



Department
for Education

Review of the Family Fund Trust

Research Report

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Moorhouse Consortium

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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.

This report provides a summary of the review report and our recommendations.

It sits alongside the main report and five appendices:

- 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

We gratefully thank the Family Fund for their responsiveness and assistance during the review, stakeholders for the time given in interviews, and voluntary organisations for responding to our call for evidence. Most of all we thank the 2,848 parents who filled in the online survey and the 40 families that invited us to interview them during the review.

A. Executive Summary

The Family Fund Trust

The Family Fund Trust (FFT) was formed in 1973 by the UK Government, originally to support families affected by Thalidomide. The Family Fund is now the UK's largest grant-giving organisation helping families with disabled children up to the age of 17, and is primarily funded by the UK Government and devolved administrations in Northern Ireland, Scotland and Wales. For over 20 years the Family Fund operated under the wing of the Joseph Rowntree Foundation but in 1996 became an independent charity limited by guarantee. In 2003 governance in England moved from the Department of Health (DH) to the Department for Education and Schools (DfES), alongside significant downsizing of the organisation reducing staffing levels from 120 to 54. In 2006 the Family Fund was well positioned to distribute emergency funding following the Farepak collapse. And a trading arm (Family Fund Trading) was set up in 2008 to generate additional income.

The Family Fund allocates grants according to specific criteria relating to the child's disability, receipt of a range of benefits, and proof of UK residency. The Family Fund has 187 advisers who undertake home-based assessments of families who apply for a grant for the first time. Grants can come in the form of cash or bank transfer or, more commonly, through gift vouchers negotiated with UK retailers such as Argos, New Look or Haven Holidays. In 2011/12, the Family Fund provided 96,397 grant items to 59,166 families across the UK, equating to an average of 1.6 items per family. The average award value was £564. Family breaks continue to be the Family Fund's biggest request and 20,354 were awarded in 2011/12, with a total value of over £10.9 million.

The model of Government funding along with the application criteria, home visits and the focus on positive outcomes for the whole family puts the Family Fund in a unique position. It is seen as helping meet the policy interests of several Government departments, as being non-competitive with other charities, and striving to deliver an efficient service that offers good value for money.

Overwhelmingly stakeholders see the Family Fund as an investment model – to support disabled children and their families and help to reduce the number of families falling into costly crisis.

Context for the Review

Prevalence of Families with Disabled Children in the UK

Estimates of the prevalence of families with disabled children range from 5% to 18% of the UK population depending on the definition of disability that is used. Prevalence is higher amongst boys than girls¹, and evidence indicates that children are the fastest growing group of 'disabled people' due to improved diagnosis and better survival rates as a result of medical and technological progress².

There are estimates of how this total number of disabled children is broken down across the four UK regions, although these are subject to certain definitions of disability and are from different years. The number of disabled children in England was estimated at between 288,000³ and 680,196⁴. The Welsh *Children in Need Census 2011* indicates that there are 19,655 disabled children in Wales. In Northern Ireland, 23,100 children and young people are estimated to have a disability⁵. Our interview with a Scottish Government representative indicated that there are 33,000 children with a disability in Scotland in 2012.

Pressures and Challenges Faced by Families

Families with disabled children incur greater expenses, have lower incomes, and find it more difficult to get in and stay in employment. The cost of looking after a disabled child is three times higher than a non-disabled child at an estimated £22,000 per year⁶ due to costs associated with specialist toys and equipment and other costs such as transport to school or hospital appointments.

As well as the additional costs of raising a disabled child, families are less placed to be able to meet these costs. Parents can struggle to access employment alongside their caring commitments and awareness and take up of benefits are low, particularly amongst the more 'hard to reach' families. Families are also more likely to rent in social housing and often in accommodation that does not physically accommodate their child's needs or located in areas with strong transport links.

¹ J. Read, N. Spencer and C. Blackburn (2007) *Can We Count Them? Disabled Children and Their Households*, Full Research Report, ESRC End of Award Report, RES-000-22-1725, Swindon: ESRC.

² Prime Minister's Strategy Unit (2005) *Improving The Life Chances of Disabled People*, London: PMSU.

³ Institute of Education (2008) *Disabled Children: Numbers, Characteristics and Local Service Provision*. Research Report: DCSF-RR042, published by the Department for Children, Schools and Families

⁴ Family Resources Survey, DWP, 2011

⁵ The Prevalence of Disability and Activity Limitations amongst adults and children living in private households in Northern Ireland, 2007

⁶ Whilst households with no disabled child have an average median (unequalised) total weekly income of £543, those with a disabled child have a median income £475 and for lone parents with a disabled child this drops even lower to £300 (Read, Spencer and Blackburn, *Op. Cit.*).

External policy changes are having an impact on low income families with disabled children, both financially today and in terms of their fears for the future. A recent study, *Counting the Costs 2012*⁷, involving an online survey of 2,312 parent carers of disabled children, describes how financial pressures are worsening for these families and also, consequently, how they can feel stigmatised for ‘scrounging’ off ‘decent people’⁸. The fear of getting into debt or more debt means that families are making new decisions about how they prioritise their spending. Many are cutting out ‘fun’ activities and others are going without basic essentials such as skipping meals or buying a new winter coat. This financial juggling and fears about future changes to benefits is adding to the stresses, social isolation and family anxiety that low income families with disabled children already tend to face. Given the findings from *Counting the Costs 2012*, a sluggish economy and increasing living costs, stakeholders in this review agree that demand for Family Fund grants is likely to increase.

Summary of our methods

We used the following methods in the review, which are described in greater detail in Section A of the accompanying Appendices document:

- A review of strategic documents, activity reports and research reports produced by the Family Fund, in order to deepen our understanding of its strategic objectives, governance arrangements, staffing structure, model for allocating and distributing grants, and contractual agreements with the four UK Governments.
- Semi-structured interviews with 22 key representatives from the Family Fund and the four UK Governments. These were a mix of telephone and face-to-face interviews and explored: the extent to which the Family Fund is meeting its objectives and contributing to those of the different UK Governments; the efficiency and effectiveness of the Family Fund; knowledge of comparable models in the UK and elsewhere; opportunities for increasing the capacity of the Family Fund and improving links with the VCS sector; and the current and future landscape in public policy funding.
- A survey of 2,848 parents/carers who had successfully applied to the Family Fund in the last 18 months. The survey explored respondents’ views and experiences of the Family Fund, including the application process and time taken to receive their grant, as well as the impact of the grant on their child, themselves and their wider family.
- Case study visits to 20 families who responded to the survey. The case study visits explored in more detail family members’ views and experiences of the Family Fund, focussing in particular on the value of home visits, the choice and control families had over how they spent their grant, and their recommendations for improvement.

⁷ Contact a Family (2012), *Counting the Costs 2012, The financial reality for families with disabled children across the UK*

⁸ See, also, the recent report by the Strathclyde Centre for Disability Research and the Glasgow Media Unit found that media reporting of disability and disabled people has worsened between 2004/05 and 2010/11, with a greater prevalence of negative reporting and the use of pejorative language such as ‘cheat’, ‘scrounger’ and ‘skiver’ (see E. Briant, N. Watson and G. Philo (2011) *Bad News For Disabled People: How The Newspapers Are Reporting Disability*, London: Inclusion London).

- Telephone interviews with 20 parents/carers whose application to the Family Fund had been turned down within the last 12 months. Interviews explored the reasons for their application; reason for rejection and how this was conveyed; impact that this had on their family; and alternative grants or local/national support they were able to access.
- Formation of an expert reference group (ERG) of 12 individuals across eight voluntary and community sector organisations operating in the field of children with disabilities. The group provide insights and commentary on: the main challenges facing low income families with disabled children; how the Family Fund is placed to respond; effective models for supporting these families; improving links with the VCS sector; and the Family Fund's strategic direction, given the future public policy landscape.
- A wider 'call for evidence' from the voluntary and community sector exploring similar issues to those covered with the ERG. Members of the ERG helped us form the 'call for evidence' and circulated it to contacts, we received submissions from four providers.
- Desk based research to gather information on alternative models. We were particularly interested in central grant models such as those used by the Department for Work and Pensions (DWP) for the Community Care grant, and the disabled facilities grant, as well as personalised models such as individual budgets or brokered markets.
- Options appraisal of four alternative models utilising different markets and supply chains for comparison. Each option was reviewed in detail and discussed during stakeholder interviews to assess the feasibility, risks, efficiency and impact on family outcomes from each model. Each comparator was scored against three key metrics (Risk, Efficiency, Outcomes) and the results aggregated and presented to enable policy teams to choose the most appropriate model.

Alternative Models

Whilst the Family Fund is a unique organisation, the outcomes achieved through support and grants to families might also be delivered by alternative supply chains and markets. Credible options include direct support through local authorities and individual budgets, voucher schemes to distribute funding to families through self-referral, distribution directly through the Parent Carer Forums, or procurement of an alternative voluntary or private sector provider to administer the grants. Critical comparison of the models suggests that the Family Fund is well placed to carry on its unique role – representing the best package of low risk, efficiency and greatest impact on outcomes.

Summary of Recommendations

The Family Fund provides additional help to families that complements the network of support from extended family members, from community sector, and from statutory services. We have reviewed the Family Fund in this context to understand:

- What are the **needs** that this resource is meeting, what is the increasing **demand** and how could the Family Fund have an even **greater impact on outcomes**?
- What can be done to **improve the financial efficiency** of the service – so that the maximum number of families can be helped?
- How does the Family Fund work alongside the four **UK Governments** and what can be improved about this relationship and links to other services?

It is commendable that 80% of families say the additional support from the Family Fund makes a *big* difference to them and their disabled child. Through our review of 2837 parent surveys, 20 case studies, 25 stakeholder interviews, extensive desk research, business modelling, procurement analysis and call for evidence in England, Northern Ireland, Scotland and Wales we substantiated this statistic and have also identified important recommendations for improvement.

The following 17 recommendations are supported by the body of evidence presented in this report. They are carefully balanced to help maximise the impact of the Family Fund, and “*shine a light*” for parents, children and siblings who face uncertain times.

Understanding Families and their Needs

- 1. Recommendation:** As a starting point, the Family Fund should continue to use the research instruments developed for this study (or an adapted version of them) as a means of capturing consistent and comparable outcome data over time.
- 2. Recommendation:** The Family Fund should explore different approaches to capturing social and economic impact and value, so that the Family Fund is more informed about the pros and cons of different techniques and is able to choose an approach which is fit for purpose.
- 3. Recommendation:** Review how the Family Fund develops and tests new ideas. Explore whether an 'innovate, test, measure, adapt' model might help evolve the Family Fund offer and social impact.
- 4. Recommendation:** Explore the feasibility and implications of embracing, more explicitly, a social model of disability. A social model of disability identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) as the main contributory factor in disabling people, rather than people's [physical](#), sensory, intellectual, or [psychological](#) variations. This would mean shifting the focus away from a narrow emphasis on 'severity of disability' to a better understanding of the barriers faced by families with disabled children, and how these barriers can best be overcome.
- 5. Recommendation:** Review Family Fund needs assessment data and processes. Link up with local authority data on needs and explore the potential application of socio-marketing datasets. Needs assessment should focus on the family rather than the child, using the social model of disability.
- 6. Recommendation:** The Family Fund should work with UK Governments to set up a mechanism for controlling, monitoring and reporting on the distribution of funding across two different pathways: families in crisis, and intervening early to reduce the barriers to normal family life.
- 7. Recommendation:** Review the distribution of funding for particular categories of grant items (e.g. family breaks, white goods, computers), based on analysis of family barriers, increasing families in crisis, social impact and changes to statutory services.
- 8. Recommendation:** Family Fund to build on current strengths of advertising through word-of-mouth and the internet / social media to increase demand so that all families that should be accessing the Family Fund are able to. Government to encourage local authorities and other statutory organisations to ensure that no particular groups are disadvantaged when accessing the Family Fund.
- 9. Recommendation:** The Department for Education and devolved administrations explore the feasibility of extending the Family Fund's age limit from 17 to 19, and potentially to 25.

Operational Efficiency

- 10. Recommendation:** Review the reasons for high levels of telephone communication, assess the extent to which this is driven by failure demand (ie where telephone communication is due to relevant information not having being communicated to families), and review processes to reduce telephone demand.
- 11. Recommendation:** Build on the Family Fund Trading arm activities by diversifying funding and driving up revenues to support more families.
- 12. Recommendation:** Build on recent success and further increase procurement savings through stronger competitive negotiation, developing staff and using Government frameworks and buying power.
- 13. Recommendation:** Strengthen the Advisor role, by increasing the proportion of first time applicants who receive home visits, ensuring all families receive consistent information on suitable alternative sources of support, and re-visiting the proposal to empower Advisors to make grant decisions according to comprehensive guidance.

Changes for UK Governments

- 14. Recommendation:** Policy teams should take on a stronger commissioning role and set the outcomes and levels of need that Family Fund should be supporting. Family Fund and policy teams should work together to ensure links to local services are in place.
- 15. Recommendation:** Family Fund should offer additional support to the four Governments by sharing data and subtle policy messages with families.
- 16. Recommendation:** Consider increasing available resources in order to meet future demand. Resources can be sourced from a combination of: greater procurement savings; increased profit from Family Fund Trading; additional contributions from Department for Education, Department for Work and Pensions, Local Authorities, NHS commissioners and devolved Governments.
- 17. Recommendation:** Establish joint governance of Family Fund administration in England between the Department for Education, Department for Work and Pensions and Department of Health. The Northern Ireland Government, Scottish Government and Welsh Government should also review governance arrangements to ensure that the Family Fund is fully held to account.

B. Research Findings

The section summarises the findings from across the review. There are detailed reports for each of the following research strands in Section B of the Appendices document: survey of families; consultation with voluntary and community sector providers; telephone interviews with unsuccessful applicants; case study visits to families; and comparator models.

Current Delivery Model

Aims of the Family Fund

The overarching aim of the Family Fund is to create “*an inclusive society where families with disabled and seriously ill children have the same choices and opportunities as other families*’. The Family Fund supports families, parents and others with parental responsibilities for caring for a severely disabled child or children living at home up to the age of 19 years by:

- Providing support by way of grants, goods and services
- Furthering knowledge about childhood disability and its impact on the child, siblings, parents and other carers provided that the Family Fund will pursue the objectives primarily with regard to severely disabled children under the age of 19 years.

The Family Fund works collaboratively with families at a local level, through its 187 self-employed advisers who undertake assessments of families in their homes.

Target Families and Eligibility Criteria

The Family Fund grant is targeted at low income-families raising disabled or seriously ill children under the age of 18 in the UK. Table 1 details the Family Fund’s definition of disability and the full eligibility criteria:

Table 1 Target families and eligibility criteria

| Family Fund definition of disability: | The applicant is eligible if they: |
|---|---|
| <ul style="list-style-type: none">▪ The child must have additional complex needs⁹ or a serious or life-threatening illness.▪ The child's additional needs must affect the family's choices and opportunity to enjoy an ordinary life.▪ The degree of planning and support required to meet the child's needs must be much greater than that usually required to meet the needs of children and young people.▪ They must require a high level of support in some of the following areas: physical environment, education, communication, access to social activities, personal care and supervision.▪ The child's condition must be long term or life limiting. | <ul style="list-style-type: none">▪ Are the parent or carer of a disabled or seriously ill child aged up to the upper age limit that the trust supports.▪ Have evidence of their entitlement to at least one of the following: Child Tax Credit, Working Tax Credit, income-based Jobseeker's Allowance, Income Support, Incapacity Benefit, Employment Support Allowance, Housing Benefit or Pension Credit.▪ Have current legal residence is the UK; live in England, Wales, Scotland or Northern Ireland and have lived in the UK for at least six months. |

However, the Family Fund cannot assist where there is a responsibility on a statutory agency to help with the requested item and all grants are discretionary and depend on the availability of funds.

Family Fund Income (all sources) 2011/12 ¹⁰

Table 2 breaks down the different Family Fund income streams over 2011/12. The total funding from Government for 2011/12 was £34.6m which represents a rise of 15.3% over the last five years, and a fall of 0.9% over 2010/11. Expenditure for 2011/12 totalled £33.4m, a rise of 16.5% over the last five years, and an increase of 2.4% over 2010/11.

⁹ See definition of complex needs here: <http://www.nhs.uk/carersdirect/guide/parent-carers/pages/complex-needs.aspx>

¹⁰ Funding and grant allocation information is taken from the Family Fund Trust activity report 2011/12.

Table 2 Income sources in 2011/12

| | Funding from Government (£) | Other generated funds (£) | Total available income (£) | Grant spend (£) |
|------------------|------------------------------------|----------------------------------|-----------------------------------|------------------------|
| England | 27,323,000 | 1,908,988 | 29,231,988 | 26,398,442 |
| Northern Ireland | 1,602,260 | 110,106 | 1,712,366 | 1,493,365 |
| Scotland | 3,020,000 | 211,037 | 3,231,037 | 3,008,182 |
| Wales | 2,641,000 | 184,476 | 2,825,476 | 2,494,407 |
| UK | 34,586,260 | 2,414,607 | 37,000,867 | 33,394,396 |

The Application Process

The Family Fund allocates grants according to specific criteria relating to the child's disability, family income and proof of UK residency. These grants can come in the form of cash or bank transfer or (more commonly) through direct supplier deliveries, supplier credits, vouchers or payment cards negotiated with UK retailers such as Comet, New Look, Argos or Haven Holidays.

To apply for a grant, a family initially completes a paper application form, or more commonly online. Families can apply for a grant every 12 months from the date of their last application. In emergency situations, for example when a child requires urgent hospital treatment, the Family Fund will consider an early application. Once the Family Fund receives the application, the family will receive notification by letter or text. Just over half of families applying for the first time receive a home visit from a Family Fund Advisor. This visit gives a personal touch to the application process, allows a second assessment of the family against the application criteria, and is an opportunity for the families to discuss their needs to ensure they maximise the benefit of the grant. Home Advisors also share information about other local services available to the family.

The visits are allocated to Advisors by the Family Fund's Regional Managers who review applications and identify the Advisor closest to the family's home. Following each home visit, the Advisor completes a form, which confirms if the child meets the Family Fund's definition of 'severe disability'. Staff at head office complete the remaining eligibility checks and make a decision as to whether a grant will be allocated. For second or subsequent applications the online application system will automate grant requests (unless the family situation changes and an Advisor is asked to do a repeat visit).

Applications Received and Grant Items Distributed

As Table 3 illustrates, applications to the Family Fund are increasing. There has been a 41% rise in the volume of applications over the last five years. This has contributed to a decrease in the average grant size from £602 in 2007/08 to £564 in 2011/12.

Table 3 Volume of applications and average grant size over the last 5 years

| Year | Applications received | Average grant size |
|-------------|------------------------------|---------------------------|
| 2007/08 | 51,725 | £602 |
| 2008/09 | 56,298 | £619 |
| 2009/10 | 62,675 | £598 |
| 2010/11 | 61,650 | £575 |
| 2011/12 | 73,076 | £564 |

The Family Fund distributed 96,397 grant items in 2011/12 – a reduction of 2.7% over the last five years, but an increase of 8.3 % over 2010/11. This equates to an average of 1.6 items per family. Holidays continue to be the Family Fund’s biggest request. 20,354 were awarded in 2011/12, with a total value of £10.9m. The Family Fund made 468 discretionary grant awards¹¹ in 2011/12, with a total value of £327k.

Significant Changes Since 2008

There have been a significant number of changes to the operation of the Family Fund. Some of these changes have occurred since the last review in 2008 and some are longer term or on-going changes reflecting a continual evolution of the Family Fund. Changes in the external landscape – both financially and in terms of policy - have also affected (and will continue to affect) the way the Family Fund operates.

Since 2008

Technology and online applications: The Family Fund has invested in a wide range of ways to improve their internal systems, both to make themselves more efficient and to improve their service to families. These systems include improvements to their online application process which can trigger an automatic grant approval which significantly speeds up the service (with the potential to assess 600 grant applications in 40 seconds) and reduces the need for manual approval. The Family Fund has also invested in automated SMS system to keep families updated with their application stage and to reduce the number of incoming phone calls.

Urgent referral process: The Family Fund has introduced an urgent referral process designed to give families access to help and financial support within 24 hours of their application. These are for families who receive emergency hospital admissions and stays either as they give birth to a disabled child or if their child requires sudden treatment. The Family Fund appoints and trains authorised referral personnel in these hospitals and prioritises their grant applications when they are submitted.

Networking and whole family approach: The Fund has also increased its links with voluntary and community sector (VCS) organizations by introducing Network Development Managers.

¹¹ This refers to non-standard grants that meet the Fund’s discretionary grants policy. This includes grants awarded: earlier than standard timescale policies; to families which do not meet the income criteria; for an unusual item not normally funded by the Family Fund Trust; a cash grant where ordinarily it would be awarded through a contract provider; and significantly larger than average grants.

These Managers support Home Advisors to forge links with local networks and partners. The Fund has also increased its interest in working with siblings and grandparents by engaging in research around the impact of disability on all family members and providing family-centric grants.

Longer Term – or On-going Changes

Changes to eligibility criteria: These have changed both before and after 2008, and are regularly monitored and updated by the policy team to reflect the latest definitions, particularly around ways of assessing 'low income'. The Family Fund now asks applicants to detail the range of benefits they claim (rather than ask for their net incomes) as this is currently the most fair way of measuring income. The Family Fund recognises that there may need to be future changes to eligibility to reflected proposed benefit reforms.

Continued move from cash to vouchers and gift cards: In early 2000 90% of grants were given in cash. By 2011 75% are in product services. The Family Fund feels this is a big achievement as the voucher and gift cards offer additional value through good quality products and extended warranties. As one stakeholder suggested, it's '*about best value, not cost*'. The contracts have earned the Family Fund £2m in discounts and these savings are passed onto families. The vouchers are also easier to audit and reduce fraud.

Culture – from charity to business: Family Fund stakeholders described the ways in which the fund has changed culturally over the last 10 years. Stakeholders suggested the Family Fund has a unique position in that it is neither a business, charity nor a Government department but that over the last few years it is 'now run as a business with a charity angle'. This move to a business model is not at the expense of the overarching aim of the Family Fund but is a means to improve efficiencies:

"The core objective of the Fund has not changed but in terms of how we go about doing that there is a change - all for the better" Family Fund stakeholder

"Not long after I started we underwent drastic modernization to drive upwards the number of families we were helping in a more efficient way. Keeping the ethos of the Family Fund but recognizing that we have to run like a business to survive in the longer term" Family Fund stakeholder

Part of this change to a business culture is the result of seeking greater efficiencies through technology and the move away from cash grants as already described. However it is also reflected in the ways in which staff are managed and motivated through targets and key performance indicators (KPIs) on a daily basis:

"A daily KPI question is 'how many families have you helped today?' We can look at data around performance and are looking for continuous improvement. It's not a target but desired minimum with our limited resources" Family Fund stakeholder

External Changes

As described elsewhere in the report, external changes to policy and the increasing hardship facing families mean that the Family Fund is experiencing an increased number of applications.

Whilst this has produced additional impetus to operate more efficiently there is a question facing the Family Fund regarding their capacity to effectively support a greater number of families in need. This challenge is reviewed in the next section.

Links with the Voluntary and Community Sector

The Family Fund has been working to increase its links with voluntary and community sector (VCS)¹² organizations at the *strategic* level, through partnerships with Council for Disabled Children, Contact a Family, Grandparents Plus, and by contributing to the Every Disabled Child Matters campaign, and at the *local* level through the introduction of Network Development Managers who support Home Advisors forge links with local networks and partners.

Voluntary and community providers who participated in the review view the Family Fund as an expert organisation which, through its database and on-going relationships with families, understands well the challenges and needs that families face. They note that the Family Fund has well established links with both poverty and disability VCS providers, as well as partnerships with other grant givers, and relationships with ‘social influencers,’ for example, through its role in Every Disabled Child Matters. VCS representatives described a number of local partnership boards and related networks on which Family Fund representatives sit.

Some VCS providers suggested specific activities that the Family Fund could do to maintain links locally, for example by continuing to attend carers’ groups and events. However, as one participant argued, creating new links with voluntary sector organizations should not be an end in itself as the ‘hard to reach’ families are not necessarily connected to these mainstream services:

“Many families with disabled children do not access mainstream services at a community level. Whilst the Family Fund 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.” Expert Reference Group member

The need to strengthen links with statutory bodies in their regions was identified by several VCS providers for example by joining strategic partnerships or by linking up more closely with frontline professionals.

Capacity of the Family Fund to Expand

Technically speaking, the Family Fund has the structure and capacity to support an increased number of applications. They have the systems (including ICT), the processes (including the regular application and urgent referrer processes), a good reputation with families and knowledge of their needs, and an experienced and passionate team already in place. Indeed, as financial

¹² Note the voluntary and community sector is sometimes referred to as the third sector or charity sector

pressures bite and the Family Fund strengthens its links with the VCS and statutory sectors, applications to the Family Fund are increasing.

However, our evidence suggests that the challenge lies not in the Family Fund's structural capacity to respond to this increase in applications but in terms of its financial resources to meet the grants applied for; in other words the Family Fund is concerned about whether it will continue to be able to award 'meaningful' grants to the families it serves from a fixed (or in real terms declining¹³) funding pot, particularly as each application also comes with a handling charge and after efficiencies have already been made.

The Family Fund's concern with awarding 'meaningful' grants reflects their concern that:

"At a certain point the grant is meaningless – it's not possible to ask families to save to top up the fund and the money can get lost". Family Fund stakeholder

Family Fund stakeholders agree that it would be a challenge to reduce overheads much further without a) impacting on service levels, home visits and response rates to families; b) beginning to make errors about which families to support through what type of grants or; c) awarding meaningless grants. This means that a further increase in applications will cause a problem to their service if internal efficiency targets are held to 91p in every £1 and if the funding pot is static.

However, there are a number of ways for the Family Fund to increase its capacity without necessarily increasing the Government funded pot. These options include:

1. Potential to match funds with other grant giving organizations – although this will require additional capacity to broker these deals which is currently beyond the capacity of the existing staff base
2. Raise new streams of funding to allow the focus on different family group members for example siblings and grandparents
3. Make additional savings from procurement negotiations
4. Generate income through its trading company, such as bidding for additional work, sharing functions with other charities, or supporting LA grant giving
5. Increasing charitable giving

All these options incur an 'opportunity cost' in that they require resourcing from the Family Fund in order to happen. This may mean that, in the short term, resources may need to be redeployed with the hope that in the longer term it will pay off.

¹³ Despite the fact the total funding is fixed there are a number of ways in which the value of the funding has, in real terms, declined over the last year. As one stakeholder said, *"the English funders used to fund us quarterly and we'd get payments in advance and we'd get the interest from the payments. But now we get monthly payments and the interest rate has fallen - meaning our income has fallen."* Family Fund stakeholder

Hopes for the Future

Family Fund stakeholders described a range of hopes for the future, which depend on levels of funding available to allow these plans to happen. These include:

Broadening work to the whole family: Family Fund stakeholders hope they can increase their work with siblings, grandparents, babies under two years old and with older young people aged between 18 – 25. This whole family approach means that the Family Fund approach cuts across different Government departments.

Maintain or increase the numbers of home visits: As families value the personal touch of the home visits (and as the home visits allow the Family Fund to keep in touch with families' latest opinions) they hope to prioritise home visits as a core part of their service.

Act as a two way conduit between Government, local services and families: Family Fund stakeholders recognise the value of their access to and knowledge of families. They see potential in formalizing advocacy opportunities or acting as a two-way conduit of information between families, local services and national Government. And, one of the reasons the Family Fund is able to access a 'hard to reach'¹⁴ family is through its perceived independence from Government. As such, the Home Advisors could take Government messages into the home in an informal, 'under the radar' approach.

That the Family Fund continues to support families: The overriding hope is that the Family Fund exists into the future, particularly as they see their service as increasing in importance. As one Home Advisor commented, her hope is that the Family Fund "*continues to shine a bit of light onto a dire situation*".

Families Accessing the Fund

The Pressures and Challenges Faced by Families Applying to the Family Fund

Our survey and fieldwork with parents revealed the many and varied pressures and challenges that they face. 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 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, although in some families neither parent is working. Financial pressures are exacerbated by cuts to welfare benefits and specialist services, as well as the cost of specialist equipment and transport. Despite the pressures they are under, many families stressed that the Family Fund is a last resort and that they will always pay their own way if they can.

¹⁴ We are using this term to refer to 'underserved' and hidden populations such as minority ethnic groups, asylum seekers, Travellers and those who are becoming, or already are, unwilling to engage with services because they are suspicious, over targeted or disaffected.

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, resulting from a range of factors including: 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 loneliness and isolation. One VCS provider in the study noted:

“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 participant

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 wider 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 attention deficit hyperactivity disorder whose behaviour can be an issue.

Demographic Profile

In 2011/12, 9,268 families (20%) completed the Family Fund’s ethnic monitoring form. 83% (n=7,652) of families identified themselves as White, with the remaining 17% of families identifying themselves as Asian or Asian British (8%), Black or Black British (6%), Mixed race (2%) and the remaining 1% made up of Chinese families, Travellers or other ethnic group.

Our survey of families provides additional insight into the ethnicity of a sample of 2,848 families, 87% (n=2,471) of whom describe themselves as White British, Irish or other. The proportion of survey respondents from England who come from a black or minority ethnic community (BME) is higher than the national average (14% of survey respondents compared with 9% of the national population). For Scotland, Wales and Northern Ireland, the proportions were the same as the national averages (2% for both Scotland and Wales, and 1% from Northern Ireland). These data indicate that the Family Fund is reaching an adequate proportion of BME families in each of the four countries¹⁵.

Family Fund data for 2011/12 indicates that of the 69,221 applications it received, 5.6% of families are caring for more than one disabled child, and almost a quarter (23.6%, n=17,016) are caring for children with autistic spectrum disorders. The next most common impairments/conditions are: learning disabilities (15.4%, n=11,055), behaviour disorders (8.6%, n=6,194), and hearing/communication difficulties (5.5%, n=3,974). Less than 5% of families have children with

¹⁵ Population Estimates by Ethnic Group 2002 – 2009, ONS, 2011

cerebral palsy, named syndrome, heart disease, Down's syndrome, mental health problems and epilepsy or convulsions.

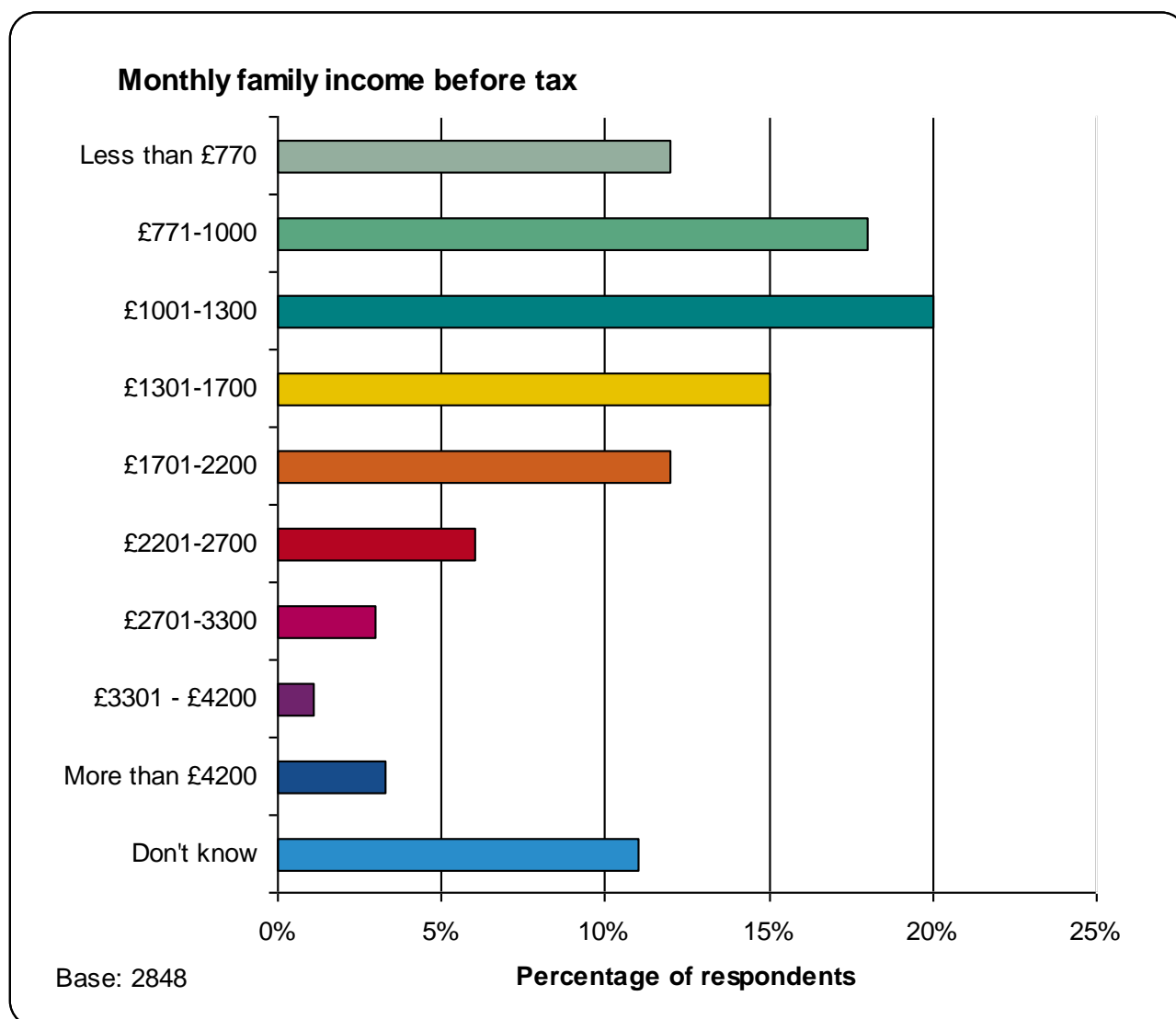
The majority of families who participated in the survey are not part of a local Parent Carer Forum or similar support group with links to their local authority (76% of survey respondents, n=2,171). Stakeholders indicated that the unique position of the Family Fund means it can access a wide range of families, including those estranged from statutory services or not receiving support from other organisations. One example put forward was the Family Fund's success in engaging with a Traveller community which refused to engage with any other services. Word of mouth can prove an important method of 'spreading the word' amongst these communities.

Most of our case study families had some contact with one or more professionals, such as child and adolescent mental health workers, social workers, occupational therapists, physiotherapists, education psychologists and/or a Common Assessment Framework (CAF) co-ordinators, but the type and frequency of contact varied from family to family. Some of the support from these 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 add to their struggle.

To be eligible for a grant, the Family Fund requires proof that families are claiming tax credits or one of a range of other benefits¹⁶. Our survey collected data on the pre-tax monthly income of families and Graph 1 illustrates the results.

¹⁶ [Families should be claiming at least one of the following: Child Tax Credit, Working Tax Credit, income-based Jobseeker's Allowance, Income Support, Incapacity Benefit, Employment Support Allowance, Housing Benefit or Pension Credit](#)

Graph 1 Survey responses to the question ‘What is your monthly family income before tax? Please include benefits, salary, grants and any other sources of income you have.’



The data reveal that three quarters of families (76%, n=2,161) have a monthly pre-tax income of less than £2,200, or £26,400 per annum. Almost 13% (n= 362) of families have a pre-tax income of £2,201 or more. It is not possible to determine from the survey what proportion of this latter group of families were in receipt of emergency grants (which are not subject to the same eligibility criteria and application process) and what proportion applied through the standard route.

A study carried out by Contact a Family Wales and the Family Fund, published in 2012, explored the relationship between the families helped by the Family Fund and the Welsh Index of Multiple Deprivation (IMD). Whilst the study found a marked concentration of families in the most deprived areas of Wales (categories 1 and 2 on the Welsh IMD), there were also large numbers of families helped across Wales living in the least deprived areas.

In interpreting the income data, we feel it important to consider previous research¹⁷ which has revealed a significant distinction between financial pressures and time pressures. Families who

¹⁷ J. Walker, K. Crawford and F. Taylor (2008) Listening to children: gaining a perspective of the experiences of poverty and social exclusion from children and young people of single-parent families, *Health and Social Care in the*

are considered to have 'sufficient' income may still suffer from time poverty, which has negative outcomes for their disabled child and wider family. Our survey and fieldwork evidence indicates that financial and time pressures often combine to doubly disadvantage families.

The research evidence indicates that, for the most part, the Family Fund is largely reaching the 'right' families, although not necessarily in a systematic way. There is potential for the Family Fund to do more to forecast demand based on existing data on the prevalence of families with disabled children and work with statutory services and VCS providers, to raise awareness of the Family Fund amongst eligible families most in need. In saying this, we recognise that demand mapping for children's services, and for disabled children in particular, is poor even amongst local authorities

The Application Process and Distribution of Grants

The two main ways in which families find out about the Family Fund are:

1. Local services/professionals including social and healthcare professionals, local charities, and carer support groups (42% of our survey respondents, n=1,194)
2. Friends/family (34% of our survey respondents, n=962).

The vast majority of families are positive about the Family Fund's application process, with the introduction of online applications and progress update texts being particularly welcome. When asked to compare the Family Fund application process with their experiences of applying for other similar grants, the vast majority of respondents (82%, n=2,032) indicated that they had not applied for similar grants. Of the 418 (17%) respondents who had, 58% (n=243) felt that their Family Fund application experience was better than that of other organisations, with 35% (n=144) indicating that it was similar to their experiences of other organisations. When asked to describe the key difference between the Family Fund's application process and that of other organisations, respondents noted that the Family Fund:

- Provides a more supportive, understanding and personal service, including during telephone calls and home visits
- Is characterised by good communication, faster response rate/decision making process
- Has an easy to understand application process
- Requires a reasonable volume of information required to be provided with the application
- Provides information about other sources of funding.

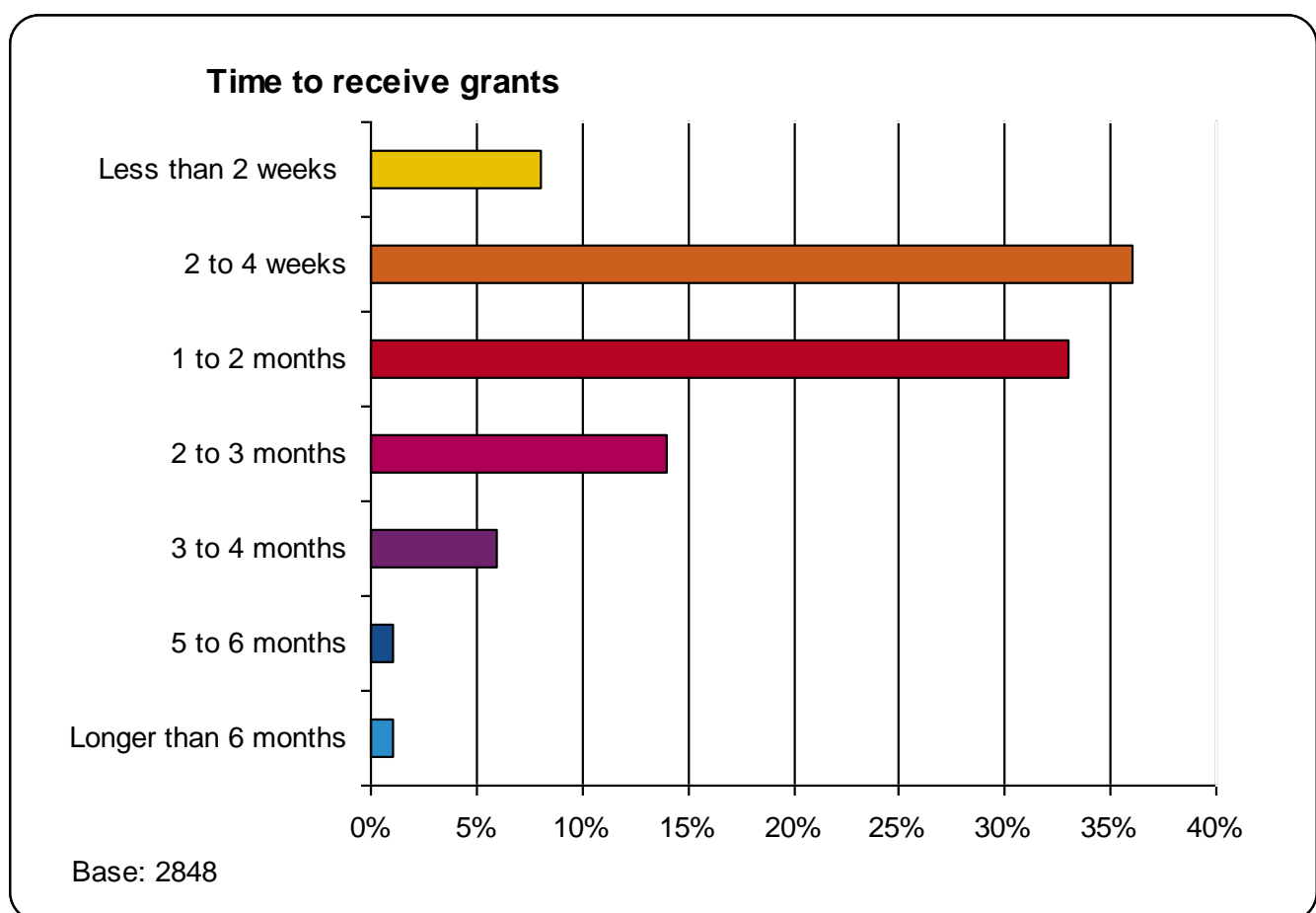
A small minority of families in our survey and fieldwork expressed some dissatisfaction with the application process, which tended to centre on one of two things:

- The time and expense involved in waiting for telephone calls to the Family Fund to be answered. Several families reported waiting up to half an hour on hold before being able to

talk to someone at the Family Fund, or hanging up. Families, most of whom are low income, complained about this being an unacceptable expense for them.

- The time taken to be informed of the decision outcome. Several families reported waiting more than three months to be informed of a decision, which they felt was unsatisfactorily long. Our survey found that the majority of families (70%, n=1,973) received their grant within two months of submitting their application, as illustrated in Graph 2. Around a fifth of families (21%, n=616) waited more than two months between submitting their application and receiving their grant, with 2.2% (n=62) waiting for more than five months.

Graph 2 Survey responses to the question: 'How long did it take for you to receive your grant after submitting your application?'



Making direct and fair comparisons with other grant schemes is challenging as each has a different application process. In the case of the Department for Work and Pension's (DWP) Community Care grant, which requires completion of an application form, and presentation of this, along with relevant documents to a Jobcentre Plus advisor, the average clearance time from decision to receipt of grant is nine working days. With the DWP's Budgeting Loans, there is a six day wait between receiving application and arriving at a decision.

Families' Views on the Choice and Control they have over their Grant

With the increasing introduction of personal budgets, individual budgets and direct payments, we explored case study families' views on the Family Fund's use of vouchers, which seemed appropriate in light of some of the negative press surrounding the recent changes to the Social Fund and the introduction of vouchers¹⁸. The majority of Family Fund families are now provided with a voucher or gift card for a specific store to purchase the item/s they require rather than a cheque or bank transfer. The use of vouchers or gift cards enables the Family Fund to take advantage of bulk buy margins and it ensures that families spend the grant on the desired item, rather than, for example, a pressing bill. Whilst we found that some families would prefer more choice in the way they spend their grant, e.g. being able to shop around for cheaper or last minute deals, most accept that vouchers are an efficient way of ensuring that the money is spent appropriately and view them as a reasonable compromise. Most families expressed gratitude for the support they were given, and were extremely pleased that purchased items come with a good warranty.

One provider was singled out for its inflexibility. For example one of our case study families told us that their voucher obliged them to spend a certain amount on a fridge and a certain amount on a washing machine, when 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.

Although the suggestion of one family for a generic high street voucher that would allow them to shop around may not be possible in practice, greater flexibility would be welcome. Families talked about one provider which allowed them to purchase the intended items and then use any remaining money to buy other things that they need. Families felt this to be 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. However this raises the question as to whether residual grant should remain with the family, given the levels of demand that the Family Fund faces.

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

The Impact and Value of Home Visits

In 2011/12, 56% of first time applicants were assessed by a Family Fund Advisor. The remaining first time applicants either had an 'immediate decision' (33%), where the child has a specific condition and the application was supported by additional evidence of eligibility, or were 'urgent'

¹⁸ www.guardian.co.uk/global/patrick-butler-cuts-blog/2012/jun/29/social-fund-welcome-to-the-era-of-vouchers-for-the-poor

cases (11%), where the application is made by authorised referrers (e.g. hospital social workers), who verify the child and family's eligibility where a grant is required to meet a crisis need.

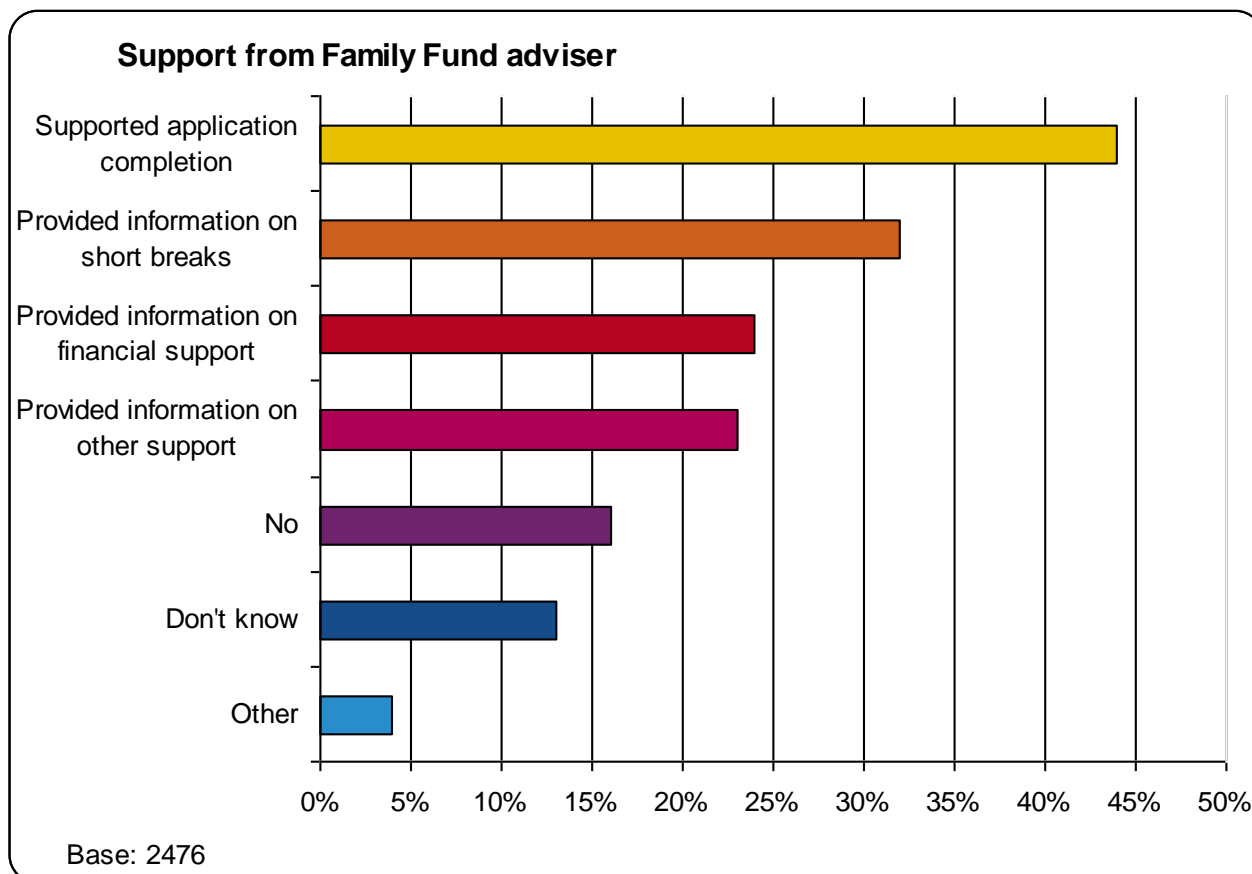
We found that the home visit performs a function greater than a simple assessment for eligibility. Face-to-face contact with an empathetic professional with expertise in disability makes the process more personal and, for some families, feeling that someone is 'on their side' and supportive of them is beneficial to their overall well-being. Some families noted that the empathy displayed by the Family Fund Advisor at the visit sets it apart from other organisations, and there was widespread praise for the skills, knowledge and approach of the Family Fund Advisors. The voluntary and community sector providers in our study agreed with our findings, suggesting that the home visit adds value to the financial grant through tailored signposting support to families. They noted that as families are becoming increasingly marginalised, and for families described as 'hard to reach', the signposting function is increasingly important alongside the practical support offered through the financial grant.

We found that the use of home visits has a range of benefits for both the Family Fund and the families involved. These include:

- Preventing fraudulent claims, by providing the Family Fund with better information about the family and helping ensure that grants are being directed to those families in the greatest need
- Supporting families to make applications for items that make the most difference to them and therefore use the Family Fund most efficiently; given that many families go on to make an application each year, this initial investment in a home visit, may prove to be good value for money overall for the Family Fund by helping families to prioritise what they apply for and reduce query handling (failure demand)
- Facilitating higher quality applications, which was felt especially important for those whose first language is not English, which saves time for both the Family Fund and the family in the long run
- Giving families the opportunity to fully articulate their circumstances and needs in a way that a written format or telephone call may not; this point was underlined in our phone interviews with unsuccessful applicants, some of whom felt unable to fully describe their circumstances and needs within the space provided on the application form
- Allowing the Family Fund to assess the needs of the whole family in relation to the disabled child. Family Fund Advisors have the opportunity to speak to the disabled child as well as their siblings and other carers such as grandparents, whose voices may not otherwise be heard
- Acting as the public 'face' of the Family Fund, and giving families the reassurance that someone (as opposed to something) is supporting them, which gives a personal touch to a process and builds a foundation of trust between the family and the Family Fund
- Allowing the Family Fund to offer a wider role of giving advice on other sources of support available to families, for example by informing families of a better Disability Living Allowance (DLA) rate, or to how to apply for other financial help that is available to them.

In relation to this latter point, our survey and fieldwork with families indicated variation in the degree to which they were given information about other forms of support available to them, which may be dependent on individual Advisors' knowledge of, and links with, the local statutory and VCS sectors. Graph 3 illustrates that around a third of our survey respondents reported receiving information on short breaks, and just under a quarter received information on financial support, and other kinds of support.

Graph 3 Survey responses to the question 'Did you receive any of the following kinds of support from the Family Fund Advisor?'



Impact of the Grant on Families

The Family Fund grant has an impact on the families of disabled children, far in excess of the financial value of the grant. Possibly the clearest example of this we found 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 unregulated financial providers.

Family Fund grants have an impact on the whole family, not just parents and/or the disabled child. 80% of parents/carers in our survey felt that the grant had made a big difference to them as well

as their disabled child, with 84% reporting a big or some difference to their wider family such as siblings and grandparents.

The Family Fund funds items that make a difference to families on a day to day basis, but which also promote longer term wellbeing. It is difficult to single out one item as having the greatest 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. 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. Parents reported less disruption at night when they have used a grant to purchase bedding, as children are able to sleep better. Extra bedding is also very useful for children suffering from enuresis.

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. Families talked about the whole family getting involved with planning holiday activities.

Computers are also greatly valued by families and many can see tangible benefits in terms of improved literacy and learning skills. Driving lessons can also have a big impact, particularly in terms of travelling to hospital appointments and doing shopping. 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.

When asked how they would have met the identified need in the absence of a grant, 35% (n=1,004) of survey respondents reported that they would have done without the item and a further quarter of respondents (n= 712) would have purchased the item on credit or borrowed the money.

Voluntary sector representatives in the study agree with the Family Fund's policy of allowing families to make one application per year, which gives families reassurance and peace of mind that they have somewhere to go for support when they are in need. It also has the benefit of building up long terms relationships between the Family Fund and families with disabled children.

Volume and Impact of Unsuccessful Applications

In 2011/12, the Family Fund received 69,221 applications, and helped 59,166 of these families (85%). This equates to a 'decline rate' of 15%, which is higher than the previous year's rate of 8%, but lower than both the DWP's Community Care grant, of which 53% of applications were declined in 2009/10, and its Budgeting Loans, of which 18% were declined in 2009/10.

We analysed 1,256 cases of declined applications covering the period 1st April 2011 to 31st March 2012. It should be noted that a range of different terms were used to describe the reason for an application being declined and we have grouped these as best we can. As Table 4 illustrates, the

majority of applications (68%, n=849) were declined because the disabilities described in the applications did not meet the Family Fund's criteria of 'severe disabilities'.

Table 4 Declined applications: reasons and numbers of applicants

| Reason for rejection | % | Number |
|---|-------|--------|
| Does not meet the Fund's criteria of 'severely disabled' | 68% | 849 |
| Application doesn't meet other criteria (e.g. age limit; items outside the Family Fund's policy) | 9% | 119 |
| Application cancelled / withdrawn / Unable to contact family / Awaiting return of documents / No response from family | 9% | 116 |
| Over Family Fund's income / savings financial limit / funding limitations | 5% | 60 |
| Applied too soon | 4% | 46 |
| Family Fund awaiting return of paper application form / Paper application has been sent to family | 3% | 33 |
| Miscellaneous (e.g. unreturned documents; reached auto grant process case limit; file being audited) | 1% | 13 |
| In the care of the local authority | 0.5% | 6 |
| Driving licence issues (e.g. not yet applied for theory test, not yet completed driving licence form, incorrect details on licence) | 0.5% | 6 |
| Already received a grant towards this item | 0.4% | 5 |
| Change in personal circumstances (e.g. death of child, change of carer) | 0.25% | 3 |

We interviewed 20 parents/carers whose most recent application to the Family Fund was unsuccessful. As would be expected, these parents were disappointed that their application had been declined, however this did not automatically translate into negative views of the Family Fund, particularly amongst those families who had previously made successful applications.

Our evidence indicates that Family Fund staff, whether providing support on the telephone or through a home visit, tended to err on the side of optimism and encourage families to apply, even when families have their own reservations. Families that had received a home visit after submitting their application tended to have a strong sense of hope of successfully being awarded a grant, which made their subsequent disillusion with the Family Fund application process greater when they received their negative decision notice.

The impact on families that had their first application turned down was more profound than on those who had previously been successful. Many families found the reasons given for not receiving a grant frustratingly 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*' feels insensitive to these families, many of whom are under a great deal of strain. These families made a strong plea, echoed by some of the case study families who had been successful in one or more applications, for more clarity and better communication about the Family Fund's definition of disability, and in particular, its definition of '*severe disabilities*'.

The majority of families whose application was unsuccessful (15 out of 20) have not managed to meet the needs of their child/family in the absence of the grant. Of the five families who had, three had done so by borrowing money from family, one had used credit, and one family had recently secured a higher rate of DLA which meant that they could meet the need in the short term.

From our interviews it would seem that very few of the unsuccessful applicants were offered suggestions of other avenues to try for support. 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.

Complaints and Appeals

In 2011/12, the Family Fund received 50 complaints, which equates to 0.08% of families who received grants last year making a complaint. Just over half (27 out of 50) of the complaints were upheld, as shown in Table 5.

Table 5 Number of complaints received 2011/12

| | Received | Upheld – number |
|-----------------------------|-----------|-----------------|
| FFT applications processing | 2 | 1 |
| FFT applications timescale | 2 | 1 |
| Driving instruction company | 7 | 4 |
| White goods company | 9 | 6 |
| Other | 2 | 1 |
| Holiday company 1 | 21 | 14 |
| FFT Telephone service | 2 | 0 |
| Holiday company 2 | 5 | 0 |
| Total | 50 | 27 |

In 2011/12, 341 appeals were received, with 28% (n=95) being upheld. This is illustrated in Table 6.

Table 6 Appeals received 2011/12

| | Received | Upheld – number | Upheld - % |
|--------------------------|------------|-----------------|------------|
| Child eligibility | 101 | 41 | 41% |
| Contract operation | 21 | 4 | 19% |
| Contract suitability | 116 | 37 | 32% |
| Grant item amount | 19 | 3 | 16% |
| Grant policy | 46 | 7 | 15% |
| Multiple requests | 19 | 2 | 11% |
| Re-application timescale | 19 | 1 | 5% |
| Total | 341 | 95 | 28% |

Up-to-date comparative data on complaints and appeals associated with other grant schemes is limited. However, we found that in the case of Budgeting Loans, the Social Fund Commissioner

reported that in 2010/11, there were 3,383 complaints about decisions (over 1.1 million awards were made that year), which represented 6.3% of its workload. Errors led to the change of outcome in 167 cases, representing 5% of the complaints received. In terms of Community Care grants, an HM Treasury report in 2011 indicated that around half of the appeals considered by the Independent Review Service were upheld, but we did not find data on the number of appeals made. They attributed this to high levels of administrative errors and failure to assess and challenge applications properly.

Overall we suggest that the number of errors and appeals is lower than expected and the Family Fund is performing well in this aspect.

The Management of the Fund by the UK and Devolved Governments

The Family Fund is currently administered by all four countries of the UK:

- Department for Education, England
- Department of Health, Social Services and Public Safety, Northern Ireland Government
- Children and Families Directorate, Scottish Government
- Department for Health, Social Services and Children, Welsh Government

Administration includes setting the grants and terms of grant letters, monitoring the Family Fund for compliance, setting policy direction and nominating representatives for the Trustee Board. There are occasional meetings between the representatives of the four Governments to discuss the Family Fund, but these are infrequent.

Each of the four Governments has an evolving policy landscape, with some divergence in policy approaches. Family Fund works hard to ensure it is engaged with these changes, such as linking up with the 'named person' for each child in Scotland, but there may be more that can be done on both sides to ensure the Family Fund is more current. To illustrate the evolving policy landscape the following are key themes that impact on the Family Fund model or client base:

- England is moving towards individual budgets in certain circumstances (direct payments in Wales) to meet family needs. Whilst take up remains low at 18% of parents we surveyed this is an inevitable direction of travel with the new Children and Families Bill which includes an overhaul of Special Educational Needs services and gives parents the rights to an individual budget. Scotland is moving towards self-directed support. Whilst take up is also low, it is hoped to increase with the introduction of the Social Care (Self-directed Support) (Scotland) Bill and progress with the 10 year National Self-Directed Support Strategy.
- Funding is being devolved to local authority level, with fewer ringfences, shifting power and possibly changing the relationships that Family Fund will want to develop.
- Governments are shifting their funding to a more commercial commissioning basis, rather than through direct grant giving, expecting the market to develop social enterprises, mutuals, consortiums and mixed models for service provision.

- The DWP Social Fund is being devolved to local authorities who are expected to adopt a voucher based scheme for distributing funding to families, similar to the model deployed by the Family Fund. The Family Fund has already expressed an interest in administering these funds on behalf of local authorities.
- Outcomes focused policy changes in children's services have had a significant impact in all four countries with greater integration between service providers and a more sophisticated understanding of outcome impact, e.g. Every Child Matters in England and SHANARRI (Safe, Healthy, Active, Nurtured, Achieving, Respected and Responsible and Included) outcomes in Scotland. In particular techniques to performance manage outcomes, or measure social impact such as Social Return on Investment are becoming more popular, although these approaches are not widespread in Northern Ireland, Scotland or Wales. Funding is also becoming more family than individual based.
- And as discussed in the previous section, there are significant challenges facing families with a disabled child which are likely to drive demand, so it is critical that Family Fund can demonstrate greatest value (outcomes as well as financial efficiency), give a clear invest to save business case for continued funding, and manage changing eligibility criteria effectively.

The Family Fund as it stands fits with elements of the shift, such as the focus on families, changes to the Social Fund and need to support parents of disabled children during the economic downturn. However, other changes leave the current model of the Family Fund vulnerable, such as the focus on social impact and move away from grants.

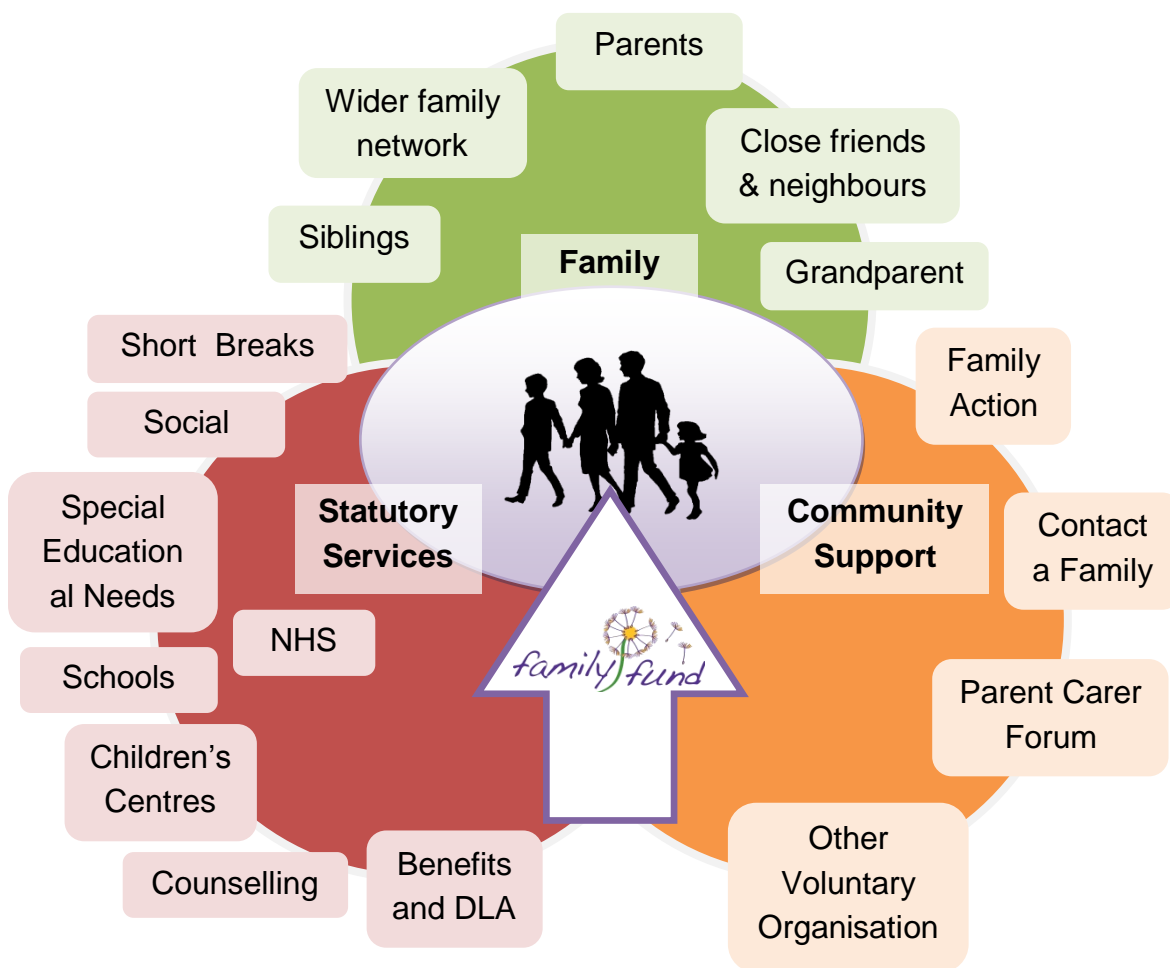
During stakeholder interviews, there was also general agreement that the Family Fund has been left to get on with their role with little interference from policy teams from any of the Governments. The role policy teams have taken over the last five years can be categorised as more administrative than policy led, and this was recognised as an area to change in order to support the Family Fund in improving services and grants to families to achieve maximum impact.

C. Conclusions and Recommendations Relating to the Current Model

Understanding Families and their Needs

Our research with families and professionals indicates that a family with a disabled child/ren has the potential to draw on a variety of networks of support, which we've categorised as Family, Community Support from voluntary and community services, and Statutory Services either provided locally or nationally. Each family will have different needs and a different balance of support and may therefore experience certain barriers to living as 'normal' a life as possible. We've illustrated the different networks of support in the diagram below.

Figure 1 The different networks of support available to families



We can draw some conclusions by analysing the support networks:

1. The **Family Fund is additional to other support** that the family draws on. Effective support and intervention needs to understand the linkages across these different networks.
2. Over the last five years there have been policy **changes to the support that families draw on**, e.g. greater funding of short breaks, a 'named person' contact for the family in Scotland, or the special educational needs (SEN) and family key worker changes anticipated in England.
3. **Changes to the economy** are leading to a reduction in support services such as Benefits and DLA, Children's Centres, NHS support (e.g. in Northern Ireland); and a reduction in the support that can be offered by local community organisations

In illustrating the different networks, we are not suggesting that certain outcomes necessarily follow from particular combinations of circumstances; only that there needs to be an awareness of the multi-factoral and fluid nature of need and support. As every family has a different set of needs, different barriers and different support networks, it is challenging to draw conclusions about the unmet need in society, or anticipate changes to that need over the next five years. However, it is important to *attempt* to understand the needs of these families as the business case for the Family Fund rests on the additional support that it provides, that cannot be met by the other statutory, community or family support networks.

An Outcomes Focused Approach

It is clear from the research that the Family Fund's home visits and grants deliver many positive benefits for families, some of which have a longer-term impact. The Family Fund has already expressed a desire to improve its understanding and measurement of the social impact of its work, and we strongly recommend that it does so. A more outcomes focussed approach will enable the Family Fund to i) better plan its achievements and impact (including improving these), ii) monitor and evaluate success and failures, and iii) better communicate the impact of its work to its various audiences.

The Family Fund has indicated an interest in Social Return on Investment (SROI)¹⁹ as a means of measuring the wider value of its work and demonstrating this to current and future commissioners. SROI is only one approach to demonstrating social and economic impact and value – there are many others. Before embarking on any kind of appraisal of social and economic impact, we recommend that the Family Fund is clear about i) the purpose of the study and ii) an understanding of what the findings will be used for. This will help guide the Family Fund's decisions about how it should proceed.

¹⁹ SROI is a form of cost-benefit analysis, underpinned by a set of seven principles, which generates a SROI ratio which reads as: *'for £1 invested in the FFT, it has created £X of social value'*. More information about Social Return on Investment can be found at: www.thesroinetwork.org

1. **Recommendation:** As a starting point, the Family Fund should continue to use the research instruments developed for this study (or an adapted version of them) as a means of capturing consistent and comparable outcome data over time.
2. **Recommendation:** The Family Fund should explore different approaches to capturing social and economic impact and value, so that it is more informed about the pros and cons of different techniques and is able to choose an approach which is fit for purpose.

Whilst some elements of the Family Fund business are easy to model, other aspects of the work relating to family needs assessment, the interaction between Advisors and parents, and the impact of grants and other services are difficult to fully measure. In these circumstances an ‘innovate, test, measure, adapt’ approach might be more appropriate.²⁰ For example:

- **Innovate** – a new variation on the current model, such as providing printed packs of information to parents for signposting, or changing grant items
- **Test** – with a segment of the population (randomly selected and geographically distributed to reject regional variations)
- **Measure** – either through social return on investment / social impact tools, or through in-depth customer feedback to test outcome improvement
- **Adapt** – review findings and implement the new model, based on a cost benefit analysis.

Such models are often used in high volume services such as the Amazon website, where small changes to layout can be quickly tested and implemented. It is anticipated that a test model will help accelerate the evolution of the Family Fund model, improve understanding of social impact, and lead to greater efficiency or outcomes for families.

3. **Recommendation:** Review how the Family Fund develops and tests new ideas. Explore whether an ‘innovate, test, measure, adapt’ model might help evolve the Family Fund offer and social impact.

²⁰ A cyclic approach to prototyping services which is becoming a more popular way of piloting and rapidly innovating new services in local Government.

Purpose of the Family Fund

In stakeholder interviews, there was a variety of views about the overriding purpose of the Family Fund, with particular differences raised by the four Governments including:

- Family Fund is to support **children** and **young people**
- Family Fund is to support the **family unit**
- Family Fund is to provide **early intervention**
- Family Fund is to support those in **crisis** (often filling gaps in statutory services)

These are all valid perspectives for the Family Fund which is currently meeting all four of these aims. However, more clarity about the end customers and outcomes will help improve the Family Fund model through social impact testing, and ultimately taxpayers' value for money.

In considering the views of policy stakeholders, Family Fund staff and family case studies, we therefore suggest that there are two key scenarios that the Family Fund is focused on:

1. **Supporting families in crisis** – There was agreement amongst stakeholders in the study, including voluntary sector providers, that families will be increasingly in crisis due to changes in benefits, employment levels, interest rates and local services. Logically, the point that the Family Fund might generate the greatest return on investment is if the services and grant provided help a family to stay together, therefore reducing the need for children to be looked after by the State at a cost of up to £250k per year.
2. **Early intervention to reduce the barriers to normal family life** – Following the social model of disability, a secondary aim is to support families so they can continue to function effectively and support the disabled child or young person. The return on investment is longer term.

As we will see, these are quite different aims, potentially requiring different referral models, assessments and responses.

A Social Model of Disability and Needs Assessment

The current needs assessment process of the Family Fund is based on the level of benefits being received by the family, and the medical needs of the disabled child. We found confusion amongst some families about the eligibility criteria, particularly concerning what falls under '*severe disabilities*'. Families whose application was declined on the basis of their child '*not being disabled enough*' found it insensitive, as if to suggest that their needs are less significant. Embracing a social model of disability would mean shifting the focus away from a narrow emphasis on '*severity of disability*' to a better understanding of the barriers faced by families with disabled children, and how these barriers can best be overcome. This would require a new model of needs assessment, which involves a shift from assessing the level or severity of a child's needs to assessing the needs of family unit and the barriers it faces. The assessment could also determine whether the family is at risk of being in crisis.

In order to understand the different needs of families, the Family Fund may also wish to draw on developments in local services – either directly accessing the needs assessment data of families in the area, or using some of the techniques developed in local authority, justice and NHS commissioning. Socio-economic marketing datasets such as the Experian Mosaic or Acorn pre-assess a postcode area to show the likelihood of particular resident social groups – these can be cross-related to Family Fund’s own needs assessment to show how predisposed a family is to particular types of need – as a first step to prepare an Advisor who is visiting and potentially speed up the assessment process or lay the groundwork for crisis and early intervention segmentation. The Family Fund may also wish to encourage fast-track referrals from local authorities and other trusted statutory services.

- 4. Recommendation:** Explore the feasibility and implications of moving to a social model of disability.
- 5. Recommendation:** Review Family Fund needs assessment data and processes. Link up with local authority data on needs and explore the potential application of socio-marketing datasets. Needs assessment should focus on the family rather than the child, using the social model of disability.

Understanding the Demand

As noted already, we feel there are two groups of families that the Family Fund supports (alongside other services): i) families in crisis, and ii) families requiring early intervention to reduce the barriers to normal family life. We would expect the two groups of families to have different ‘pathways to support’ with different referral processes, assessments and responses, and this is reflected in the current Family Fund model. We feel that there is now an opportunity to formalise these two different pathways, in particular working with the four UK Governments to understand their expectations about the distribution of funding across the two groups and how this is likely to change over time.

- 6. Recommendation:** The Family Fund should work with UK Governments to set up a mechanism for controlling, monitoring and reporting on the distribution of funding across two different pathways: families in crisis, and intervening early to reduce the barriers to normal family life.

Making the Grants Go Further

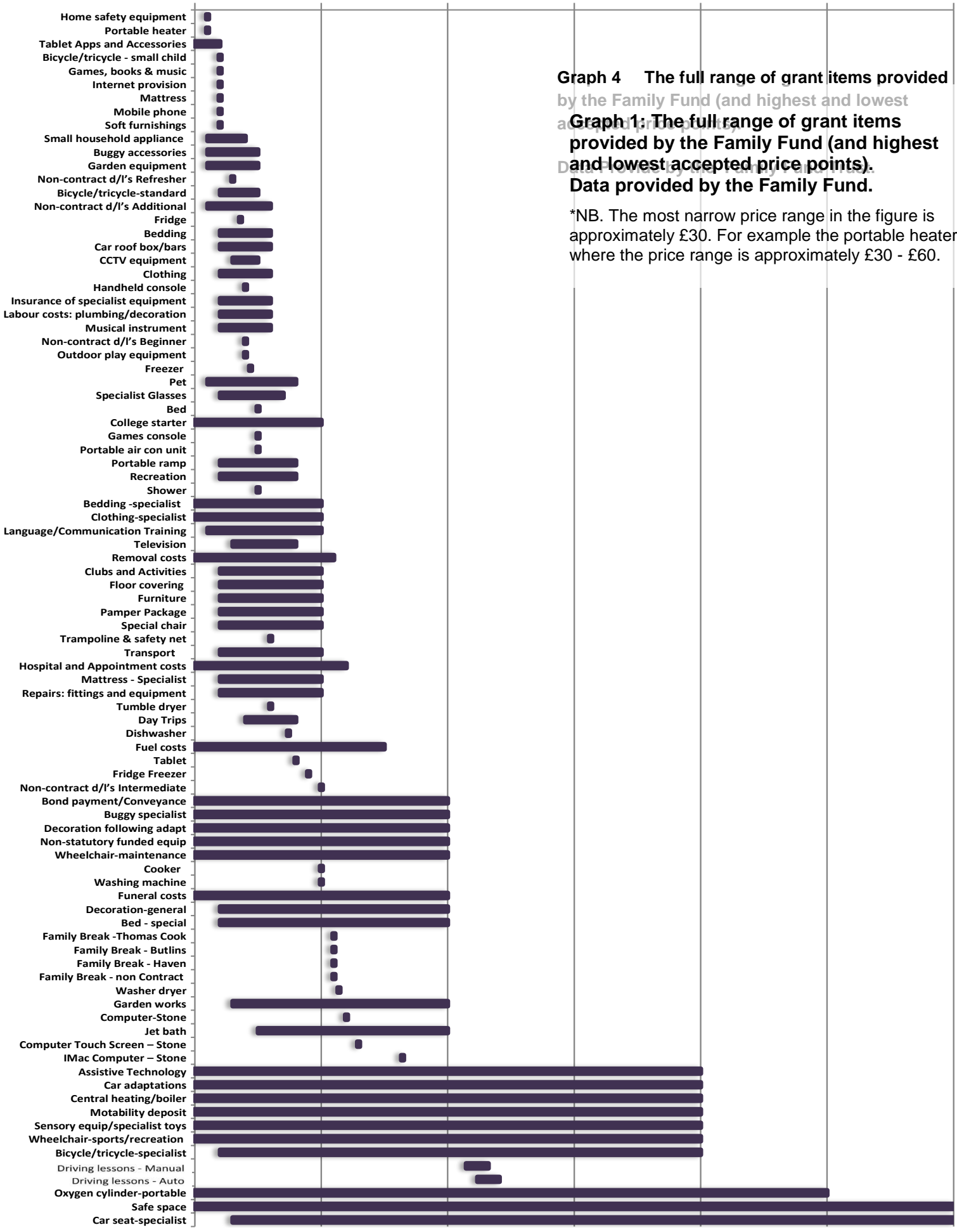
The Family Fund distributes a vast number of grant items to families – see Graph 4 for a complete list and range of values of those grants. This review suggests several changes to the needs assessment process, and reflects on changes in policy, which might impact on the types of grants that are distributed in the future. For example:

- Grants should be analysed for their social impact on families, and the wider benefit such as helping individuals remain in employment or participate more fully in society. This will change based on family needs and barriers they face, and it will take time for the Family Fund to fully understand the likely social impact of different grants. We can however expect

that this analysis will lead to changes in grant distribution to optimise the social impact on outcomes vs. the financial cost of each grant item.

- If the needs assessment process moves from assessing the medical needs of the child and family income, to a social model of disability, then we can expect the types of grants to change. E.g. there may be more grants to help a family overcome the barriers that they face, rather than to solely meet the needs of the child. However, the needs that are met by different items are very difficult to fully assess so whilst we may expect the number of computers / iPads / games consoles / play equipment to be reduced in the future, often these are effective in keeping a child occupied and allowing a parent to spend time with other family members. It is difficult to predict impact on the grant distribution.
- It is likely that more families will be in crisis in the future, and families reported in the survey that grant items that are viewed as discretionary (such as family breaks) are being displaced by items that are essential (such as white goods). The Family Fund will want to review which items are most appropriate for the crisis based needs assessment and pathway.
- Over the last four years there has been a significant increase in the number of short breaks available to families in England and Wales through statutory funding. As the Family Fund is designed to supplement statutory services, we can expect a decrease in the number of family breaks / holidays that are distributed by the Family Fund in order to avoid duplication. Whilst there are differences in the purpose and outcomes between the Family Fund family breaks and statutory short breaks – Graph 5 shows a clear and continuing decline. The Family Fund may want to ensure that families are aware of the additional statutory supply of short breaks in their information packs and Advisor interaction.

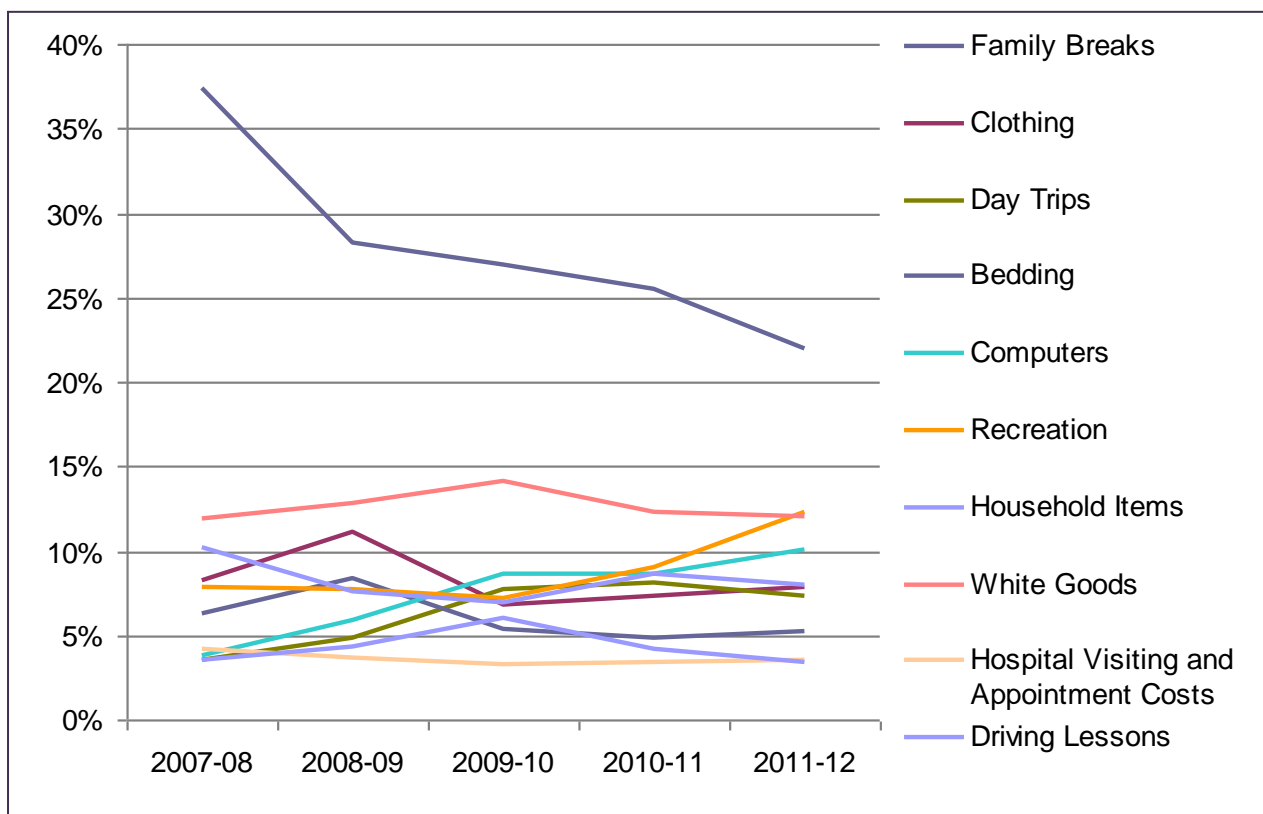
£ £500 £1,000 £1,500 £2,000 £2,500 £3,000



Graph 4 The full range of grant items provided by the Family Fund (and highest and lowest accepted price points).
Graph 1: The full range of grant items provided by the Family Fund (and highest and lowest accepted price points).
 Data provided by the Family Fund.

*NB. The most narrow price range in the figure is approximately £30. For example the portable heater, where the price range is approximately £30 - £60.

Graph 5 Top ten grants supplied by the Family Fund over the last five years



In an open question, parents reported the following items had the greatest difference to their families' lives: holidays (family breaks), 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 and clothing.

Due to the complexity of family needs and barriers, it is not possible for this review to ascertain whether the grants in each category are optimised. However, we can expect changes to the number of different grants provided and there have already been changes, such as a reduction in the number of family breaks, supplemented by shorter, cheaper day trips and recreation.

7. Recommendation: Review the distribution of funding for particular categories of grant items (e.g. family breaks, white goods, computers), based on analysis of family barriers, increasing families in crisis, social impact and changes to statutory services.

UK Demand Analysis

Current estimates of the number of families with disabled children in England, Northern Ireland, Scotland and Wales are difficult to pin down with a variety of definitions of a disability, and a several techniques for sampling and measurement. It is usual for statisticians to use an upper and lower estimate for numbers based on surveys and national census data^{21 22}. A lack of clarity about the number of families with disabled children who require support is a challenge and it is recommended that the Family Fund and four Governments work together to improve estimates of need, and validation of current levels of demand. In the absence of accurate data, we propose the following calculations to estimate demand.

Number of Disabled Children (estimates from data provided by the four Governments):

| | England | NI | Scotland | Wales | Total |
|----------------|-----------------------|--------|----------|--------|---------|
| Upper estimate | 680,196 ²³ | | | | |
| Mean | 484,098 | 23,100 | 33,000 | 19,655 | 559,853 |
| Lower estimate | 288,000 ²⁴ | | | | |

Our survey of parents shows that for every 100 disabled children, there are 84.9 families. We can therefore make a more accurate estimate of the number of families with disabled children.

Number of Families with Disabled Children (based on responses from parent survey):

| | England | NI | Scotland | Wales | Total |
|------|---------|--------|----------|--------|---------|
| Mean | 410,999 | 19,612 | 28,017 | 16,687 | 475,315 |

An assessment by Contact a Family²⁵ and a separate study by DWP reveal the following high levels of need which suggest an appropriate percentage of families with disabled children that would benefit from support by the Family Fund:

- 17% are going without food
- 21% are going without heating
- 21% of families are living with material deprivation and low income²⁶

²¹ Wales: Children in Need Census 2011 <http://wales.gov.uk/docs/statistics/2012/120229sdr322012en.pdf>

²² The Prevalence of Disability and Activity Limitations amongst adults and children living in private households in Northern Ireland <http://www.csu.nisra.gov.uk/NISALD%20Household%20Prevalence%20Report.pdf>

²³ Upper estimate of disabled children in England based on 2011 census data and DWP analysis showing 6% of children in the UK have a disability (Family Resources Survey, DWP, 2011 http://research.dwp.gov.uk/asd/frs/2010_11/frs_2010_11_report.pdf). Also the Childcare and Early Years survey of Parents for 2010 study by DfE suggests that 6% of children have longstanding health conditions or disabilities <http://www.education.gov.uk/researchandstatistics/statistics/allstatistics/a00210473/childcare-and-early-years-survey-of-parents-2010>.

²⁴ Mooney, A., Owen, C. and Statham, J. (2008) *Disabled children: numbers, characteristics and local service provision* (DCSF research report 042), London: DCSF (available at www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RR042.pdf) likely to have missed some individuals in the lower bound estimate used here

²⁵ Contact a Family: Counting the Costs 2012, note that sampling methodology was not included in the report, so results are augmented by additional findings from DWP research Households Below Average Income <http://research.dwp.gov.uk/asd/hbai/hbai2011/index.php?page=contents>

- 21% threatened with court action for failing to keep up with payments
- 26% of families with disabled children are in the bottom quintile of income ²⁷
- 26% are going without specialist equipment or adaptations
- 29% have taken out a loan (often for food and heating)
- 32% of families with disabled children are in the bottom quintile or second quintile of income ²⁸
- 60% are going without clothes
- 86% are going without leisure and days out

It is not certain at which point the Family Fund should be supporting families, and whether the Family Fund should be used for early intervention support (before these needs and barriers occur) or for families in crisis. In the absence of clear data we have made an estimate of the percentage of families that should apply for support from the Family Fund (if they are aware of it), based on the levels of national need uncovered by DWP and Contact a Family.

In the remainder of this report we make the **assumption that 33% of families require support:**

| | England | NI | Scotland | Wales | Total |
|-----------------------------|---------|-------|----------|-------|---------|
| Mean (33%) | 135,630 | 6,472 | 9,246 | 5,507 | 156,854 |
| FY11/12 Family Fund support | 46,781 | 2,788 | 5,130 | 4,467 | 59,166 |
| Supported (%) | 34% | 43% | 55% | 81% | 38% |

Based on these assumptions, it can therefore be concluded that the Family Fund **currently meets 38% of the anticipated demand** in the UK.

Routes of Referral

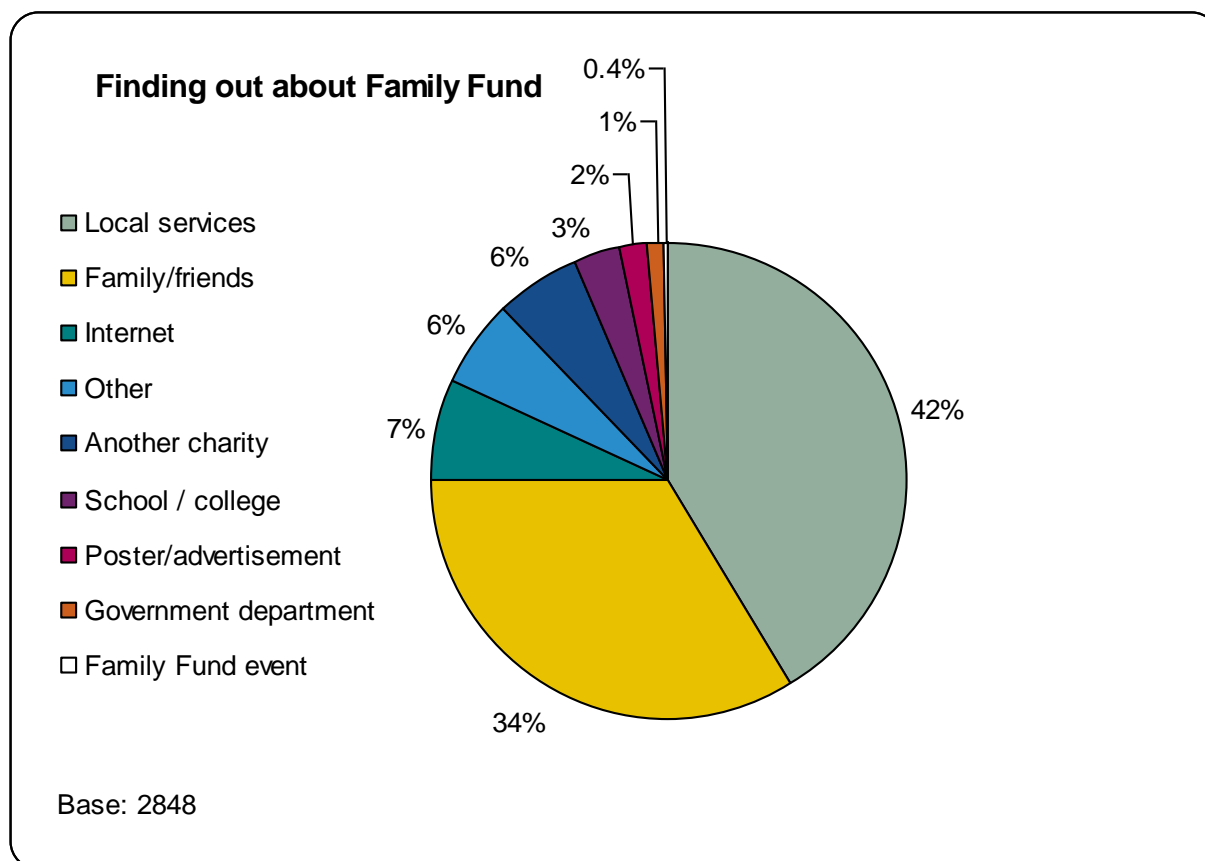
Our survey showed that the majority of parents find out about the Family Fund through local statutory services such as health visitors or social workers, and from word-of-mouth through family and friends, see Graph 6.

²⁶ Table 4.5db, DWP research Households Below Average Income

²⁷ Table 4.1db, DWP research Households Below Average Income

²⁸ Table 4.1db, DWP research Households Below Average Income

Graph 6 The routes by which parents are made aware of the Family Fund



However, it is interesting to note the change over time in the number of people finding out about the Family Fund from statutory services:

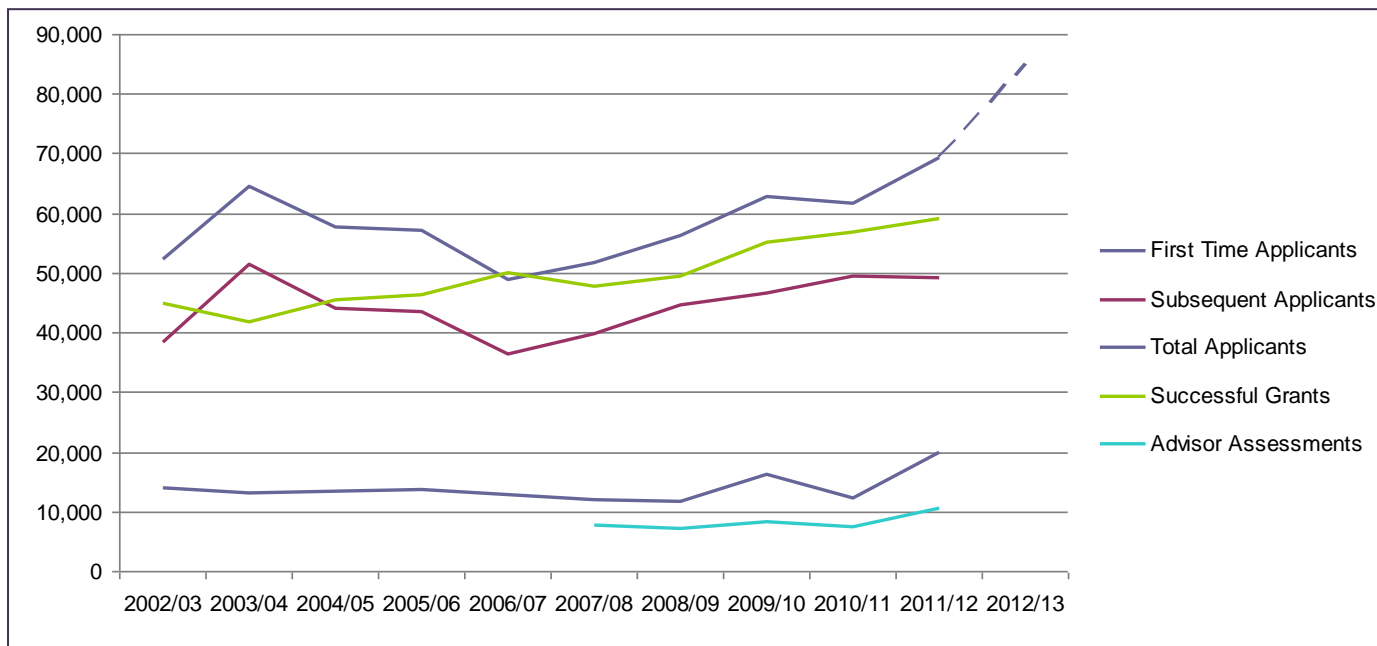
| Source (sample size) | Percentage finding out about the Family Fund from Statutory Services |
|--|--|
| 2005 PwC Customer Survey (152) | 70% |
| 2010 Family Fund Customer Survey (1,001) | 54% |
| 2012 parent survey all applicants (2,848) | 42% |
| 2012 parent survey first time applicants (866) | 30% |

The data appear to show a decline in the percentage of parents learning about the Family Fund from statutory services. As the number of applicants is rising, we expect this is because of stronger communication through word-of-mouth and internet advertising driving new demand (such as through the Family Fund’s social marketing on Facebook). This is commendable and the Family Fund may wish to explore changes further in the next customer survey.

Based on the figures from early FY12/13 we anticipate 85,000 applications this year, a 23% increase from 69,221 in FY11/12, but some way short of the 157,000 families that are likely to require support. We therefore recommend that the Family Fund builds on their strength of raising awareness through word-of-mouth and internet / social media advertising, perhaps coupled with stronger revenue generation through charitable giving.

We would also like to suggest that the four Governments redress the balance of awareness raising by statutory services and ensure that local authorities and clinical commissioning groups are doing their bit in driving demand towards the target figure of 157,000 families.

Graph 7 The changing demand for Family Fund grants – in particular an increase in the number of first time grants, and overall demand



8. Recommendation: Family Fund to build on current strengths of advertising through word-of-mouth and the internet / social media to increase demand so that all families that should be accessing the Family Fund are able to. Government to encourage local authorities and other statutory organisations to ensure that no particular group is disadvantaged when accessing the Family Fund.

Age Limits for Families

Currently, the Family Fund provides grants to children up to the age of 17. As SEN (Special Educational Needs) special school/college education runs through to 19 years, there could be value in helping to support families and young people at this transition period to adulthood by extending the age limit.

This sentiment was echoed by some families in the research who expressed concern about their support from the Family Fund ceasing after their child reached 17, arguing that the Family Fund's age limit should be increased. Given the new single Education, Health and Care plan (which replaces a statement of SEN) being introduced by the UK Government will extend to disabled children up to the age of 25²⁹, there could also be a rationale for increasing the age limit to 25 for some young people. This would clearly have significant implications for Family Fund in terms of widening its target group and would need to be considered alongside the other recommendations being proposed.

9. Recommendation: The Department for Education and devolved administrations consider the feasibility of extending the Family Fund's age limit from 17 to 19, and potentially to 25 for some children, and the implications of doing so.

Operational Efficiency

Financial Model for the Family Fund

As part of the review we constructed a high-level financial model of the Family Fund (based on FY10/11 audited accounts and demand figures) to show two key parts of the business:

1. The levers that the Family Fund management pull to balance the books at the end of each financial year, and to satisfy the requirements from the four Governments
2. Understand the sensitivity of the model to changes in demand, especially from first time applicants; and model future changes

Key elements of the model are:

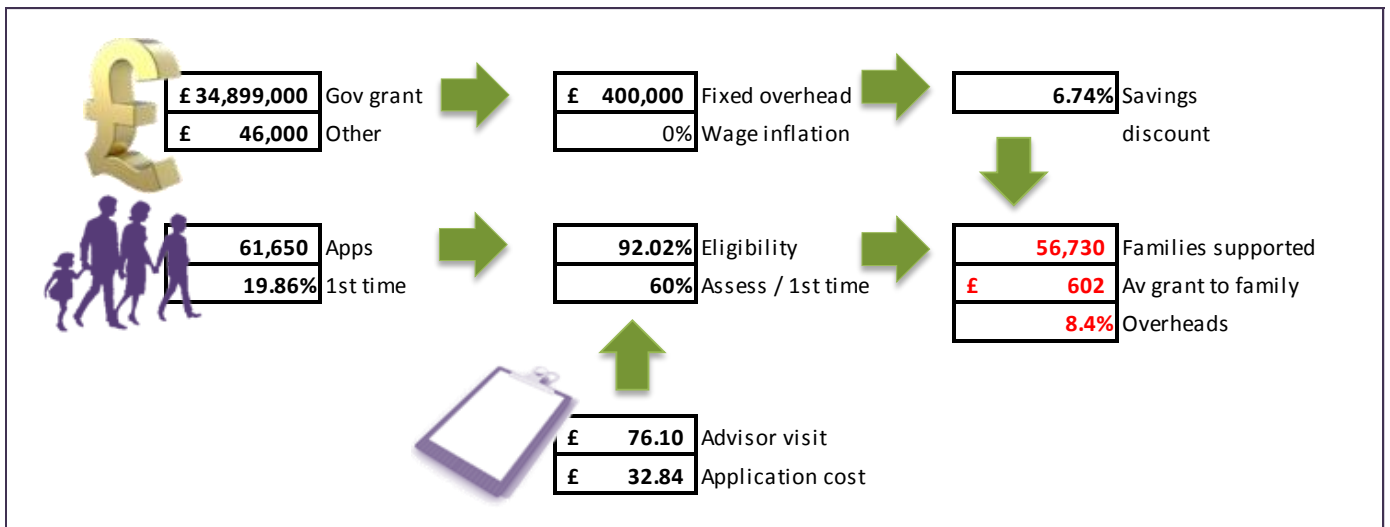
- **Money coming in** – through Government grants or trading / charitable giving / investments
- **Number of applicants** and the mix of first time applicants and families who have made multiple applications
- **Overheads** – for the office including fixed overheads and variable overheads (based on the volume of demand)
- **Advisor visits** – the cost of each visit and assessment for first time applicants
- **Wage inflation** – to calculate interest rate increases in staff costs over time, based on the Retail Price Index in July 2012

²⁹ Those young people who already have a statement of SEN or a learning difficulty assessment for post-16 provision are expected to have a single Education, Health and Care plan in the future

- Average **discount** achieved through negotiation with providers, such as white goods companies
- The total **number of families supported in a year**, the average grant provided, and all overheads as a percentage of the grant from the four Governments

The model shown in Figure 2 will be used in this section of the recommendations to test funding requirements, and is available in a spread-sheet should policy officers wish to test new settlements.

Figure 2 Financial model describing the Family Fund, with FY10/11 figures (note that the average grant given to families was actually £575 as some funding was retained to carry forward for next financial year so that the balance sheet was no-longer negative)



Back Office

Whilst the majority of families are happy with the application process, there was dissatisfaction expressed by some families about the time and expense involved in waiting for telephone calls to the Family Fund to be answered. To improve back office efficiency and reduce dissatisfaction, it is suggested that the Family Fund continues in its attempts to move parents from telephone communication to the web or email, accepting that due to the support that some families require, and their access to technology, it will never be appropriate to reduce this to zero.

Failure Demand

The Family Fund is currently answering around 250,000 phone calls a year, with an average team of three. This is an average of 3.6 calls per application (including those which are handled by email / web) which suggests a large number of calls are being generated by parents checking on applications, on eligibility rules, to get information, or for complaints. This type of demand is often referred to as failure demand because the information might have been communicated in a different way, or an application might have been completed more quickly therefore reducing the parent's desire to call. Whilst it was not within the scope of the study to analyse the customer call centre, we suggest that the Family Fund reviews the number of calls that might be classed as

failure demand (by interviewing a selection of customers), and sets a Key Performance Indicator (KPI) to continue measuring and reducing that demand.

Potential solutions suggested by parents in our case studies and parent survey include: empowering Advisors to make immediate decisions and then communicating these quickly to parents, great clarity about grant eligibility, and being clearer about the reasons for failed applications, particularly in those cases where a child does not meet the Family Fund's definition of '*severely disabled*'.

Family Fund might also want to consider reducing the number of grant options on the application form from three to one or two, to reduce parental expectations and sense of disappointment on receiving a subset of requested support.

10. Recommendation: Review the reasons for high levels of telephone communication, assess the extent to which this is driven by failure demand, and review processes to reduce demand.

Diversification

Since establishing a trading arm, the Family Fund has been seeking to diversify income streams and grow its unrestricted revenue generation in order to increase the number of families that can be supported. This is laudable and it is recommended that business developments are accelerated, including:

- Building on the low overheads and strong experience of grant giving by offering a similar service to local authorities to administer their **Community Care grants**
- As the Family Fund is already providing payroll services to two local charities there is an opportunity to **integrate with other local charities** to share services and accommodation
- **Bidding for further work** from Government administrations, e.g. the recent telephone support contract for parents with disabled children that was won by Contact a Family
- Despite the difficult market, build a much stronger **charitable giving** arm to increase revenues and to drive demand by promoting the work of the Family Fund

Business development funding may be available from the Department for Education to support this diversification.

11. Recommendation: Build on the Family Fund Trading arm activities by diversifying funding and driving up revenues to support more families.

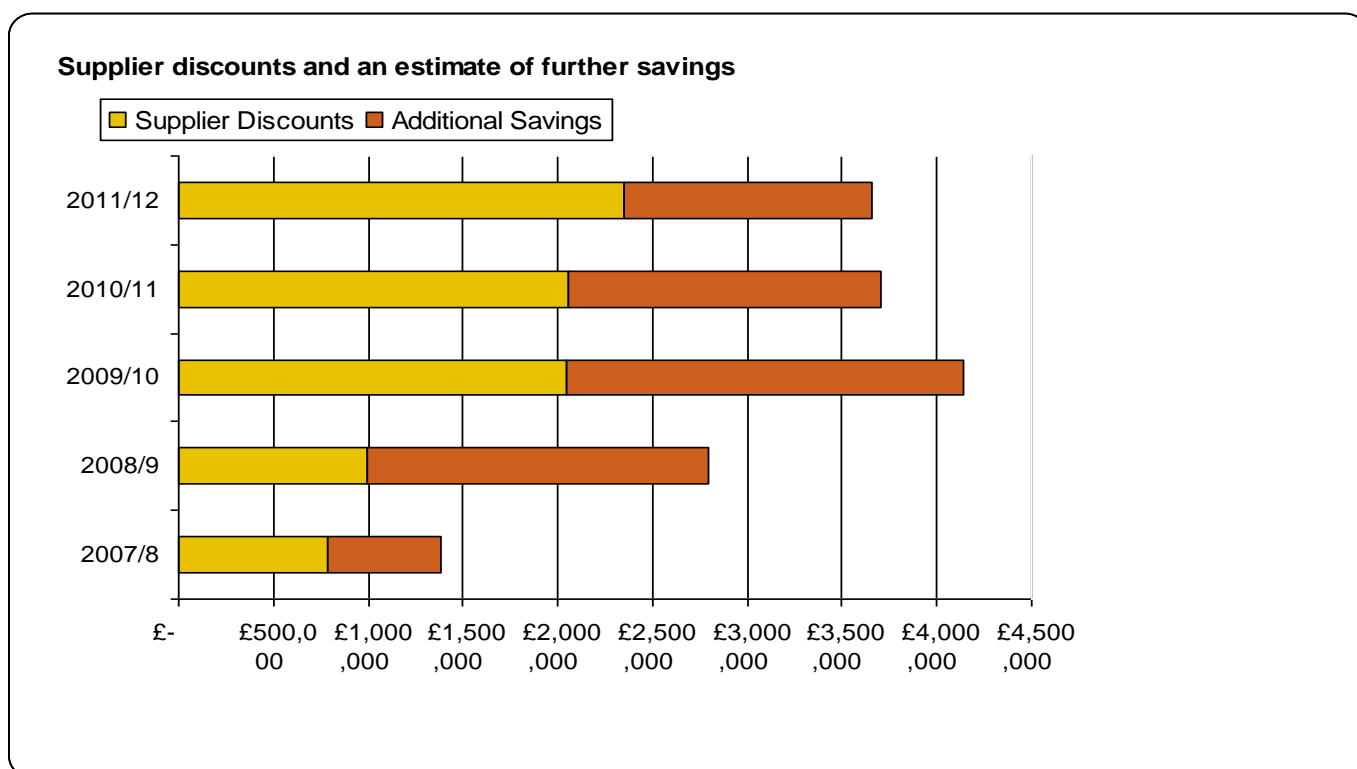
Procurement

Procurement expertise in the Family Fund has been growing as evidenced by the savings achieved each year, in negotiation with suppliers such as Comet, New Look, Argos, Haven and Thomas Cook, see Graph 8. This has been supported by moving 75% of grants to store cards through pre-negotiated contracts – which reduce the opportunity for fraud and increase the volume of spend that can be negotiated with providers. A sample of procurement contracts show these are well designed and figures shared confidentially with the review team demonstrate significant levels of savings with some providers.

However, the overall savings in FY11/12 are around 11.7% which is just a little less than anticipated (comprising 7.6% contract supplier negotiation discounts, and 4.1% in other additional savings). Discounts for family breaks are less than the average and as volume is likely to reduce, we anticipate the Family Fund being able to drive up the average savings from procurement activity.

It may also be possible to draw on corporate social responsibility by supporting providers who wish to use the Family Fund in advertising, increasing savings and building visibility of the Family Fund brand.

Graph 7 The amount of discount negotiated from providers over the last five years, comprising contractual supplier discounts and an estimate of further savings from the Family Fund (e.g. by securing higher specification computers). FY11/12 represents an overall



As discounts represent a significant saving Family Fund should consider strengthening the procurement expertise in the team, e.g. training a member of staff to NVQ level 3, and designating a member of the team to lead on procurement. We also noticed in our assessment that a contract

with one provider included a number of indistinct clauses which might be unhelpful in a dispute. A small investment in training is expected to lead to larger procurement discounts.

As the Family Fund can be defined as “a corporation established, or a group of individuals appointed to act together, for the specific purpose of meeting needs in the general interest, not having an industrial or commercial character, and—(i) financed wholly or mainly by another contracting authority”³⁰ it is subject to EU procurement regulations, and has been following these in tendering. Therefore the Family Fund will be able to draw on frameworks and the more considerable purchasing power of central Government for future procurement exercises, Government Catalogues, and providers such as Pro 5, e.g. for IT, furniture and some grant items. It is recommended that the Family Fund explores the potential for savings from these options.

12. Recommendation: Build on recent success and further increase procurement savings through stronger competitive negotiation, developing staff and using Government frameworks and buying power.

Advisors and Home Visits

There was a strong and repeated message from participants in the review about the positive impact of home visits. The signposting function is considered particularly valuable, as many families do not have regular contact with their local parent carer forum or other similar support group. Given the weight of evidence in its favour, there is a strong argument for viewing home visits as part of the ‘service’ to families, rather than an overhead, and we suggest that the Family Fund considers this proposition.

Evidence from the review indicates scope for further increasing the impact of the Advisor role through a more systematic approach to signposting families to other sources of support. This would mean all families in a locality receiving consistent information about local groups, short breaks provision and other sources of support (financial and otherwise), rather than leaving it up to individual Advisors. One way of achieving this would be through the use of an electronic information pack that is emailed to families in advance of the home visit and then discussed as part of the visit (with provision of a hard copy for families without access to a computer). It is possible that strengthening the additional support provided by an Advisor service could lead to some families receiving greater social impact from this support, than from the provision of a grant item or service.

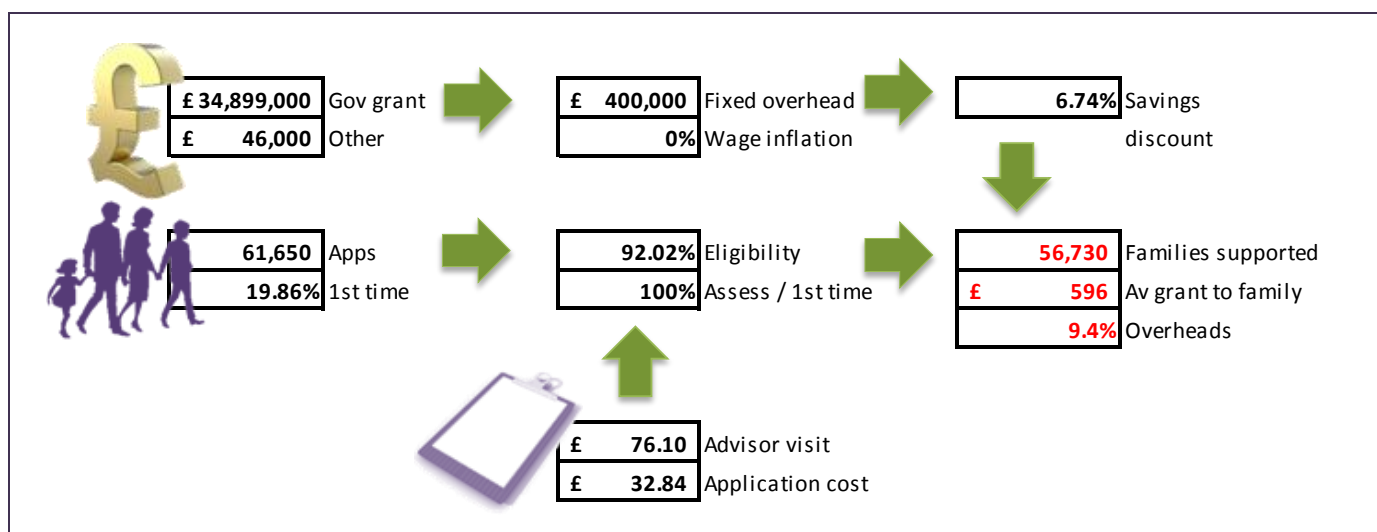
In order to speed up the decision making process, there is a case to be made for empowering Advisors to make the final decision about whether a grant should be awarded. Advisors have the most comprehensive understanding of the family’s needs and circumstances, and are arguably the best placed to make the decision. We understand that this is something the Family Fund has considered in the past. Whilst it raises issues about the Advisor being in a difficult position with a family, a delay to communicating the final decision would be appropriate (e.g. by letter), and we would recommend that this option is re-visited in light of the review findings.

³⁰ The Public Contracts Regulations 2006 (No. 5)

Currently the Family Fund is able to provide home visits to just over half of first time applicants. We recommend that all first time applicants who meet the basic eligibility criteria should receive a home visit, however recognise that the Family Fund would incur additional costs. Using the FY10/11 figures in our financial model, we can estimate the impact on back office overheads of increasing the Advisor visits from 60% of first time applicants to 100%. Implications are:

- Advisor costs increase from £515,378 to £857,392
- Overheads for the whole Family Fund increase from 8.4% to 9.4%

Figure 3 Financial model for the Family Fund for FY10/11 showing the cost of increasing first time assessments from 60% to 100%



13. Recommendation: Strengthen the Advisor role, by increasing the proportion of first time applicants who receive home visits, ensuring all families receive consistent information on suitable alternative sources of support, and re-visiting the proposal to empower Advisors to make grant decisions according to comprehensive guidance.

Changes for UK Governments

To a certain extent, the Family Fund has been left by all four Governments to continue driving down costs, and providing grants to the families it chooses to support. For example, one grant letter gives the instructions

“To support core costs in connection with activity undertaken by The Family Fund to meet the... key priorities for children and young people, as set out in the National Performance Framework.”

In this instance, there are no other policy or commissioning directions for the Family Fund.

Changing to a social model of disability, measuring social outcomes, and focusing on the barriers to family life and families in crisis, will help to direct the resources of the Family Fund to have greatest impact. These changes will allow the four Governments to state the outcomes they would like to achieve, and the extent to which the fund should be addressing the needs of families in crisis, or reducing barriers to normal life through early intervention.

The Family Fund and four Governments should also continue to work together to ensure that any policy changes are reflected in the services and grants distributed, and that any links with local services and benefits can be recognised and implemented. For instance, there is a strong opportunity for the Family Fund to be linking up with the ‘named person’ in Scotland, or family key workers in England.

14. Recommendation: Policy teams should take on a stronger commissioning role and set the outcomes and levels of need that Family Fund should be supporting. Family Fund and policy teams should work together to ensure links to local services are in place.

During stakeholder interviews, there were several suggestions for Family Fund to further support policy teams:

- Family Fund collects a considerable amount of data about the needs of disabled children and their family, as the organisation that has the greatest contact with this population. The collection of information is likely to improve as Family Fund look at social impact and improve their measurement of outcomes. There is an opportunity to share this information with the four Governments – particularly to help understand the increasing pressures that families are going through over the next few years.
- As Family Fund engages with up to 85,000 families each year, it is possible to share subtle policy messages and information with families – either through Advisors or web / email / telephone communications. E.g. encouraging take up of new policy programmes and support.

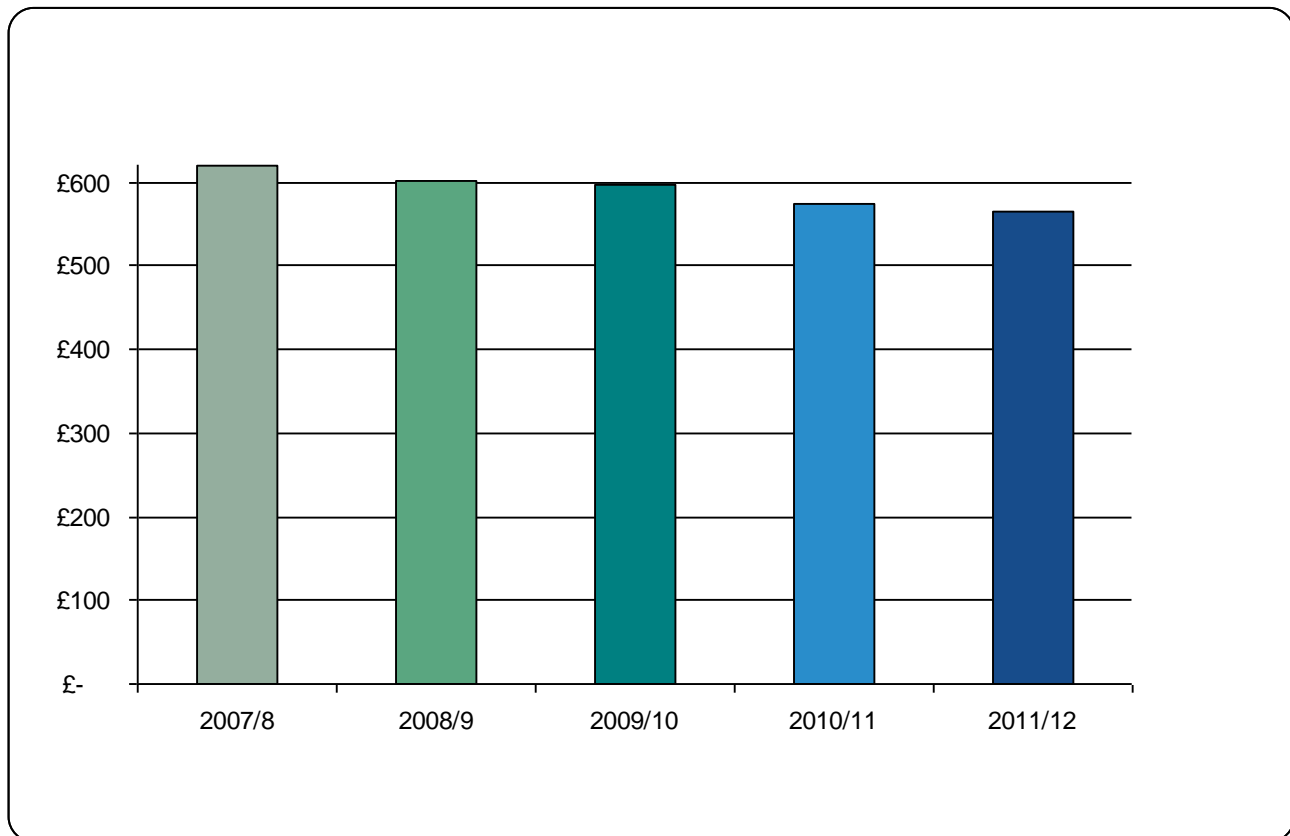
- Anecdotally, families are unclear about where the funding comes from. The four Governments might find it politically beneficial for families to understand that they are being supported during these difficult economic times. However, there is a risk that harder to engage families are less willing to accept support.

15. Recommendation: Family Fund should offer additional support to the four Governments by sharing data and subtle policy messages with families.

Funding the Demand

The average grant distributed by the Family Fund to parents has dropped by 9% over the last five years, or taking inflation into account the reduction is 16% in real terms³¹. It has not been determined, but there becomes a point where the financial value of a grant stops having the desired effect on families in crisis or on early intervention – the four Governments will want to monitor the average level of grant to families.

Graph 9 Reduction in average grant value given to families in the last five years

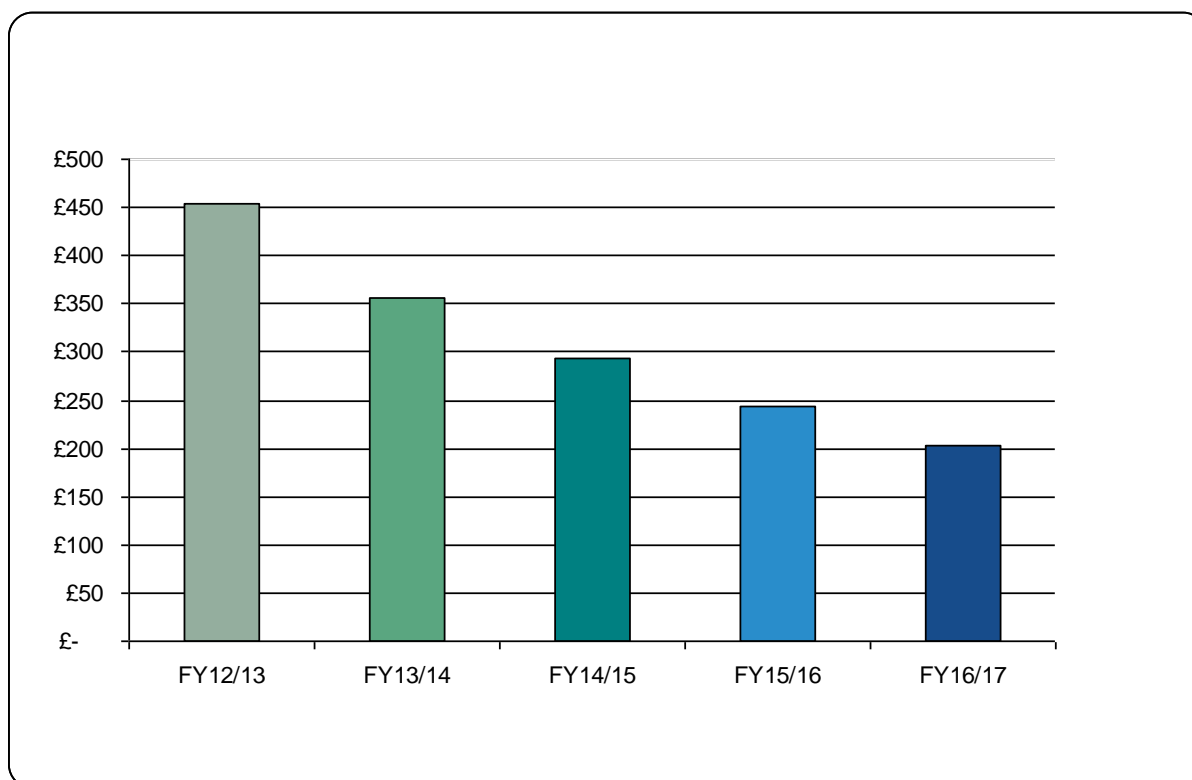


³¹ Retail Price Index - ONS

As demand grows, the Family Fund has little choice but to cut the value of the average grant in order to meet financial restrictions. We have modelled the proposed changes suggested in this report:

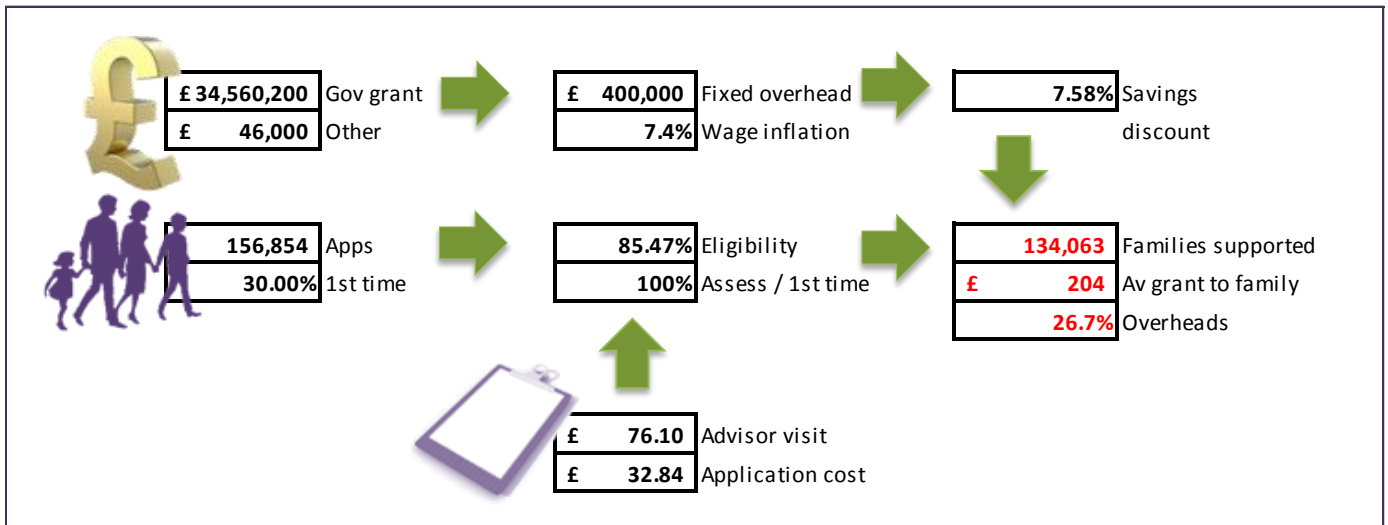
- Visiting 100% of first time applicants (currently 53%) – to assess eligibility which is likely to tighten, to assess whether the family is in crisis, and to secure additional social impact such as through the information packs and signposting to parent carer forums (we have assumed this will take five years to implement)
- Increasing applications from a predicted 85,000 this year to 156,854 (we have assumed this takes five years to implement), first time applicants will remain stable at 30%
- Increasing staff and Advisor unit costs by the Retail Price Index of 2.4%, maintaining 85.5% success rate of applicants, and continuing to deliver 7.58% savings on procurement deals

Graph 10 A model of average grants to families, based on increasing demand and assessments of first time applicants, and an annual Retail Price Index of 2.4%



In this scenario by FY16/17 there are 156,854 applications for support. 134,063 families are supported every year, the average grant drops to £204 per family, and overheads grow to 26.7% as shown in the following model. See Figure 4 for more details.

Figure 4 Model of the Family Fund showing FY16/17 scenario without any changes to funding



We can therefore conclude that the current model is unsustainable and there are two main levers that the Family Fund and Government departments can pull:

- **Increase eligibility criteria** – possibly shifting the model to families in crisis rather than early intervention
- **Increase funding** – from the four Governments, local authorities, or the trading arm of the Family Fund (stakeholders reported that funding from the four Governments is currently based on historic settlements rather than needs assessment)

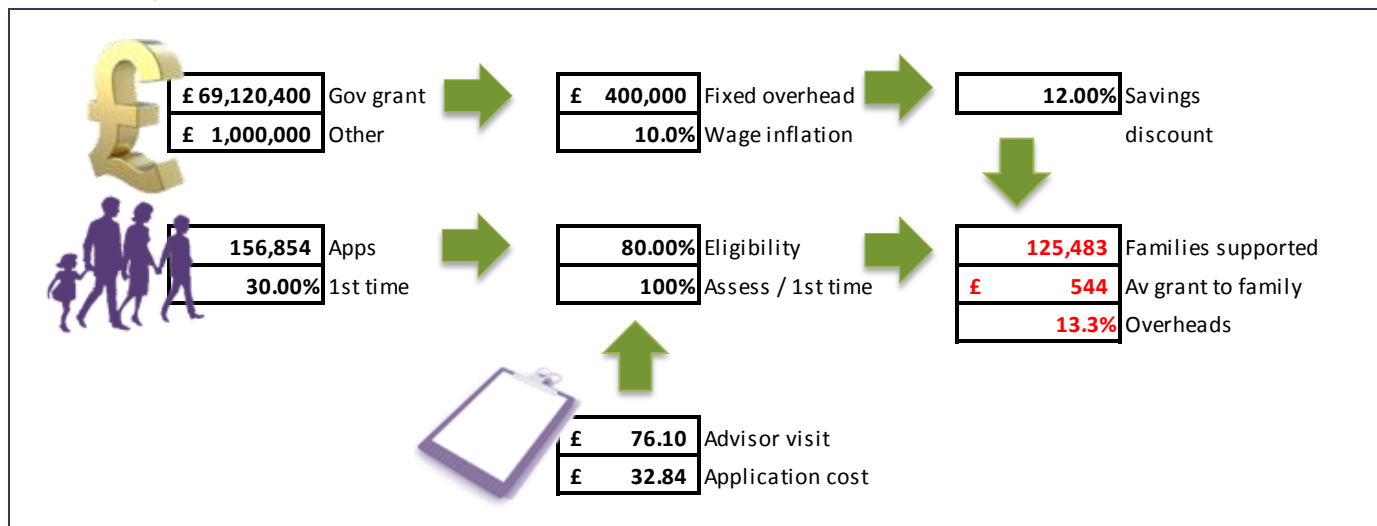
Neither option is desirable in the current economic climate, although it is helpful to be reminded of the business case for the Family Fund. Every family unit that is kept together reduces the cost to the state of a child going into care, at up to £250,000 per disabled child. This is an investment model.

We have modelled various scenarios and discussed the implications in stakeholder interviews; collating those views we therefore suggest the following changes, although these will require further analysis if they are taken forward:

- 1. Family Fund to double the impact of the grant and services on each family** – by analysing social impact and making more use of the services provided such as signposting, information packs, linking to parent carer groups, linking to other public and voluntary support services, promoting Government policy changes and information sharing
- 2. Family Fund to increase procurement savings to 12%** – through training, competitive tendering and use of Government frameworks
- 3. Increase profit from the Family Fund Trading arm to £1,000,000** – through charitable giving and business development options

4. Subject to Ministerial decisions, **Local Authorities, NHS Commissioners, the Department for Work and Pensions to match funding** – if the Family Fund is viewed as an investment model, the benefits from families staying together mostly fall on Local Authorities, NHS and DWP
5. **Eligibility for grants to drop to 80%** – to maintain a reasonable level of average grant, and recognising that some applications will fall below reasonable eligibility thresholds

Figure 5 Model of the Family Fund showing potential changes by FY16/17, to deliver an average grant of £544 to 125,483 families



16. Recommendation: Consider increasing available resources in order to meet future demand. Resources can be sourced from a combination of: greater procurement savings; increased profit from Family Fund Trading; additional contributions from Department for Education, Department for Work and Pensions, Local Authorities, NHS commissioners and devolved Governments.

Governance

As discussed earlier in this review, the Family Fund has the greatest impact when supporting families that are in crisis, or supporting families through early intervention. In each case, the support is for the family because that impacts on the outcomes of the child. Given the outcomes are for the child and family, it makes sense for the Governments' governance arrangements to reflect this. There are two further benefits to joint Department governance arrangements:

- To a certain extent the four Governments have been administering the Family Fund, rather than providing policy direction. Joint governance will help keep each Department to account for the outcomes that are expected from the funding.
- There are benefits in linking up the Family Fund with other local services such as health and the benefits system – such links will be best promoted through the engagement of relevant Departments.

Northern Ireland, Scotland and Wales have joint children and adult Departments which provide some of the benefits of joint governance, although even then there has been a lack of challenge. However, it will be most beneficial for the Department for Education to invite joint responsibility from the Department of Health and Department for Work and Pensions as appropriate.

This recommendation is supported by stakeholders who stated that Family Fund spans policy agendas of several departments, and ought to be recognised for doing so.

17. Recommendation: Establish joint governance of Family Fund administration in England between the Department for Education, Department for Work and Pensions and Department of Health. The Northern Ireland Government, Scottish Government and Welsh Government should also review governance arrangements to ensure that the Family Fund is fully held to account.

D. Summary of Potential Future Options

Introduction

As part of this review we were asked to assess alternative options that the UK Governments might consider to meet the outcomes currently delivered by the Family Fund. This review considers alternative markets and supply chains and compares each option against the baseline.

Efficiency

We have researched many different models and schemes from across the UK, EU and globally (see section D. Comparators and Alternative Models in the Appendices document) and found very little that compares directly to the Family Fund due to its unique nature of distributing grants directly with face-to-face assessment and support.

However, we can compare the administrative efficiency of the Family Fund against the Social Fund Budgeting Loans distributed by the Department for Work and Pensions (DWP). These are of a similar financial size, but the DWP model lacks the Advisor visit. Excluding Advisor visits the Family Fund costs £39.64 per application; whilst the DWP Budgeting Loan costs £86 per application.³²

We can also make a comparison with the DWP Community Care grant which has administrative costs of 13%, compared with around 9% costs of the Family Fund (including Advisor visits. These are different schemes with differing assessment criteria but show a comparable level of efficiency to validate the Family Fund model.

Alternative Options

If we now look to a larger variety of markets and supply chains we can identify four clear alternative options for comparison:

1. Local Authority administration through **individual budgets**
2. **Voucher scheme** with self-referral
3. Distribution through **Parent Carer Forums**
4. **Procurement** of a new distributor

Assessment of Options

Each option is presented, assessed and then compared in the final section of this report. We have built on information supplied through Stakeholder interviews and the call for evidence from the voluntary and community sectors.

³² Independent review of the Social Fund

0. Family Fund (Baseline)

By way of comparison we include the Family Fund as the baseline option, including the additional features suggested in this review such as:

- Advisor assessment of all first time applicants
- Clear focus on improving outcomes, and increasing social impact from additional support such as signposting, information packs, links to Parent Carer forums, coaching of families
- Support to families both through early intervention, and to families in crisis

Note that Northern Ireland recently reduced funding to the Family Fund by 11.25%, resulting in a three month cut to services, significant lobbying and political issues.

1. Local Authority Administration through Individual Budgets

This alternative model is to provide families with funding directly, through local authority administration, and allow parents to choose how that money is spent. In many ways this approach fits better with current political thinking: devolving funding to local authorities and allowing recipients flexibility in how they use the additional support. Individual budgets have been widely piloted for children's services and are likely to become standard for Special Educational Needs support, and are standard in Adults' services.³³

Pilots of individual budgets have found clear benefits over statutory services:

- Flexibility to meet a range of needs and package up funding so that outcomes can be more holistically addressed
- Creating a culture of user choice and encouraging co-production so that the family is more strongly contributing to their own care
- Often more efficient care is purchased by the family as the type of provision is not one-size-fits-all but tailored to needs
- Option for the local authority to provide brokerage support, although this raises the costs

However, current take up of individual budgets, personal budgets and direct payments by families receiving grants from the Family Fund is only 18%.

Transfer to this option would be reasonably easy to achieve, as the funding streams are already set up with local authorities. However, it is unlikely that funding could be ring-fenced, so there is a risk that the current funding would no longer meet the specific needs anticipated.

The market and supply chain for individual budgets is well established, however the maturity of the market is poor (but likely to improve in the next five years) and efficiency is difficult to establish.

³³ It should be noted that currently Wales is using direct payments rather than individual budgets – requiring a slight tweak to the system, but with the same administrative and market issues discussed here. Scotland is moving towards self-directed support, with similar administrative and market issues.

2. Voucher Scheme with Self-Referral

The new pilot Classes And Network (CAN) parenting scheme makes parenting support available through a voucher scheme distributed by statutory services and through self-referral to the high street store Boots. The new service has several key points that can be considered alongside the Family Fund:

- An assured list of pre-selected providers to deliver training and support
- Distribution scheme through direct referral from statutory services
- New distribution option via private businesses, using the foot-fall of established brands
- Parent self-direction to services

There is the precedence that relying on self-referral doesn't always work (for instance take up of children's centres by families in deprived areas), but the lack of needs assessment and low cost of distribution is attractive in reducing unit costs, if not necessarily improving outcomes.

3. Distribution through Parent Carer Forums

Parent Carer forums or networks have been growing significantly in the past five years since Every Disabled Child Matters and Aiming High funding. Not only are they becoming more representative of local parents with disabled children, but also beginning to make applications for funding from local authorities. And in some cases local authorities have strongly considered devolving funding to these groups and supporting the operational commissioning decisions made by members. In particular this fits well with the Big Society and new Right to Challenge.

However, there are some stumbling blocks with such a model of Family Fund grant distribution, such as:

- Difficulty in ensuring financial governance, distribution and probity; in particular there has been a recent experience of a lack of probity in the use of a voluntary sector grant in one of the UK regions
- The volume of work would require the Parent Carer Forums to move from voluntary to paid roles to distribute the funding, with changes to governance arrangements
- Lack of engagement between the parents currently receiving support from the Family Fund, and their local Parent Carer Forum, currently only 18% are engaged

These issues prevent this model of grant distribution from being a serious contender at this stage, but as Parent Carer Forums expand this may become an option, however would require a significant change in their governance and management arrangements.

4. Procurement of a New Distributor

A final option to consider is outsourcing the distribution of Family Fund resources to a new provider. Whilst there are no directly comparable organisations to pick up the work, there are many organisations that have the capability to administer the resources on a similar basis, for example: large voluntary sector organisations that run customer contact service such as NSPCC,

or those that have the disabled children and family expertise such as Action for Children or Contact a Family. There are also large suppliers of Government administration such as Capita, Capgemini, Accenture or Serco that would have the capacity to administer Family Fund resources. Note we have not tested this option with the named suppliers.

Again, there are pros and cons with such an option. On the one hand it may be beneficial to bring extra innovation and a new perspective to the delivery of the Family Fund, e.g. getting maximum outcome impact for the money. However, changing to a new provider will see the end of the Family Fund brand, specialist skills and reach, and due to the popularity of Family Fund (the Family Fund's 2010 Customer Satisfaction Survey indicated very high level of satisfaction amongst families) and strong political lobbying of the sector this may be difficult to implement.

We have also assessed the procurement route that is most likely to implement this option, with the following features:

- Pre-market testing with a range of suppliers to test appetite and gain understanding about efficient models and appropriate procurement options
- Competitive dialogue gives the best option of up-skilling potential providers (as the market is not experienced at delivering funds and advisors such as this) and levelling the playing-field, as well ensuring the four Governments develop their sense of the final specification (Note that HMT requests strong justification for using competitive dialogue procurement)
- A competitive dialogue procurement exercise, under EU procurement rules, is expected to take 6 months to complete – this is a costly exercise for providers and depending on whether the authority would like smaller or voluntary sector providers to compete – it may be necessary to pay for the time and / or expenses of those competing post-shortlist
- Three shortlisted providers will be appropriate, recognising that the Family Fund is likely to be one of these competitors
- During the competitive process, it will be helpful to require potential providers to suggest performance measures to be used when the contract is in place; whilst payment by results looks attractive, this may place too large a burden on back office costs of evaluation so a simplified performance management model based on outcomes is recommended
- If the Family Fund does not win, there are likely to be additional costs of TUPE³⁴ or pension liabilities for current employees
- It will be challenging for a new supplier to get up and running to replicate the back office and advisor base, and no guarantee that outcomes will be delivered any more efficiently than the incumbent supplier
- To reduce the risks, UK Governments may wish to consider running a competition for a smaller section of the country, e.g. London, Wales or the South West. However, this option may incur additional risks around duplication of services and confusion about branding.

³⁴ Transfer of Undertakings (Protection of Employment)

Comparison of Options

The following table compares the five options listed above, scoring them out of ten in terms of outcomes that are expected, efficiency of meeting those outcomes and risk of implementation.

Notes: because the provider is unknown in the procurement exercise we have assumed a similar model and level of unit costs and outcomes to the Family Fund. Scores are based on a comparison of models and should be further refined with a wider stakeholder group. See the Appendices document for details of the scoring methodology.

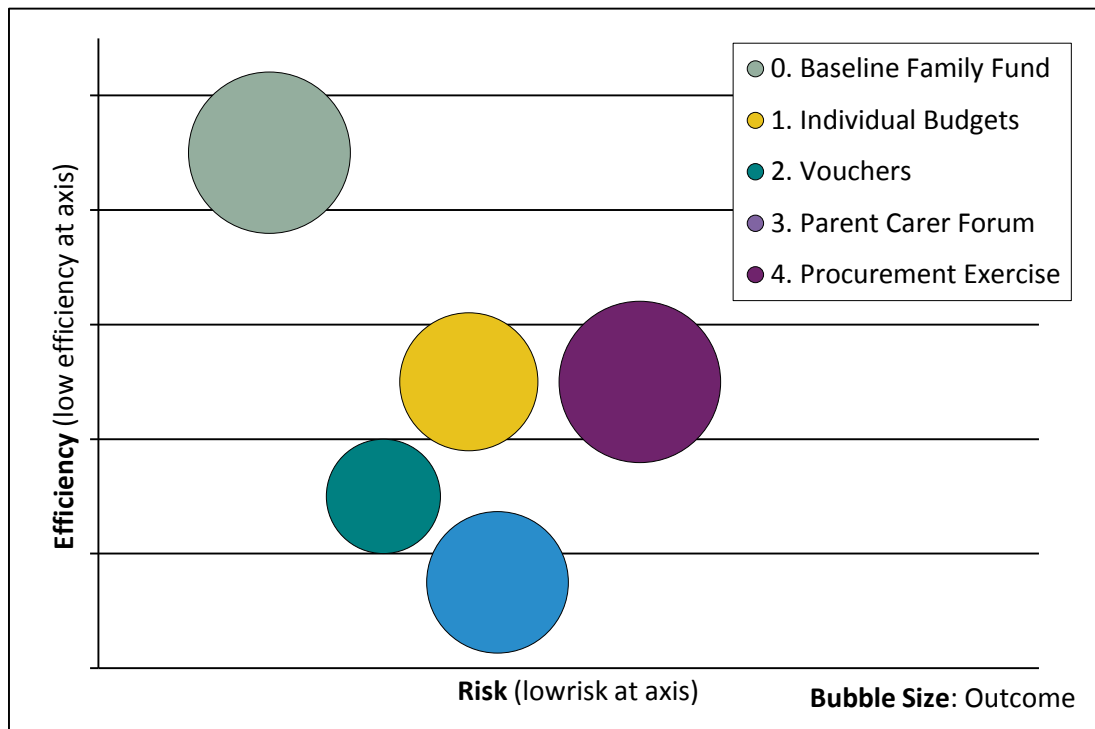
- **Efficiency** – A short time / cost to set up and low overheads for administration scores 10
- **Outcomes** – High impact on family outcomes, accurately targeted to those in need and with a good customer experience will score 10
- **Risk** – Consideration of the risk of failure, reputational damage and opportunities for fraud or error – low risk options score a 10

Table 7 Comparison of options

| Comparator | | 0. Baseline Family Fund | 1. Individual Budgets | 2. Vouchers | 3. Parent Carer Forum | 4. Procurement Exercise |
|----------------------|---------------------------------------|-------------------------|-----------------------|-------------|-----------------------|-------------------------|
| Efficiency | Time to set up market / supply chain | 10 | 3 | 8 | 1 | 3 |
| | Cost of implementation | 10 | 9 | 5 | 8 | 4 |
| | Overhead costs / unit price | 7 | 8 | 10 | 10 | 7 |
| Outcomes | Family experience of service | 9 | 10 | 10 | 10 | 9 |
| | Accuracy of targeting | 8 | 4 | 1 | 3 | 8 |
| | Social impact on outcomes | 9 | 5 | 2 | 7 | 9 |
| Risk | Safeguards against fraud and error | 8 | 3 | 1 | 1 | 8 |
| | Risk of implementation inc reputation | 10 | 7 | 5 | 2 | 2 |
| AVERAGE SCORE | | | | | | |
| | Efficiency | 9.0 | 6.7 | 7.7 | 6.3 | 4.7 |
| | Outcomes | 8.7 | 6.3 | 4.3 | 6.7 | 8.7 |
| | Risk | 9.0 | 5.0 | 3.0 | 1.5 | 5.0 |

10 is good / quick / efficient / low risk; average scores are evenly weighted

Graph 11 Bubble diagram showing the five comparator options in terms of back office efficiency, risk and social impact on outcomes (size of bubble).



The bubble diagram shows that, in this assessment, the Family Fund is still a stand out option. This is backed up by the parent surveys, case studies, call for evidence from the sector and stakeholder interviews as detailed in this review. Support for the current model is strong.

The procurement exercise and individual budgets through local authorities offer the strongest secondary options at this point in time. Whilst there is a range of options for the UK Government to consider, this assessment suggests that more in-depth consideration will be required before replacing the Family Fund, and it is recommended that these high level conclusions are tested with a wider group of stakeholders.



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