Department
for Education

Review of the Family Fund Trust

Research Brief

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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. About 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 aged 17 or under, 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 and 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.

B. 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 girls[1], 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 progress[2].

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 288,000[3] and 680,196[4]. 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 disability[5]. 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 year[6] 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.

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[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 (unequivalised) 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[9].

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[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).

[9] While the *Counting the Costs* survey highlights important contextual information, it should be noted that the sample was self selecting and therefore from a research perspective, the findings cannot claim to be representative of the UK as a whole.

C. 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.
- 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.

D. 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.

E. 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.

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