with an autistic son

appreciated the personal contact and said she was convinced that she would not have been able to articulate their circumstances over the telephone or just on paper and might have missed out as a consequence.

Many of the families also described how the information they received through the process of the home visit opened up channels of support for their family that would otherwise have remained unknown to them. It should be noted that, in many cases, the Family Fund worker provided additional advice over and above that given in relation to the Family Fund application. As an example, one family had an Family Fund worker show them how to get a better rate of DLA and others received advice about how to claim for car tax and insurance or hygiene items on prescription.

All the case study families felt that the home visits should continue as part of the process of applying to the Family Fund. The visit was a positive experience for these families and many felt that it should be part of the application process for everyone making a first application and, if necessary, repeated as the child gets older and their needs change. Many felt they would have missed out on the well-targeted and appropriate help that they received from the Family Fund, as well as signposting to other forms of support, if the home visit had not taken place.

Impact

The Family Fund grant clearly has a huge impact on the families of disabled children, as well as the children themselves and has greatly improved many people's quality of life. Possibly the clearest example of this is the family whose child has multiple health conditions who used the Family Fund grant to replace a broken boiler before winter.

Another impact of the Family Fund grant that should not be underestimated is that it has meant families have often avoided having to take out loans from family, banks or 'loan sharks'.

'If Provident had knocked on my door I would have said "yes" and ended up paying back £400 for £200 loan.' Family 17, mother whose child is autistic

It is difficult to single out one item as having the biggest impact because it is different for each family. Kitchen appliances tend to impact the lives of the parents of the disabled child most, allowing them to spend less time doing household chores and more time with their children, which in many cases has led to an improvement in behaviour. One family described it as having *'made a happier home, where there are fewer arguments and we are able to spend more quality time with one another.'* (Family 6, mother whose son is autistic).

Garden play equipment, in particular trampolines, help to keep children active and contribute positively to their general well-being. They are particularly beneficial for children who have hyperactivity and behavioural issues. In one family the boy who is on the autistic spectrum, has ADHD, anxieties and hypermobility was 'very excited' about the trampoline they were about to get via the Family Fund grant.

Holidays and days out provide time together as a family in a different environment, away from the challenges and strains of normal life. Parents see them as a chance to recuperate and recharge

their batteries plus an opportunity to 'treat' the other children in their family who can sometimes feel overlooked when so much effort is being put into caring for their disabled sibling. Holidays and days out also have a huge impact on the disabled child. Families talked about the *whole* family getting involved with planning holiday activities. One family talked about how the siblings relished the role they have supporting their severely autistic brother when 'on the road'. A child with Downs Syndrome 'absolutely loved' a specialist holiday because of the clubs and activities and one parent described a holiday's effect on her son as 'life-changing'.

'My daughter doesn't deal with change very well, so socialising her skills to other environments is huge. It increases her confidence, independence skills, flexibility and tackles her resistance to change. It also helps her spend time with family.' Family 18, mother whose child is autistic

'He is happy enough at home playing his video games, but it's so much better to be able to get him out and doing things that he will have really good memories of.' Family 2, mother whose son has Asperger and ADHD

Computers that are purchased with the Family Fund grant are also greatly valued by families and many can see tangible benefits in terms of improved literacy. In addition, one parent with an autistic child said that the computer is essential to her son's day-to-day well-being and sense of self and that it helps him to maintain control and a sense of predictability, as well as helping him to connect with others socially.

Driving lessons can also have a big impact, particularly in terms of travelling to hospital appointments and doing shopping and reduces the stress on families. Independent transport also facilitates better social links with extended family and friends. Several families also talked about the importance of being able to drive for their autistic children who need routine and structure which is not possible when relying on public transport.

The Family Fund is particularly impactful to families because, although some mentioned the DLA, most do not receive financial support from any other organisations. The Family Fund was described as better than other sources of support because it is quicker and less complicated and allows applicants to list the items that they need. One mother believes that the Family Fund fills a valuable gap in the range of support available; she has found that most organisations cater for end of life care or are aimed at people with an obvious physical disability, while support for people with ADHD and high functioning autism is seriously lacking.

Families' Future Intentions Regarding the Family Fund

Many families stressed that the Family Fund is a last resort and that they will always pay their own way if they can:

'There wouldn't have been any particular change if we'd not received it, we would've just carried on with what we were doing, struggling along.' Family 5, mother whose child is autistic and has ADHD

While some were already planning their next application (examples include a trip to Kenya to see relatives for the mother and child, annual holidays and day trips, play equipment and swimming

lessons), others simply said that they expect they will have to apply again when kitchen appliances need replacing because their income cannot cover unexpected, large expenses.

One family said that they always think very carefully about any application they make to the Family Fund because they are mindful of the costs of the award but are considering applying for driving lessons for their older daughter and money towards repairing the windows in the house or towards completing the loft conversion, which they began with a view to having a carer for their daughter when they get older:

'It's free to me, but somebody has paid for it – that's always in the back of my mind and I always ask myself, do we need this or does somebody else need it more? In a way you could see things like a dishwasher as an 'extra' – but when you have a disabled child, everything that makes your life that little bit easier is so important.' Family 10, parent whose daughter is Downs Syndrome and multiple health conditions

Another family said that they would welcome the Family Fund providing services, for example, someone who could help them design and modify their garden and home to make it more suitable for their autistic son's sensory needs because they lack the expertise to do this.

A suggested change from a number of parents was for more publicity for the Family Fund, with a particular focus on who is eligible to apply. This would help to overcome the belief, held by some families, that the Family Fund is just available for the most severely disabled children, in particular those with a physical disability. Improving communication connected with the application process would also be welcomed. Families asked that the Family Fund send an acknowledgement that an application has been received and improve their telephone and email response times.

D. Phone Interviews with Unsuccessful Applicants: Summary Report

Overview of Families

Among the twenty families that were interviewed the majority (seventeen) lived in England, two lived in Wales, and one in Scotland. Everyone interviewed was extremely helpful and talked openly about their situation. Seventeen out of the twenty parents interviewed were women and many of these were single parents.

For most of the families that we spoke to, this was their first and only application, however eight families had previously made successful applications. Those who had applied more than once included two families who had already been successful on a number of occasions; one of these had eight successful applications and the other had ten.

The disabilities of the children for whom the application was made were wide ranging. Conditions that were mentioned with most frequency were forms of autism (seven) and diabetes (four), but families with the following conditions were also interviewed: eczema and skin disorders, Asperger's syndrome, behavioural difficulties, learning difficulties, disorders affecting bone health, hearing impairment, severe asthma, and Phenylketonuria (PKU).

Seven of the twenty families had a child with multiple difficulties and four of the families had more than one child with disabilities. Although only one of the respondents spoke specifically about her own long-term health problems, it was clear from the discussions that several others were experiencing stress and anxiety as a result of caring for their disabled child and worrying about money.

Reasons for Applying to Family Fund

When asked how they had first heard about Family Fund, the main two sources of awareness were charities and other organisations that support children with disabilities (nine families) and friends/colleagues with a child with a similar disability (six families). It would seem that in many cases the family was put in touch with sources of support when their child was diagnosed; sources which included centres for carers, child development support units, charities and other organisations that support families with disabled children. Other less frequently mentioned sources of awareness included leaflets/booklets with information, the family's social worker, a specialist teacher, Teachers Support Network and, in one case, because the parent had previous experience of helping other families make applications through her work with a charity.

Around a third of the families interviewed applied to the Family Fund for a family holiday or short break. In some cases this was a specialist break (such as weekends run by Diabetes UK) or a holiday for families with specific needs, but in other cases it was for a straightforward holiday to give the whole family some time away together. Electrical appliances for helping to manage the needs of a child with specific hygiene regimes were also requested with some frequency. Items such as washing machines and tumble driers, which were needed to deal with higher than usual

bedding and clothing laundering requirements, were applied for, as well as in one case specialist clothing and bedding needed to help the child's skin condition.

Non-electrical items such as kitchen equipment for specialist food preparation and storage (for the family with a child with PKU) and replacement furniture (new bed) were also requested. Computer equipment, such as laptops to assist with their child's schooling and homework, were also applied for. One family had applied for driving lessons to enable the disabled child's older sibling to take on more of a caring role and give relief to the main carer (the mother) whose own health was deteriorating.

Some of the families who had previous experience of successful claims commented on the way applications were decided. One family talked about applying for both a washing machine and new flooring for their child with multiple allergy and breathing problems. They were awarded the washing machine but not the flooring and decided that the flooring was more important and went ahead with this. However, they were frustrated because they were not allowed to save some of the Family Fund money by fitting the flooring themselves, as the fitter and floor came as a package. Another family with experience of many successful applications to the Family Fund said that holidays always seemed to be awarded while applications for items such as washing machines were less likely to be assured a successful outcome.

Families' Contact with the Family Fund During the Application Process

Families were asked whether, before submitting their application, they had spoken to anyone at Family Fund by telephone or had email contact. Only seven of the twenty families had made contact at this stage of their application. Among these, the main reasons for making contact were to get some clarification about whether it was worth their while making an application, whether or not they fulfilled the criteria and also to get help with the application itself. Some talked in particular about there being a maximum number of times a family can apply online and that when they found this out they telephoned or emailed to check and find out the correct format for their application.

For most families, this contact before submitting their application seemed very helpful at the time it was happening, however some changed their view over time and after they had been informed that their application was unsuccessful. Those who were unsure about whether their family fitted the criteria for making an application appeared to have been advised by Family Fund to put in an application and "*see what happens*". This advice seemed encouraging at the time but one respondent said that, on reflection, it was unhelpful because the criteria on which they were refused had been discussed with the adviser on the telephone and had she been given more tailored guidance at this point she would not have put in an application.

One respondent did not find the adviser on the telephone helpful and actually made her feel guilty for wanting to make an application, however this view does seem to be unusual:

"Not at all helpful and rather stand offish. She actually said to me at one point that I shouldn't rely on other people." Mother of diabetic child on higher rate of DLA, applied three times successfully previously.

A more general comment from a couple of families was that contacting the Family Fund by telephone was very time-consuming and expensive because of the length of time they had to hold on before they got to speak to an adviser:

“I had to hang on the phone so long and it is a 0844 number and expensive. I waited 30 minutes before hanging up.” Mother whose son is autistic; has had one previous successful application.

Five of the families interviewed had received home visits after they had submitted their application. All five of these families felt the person who conducted the home visit was very personable and helpful. Three of them said that the person who carried out the visit had encouraged them to believe that their application had a good chance of being successful, and two of them were told by the home visitor to apply for other items in addition to those on their initial application. This made these families feel very positive about their chances of getting the funds they needed. As they were in fact unsuccessful in their application, the raising of their hopes at this point in the process only served to increase the disappointment they felt when the decision came through: One respondent said:

“She was a specialist. She understood our need and allocated everything straight away. The only problem was that she raised our hopes by saying we should get everything and then didn’t get it all.” Parent of child with bone condition and learning difficulties, applied once before with partial success.

Reasons for Failed Applications and Families' Views and Experiences of the Process

The majority (seventeen) of the families interviewed were notified of the outcome of their application by letter which was reported to have come through several weeks after applying, and in some cases took as long as fifteen weeks to arrive. Opinion was divided regarding whether or not the waiting time was too long, with some families saying that it was acceptable and others berating the length of time they had to wait.

Most of those who received letters felt that this form of notification was the most appropriate one but some would have preferred more opportunity to enter into a dialogue with the Family Fund:

“I think a phone call or a visit would be better. If someone came to see what it is actually like when he gets home from school they would understand. You can’t always get everything about what it is really like down on paper, although I did fill everything in it’s not the same as seeing for yourself what it is really like.” Lone parent of son with severe behavioural difficulties, first time applicant.

One family had been notified by email and two by telephone but in both cases this was because the families themselves had ‘chased’ their application in these ways. The family who had enquired by email and then received a prompt email response was satisfied with that channel of communication. However the two families who had telephoned because their ‘chasing’ emails were unanswered and were then told about the unsuccessful decision were less positive. Not only was it expensive to telephone the Family Fund because of the long waiting time but they were also angry that their emails had not been answered in the first place.

The reasons given by the Family Fund for failed applications appeared to be frustratingly unspecific for many of the families interviewed. Not fulfilling the criteria was a very common reason given to many, but the specifics were often unclear and for some this meant they could see no point in pursuing the process any further:

“No, they didn’t give clear reasons otherwise I would have challenged them but I knew I was onto a losing battle. “ Lone parent of son with severe behavioural difficulties, first time applicant.

Interestingly, dissatisfaction was often more pronounced amongst those families with previously successful applications as they struggled to make sense of why they had not been successful this time. One parent queried how they could have met the requirements before but not now, when actually the situation has got worse:

“It doesn’t seem fair. None of our circumstances have changed. In fact they are worse now as my daughter has to go into hospital every 6 weeks’. Mother of diabetic child on higher rate of DLA, applied 3 times successfully previously.

In some cases families were told that their application was unsuccessful because their child did not meet the disability criteria required. For families struggling with the daily needs of their disabled child this seemed to be a very difficult message to receive. Families interpreted this as their child not being disabled enough:

“He gets disability living allowance but isn’t disabled!” Mother whose son has a bone wasting condition; not applied to Family Fund before.

“It was quite vague. Just said that she didn’t meet their severe disability criteria. Perhaps they didn’t think it was serious enough but she is on the highest care component for DLA.” Single mother whose 6 year old daughter has Type 1 Diabetes, first application.

Alternatively some families were told that they did not meet the qualifying financial criteria or were not receiving qualifying benefits. This was particularly galling for some respondents as they had asked about these criteria and explained their financial circumstances to an adviser at the Family Fund before submitting an application. They felt that perhaps if they had received more accurate advice prior to applying, a layer of unnecessary work and effort for both them and the Family Fund could have been avoided.

A minority of families had misunderstood the guidance for age of the disabled child and therefore found that their child was too old to qualify for help.

Impact of Unsuccessful Applications on Families

The impact on families that had had their first application turned down was more profound than on those who had previously been successful. These negative feelings towards the Family Fund were compounded by the lack of detail about why the application had been turned down.

Families that had a history of making successful applications had a much more positive view of the whole process and some showed considerable appreciation of the Family Fund:

“Family Fund has been fantastic. A Godsend. I wish it could go on forever. We have to try the lottery now. I have nothing negative to say”. Mother with autistic son with severe learning disabilities, eight previously successful applications.

The majority of families (fifteen) who were unsuccessful in their application have not managed to meet the needs of the child and for some this equates to “going without but struggling”. Father of autistic son, needing a computer to help with his school/home work.

Only five of the twenty families interviewed had been able to meet their child’s needs in the absence of a Family Fund grant. Three of these had done so by borrowing money from family and the other one funded the need on credit. The fifth family had recently secured a higher rate of DLA which meant that they could meet the need, at least for a few months until the DLA returns to a lower rate.

The Family Fund showed a poor record of referring families that were unsuccessful to other sources of support that might be able to help with their needs. Only three of the twenty families interviewed said that the Family Fund had referred them elsewhere but even in those cases the referrals did not appear to be very useful in terms of the family being able to secure the funding they required.

Approximately half of families (eleven) said they would consider applying to the Family Fund again, however most of these said that they would contemplate it rather than definitely do it. Among the group that said they would not apply again, most did not want to because of the disappointment they had experienced and uncertainty over whether or not they could be successful:

“Not as it stands. Would need to know more about what the criteria are.” Mother whose son has a bone wasting condition; not applied to Family Fund before.

“Yes and No. The first time I applied it took a lot of time negotiating what I could get. Second time, I thought they had the money to help me and then turned me down. What is the point?” Mother whose son has learning difficulties and a bone condition; not applied to Family Fund before.

However, some families thought it was not worth making another application because the process had been so lengthy and involved and they did not want to repeat it with little hope of success.

“Reluctantly, yes, out of necessity. But the process is so long-winded (5 months) and communication is diabolical.” Mother whose child is diabetic; not applied before.

A bad first experience with the Family Fund may prevent people from applying again, even if their circumstances change. Not receiving a grant and then not receiving a clear and detailed reason for that decision reinforced some family’s feelings of the process being pointless for them:

“No, (will not apply again) because of how it was the first time.” Mother of child with Aspergers and hypersensitive disorder, first application.

From their experiences, some families have concluded that the Family Fund’s criteria will prevent many families from successfully gaining a grant and they feel that this is not currently clear when

first applying. A couple of respondents queried how the Family Fund consider ectopic eczema, food allergies and diabetes and, if they are not regarded as acceptable disabilities, then this should be made very clear upfront.

“The criteria should be very clear. Much more explanation needed. It was a disappointing experience.” Mother whose child has a bone wasting condition; not applied to Family Fund before.

“It was a slap in the face. It’s a shame the cut off is so low. Very disappointing. The information they give you at the beginning should be better so you don’t have to go through it all just to find out you earn too much” Father whose child has a hearing impairment and verbal dyspraxia; he has not applied before.

A couple of respondents said that in their opinion the form does not ask for enough details and therefore it is difficult to explain how the disability affects their child’s life:

“Disability isn’t just about physical appearances. My daughter can’t live a normal life but it was hard to get this across on the form.” Mother whose child is very asthmatic; she has not applied before.

“There should be more room on the form to explain about the condition. I have to get up twice a night to check my daughter’s insulin levels but the form is a bit flimsy and no room to write in detail.” Mother whose child is diabetic; she has not applied before.

“No, there is no point. They don’t ask enough information about the disability and its severity, therefore they don’t know about my daughter’s medication, adaptations etc. It was embarrassing when they said no. When we were turned down it felt like begging.” Mother whose daughter is very asthmatic; they have had a previous successful application.

Conclusions

The one strand that ran through every discussion was that parents were not only disappointed that their application had been unsuccessful but that they sounded let down. Living with their child’s condition is stressful and tiring and some sounded as though they were not coping very well at all. The Family Fund gave them hope of a solution to one, or more of their needs, but managing families’ expectations and how information is communicated to them should be reviewed.

Many unsuccessful applicant families felt as though their hopes had been raised by the information in the Family Fund brochures and by the contact they had with the Family Fund. Even when families had explained their reservations about applying to advisers on the telephone they were still encouraged to apply. Families that had received a home visit after submitting their application had their expectations raised still further and it would seem that some families were encouraged to apply for items over and above those on their original submission. This fostered a strong sense of hope of successfully being awarded a grant and made their subsequent disillusion with the Family Fund application process greater when they received their negative decision notice. Given these findings it would seem important for the Family Fund to look at ways of managing families’ expectations.

Several families felt that they could not express their case well enough within the confines of the existing application form. They suggested that the Family Fund re-evaluates its application form to see if there is a way of usefully allowing greater space for families to provide further information about their child's condition and the situation the family finds themselves in.

The content of the communication regarding the outcome decision was repeatedly mentioned by unsuccessful families as a problem and served to enhance negative perceptions of the Family Fund application process. Many families found the reasons given for not receiving a grant frustratingly vague and inconclusive: a message of 'not meeting the criteria' does not tell the family exactly what criteria they have failed to meet and more importantly why they have failed to meet it. In addition, some families found the general reasons phrased around severity of disability hard to deal with when they are coping daily with the needs of a disabled child. The implication that their child 'is not disabled enough' is insensitive to these families, many of whom are under a great deal of strain.

From the interviews it would seem that very few of the unsuccessful applicants were offered suggestions of other avenues to try for support and the minority that had, were given suggestions that were inappropriate to the nature of their circumstances. Details of genuine and suitable alternative sources of support, financial or otherwise for the specific needs of that family and child would be welcomed by unsuccessful applicants.

Finally, there was mention of both unanswered emails and waiting times on the telephone being unacceptably long and expensive.

E. Consultation with Voluntary Sector Providers: Summary Report

The Main Challenges Facing Low Income Families with Disabled Children

VCS providers described a range of issues facing low-income families with children with disabilities. This includes the costs of living associated with specialist support, equipment and food, the problems facing parents in gaining employment that they can balance alongside their caring duties, the increased strain that this can cause for family life and the pressure it can place on siblings as well as a general low awareness of support available to parents through benefits and other services, particularly for families where English is not their first language. They also described the difficulties facing families in sourcing affordable, appropriate accommodation and childcare.

As well as these general issues, ERG members also described how the situations facing low-income families with children are worsening. This is largely due to the financial climate and policy changes which have led to a rise in the cost of living and changes to benefits and services. These changes have a two fold impact: they affect low-income families in general and also for those raising a child or children with disabilities. This means that families are finding it increasingly difficult to fund 'basic' costs and are reducing spends on either specialist or 'fun' costs such as play or holidays as a result. Families are less able to replace broken equipment and are often going without and families in rural areas are struggling to access services. In these ways, members describe these as vulnerable families who are getting closer to crisis point. Supporting this point, one VCS respondent commented:

"These families are continually experiencing pressure but when something happens within the household such as the breakdown of a tumble dryer, washing machine or similar, this can bring the family unit to breaking point". VCS respondent

Families are facing significant social impacts as a result of these financial pressures. This includes greater social isolation for families (including parents, siblings and the disabled child or young people themselves), a notable increase in hate crime, bullying and local stigmatization. VCS providers also noted how a reduction in the 'fun' time spent as a family can lead to a range of problems including stress, mental health issues and even family breakdown.

How the Family Fund is Placed to Respond to These Challenges Versus Other Organisations

VCS providers describe a range of ways the Family Fund responds well to these challenges. One such strength lies in the Fund's strategic position: members see the Fund as an expert organization which, through its database and relationships with families, understands who the families are, where they are based and the different types of need they have. Similarly, the Family Fund is seen to have well established links with the VCS, partnerships with other grant givers and relationships with 'social influencers,' for example, their role in Every Disabled Child Matters. It is also perceived to be a trusted organization of a range of government departments.

VCS providers also feel that the Family Fund is well placed to support families as the Fund offers both financial and signposting support, to improve immediate conditions for families but in a way that makes positive change sustainable. For example, they describe the ways in which the organization funds equipment that makes a difference to families on a day to basis but also promotes longer term wellbeing. They suggest that the home visit is crucial to this long term by adding value to the financial grant through signposting support to families, tailoring their knowledge of services available in the local area to needs of the families they visit. As families are becoming increasingly marginalised, and for families described as ‘hard to reach’, this signposting service is seen to be increasingly important alongside the practical support offered through the financial grant.

ERG members also feel that the process of applying for Family Fund funding is broadly accessible to low income families with disabled children. The application criterion – particularly the fact that the Fund accepts applications for a wide range of disabilities – means that families do not have to spend a lot of time searching for specialist grants as other means of support. Furthermore, ERG members feel that the Family Fund encourage long term relationships with families by accepting one application per family per year; they describe the way in which this gives families reassurance and peace of mind that they have somewhere they can go for support when they are in need. They also felt that the application form was easy to fill out and the application process non burdensome for repeat applications.

Our VCS ‘call for evidence’ respondents echo these views. In particular, they feel that the Fund is well placed to support families, particularly in the current financial climate, as they have experience and knowledge of the specific needs of families with disabled children. Also important is the way in which the Family Fund is family-centred; it provides grants based on the individual needs of family members (such as siblings and grandparents) to support the well-being of entire families and not against any predetermined criteria.

“Grants are available for items which benefit the whole family, not just the disabled child. This holistic approach to supporting disabled children is very successful and enabling. Grants for ‘ordinary’ domestic items such as washing machines provide support for the whole family and provide opportunities for families to spend more time together in less stressful circumstances leading to more positive outcomes for the whole family.” ERG member

As such, this allows the family greater flexibility to find creative ways to relieve immediate stress and enjoy day to day family life as much as possible. As one respondent commented, the role of the Family Fund is in “*sustaining family life*” (VCS organisation).

Other Models Which are Effective in Supporting Low Income Families with Disabled Children

ERG members described a range of services, statutory and charitable organizations that are also effective in supporting low income families with disabled children. The list includes:

- Family Support Hubs;

- Benefits advice;
- Steps to work and essential skills programme;
- Surestart and Surestart Maternity Grants;
- Health visitors; and
- Contact a family Helping and Family Support Service.

VCS call for evidence respondents suggested:

- Community Care grant;
- Turn2us;
- Crisis loans and Budgeting loans;
- Local charities;
- Credit Unions;
- Department for Education;
- Council for Disabled Children;
- Contact a Family;
- Caudwell Children;
- Children's Hope Foundation; and
- Christians against Poverty group.

However, all respondents offered caveats alongside these recommendations. One caveat is that these types of services or organisations complement the work Family Fund, for example by providing ways for families to maximise their benefits or access to other services, rather than offer a model of grant giving that is directly comparable. Similarly, respondents often felt that these alternative services were not suitable to deliver the work of the Family Fund, for example work on a national basis, or have the specific expertise to work with and advise low income families with disabled children. Finally, respondents that mentioned loan services also warned that repayment of such loans could leave families in greater debt in future; the grant giving approach is singularly preferred by respondents, although other grant giving organizations are generally more prescriptive in which families or disabilities they support. There is the sense that without the Family Fund some families would have no other options and would have to do without.

Links Between the Family Fund and VCS Organisations

All ERG members feel they and their organisations have good links with the Family Fund. These links can be at a local level, as Family Fund advisors network with local organisations or groups delivering services to families, and at a national strategic level, utilising Family Fund's knowledge of low-income families with disabled children, conducting research, lobbying government and advising or influencing on policy. Members generally feel that the Family Fund has links both with poverty and disability organisations and described a number of local partnership boards and related networks on which representatives sit.

VCS call for evidence respondents also feel that they and their organisations have close links with the Family Fund. As well as the local and national relationships they also describe more detail around the nature of two-way interactions between Family Fund home advisors and their local services. In particular, their experience is that the home advisors supply information about their services and they refer families to the Fund in turn:

“We sign post families of blind and partially sighted children to the Family Fund. We have also had a representative from the Family Fund come and speak to parents regarding application and eligibility for grants.” VCS respondent

Whether the Family Fund Could Improve Their Links With the VCS (and How)

ERG members debated whether the Family Fund could improve links with VCS. Those with existing links with the Fund generally felt that links were already strong and felt this was true of other organizations. Other members described specific activities the Fund could do to maintain links locally, for example by continuing to attend carers groups and events. However, as one member argued, creating new links with VCS organizations should not be an end in itself as often the ‘hard to reach’ families are not necessarily connected to the mainstream services:

“Many families with disabled children do not access mainstream services at a community level. Whilst the Family Fund trust may need to have more contact with mainstream services such as Communities First it is difficult to know whether these kinds of contact would have much impact. An on-going relationship with key local authority personnel such as children’s disability team, integrated Children’s Centres and play services may be more key to continue to develop and maintain rather than making new links that may not be fruitful.” ERG member

Other members suggest the Fund could strengthen links with statutory bodies in their regions, for example by joining the disabled children’s sub group of the Children and Young People’s Strategic Partnership in Northern Ireland, or by linking up more closely with other front line professions.

The Policy Landscape and the Family Fund’s Strategic Direction

ERG members anticipate that the worsening financial landscape, increases in costs of living and changes to benefit and welfare, will lead to an increase in Family Fund applications from families hitting crisis point and who have no other places to turn. As one member commented:

“I believe the Family Fund will have an increase in the number of applications for help from low income families particularly as the Welfare Reform cuts start to take effect. It is anticipated that there will be an increase in relative poverty in families, particularly working families, who will see a reduction in their income and an increase in outgoings leaving them more vulnerable to stress, hardship and debt.” ERG member

As such, members feel strongly that the Family Fund needs to maintain its position and approach to supporting low income families with disabled children – and that it should continue to support families with ‘fun’ family solutions as well as for basic needs. They suggested that the Fund could respond to the broader policy landscape in the following ways:

- **Plug gaps in service:** Map out to identify and respond to gaps in service and increase awareness to attract more applications. They felt the Fund could share this mapping exercise with new networks and partners so that they can also understand the existence and nature of gaps;
- **Work collaboratively with other grant giving organisations:** As an increase in applications will have an impact on the size of grants available, members suggested the Fund pursue other grant making partnerships, possibly looking at social enterprise status;
- **Evidence the impact of their work:** Create a body of evidence of the impact of Family Fund grants upon the families' lives through case studies, showing off how early and 'low intervention' can make a difference and build up a case for future funding;
- **Recognise the value offered by the home visits:** Present the Family Fund service as something that goes beyond the financial value of the grant and the goods that it secures. Instead recognise the value of the support by home advisors and the range of ways they contribute to the process;

There is an intrinsic value to the impartial support provided by Family Fund to families that goes beyond the financial support of the grants. Any strategic changes must recognise the value of the support provided to families – through home visits, telephone contact - and build upon the success of this.

- **Signpost families locally and nationally:** Keep up to date with changing policy to support families with specific welfare questions and think of ways to support families in response to changed funding locally e.g. changes to transport provision;
- **Influence policy:** Use their knowledge and links with 'hard to reach families,' impact case studies and partnership work to influence different policy agendas including that of hidden carers such as grandparents and siblings at local and national levels, lobbying and influencing politicians etc;
- **Whole family approach:** Continue to support the whole family by taking into consideration possible reductions in welfare benefits, and community care charging (which may not be for children's services, but for other services supporting the family). As one member commented:

“The health and well-being of the whole family is vital and the Family Fund is currently best placed to recognise and meet this need.” ERG member



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