



Department  
for Education

# **Review of the Family Fund Trust**

## **Appendix C – Individual Case Study Reports**

### **Research Report**

**April 2013**

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# Contents

Review of the Family Fund Trust	3
Family 1	5
Family 2	9
Family 3	12
Family 4	15
Family 5	19
Family 6	22
Family 7	25
Family 8	29
Family 9	32
Family 10	35
Family 11	39
Family 12	42
Family 13	45
Family 14	48
Family 15	51
Family 16	54
Family 17	57
Family 18	61
Family 19	65
Family 20	68

# Review of the Family Fund Trust

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

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

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

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

We undertook case study visits to 20 families in receipt of Family Fund Trust grants. This appendix sets out our case study reports.

**Please note that we have used pseudonyms throughout the case studies to protect individuals' identities.**

# Family 1

## Family Context

The family live in west London and are originally from east Africa: they are mum, dad and six children (four daughters and two sons); the eldest is six and the youngest a newborn. Their three year old daughter, Habiba, is deaf and had autism. The daily pressures they face include caring for the six children in a modest-sized house. Transport is a major issue - getting the three older ones to school each day on the bus, including Habiba to her special nursery which is about 5 miles away, is challenging and stressful particularly in bad weather as Habiba is prone to ear infections and anaemia. The parents also get very tired from coping with Habiba's behaviour – during the day, she needs constant attention as she is prone to get into trouble and hurt herself, such as climbing over the fence into the neighbour's garden, and at night she wakes frequently and makes a noise so the house is disturbed.

The family does not receive a personal budget/direct payment/individual budget for Habiba. Their monthly income before tax is less than £590. Neither parent works currently; dad has been looking for work since being granted temporary leave to remain in the UK last summer, but his lack of qualifications and experience in this country mean he has not been able to find work despite his best efforts and willingness to take any kind of work.

## Applications to the Family Fund

The family applied to the Fund about two years ago, and again just under a year ago; they filled in the forms themselves and found it easy to do. Both applications were successful. Through the first application they received a voucher for Comet, to get a washing machine and a fridge. Through the second application they received a voucher for Argos, to get a trampoline and swings for the garden.

The family was happy with the system of receiving a voucher rather than cash. At Argos, they found that they could get the trampoline and swings for less than they had expected, so they were able to purchase a television too; Argos was happy for them to spend the voucher as they wished<sup>1</sup>. However, at Comet, the voucher obliged the family to spend a certain amount on the fridge and a certain amount on the washing machine; in fact they would have preferred to get a slightly more expensive washing machine and a less expensive fridge, which would have totalled the same amount, but they were not allowed to do so. The dad pointed out that during the time between the application and the award, stores may change their prices e.g. offering sales or discounts, so more flexibility in the choice of how to spend the voucher would enable families to take advantage of these.

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<sup>1</sup> Family Fund guidance for situations where the agreed goods cost less than their anticipated amount, is for the family to get in touch to discuss the spend of the outstanding grant monies: <http://www.familyfund.org.uk/sites/default/files/Home%20entertainment%20leaflet.pdf> . It is not understood whether the family contacted the Family Fund in advance of buying the TV set with the remaining funds.

## Home Visit

The Family Fund worker came to visit the family's home after their application, staying for around 45 minutes, meeting and chatting with the family, and attempted to communicate with Habiba, but Habiba is not able to communicate. She also spent time looking at Habiba's medical records and asking about the family's financial circumstances and support needs; including whether they were receiving the benefits to which they were entitled (these were carer's allowance, income support and disability living allowance; which the family was already receiving). She asked the family why they needed the items applied for, to make sure these were the most appropriate items for which they should apply. They had applied in mum's name, as at that time dad did not have the required immigration status, and the worker confirmed this was the correct thing to do.

The parents were happy to receive a home visit and thought it was a helpful experience for several reasons. They felt it was good for the worker to see their situation for herself, because it gave a more detailed and accurate picture than writing or explaining on the phone (in addition, they had found it difficult to contact the Fund by phone).

*'You can say how things are to someone, but if they see it, it's better. On the visit she can see how things are and you can also talk – both together are good.'*

Another reason that the family preferred a face to face visit was that the parents' English, although very good, is not perfect and so at the visit they felt they had the opportunity to communicate their situation and needs more effectively than in the written application. They thought that the visit had saved time too, because otherwise there may have been a need for to-ing and fro-ing by email or letter in order to clarify all the information and detail in the application.

The visit also helped the family to think through and clarify what they most needed to make sure they were applying for the right items; the worker helped them to make a clear case for their need for the items.

They felt that they would have missed out had they not had the visit and were it up to them, would continue to offer the visit to families applying for the first time.

## Impact

The new washing machine has made the biggest difference to the family; the old machine was too small to cope with all the family's laundry. The new machine also has a dryer, which the old one did not – so previously, clothes had to be dried next to the heater, from where Habiba would pull them onto the floor, making them dirty again.

The fridge has also made a big difference to the family because it is larger than the old one, which means they can keep more food in the house so they don't have to go shopping so often (shopping was a challenge with six children in tow and took up a lot of time, especially added to the amount of time it takes to get the children to their different schools and nurseries). It also means they have enough room for the extra food required for Habiba's special diet.

The swings and trampoline provide vital exercise for the children, which is particularly important for Habiba as she has a lot of energy. The trampoline and swings allow her to play and enjoy herself, which helps to keep her out of mischief and to tire her out so that she sleeps better at night (which means that everyone else can sleep too).

The TV which they got from Argos with the surplus left over after buying the trampoline and swings is benefiting the family because it can be mounted on the wall out of Habiba's reach; the old television stood on the floor, and Habiba once climbed on top of it, falling and breaking her leg.

The family found that the total value of the vouchers they received was sufficient for their needs, but that the inflexibility around how they spent the Comet voucher meant that they could not get the exact appliances they wanted (as explained above). They did ask permission from the Family Fund Trust to spend the voucher differently but this was not granted.

Without the awards from the Family Fund Trust, the family would have continued to manage with their existing fridge and washing machine, which were making their lives more difficult. They would not have been able to afford to buy the garden toys.

## **Other Sources of Support**

The family is in regular contact with a range of professionals in relation to Habiba's disabilities. These include those in the hearing clinic, child development, speech and language, educational psychology, deaf teacher and occupational therapist. The latter two visit the family home to see Habiba.

They do not receive financial support from any other organisations at the moment. They applied to the local authority for direct payments for Habiba, but were rejected; however with the support of one of Habiba's doctors, they have requested a sitting service for 8 hours per month for Habiba, which they are waiting to have confirmed.

The family has received advice and support from two local groups which support families with a disabled child, who helped them to obtain a place at the special nursery for Habiba, and is going to enable them to take all of the children on a trip to London Zoo.

## **The Future**

The family plans to apply for two further items from the Fund. One is for money to enable mum to take Habiba to Kenya to see her relatives. Habiba's grandmother in Kenya wants to see Habiba especially, because she is a 'special' child. They may also consider applying for driving lessons for mum, so that if they could afford a car, it would be easier to take the children to school and do the shopping.

## **Recommendations for Improvement**

The family had two suggestions for improving the Family Fund:

- The first was around the flexibility of the Comet vouchers, as described above – if they worked in the same way as the Argos voucher, i.e. can be spent on any item rather than fixed ones, this would be better.
- Secondly the family had found it difficult to get through to the Fund by phone, which they wanted to do in order to have a discussion, rather than an email exchange. A more responsive phone service would help to resolve queries and reach a conclusion more quickly.



## Family 2

### Family Context

The family is mum and ten year old Evan, they live in north Wales. Evan has Aspergers, ADHD and anxieties, and they are awaiting a diagnosis of hypermobility. Evan is extremely bright and high-functioning in terms of academic learning; he is in year 5 but learns alongside year 6 pupils at school. He has poor social skills, and has difficulty maintaining friendships, so he is socially isolated. He also lacks a sense of danger which means he can't go out by himself in case he gets hurt on the roads. He finds it difficult to concentrate and can experience high levels of stress and anxiety which impact on his ability to go out and take part in activities (for example, a serious phobia of dogs and wasps). He also has a condition which makes his feet and legs ache, so he can't walk long distances and needs frequent rests.

Mum is the sole caregiver for Evan and she doesn't work. They have a social worker and receive carers' allowance and disability living allowance. They don't receive a personal budget/direct payment/individual budget, but they have a support worker provided by social services to accompany Evan to St John's Ambulance each week, where he can mix with older children, who he gets on better with than those his own age. Evan recently moved school because his old school was not catering well for his needs; the new school is 11 miles away and mum spends around 5 hours a day on buses to and from school.

### Applications to the Family Fund

Evan is now ten and his mum first applied to the Fund when he was three. She has made several applications in between, all successful, including for Days Out (to Legoland, to London, and visitor attractions in Wales), a sofa and carpet when they moved house, driving lessons and a trampoline. Days Out are their most frequent applications. Mum finds the application process straightforward and has always received the grant within a couple of months, which is satisfactory.

The Days Out grants are received by bank transfer so that mum has a good degree of choice and control over how they are spent. She keeps all the receipts for travel, hotels, entrance to attractions etc, in case the Fund requests them for audit purposes. Receiving money for Days Out means that she can make it go further by asking for concession prices at museums etc, and spend the surplus on snacks or another activity.

The voucher for the trampoline was spent in Argos and there was some money left over from it; mum rang the Fund to offer to return it, but they allowed her to spend it on something else for Evan, which she appreciated.<sup>2</sup>

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<sup>2</sup> Family Fund guidance for situations where the agreed goods cost less than their anticipated amount is for the family to get in touch to discuss the spend of the outstanding grant monies.

<http://www.familyfund.org.uk/sites/default/files/Home%20entertainment%20leaflet.pdf>

As highlighted above, families are frequently permitted to reuse surplus funds if they can source what they need for less than expected.

The driving lessons package was less helpful for mum because she had to take the lessons through BSM, who she did not think were very good, and she has not yet passed her test. If she had had a choice, she would have changed to a local instructor instead.

## Home Visit

The family received their home visit seven years ago so it was hard to remember the details. However, mum recalled that she found the Family Fund worker very nice and helpful. She understood that the worker had come to find out more about the family, check their eligibility and whether they needed the items requested (driving lessons). The worker suggested that they also apply for a carpet for Evan's bedroom, as the room had bare boards at the time because they had just moved, and for a new sofa, as their second-hand sofa was in very poor condition. It would not have occurred to mum to ask for a new sofa, as it wasn't something 'for Evan', but the worker explained that it was OK to apply for it – so they would have missed out on this without the visit.

Mum thought that the visit was an important part of the application process, because the worker could make helpful suggestions about what to apply for:

*'She knows families, and she can ask you questions to find out what you need, when you might not have even thought of it yourself.'*

She also thought that the visits help ensure that applicants' needs are genuine and therefore avoid fraudulent applications. She would offer home visits to families applying for the first time, if it was up to her.

## Impact

Of the various items they have received through the Family Fund Trust, the Days Out make the biggest difference for mum and Evan. Evan 'absolutely loves' going on trips and activities, and mum feels it helps to make him less isolated, more active and spend time meaningfully:

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

It's especially important for Evan to have these opportunities because his conditions mean he cannot play out in the park with other children because of his anxieties, social difficulties and need for stimulation; he prefers more stimulating activities such as visiting a historic site or museum.

For mum too it's an enjoyable experience that 'does me the world of good too.' Without the Family Fund Trust they wouldn't be able to do these days out, because living on benefits they don't have a lot of spare money (plus Evan only eats certain foods, which increases their grocery bill). Mum would find it difficult to justify spending money on days out compared to basic everyday expenses.

The new carpet for Evan's bedroom meant he could play in there without being on the bare floorboards. The new sofa provided a comfortable place for the family to sit, and also being new and good quality it has lasted well. If she had had to buy these items herself, mum would have had to save up for a long time and/or put it on a credit card; she would only have been able to afford second-hand things which would probably not have lasted so well and needed replacing.

The trampoline has not been installed yet but Evan is very excited about using it soon. Because of his ASD he has a lot of energy to burn off, and mum says that it has been shown that trampolines can be particularly therapeutic for children with ASD.

## **Other Sources of Support**

The family is in regular contact with their disability social worker, who comes to the house and helps the family a lot in terms of making sure Evan gets the support he needs. They are also in contact with the CAMHS team: every 5-6 months they go to the hospital to check Evan's ADHD medication. Evan will also be seeing an educational psychologist about his anxieties, but they are currently waiting until he feels ready for this.

The family has also applied to Merlin's Magic Wand, which gives out free tickets for attractions such as Legoland and Alton Towers. They went to Alton Towers but Evan did not enjoy it as he was scared on the rides. However it was an easy process to apply for the tickets, because it was online, as the Family Fund Trust now is. Mum is aware of other charities to which she could apply for similar things i.e. trips and holidays, but they are limited in travelling by Evan's anxieties (for example, he would not go abroad because he is made anxious by news stories about bad things that have happened).

## **The Future**

There are no plans to apply again to the Fund in the near future; there is nothing that they especially need at the moment and mum will always pay for things herself if she can afford to, rather than apply. If she applies again, it cannot be until September (a year since their last application), which would mean that they would receive Days Out money in the winter – so mum would rather wait until the weather is nicer so they can enjoy their days out more.

## **Recommendations for Improvement**

The only recommendation that mum offered for Family Fund Trust was that they should encourage more parents to get involved in fundraising. This is something that mum has done herself and finds very rewarding personally, as well as helping to contribute to the Fund which she is aware may be affected by cuts to public spending (either to the Fund itself, or more widely – leading to a greater demand from families to apply to the Fund).

# Family 3

## Family Context

The family live in Leeds. They are mum, dad and two daughters, aged 12 and 2. The older daughter has a cleft palate and has undergone many operations. The younger daughter, Amala, has a number of disabilities, making her condition very complex; these include a heart condition, spina bifida, gastric reflux and a club foot. When she was born Amala was not expected to survive beyond three months without an operation which was almost certain to leave her brain-damaged; however, she survived the operation and there is no evidence of cognitive impairment so far. There is a chance she may develop cognitive impairment in the future. Until the age of 18 months, Amala did not sleep for more than half an hour at a time because she could not move her body and became uncomfortable. Now, she can crawl but has no movement in her lower legs, so she will use a wheelchair when she is old enough. Amala does not eat normally because she cannot swallow, so she is fed through a tube into her stomach.

Amala's parents and sister are her main carers, as there is no wider family in Leeds. Their monthly income before tax is in the £1,301-1,500 bracket. They receive disability living allowance for Amala, but do not receive a personal budget/direct payment/individual budget. Dad used to work as a solicitor, but had to give it up as full time hours didn't fit around caring for Amala and attending her many hospital appointments. Sometimes they have 4 or 5 appointments in one day because of the complex nature of Amala's disabilities. Dad now works part-time as a driving instructor, so that he can be flexible. Mum has health problems too: she has diabetes and can experience hypoglycemia, as well as having mental health problems (depression), so Dad needs to be able to come home quickly if there is an emergency. Both parents carry a considerable burden of stress and worry about Amala's health and about the financial implications of their limited capacity to work because of her care needs.

The family are currently looking into moving, because their home will not be suitable for Amala as she grows bigger.

## Applications to the Family Fund

The family has applied to the Fund only once, in 2011. They were advised by their health visitor to apply to the Fund when they needed to get the boiler replaced. They had to get some quotes and send them to the Fund, and then received a cheque for £1000.

They were very happy with the process, although they were lucky to find a quote for this amount, as most were considerably higher. They had understood that the maximum that could be applied for was £500, so were extremely grateful to receive an amount sufficient to cover the whole boiler.<sup>3</sup>

The application was turned around within a short time and they found it a straightforward process.

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<sup>3</sup> The Family Fund do not advertise an upper limit to the value of grants on their website. Instead they state that they will assess each application individually: *'we will look at any grant request that relates to the needs of a disabled or seriously ill child, young person and their family...Due to our limited funding, we are not always able to meet the full cost of every item requested.'* <http://www.familyfund.org.uk/grants/how-we-help>

## Home Visit

The family received a home visit following their application. The worker who visited saw Amala, looked at the medical and financial paperwork, and talked to the parents about their problems, needs and feelings. She stayed for about an hour.

The family were very glad to receive the visit. Dad thought it saved a lot of 'red tape' because the worker could ask questions and clarify information, which otherwise would have had to take place by letter, taking up time and slowing the process down. It also gave the family a chance to ask questions of the worker - about their application, the criteria for a successful application, and what other kinds of things they could apply for.

More than this, they felt it was important to them to have someone come and see their family in person, in order to really appreciate the impact of Amala's complex disabilities on their daily lives. They felt that the personal empathy shown to them by the worker made a real difference to the process, as compared to other grant giving situations in which they might receive a 'no' without any explanation or interaction.

Asked whether they would have missed out had they not received the visit, and whether they would offer visits if they were in charge of the Family Fund, mum and dad said yes to both questions.

## Impact

The grant from the Family Fund meant that the boiler could be replaced in time for winter, when the family needed to put the heating on and have hot water. This was vital with a small child in the house, particularly as Amala's limited mobility means that she can't move about a lot in order to keep warm. While the boiler was broken it was summer, and they could manage with their electric cooker and electric shower, but it would not have been practical in winter.

Without the grant, they would have had to borrow the money from the bank or on a credit card, because they would not have been able to save up enough money in time to get the boiler installed before winter. If they had not been able to replace the boiler then it is likely that the family's health would have been seriously affected, particularly the children's.

## Other Sources of Support

The family is in regular contact with a number of professionals around Amala's health needs. These include their CAF Coordinator, health visitor, Sure Start staff, community nurse, physio, occupational therapist, education and housing. The team meets every 4-5 weeks at the family home to discuss the situation, because Amala's needs are always changing as she grows – for example, they are currently discussing housing options because Amala will need a specially adapted accommodation when she is big enough for a wheelchair.

## The Future

The family has no immediate plans to apply again but they may do so in future, probably to replace old kitchen appliances if they broke – these kinds of unexpected and large expenses are hard for the family to cope with, because their income only covers their day-to-day expenses.

## **Recommendations for Improvement**

The family did not have any suggestions for improvement - as dad said, they are 'satisfied customers' of the Family Fund.

# Family 4

## Family Context

The family live in Leeds. Mum has four kids, aged 8, 7 and 6 year old twins. The children go to stay with their father every other weekend, and mum has a partner who has worked with children and helps to provide care (he doesn't live with the family). One of the twins, Jacob, has special needs affecting his behaviour and learning. They are currently awaiting a specific diagnosis. It is likely he will be diagnosed with Aspergers or autistic spectrum disorder. He needs a lot of extra care and attention compared to the other children, for example when out and about he can become stressed and is liable to run into the street. His speech is poor, he takes things very literally and has trouble interpreting body language, making it difficult to relate to his siblings and to form friendships. He needs strong routines and boundaries and can become distressed by any change in routine. He also requires a special diet. Jacob is in mainstream school, he has a CAF and does not receive a personal budget/direct payment/individual budget.

Mum does not work at the moment; until shortly before the family moved to Leeds six months ago she worked as a PA but full time hours did not work with Jacob's needs – he was excluded from his childcare placement during the holidays because of his behaviour. She would like a part time job and/or to study to enable her to work around the family's needs in the short/medium term and in the longer-term, to get a better job in the future. The monthly family income before tax is in the £1001-1201 bracket.

The main pressures for the family are: keeping on top of Jacob's challenging behaviour; being limited in terms of accessing amenities and shops because mum can't drive; and making the family budget stretch to cover heating, clothing and food for everyone (Jacob needs a special diet so mum has to buy more food and make two meals at each mealtime).

## Applications to the Family Fund

The family applied to the Fund in 2010 for driving lessons for mum. Through the CAF, the family was in touch with a volunteer support worker, who helped mum to fill in the form. She thought it would have been quite daunting to fill in by herself, in case she didn't get all the wording and information right. The award came through after 5-6 weeks, as they were expecting, in the form of a letter advising mum to get in touch with BSM to arrange the driving lessons.

Progress with the driving was slow because of problems with the instructor. Mum rang the Family Fund to complain, who explained that they do not regulate BSM so she would have to take it up with BSM directly. After doing so, she got a new instructor and began to make more progress; however, because of the initial problems there were not enough lessons left in the package to get her to the point of passing the test.<sup>4</sup> For this reason, mum thought it would have been much better if she had been given the flexibility to choose her own driving instructor rather than have to use

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<sup>4</sup> The driving lessons grant is made up of: theory study materials, up to two attempts at the driving theory and hazard perception test, 44 hours driving tuition and up to two attempts at the practical driving test. Guidance for this grant also makes clear that, *'the Family Fund will not be able to pay for any additional lessons, so please make sure that you will be able to cover the cost of these if you need them'*.

<http://www.familyfund.org.uk/sites/default/files/Driving%20lessons%20leaflet.pdf>

BSM. This would have enabled her to stop the lessons with the unhelpful instructor sooner, and would also have saved money because local instructors are cheaper than BSM.

## Home Visit

The Family Fund worker visited following the application, in order to assess whether or not the family should receive the award applied for. The worker stayed for about 45 minutes, asking questions about the family, Jacob, and what their needs were. Mum felt 'fine' about the visit, both before and after, finding it a very positive experience.

The visit was useful in a practical sense because it helped to improve the application form, ensuring that all the necessary information was provided and in sufficient detail to avoid a situation in which the award could not be granted or the Family Fund would have to contact the family by letter, email or phone to clarify details.

The visit was also important to mum in the sense that it gave a more 'human face' to the process, and made it possible for the Family Fund to understand the family's situation in a more authentic way:

*'If they come to your house, they can see that the problems that you are facing are real, genuine. They get to see that this is your reality.'*

While she did not consider it an essential part of the process, mum strongly appreciated the visit, and, if it were up to her, would 'definitely' offer it as part of the Family Fund's future service to families.

## Impact

As described above, the package of driving lessons received from the Family Fund had a limited impact on the family because mum was not able to pass her test within the number of lessons available; therefore she is still unable to drive. However, she stressed that had it not been for the problems encountered with her driving instructor, the package of lessons probably would have been sufficient to enable her to pass the test and be able to drive.

Had she passed her test, or if she passes it in future, the impact on the family would be very significant:

*'When I pass it will have a major effect. We'll have the freedom to get about and do things that we need to, like shopping, and that are good for the kids, like sports and swimming.'*

One impact of mum being able to drive would be on the shopping – they would be able to get to the big supermarkets which are on the edge of town, where they could save money because of the discounts they offer, which aren't available in the nearby shops. At the moment they have to walk to the shops, which is difficult with four children. In winter the children get wet feet and are cold, and Jacob gets tired and distracted so extra care is required to keep him safe when out in the streets.



Another impact would be being able to take the children to the swimming pool, to sports clubs and parks – they are typical energetic children who love being active, being outdoors and enjoying nature, so it is frustrating when they can't do the activities they want to.

Having a car would enable the family to maintain their social networks better too; the wider family is in Bradford, Huddersfield and London, and often they have to miss out on family occasions and get-togethers because they can't get there without a car. This is sad for mum; while the children have made good friends in Leeds, she wants them to stay close to their cousins elsewhere:

*'It's about feeling a sense of belonging, instead of feeling like we're cut off.'*

Finally mum would like to be able to drive so that in the case of a medical emergency they would be able to get to the hospital; she would feel reassured knowing that if necessary, she could put all the kids in the car straightaway.

Despite being unable to realise these impacts yet, mum feels that it has been positive to pass her theory test at least. But she is worried that because she cannot afford to pay for further lessons herself, she will forget what she has learnt so far and the grant will have been wasted.

## **Other Sources of Support**

There are no other organisations that the family has received financial or other support from. They have been in touch with some professionals through the CAF: a volunteer worker from a family charity and the local CAMHS service.

## **The Future**

Mum would like to apply to the Fund again in the future. This might be for Thomas Cook vouchers to take the family to 'Pirate Island', a holiday resort catering especially for children. The children would 'absolutely love it'; there are child support workers who could care for Jacob, and mum would be able to have a break. She could not afford to take the children on holiday otherwise.

Another item which they might apply for in the future would be a chest freezer – they applied for this the first time alongside the driving lessons but it was not possible to receive both at the same time. The freezer would mean that they would not have to go shopping so often, because they could store more food at home; this would save time which would be particularly helpful if mum was working or studying, as she hopes to do in the future.

## **Recommendations for Improvement**

Mum had three suggestions for improvements:

With regards to the driving lessons package provided by BSM, Mum suggested that the Family Fund should monitor BSM to prevent the poor practice which she experienced, or should allow recipients of the grant to choose their own local driving instructor.

- She also thought that the Family Fund could be better publicised so that families who could benefit from it know about it. For example, staff in local authority 'one-stop shops' could give out information about the Fund.
- In addition, more support throughout the application process could help families to complete the form correctly and avoid disappointment if their application is unsuccessful, and following up with families once they have received the award to make sure it is being spent appropriately would help to avoid fraud.

# Family 5

## Family Context

Anna, her partner Pete and their three children live on a housing estate near a busy town in Kent. All three of the children have some form of disability. The eldest boy is 13 and has ADHD and Aspergers, the second boy has ADHD and Autism and their young daughter aged 5 has recently been diagnosed with rheumatoid arthritis. The impact on family life of all three children having different disabilities is huge. In the interview, Anna found it difficult to describe the range of day to day stresses that she and Pete face both in terms of coping with their children's needs and in terms of remaining positive about their futures. When asked about a typical week in her life, she started to cry.

The older boys' conditions mean that they are difficult to manage and constantly need attention and – often – discipline. The eldest goes to a special school over forty minutes away after having problems at his previous school. There were fears that he would have to be taken out of the family after he got excluded from school and ran away, although the specialist school now seems to be helping. The younger boy is about to move from primary to secondary school and is exhibiting a range of anxious behaviours as he faces the transition and requires a lot of support. The younger daughter is likely to require a wheel chair at some point but at the moment is exhausted by just standing up. She has to have regular injections and hospital check-ups. On the one hand Anna and Pete juggle a busy diary of various different local services; on the other hand they struggle to get any family support in caring for the children as their elder mothers can't cope with their demands.

Anna and Pete receive a monthly income of £771 - £910 each month before tax and they do not receive any personal budgets, direct payment, individual budgets or personal health budget from their local authority or NHS. Anna is a full time mother and carer and Pete is a roofer, although he is out of work at the moment as much of local construction work has stalled due to the recession.

## Applications to the Family Fund

Anna first applied to the Family Fund in 2004 and has since applied every year, each time being successful. The process for applying has changed over those years. For the early applications Anna would phone for a form which she would have to fill out and send back. Now she can apply online which she finds much easier as she can do in her own time and she receives texts to update her on the progress of each application. She says that there can be a wait to get through to the fund on the phone but that she understands that they are busy helping lots of other families, *'you can be for ages in a queue on the phone but everything else is brilliant'*.<sup>5</sup> Grants normally come through within two to four weeks which Anna feels is an appropriate length of time.

The first application was for some garden toys including a swing and a slide and all subsequent applications have been for a family holiday. The grants used to be mainly in cash but Anna noted that they now are in a voucher format. She says she understands the move to vouchers as it ensures that the families spend the money as intended in the application. However, Anna and her

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<sup>5</sup> Families have to cover the cost of phonecalls to the Family Fund, which uses the lowest 0800 call rate.

family have never felt restricted by the vouchers as they offer a lot of choice at resorts across England.

## Home Visit

The family has experienced at least two home visits. The first one was alongside her first application and the others have happened at different points over the years. Although Anna can't exactly remember why some applications have triggered a visit whereas others haven't, she thinks that the birth of her daughter might have led to a visit five years ago and they had another one more recently when the family moved into their new home.

Anna welcomes the home visit as a part of the Family Fund application process. She feels it is a good opportunity for the advisor to meet with every member of the family and talk to the children to understand more about the nature of their disabilities and needs, so that the Family Fund are confident they are supporting her family in an appropriate way. Anna says that these visits are different to those they receive through other local services as the advisor also spends time talking to the children about their wishes, and what they would enjoy to do together as a family. Anna feels that this means that the Family Fund looks beyond ways to meet the individual children's needs to find ways to improve the overall quality of their family life. After the advisors leave Anna's home she says she always feels better, that *'it's nice to know they are so supportive'*.

The home advisors have offered Anna and her family support beyond the Family Fund application process. In particular the advisor sign-posted Anna to the Community Care grant as a means to get the funds to pay for a computer. As Anna has three children with disabilities she feels that she is aware of other services available to her in her local area and so was surprised that the advisor could help point her to something new, like she did the Community Care grant.

## Impact

The impact of the Family Fund grants upon Anna and her family is huge. The play equipment she received through her first application was erected in her mother's garden as Anna didn't have a garden at the time. Not only did this give the children some outdoor space in which to play it also meant that her mother could care for the children for short periods of time as they were occupied outside. It also means that Anna's sisters' children could visit and enjoy the equipment too.

More significantly is the impact of the holiday vouchers on Anna and her family. Anna is extremely organised and thrifty, making sure every penny of the vouchers is maximised to its full potential. As such, when she receives the grant she books her holiday for the following year for half the price. This means the family of five has two week long holidays each year for £500. It also means that Anna and Pete only need to save for the petrol to travel to the site and for a weekly pass for each child (at around £70) so that they have full access to a whole range of activities when they are there.

All five members of the family enjoy planning their holidays. They take time to each look at the brochure and talk about what it is they want to do, whether it's swimming, adventure play or more creative activities, and identify which holiday parks match up. What Anna values most about the holiday is that the children are allowed to play and be carefree as children and that she and Pete

are able to have a bit of time and space as a couple, and not feel that they are constantly battling to keep their family together. She says that she can see her children are happy, that they are smiling and having fun, *'it's a relief to them that they can go off and play, and not just keep getting moaned at all the time... We've always had a great time'*. The family feels better as a unit after the week away, less stressed and happier with each other.

Without the Family Fund grant, Anna does not feel that she or Pete have the means to be able to afford to save up for the full holiday, particularly as their spare cash goes into travel and the children's activity passes. *'We'd either save up or go without – but I don't think we could save up for it all'*. The annual grant her family receives gives Anna a great deal of comfort as she knows that her family can have the two weeks each year where they will enjoy themselves and each other. Anna did not want to contemplate how she'd feel without that kind of reassurance.

## Other Sources of Support

Anna and her family meet regularly with a wide range of services – to the extent where Anna has to be very organised to keep up with the different appointments and meetings. These services include a social worker and social services, CAMS, counseling services, Family Action, Autism Outreach services, youth workers and SENCOs through the school. These visits can happen at home or at the hospital. Anna also looks out for local parent education classes where she can meet with other parents in similar situations and learn about ways to manage issues relating to their disabilities.

Anna has applied for financial support from a Community Care grant and used the money to pay for a laptop. She is aware of other sources of funding such as Home Access grant, Social Fund loans and Care Loan grants but hasn't applied for them as she didn't feel she fit the criteria. In Anna's opinion, the *'Family Fund is definitely better. They are quicker, you don't have to wait as long to get in touch, and with the Family Fund you can list out what you want, whatever that is'*.

## The Future

Anna intends to apply each year for the same sum of holiday vouchers so that she can continue to give her family a weeks' holiday twice a year. She has no recommendations to change the Family Fund – instead she asked to be part of the research so that she could *'say a big thank you [to the Family Fund] for all their support and help they've given us'*.

# Family 6

## Family Context

The family lives in Newport in South Wales: they are mum, dad and the sons aged 13, 17 and 23. Their youngest son Steven is profoundly autistic and he can't read or write. He has sensory impairments and exhibits difficult behaviour. He attends a special needs school which is luckily enough located very close to their home.

Steven likes music and using his computer and his mum and step dad note that parenting Steven is very much about finding things to keep him occupied. He particularly likes interesting lights and sounds and is fascinated by rippling water and the sound of pebbles dropping into water. His behaviour can be challenging. When he gets frustrated he tends to break things and he enjoys making noises, for instance he will repetitively hit an object to get a noise that pleases him – and this can be difficult to tolerate. They've built an extension in their home which they've turned into a 'time out' room for Steven. It's somewhere he can go to calm down if he's been behaving badly or if he needs to 'let off steam'.

The family doesn't receive any form of personal/individual budget and their monthly household income falls into the £2201-2400 bracket.

Cost of living is a real challenge and they've racked up credit card debts which they are constantly trying to drive down. Because Steven is energetic and prone to breaking things they have to find furniture that is basic, well designed and very hard wearing and they often have to replace items. They can't buy budget furniture and equipment because it is too fragile, but equally they can't afford to buy specialist furniture and household items as the prices are sky high. Since Steven stopped using nappies he can sometimes make a mess, this means that the family have to spend a lot on cleaning products and on replacing bedding and mattresses.

As well as struggling with the cost of living, Sharon notes that their home life is challenging - with three teenagers in a small home, Steven's poor health and misbehaviour, levels of stress in the home have been high. Steven's siblings can also struggle to cope in this environment when they need to study. Having a profoundly disabled child has been isolating for mum and she talks about how several of her friends have drifted away from her because they found it increasingly hard to connect to her and her situation. This is a societal issue about disability.

## Applications to the Family Fund

The family have applied for the fund for the last seven years and they've never had an unsuccessful application. They mainly used it to buy white goods with highstreet vouchers – including a fridge, a dishwasher and a washing machine. They've also used the fund for purchasing new bedding and once they used it to go on a holiday.

The application form asked them to prioritise what they need – this was helpful as it ensured that they got the things that they needed most. They also think that the warranty that must be included when you purchase electronic goods is very sensible.

Reflecting on the fact that white goods must be purchased using retailer specific vouchers they feel that they were restricted from finding the cheapest deals. They would have liked to have gone online for better bargains. More choice would allow them to achieve better value for money – to make their money go further. However they also recognise that a voucher is an efficient way of ensuring that people use the fund appropriately. In terms of improving choice, they suggested that a generic high street voucher would be good as it would allow families to shop around for better deals.

They can't understand the fact that the fund application focuses on assessing the needs of one child, despite the fact this it is called a *Family Fund* and their two other sons also have disabilities (e.g. one has a hearing problem). When it comes to making their application, they chose to apply for Steven because he had the highest level of need.<sup>6</sup>

## Home Visit

Mum feels that having a home visit with their first application was helpful for both sides. The purpose of it in her view was primarily to assess their needs and eligibility for the fund, and to ensure that the right families – those with the highest level of needs - receive the fund. It was also nice for the family applying to have face to face contact given that it was the start of a relationship of sorts as they've applied over the last seven years.

The home visit was crucial in their view because it allowed the family to highlight the severity of Steven's needs and their situation. Without the face to face visits, mum and dad worry that families with only minor issues could get the fund – this wouldn't be an appropriate use of public money, especially when resources are so finite. They also support the use of home visits because it gave the assessor a chance to better understand the families' needs and circumstances and gain a more detailed and accurate picture of their circumstances.

In terms of the process, they got a call to explain that a visit would be required. The visitor came at a time that was convenient to them. The home visitor was very professional but was also very friendly and down to earth. She was attentive and wanted to get a detailed sense of their needs and how they were coping day to day. The home visit lasted two hours, which felt like the right amount of time - they could go into detail, but it didn't 'drag'.

The family do not recall getting any advice during the home visit but the home visitor was very helpful and accommodating in the way that she communicated and explained things to them.

## Impact

Sharon and her partner emphasise that the Family Fund has led to tangible benefits for their quality of life for the family. The goods and services purchased through the Fund have made a

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Applications for the Family Fund are considered where they relate to *'the needs or well-being of a disabled child, young person and their family'*. Unless there are exceptional circumstances, families can only make one application per year, applying for up to three items.

[http://www.familyfund.org.uk/sites/default/files/Grant\\_Application\\_Brochure\\_1.pdf](http://www.familyfund.org.uk/sites/default/files/Grant_Application_Brochure_1.pdf)

happier home, where there are fewer arguments and family members are able to spend more quality time with one another.

Having a dishwasher and washing machine has had a positive impact on the whole family. Steven is very picky with his food and so this creates a lot of washing up. With the dishwasher purchased, it has meant that Steven's older siblings can now spend much less time washing up – so they have more time for themselves. The white goods have also meant that Sharon also spends less time doing chores and household tasks spend more quality time Steven – with more attention his behaviour has improved.

The computer has been great for Steve, allowing him to develop a keen interest in IT and encouraging him to read and write when he uses social network website. Steven really enjoys playing the games, and he regularly uses it to listen to music and watch films. He also loves the touch screen.

The holidays have been great for their quality of life, helping them to relieve stress and give everyone time to relax. Going on holiday is something that everyone really looks forward to.

## **Other Sources of Support**

Mum doesn't recall making any similar types of applications so isn't able to compare her experience. However she is keen to emphasise that her experience of applying and using the Family Fund has been very positive.

## **The Future**

The family would like to continue applying to the fund as long as Steven is of the eligible age. They note that Steven's needs are changing – he's becoming very technically focused and likes gadgets, future application might focus on getting Steven gifts that would allow him to expand and learn. The Fund could also become more focused on supporting Steven to do a range of activities. They would really welcome the Family Fund providing services – for example, they suggested someone visiting their home and helping to design and modify their garden and home to make it more friendly and suited to Steven's sensory needs. Sharon and her partner lack the expertise to do this. For example, what would be the best choice of colours in their home? Steven is very sensitive and effected by colours.

## **Recommendations for Improvement**

Their recommendations focus on the application process. They note that they took time to process and that they become frustrated with the lack of progress. They think it would be helpful if the website gave some indication of what stage the application process was at rather than seeing the same old message – 'your application is being processed'. They also said that when they have reapplied for the Fund they should have been able to carry over application data from previous years to save them time and effort.



# Family 7

## Family Context

The family lives in Shoeburyness in Essex about 3 minutes from the coast. The family is mum and her two teenaged sons aged 13 and 15. A few years ago mum separated from her children's father and he has since passed away. Her oldest son Cameron has an autistic spectrum disorder but he is high functioning, in fact people don't often know he has a disability. The family receives Direct Payments of £41 per month which is used to provide respite – which mum uses in the evening to see friends and do some volunteering in a local disability charity, providing advocacy. Mum was a nurse on a cancer ward but she's given up work to look after her children full time.

Cameron loves to learn about animals – he particularly likes reptiles and tropical birds and he has recently done some work experience at a pet shop. He also loves water – the sounds and sensation of it. He is fascinated by airplanes and recently joined the air cadets with mum noting that their regimented culture suits him well.

Cameron easily get restless and won't speak to people he doesn't know. But he can also make very blunt observations and comments – because of his autism – so he can be perceived as very rude by people who don't know him. Mum has struggled with Cameron's challenging behaviour – he can be aggressive and physically violent to the point where she was considering putting him into care. When her youngest son got meningitis she made the decision to stop working altogether. As Cameron has started taking medications his violence has reduced.

Since she stopped working, making ends meet has been a struggle. Coping with Cameron's challenging behaviour has been very draining for her.

## Applications to the Family Fund

They have applied for the Family Fund four times and have never been unsuccessful. Mum has applied each year since her social worker suggested it to her and she intends to continue until Cameron reaches the maximum age.

Reflecting on the application process, mum feels that it was quick and easy. The application process began with mum filling in an extensive form and gathering the supporting evidence that was required. The process was about getting an in depth understanding of Cameron's disability and situation. Having completed the application and received the home visit it took four weeks to process and receive the grant – which felt quite quick. She has since applied both online and using the paper forms which was necessary when she moved home. Both formats felt simple and straightforward, but online was definitely felt to be the easiest. When you apply you get a unique number – they can also carry over the data across applications, so you have only to ensure that it is still correct.

The family have used the fund to purchase a laptop which Cameron is 'surgically attached to'. When Cameron first started using it his written English was very poor – but by using social networking sites like Facebook and MSN messenger it has vastly improved. They have also used the fund to go on a holiday each year.

Reflecting on holidays, mum can understand to some extent understand why they use Thomas Cook vouchers – as it is simpler and cheaper to process, and they can be sure that the money is used for what it was intended for. However, it restricts their ability to shop around for the best and often last minute deals, and also to go on holidays specially aimed at single parents. While this is frustrating, she feels like it's a reasonable compromise.

Thinking about the system making purchases with a personal budget, she wonders why users of the Family Fund grants can't simply collect and submit receipts? However, she recognises that this would create more admin costs.

They have also used the Fund to make day trips. A recent trip was to the London Eye. While Thomas Cook vouchers can be used for attractions like the London Eye, Thomas Cook's staff often do not know that the vouchers can be used in this way. Mum emphasises that staff need to be briefed about how they can be used. She also feels that it is a shame that the vouchers don't accommodate the needs e.g. concessions for carers, as well avoiding the queues, that can be very difficult for an autistic child to have to endure. Mum has had to rely on the kindness of individual staff to accommodate their needs, instead of being able to take this for granted.

## Home Visit

When she completed the application form for the first time she was informed that a home visit would be likely. She thinks that perhaps not all applicants have home visits, but isn't sure.

She received a call to arrange a convenient time. The primary purpose in her view was to check that the details she'd submitted about their needs were correct – that in effect they were who they said they were and their needs were genuine. The home visit allowed the Family Fund staff member to get an in-depth understanding of Cameron's emotional and physical difficulties. While the visit was about checking things, the visitor was 'lovely' and didn't make it feel like a test or like she was trying to catch the family out.

Mum greatly values the fact that her home advisor was able to give her advice about her DLA – the advisor pointed out that she wasn't getting as much support as she was eligible for.

The visit was quite long, it lasted at least an hour and twenty minutes, but this felt appropriate given that she also received useful information about her benefits. Reflecting on the experience she feels that there was nothing that could have been improved about it.

## Impact

The holidays have been 'brilliant' for the whole family – they give some much needed time out from their daily lives. They give Angela some time to recuperate and 'recharge her batteries'.

The first trip was a trip to the Caribbean, where Cameron had the chance to swim with dolphins. The family selected the particular destination as the holiday complex offered a secure ground floor room that would help to prevent Cameron from wandering off or jumping out of the window (something he has done in the past). Cameron is also 'obsessed' with water and animals and so the chance to swim with dolphins was a 'life changing opportunity' for him. Mum describes how the

dolphins were able to interact with her son and to swim underneath him and launch him up and out of the water.

*‘Swimming with dolphins was a life changing experience for Cameron which he will cherish forever.’*

For these reasons mum felt she could justify the destination – as an exceptional and ‘one off’ experience<sup>7</sup>. Using the Fund has allowed mum to be more choosy about where they go. When mum is choosing a location she has to do a lot research to ensure that the site meets their needs.

When they go on holidays there are also educational benefits – Cameron is inspired to study the country of their destination – learning about the culture and history. The experience of travelling has helped Cameron to become more mature and resilient. While the first holiday they went on was really difficult, as Cameron struggled to deal with a change to his routines, as they’ve gone each year, Cameron has become better at dealing with new experiences such as eating different food and he has become better able to deal with the uncertainty that is sometimes involved in travel. His brother Brady also had a great time. Without the fund, Angela thinks that they simply wouldn’t be able to afford to go away at all as money is limited.

With Cameron busy using his laptop to explore his interests and chat with friends, mum is able to get some much need space and respite. It has also allowed her to spend more time with her other son. Using the laptop has also improved Cameron’s literacy – his typing and reading are now closer to where they should be for his age.

Mum believes that the Family Fund fills a valuable gap in the range of available budgets – she has found that most cater for end of life care or are aimed at people with an obvious physical disability. On the other hand support for people with ADHD and high functioning autism – that can be invisible to most – is often lacking.

## **Other Sources of Support**

Mum reflects on the experience of arranging direct payments. She recalls the application process being quite lengthy and thorough and the application having to go to a panel to be reviewed. Her social worker helped her through the process and it took quite some time before it was approved by the council’s panel. By comparison the Family Fund process felt quick and easy.

## **The Future**

Mum is keen to continue applying for the Fund each year. She would like to use the support for another family holiday as it’s become the ‘highlight of each year’ for the family. With the laptop being about five years old now she would also like to replace it with a newer faster model.

## **Recommendations for Improvement**

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<sup>7</sup> Families have the option of adding their own funds if the cost of their holiday exceeds the value of the grant.  
<http://www.familyfund.org.uk/questions-and-answers>

Mum is very positive about the Family Fund. Her only suggestion was that the Home Visitors could expand on their advice giving role, as families know benefits and support that is available. If verbal advice is too expensive, she suggests that some sort information pack could be handed out during the visit. While this would helpful for a great many families, mum benefited from being 'fairly clued' up about the support that is available. She has reached this point by attending parent support groups.

# Family 8

## Family Context

The family lives in a rural area on the outskirts of Huddersfield. They are mum, her new partner and her three young sons. Two are twins aged five and her third son is aged nine. All three have severe haemophilia – requiring mum to administer injections every other day. Her sons also have to make frequent trips to their doctors and to the hospital in Leeds for check-ups and operations.

Because her sons take their treatment they have been able to live a relatively normal life but they must limit their behaviour. For example, they can't do contact sports like rugby or boxing.

In terms of challenges the family faces, parenting and managing their health is very time consuming. For example their school will often ring up mum and she will have to come in to collect them. In their home life the children need constant attention. Because it has become like a full time job she made the decision to stop working.

Without work the family struggles financially to make ends meet. Going on a holiday, for example, would be out of the question without some financial support. Their monthly family income is in the £2201-2400 band and she doesn't receive any kind of personal budget or direct payment.

## Applications to the Family Fund

Mum first heard about the Family Fund through a friend and they have applied for the grant twice.

Mum describes herself as very satisfied with the application process. On both occasions it was quick to fill in the forms by hand and they were processed quickly. In her view the benefits of the fund far outweighed the effort of applying. Compared to the first, the second application process was even easier as lots of the info was still correct so it only had to be double checked.

On both occasions they have used the fund to go on holidays. The first time the money allowed mum to go away with her sons. The second time the money was used for the children and their father and grandmother to go on a holiday. This gave Tracy some much needed time out. Because the second holiday was not involving Tracey it took slightly longer to process as their grandmother had to give additional details, but this was reasonable and the process didn't take much longer.

The fund has also been used to purchase a fridge for storing their medicine which has freed up fridge space for food. It has also provided much needed money to go towards petrol and parking costs. Living in a rural location she has to do a lot of driving to get to the hospitals.

When they bought their fridge she felt that Comet vouchers were able to give her enough choice. The petrol money was sent as cash to the bank which was very convenient.

## Home Visit

The home visitor called them to arrange an appointment at a time that was convenient to them. She arranged a time when she could come and see mum and the children. She helpfully told mum what she would need to see in advance in terms of document. Mum felt happy about the prospect of the home visit as it felt like a chance to learn about the fund and tell their story. At the visit she was able to show the documents and tick them off, this saved having to post the originals.

The purpose of the visit in mum's view was to provide help and advice with the process, as it was the first time they were applying for the Fund. It was also a chance to check their eligibility. Mum most liked the fact that the home visitor was friendly and that she was able to highlight the additional things that she could get from the fund. The fridge they used to store the medicines was the home visitors' suggestions – it hadn't occurred to mum that she could ask for this. Having the extra space makes food shopping that bit easier as she can buy in bulk more easily.

The duration of the visit was long enough to be thorough but it didn't drag. It was nice at the beginning of the process not to be dealing with a computer or a telephone, the process felt more personal. Meeting someone face to face allowed her to explore the purpose of the fund and explore their families' needs in more detail. It also allowed the home visitor to give them some helpful information relating to their DLA. Mum would definitely recommend a home visit for first time applicants.

## Impact

The Family Fund allowed them to go on a longer holiday and to a nicer destination. Holidays are a really important experience for the children and for mum and dad. Mum feels that holidays will also give them nice memories when they get older. At home things can get quite intense with everyone fussing over them so holidays are a nice 'time out' of this they are also a chance for everyone to relax and 'let off steam'.

*'It was a time when they could get away and be a family where we had the peace of mind that it was being paid for.'*

Mum also feels that holidays are important because they provide an enriching life experience for the children, some time out from them simply sitting at home playing computer games. In the weeks running up to the holidays the kids got very excited and everyone in the home felt less stressed.

If they hadn't been supported with the holiday it would have meant the family would have had to scrimp and save (including cutting down on food bills) and it also would have meant that the duration of the holiday would be shorter and the location not as nice.

When the kids went away with their dad and grandma it gave mum a well earned break, which is very necessary when you have three kids with bags of energy. They fight a lot and ride bikes and are a lot to handle.

With the new fridge they can buy more food, they no longer have to dismantle the fridges shelving and play Tetris to get the food in. This was a purchase that has been very useful saving them time

and hassle in the kitchen, but it's a purchase which they couldn't have made if they had had to finance it.

The petrol is actually a huge cost, before they got help with it, they hadn't really thought about how much they were spending. It also helped with the hospital car parks costs. With help with the petrol it has meant that they can buy better quality food for the family, and be a little less focussed on the most budget items when they go shopping.

## **Other Sources of Support**

Mum isn't able to compare the application process to any similar processes but she describes her relationship and the support she received from Family Fund as 'really positive', with 'very little that they could improve'.

## **The Future**

Mum is keen to apply for the fund again. Next time around the top priority will be purchasing some play equipment – such as a bike. Mum would also like to use the money to help pay for their swimming lessons, which cost £53 each school term. She adds that her children are at an age where they enjoy being active and exercising. She is also likely to apply for petrol money so that they can make some more day trips to places where they can play in the outdoors.

## **Recommendations for Improvement**

Reflecting on using the Family Fund support for holidays, mum felt a bit restricted by the holiday providers that the Family Fund work with. Mum would have much preferred it if they could have had cash so they could choose the most appropriate places and then simply submit receipts. This is because of the quite specific needs of the children. When they go away finding safe and secure locations is always the challenge.

## Family 9

### Family Context

The family lives in a suburban part of Manchester. The family is mum, her son aged 13 and two daughters aged 16 and 19. Her son Michael has severe autism and learning disabilities. Communication is challenging – from the age of 10 he was completely non verbal and he uses visual timetables and PECS (Picture Exchange Communication) to help him communicate. He exhibits challenging behaviour and he is an extremely anxious child who finds new experiences and disruptions to his everyday routines difficult to deal with.

In terms of pressures and challenges mum talks about the high level of restrictions on what they can and can't do as a family – the range of choices about what they do and where they go are extremely limited. Because of Michael's anxieties and worries he finds trips to new places very daunting. It's often places aimed at younger children that are more appropriate to his needs. The family also need to pick places where it's okay to be noisy so they don't disrupt others, so they will often end up going to a busy fast food restaurant or a pub. When they go away they tend to spend a lot of time driving around, as the car is a 'safe space' where he feels comfortable when he's away from home.

Another big challenge is that Michael needs constant care and attention. For example, he isn't toilet trained and uses nappies. He needs help with most daily tasks – for example, he can't wash and dress himself or prepare a meal. He would struggle to open a packet of crisps as he motor skills are poor. He isn't able to cross roads unattended because he has little sense of danger. He can also get lost quite easily. This means that parenting and care responsibilities are considerable so mum can't spend as much time with her daughters as they would like.

They have direct payments which cover five hours of respite for mum per week. They use this time on the weekends, when a PA will come and spend time with Michael.

### Applications to the Family Fund

They started applying to the Family Fund in 2004 and have applied six times, about once a year. They have never had an application that was unsuccessful. Mum feels that the time between submitting the form and getting the grant has always been quick.

Their first application was for a clothes dryer, and they've since used the fund to make lots of technological purchases including: a computer, a laptop, an mp3 player and a games console. Michael loves playing in the garden so outdoor play equipment including a trampoline and a scooter have also been purchased with the Fund. Alongside goods, they've also used the fund to go on holidays and day trips. Early on they also received a £100 grant to buy clothing.

For white goods and technological purchases mum has generally found that Comet have offered a good level of choice, however occasionally they haven't had what they've been looking for, such as a particular computer game. Mum feels that Family Fund can provide a good level of choice because you are free to list what you want – even if it is not something their preferred retailers



stock – and the Family Fund will then make efforts – in her experience – to try and fulfil the request for example, by giving a cheque.

Applying online is mum's favourite format because of the speed and convenience. However she thinks that when selecting what you need it would be helpful if the form could include a free text space below the drop down boxes, so that families can make their requests more specific. This would increase the level of choice and specificity in the application process.

## Home Visit

The first time they applied for the Family Fund grant they received a home visit. Mum thinks that all first time applicants should get a home visit, and those families whose needs significantly should get follow-up second visit.

Mum felt happy at the prospect of the home visit. As a parent of a severely disabled child, she'd had a few visits in the past and so she was used to the process and didn't find it daunting in any way. The home visitor phoned her to arrange the visit and the visit took about an hour. The purpose in her view was primarily to check her eligibility first hand. At the beginning of the visit mum shared some reports and documents relating to her son's diagnosis and needs that were drawn from her son's health and social care professionals. The visit then became more of a chat about their family before ending on some focus benefits advice.

Reflecting on the home visit, mum really appreciated the fact that the home visitor was positive encouraging and 'on her side'. The experience of the visit also gave her peace of mind and a sense of dignity about receiving this type of financial support.

*'The visit made the fact we were getting the grant feel normal and justified rather something than something we were simply lucky to get'.*

Mum also appreciated the home visitors' ability to chat to her son and make him feel at ease. The rapport the home visitor achieved made mum feel like the Family Fund were a part of the disability community and that their needs and experiences were truly understood. She also appreciated the advice the home visitor gave about the DLA (their application for this was pending at the time) and about other funds including the carers allowance and carers breaks that they could apply for.

Mum wasn't able to identify any ways in which the home visits could be improved and if she was to run the Family Fund she would continue with home visits as. This is because face to face contact at the beginning of the process is very beneficial for both the Family Fund and the applicants. Mum has looked into the Family Fund and she feels positive that a high rate of their money goes directly to families (90p in every pound she thinks), with the minimum amount spent on administering the service.

## Impact

Mum feels that the level of impact for her and her family of using the Family Fund grants has been significant. In terms of day trips and holidays she feels that they have helped Michael to become more resilient and able to deal with new and 'stretching experiences'. The money has also allowed them to pick and afford the more specialist locations that their son requires. The first time they go

to a place it tends to be a difficult experience for him and he needs lots of preparation and reassurance before they can go somewhere new. In this sense the holidays are about broadening Michael's horizons and giving him a long term future as an adult who is able to be more independent and confident than he is now.

As well as giving him the opportunity to develop his technological skills, his laptop and other equipment are a vital 'coping mechanism' when things feel difficult. Using his laptop and other gadgets serve as a vital 'pieces of home' which make him calmer and more secure when he's in an unfamiliar place and struggling. In fact the family have to plan in laptop battery recharges when they are driving – something which adds a challenge of traveling. Mum also emphasises that the technological purchases are not 'nice to haves', but things that are essential to Michael's day to day wellbeing and sense of himself – *'they help him to maintain control and a sense of predictability'*.

Because Michael uses this technology so much he tends to wear things out. So the Family Fund grants have allowed them to replace worn out items that they otherwise would have struggled to afford.

The whole family greatly enjoys holidays and daytrips and mum describes them as providing quality time together as a family, and providing a nice experience that they will be able to reminisce about for years to come. Michael's two sisters enjoy the holidays and they see supporting their brother to have a nice time when they are on the road together as a challenge which they relish and enjoy.

## **Other Sources of Support**

Mum has experience of applying for First Time Fund, which is provided by a local charity in Manchester. They were unsuccessful due to the huge numbers of families applying for the grant. By comparison mum values the fact that they can feel reasonably confident that their Family Fund applications will be successful. Comparing the application, she found that the First Time Fund process took much longer than the Family Fund and that lots of the information had to be verified and signed by third parties which was more difficult and time consuming to arrange compared with the Family Fund.

## **The Future**

The family would like to continue to use the Family Fund for as long as they can. They intend to use it to apply for another holiday and to purchase an ipad for Michael as they suspect he would greatly enjoy the touch screen.

## **Recommendations for Improvement**

Mum struggled to think of ways of improving the Family Fund. Her only recommendation were to focus on minor things related to increasing the levels of choice and specificity of the goods and services that people can access with the fund. This included open ended spaces on online application forms for describing needs and considering offering a choice of retailers for purchasing white and electronic goods.

# Family 10

## Family Context

Mum, dad and two daughters live in Essex. The elder is 16, while younger daughter Lauren is 9 and has Down's Syndrome, heart conditions, lung problems, gastric problems and partial visual and hearing loss. Lauren needs constant attention, because left to herself she is liable to accidents such as climbing into the oven, pulling over the kettle, or running out of the front door. She is also prone to break her glasses and hearing aids. Her parents have to explain things to her many times before she can remember them. She wakes up most nights so mum and dad take turns to get up, according to dad's work shifts, and often need to have a nap during the day.

The monthly family income before tax is in the £1,001-1,200 bracket. The family receives disability living allowance and carers' allowance, and dad works part time teaching at a college. Both parents worked before Lauren was born, but mum gave up work in order to provide full time care for her. Shortly afterwards dad was made redundant and has only been able to find part time work since then. Mum would like to work, but it is not possible because of Lauren's hospital appointments and because she receives frequent calls from the school requesting her help with Lauren.

Money is a worry for the family because of the many expenses associated with having a disabled child. For example, they are unable to replace the old windows in the house, which are mouldy, and are worried about this affecting Lauren's lung problems (which are similar to asthma). They are able to pay the interest only on their mortgage. The parents are in their late fifties and worry about Lauren's future when they are no longer able to take care of her. They are also concerned for their older daughter, who worries herself about Lauren a lot. Despite mum's efforts, inevitably the older daughter has to 'take a back seat' to Lauren's needs and while she is very understanding, she can become depressed.

## Applications to the Family Fund

The first application to the Family Fund was when Lauren was three; at the health visitor's suggestion, they applied to replace the fridge freezer and were successful. Since then they have also received a washing machine, a tumble dryer, two holidays and a new bed and carpet for Lauren's bedroom. They applied for a cooker at the same time as the tumble dryer but did not receive both, which mum thought was reasonable.

They found it easy to do the application form, and were happy with the amount of time between applying and receiving the awards.

For the kitchen appliances, they received vouchers for Comet. They were happy with the vouchers and were particularly pleased to get the 5-year warranty. For the first holiday they received a cheque, which they used to pay for the holiday camp which they go to every year, because it has provision for children with special needs so that Lauren is well cared for and the rest of the family can have a break. The second time they applied to Family Fund for a holiday, they were given a Haven voucher, which they could not use to go on their regular holiday. They went on the Haven holiday, but without any specialist staff to look after Lauren, mum and dad had to supervise her all

the time. For this reason the family would have preferred to receive a cheque so that they can choose their own holiday, suited to their needs.

## Home Visit

They received a visit from a Family Fund worker following their first application when Lauren was three. They found the worker warm and friendly as she chatted with them about Lauren and their needs as a family.

She asked the family about what benefits they were claiming, as a result of which they went on to take up their entitlement to carer's allowance.

The worker also made lots of helpful suggestions as to what else the family could apply for, including repairs to their car (which she saw dad trying to fix when she arrived), money for hospital visits (fuel, and meals at the hospital in London), and childcare for their other daughter so they didn't always have to take her to the hospital too.

Mum felt that they 'definitely' would have missed out had they not received the visit, describing the worker as 'extremely informative':

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

Mum thought the visit should be a part of the application process for everyone, and thought that in addition there should be return visits to assess the child's needs as they grow older and their needs change.

## Impact

The Family Fund grants received over the years had made a very big difference to the family. The first item they received, the fridge freezer, replaced the old one that was 32 years old. At the time the family was in need of both a new fridge and a special car seat for Lauren, but they could not afford both, so without the grant they probably would have got a second-hand fridge and a standard car seat, i.e. going without the special car seat. Because the fridge was provided by the Family Fund, they were able to buy the seat themselves which meant they could feel confident that Lauren was safe and comfortable in the car.

The new washing machine obtained through the Fund replaced a broken one – until it was replaced, the family had been relying on their neighbours to let them do laundry at their house. The new washing machine has a large capacity so that all the bedding can be easily washed, which is necessary most days as Lauren is not continent at night (and sporadically continent during the day). The tumble dryer is essential to the family too, for the same reason.

The holiday which the Family Fund paid for, to the holiday venue which provides specialist care for Lauren, impacted on the family in several ways. For Lauren, she 'absolutely loved it', because the activities and clubs are specially tailored for children with special needs. For the rest of the family,

they could relax and have a real break in the knowledge that Lauren was being properly looked after. It provided much-needed respite for the parents and Lauren's older sister.

The other holiday which they took through the Fund was the Haven holiday. This had less positive impact for the family as it was not geared to Lauren's needs, so she needed the family's attention even more than usual, as she can get into trouble in unfamiliar places e.g. by wandering off.

Without the Family Fund grant they would still go on their holiday because it is so important to them that the family has this break and that Lauren can enjoy herself. They find the money by paying only the interest on their mortgage, which does add to their worries about the future.

## Other Sources of Support

Because Lauren goes to a special school she receives most of her on-going care there, including occupational therapy and physiotherapy. Social services provide respite care for Lauren one weekend a month, which gives the family a chance to have a rest, get the house in order and spend quality time with their other daughter. Lauren used to go to a playscheme in the school holidays, but she was not well cared for there so she no longer attends.

## The Future

There are no current plans to apply to the Fund, but there are a number of things that they may consider applying for in the future. These include driving lessons for their older daughter who is 16, and money towards repairing the windows in the house or towards completing the loft conversion, which they began with a view to having a carer for Lauren living there when the parents get older, but cannot afford to complete.

Mum always thinks very carefully about any application they make and whether or not they really need it. She is very mindful of the costs of the award:

*'It's free to me, but somebody has paid for it – that's always in the back of my mind and I always ask myself, do we need this or does somebody else need it more?'*

*'In a way you could see things like a dishwasher as an 'extra' – but when you have a disabled child, everything that makes your life that little bit easier is so important.'*

## Recommendations for Improvement

The family are generally full of praise for the Fund, but had some ideas about what else could be offered to families which would help them:

- Counselling for siblings – it would have been very helpful for their older daughter to have some kind of support or counselling at the time of Lauren's birth and diagnosis, and on an on-going basis. Siblings of disabled children can bear a lot of stress and worry as well as being likely to receive the lesser portion of their parents' attention.
- Upgrades to basic medical equipment – for example Lauren has a nebulizer from the NHS, but they would really like a more expensive model which is more portable.

- Specially-adapted toys and play equipment for disabled children – while it is possible to apply for toys and games from the Fund, it would be helpful if the Fund also offered the option of getting these from a specialist supplier so they could be more appropriate for disabled children.
- Offer the option of applying for fewer, larger awards, rather than one award per year up to a limited amount - this would mean families could apply for a single high-cost award that would make a very significant difference to them over a long period of time, for example, a car, or major building works to the house.<sup>8</sup>

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<sup>8</sup> There are four ways by which a family can receive their grant, either as a payment card (where the money is pre-paid to be spent in specific stores), as a product delivered direct to their home, as a direct payment or a voucher from a supplier or as cash paid direct into an account. Families can use these cash payments against agreed purchases as a form of capital expenditure although families need to save receipts to prove proof of purchase  
<http://www.familyfund.org.uk/grants/after-you-apply>

# Family 11

## Family Context

The family lives in a leafy suburban part of Warrington in the North of England. The family are mum and her partner and her two sons aged 11 and 14. Her oldest son Kyle has severe physical and learning disabilities and uses a wheel chair. While his condition is not diagnosed, he exhibits some of the traits of people with cerebral palsy.

Kyle loves music and bright colours and he interacts really well with the families' new budgie which they keep in their front room. He goes to a special school five days a week. Kyle has significant care needs, he wears nappies and they need a hoist to wash him. One of the challenges they face is that they have little close family to share the significant care duties, so this places a big responsibility on mum and her partner.

Because of their care responsibilities mum works part time and her partner was forced to reduce his hours as the company he works for has lost business. Their current household income falls in to the £1,901 – 2,200 band. They describe themselves as struggling to make ends meet. They point out that their cost of living is higher than most families because things like bedding and their washing machines have to be replaced more often because they get so much use. Another challenge for the family that mum highlights is that amount of preparation required for them to make go out or to have holidays as a family in order to accommodate Kyle's needs.

## Applications to the Family Fund

The family have applied for the Fund twice. She found out about it from Kyle's paediatrician. The first time she applied was when Kyle was very young. They used the Fund to purchase some clothes for Kyle and to purchase a fridge freezer and washing machine. The second application, which she made last year, was for some money to go on holidays and trips as a family. Both applications were successful.

Mum found the application form straight forward and the process felt 'self explanatory'. While the form was perhaps 'a bit long' she feels that the amount and type of information they were asking for seemed reasonable and justified.

The fridge they required needed to be a very specific size because of the layout of their kitchen; however Comet didn't stock this less common size. Because they were in a desperate rush for a replacement they settled for a smaller fridge and have ended up struggling to store all their food. Reflecting on the use of cheques to buy clothes mum liked the fact that they weren't limited to a particular shop which meant that they could shop around for the best price and quality. Her main recommendation is that the Family Fund should try to give families as much flexibility as possible when they are buying household goods as they are likely to have quite particular needs.

## Home Visit

The home visitor called in advance to book a time that was convenient to Tanya and her son. She came and gave them plenty of time to go through the process – they didn't feel rushed. The home

visit began with a helpful and thorough explanation of the purpose and aims of the Family Fund then they looked at some of Tanya's supporting documents and evidence. Next they moved into a more open conversation exploring the families' needs and circumstances.

Tanya liked the fact that the home visitor was relaxed, friendly and professional and also praised her ability to interact with her son. Reflecting on the home visit feels that the main purpose was to get an accurate picture of the families' needs.

The thing she liked most about the visit was the fact that it gave her a chance to learn about the Family Fund. She also liked the fact that the home visitor was helpful and friendly and able to put them at ease. Tanya feels quite certain that home visits are worth having for all first time applicants.

During the visit mum didn't receive advice about DLA or other forms of support, but she notes that actually, she didn't want this. This was because she felt that she 'done her homework' about the different forms of support that she could access. However she did suspect that other parents with disabled children might benefit from more wide ranging advice about benefits and grants.

## **Impact**

The Family Fund has allowed the family to replace their washing machine and fridge freezer which were both 'on the brink'. The fact that the Family Fund encourages warranties was something that mum thinks is very sensible.

If they hadn't received the grant they would have had to have gone without, and when it came to replacing their white goods they would have been forced to borrow the money from relatives. This would have been a bit embarrassing and also something that would have added to the financial pressures of their wider family.

Reflecting on the value of the holidays, mum sees them as a providing much needed 'time out' for the family, where they can leave behind the stresses and challenges of their daily lives and focus on their relationships. She also emphasises how much Kyle enjoys going away, as in normal life he tends to be quite confined because of the preparation involved in going out. Mum has fond memories of how much Kyle enjoyed the sunshine and the chance to go swimming and Kyle's brother always has a great time too.

One frustration is that holiday providers like Thomas Cook class Kyle aged 14, as an adult, which considerably drives up the costs of going away. Mum wonders if there are providers out there who don't do this?

## **Other Sources of Support**

The family gets five hours a week through the council's direct payments system. They use the money to pay for a PA to care for Kyle over the weekends which is the time when they take his brother to play football at the local club. Reflecting on the process of securing getting direct payments, she feels that the process was a lengthy and complicated process and that it's 'felt like



a battle' to get the hours increased. By contrast the Family Fund application was a much quicker and easier process.

## **The Future**

Tanya definitely wants to apply for the Family Fund again. They are quite sure that they will focus on using the fund to go on another holiday as the family really benefits from having some quality time together and it allows them have an experience where they can be less worried about their finances.

## **Recommendations for Improvement**

Mum thinks that it would be nice if the Family Fund would allow families to make white goods purchases at retailers of their choice and then submit the receipts to show proof of purchase. This would vastly expand the amount of choice that recipients would have.

# Family 12

## Family Context

The family lives in a leafy suburb of the North West of Belfast. Carol and John have two children one of whom has a disability. Sarah is 13 years old and has Autism and ADHD, she was diagnosed when she was 4 and now attends a special school. Suzie is 5 years old and attends the local primary school. Carol and John are the sole carers for the girls; the main pressure for the family is the inability to be spontaneous. Sarah's behaviour is very challenging; when out in public she can be very loud and often has tantrums which are difficult to control. Other people tend to stare in situations where Sarah's behaviour attracts unwanted attention, and this can be tough on both the parents and Suzie. As a result the family tends to avoid family outings altogether and instead go out separately or not at all. Sarah also tends to go through lots of clothes as a result of her approach to eating. Carol has a close extended family and regularly sees her sister and mother who help out with the care of Sarah when needed; it is important to Carol however that she does not rely on them too much for support.

Sarah receives the higher rate of both Disability Living Allowance and Mobility Allowance. Carol has recently made a successful application to receive a carers' grant of £250 which she and John will use to have a weekend away. Carol doesn't have paid employment but is hoping to start voluntary work next year, and John is a bus driver. Carol was told about the Family Fund by Sarah's social worker.

## Applications to the Family Fund

The family made their first application to the Family Fund in 2004 and have made five applications in total with roughly a year and a half between applications. Following an application the typical time between application and grant is approximately four months. They have never had an unsuccessful application and have applied again this year but are yet to hear the outcome. Carol felt the application process was straight forward and help with the application form has not been needed. The fund has been used for a range of things such as holidays for the family to Disneyland Paris and also within Northern Ireland; a mattress for Sarah because she regularly jumps on her bed and wears out her mattresses, and clothes for Sarah who tends to go through clothes very quickly. All grants have been in the form of shop vouchers such as Argos, Thomas Cook or BHS.

While they were able to use the vouchers to buy what they needed from the designated companies Carol feels she could have got a better deal if she'd had more control over where she could spend the grant. For instance, she has a close family member who works in the travel industry and who could have got them a cheaper deal on the holiday to Disneyland that they bought from Thomas Cook. Carol felt the holiday cost a lot more booking it through Thomas Cook and the family ended up spending more money than they had hoped to. Equally, she could have bought cheaper clothes from shops other than BHS. She was happy with the Argos voucher however.

## Home Visit

The family received a home visit after their first application to the Family Fund approximately 8 years ago. With it being such a long time ago Carol's recollection of the meeting was relatively limited, however she remembered that it was around an hour. The woman met Carol and Sarah and chatted about their family situation; she was pleasant and provided them with some information on the Family Fund and what they were eligible for.

Carol was happy to receive a home visit however she is not sure whether she would have missed out had she not received one. To Carol the Family Fund is a very 'faceless' organisation, she has never received an acknowledgement of an application or any correspondence or communication from them other than the receipt of the grant, and the initial home visit. To her the organisation is not particularly friendly; it is simply a source of additional funding for her family. Despite this she would still offer a home visit if she were in charge of the Family Fund, it gave her the initial connection to the organisation and set up her relationship with them, she likened this to her initial meeting with their social worker – it is only since the home visit that she has had no real personal contact from them.

## **Impact**

The biggest impact of receiving the Family Fund for the family has been the ability to take a holiday. The lack of spontaneity for the family means they have few opportunities to get away from the routine of everyday life, and the onset of the recession and the subsequent rise in the costs of living have meant that money for holidays, particularly those abroad, has been scarce. The Family Fund has given Carol and John the opportunity to take their two girls away, if only for a small break. While Carol said that it was not much of a break for her as Sarah's behaviour continued to be challenging, it was good for her and her sister to be somewhere different if only for a short time. She highlighted the importance of this for Suzie, the younger sibling, who often missed out on activities as a result of Sarah's disability.

The other items the family has received through grants from the Family Fund, such as clothing and mattresses, has helped towards Carol ensuring Sarah has what she needs when she needs it – such as new clothes when old ones have been worn through, and a new mattress when she'd jumped on her bed so much the mattress had worn out. Despite this, Carol felt that while the grant had helped towards providing these items, and the holiday, they had had to find extra money to fulfill the needs of the family. In the case of the foreign holiday, if their application had been unsuccessful they would have gone without, which Carol believes would have been a real shame, as all families, and especially the children, deserve a holiday.

## **Other Sources of Support**

The family is in relatively regular contact with a social worker, who has recently supported Carol to submit her application for a Carers' Grant, something which she has only recently discovered she is entitled to. Sarah also gets support from an educational psychologist and speech therapist at the school she attends. Sarah's DLA and mobility allowance (high rate) goes straight into their joint bank account on a weekly basis and they have control over how they spend that money to support Sarah.

Sarah also attends a number of voluntary sector groups providing social activities for children with Autism, such as arts and crafts. These provide Sarah with an opportunity to mix with other children, and Carol and John with some regular respite at the weekend and during the school holidays. Having contact with other parents of autistic children also keeps Carol up to date with the various entitlements that she may have, and how she might access them.

## **The Future**

The family plans to apply for grants in the future, however Carol is conscious that she will only be able to apply up to the age of 17; she is currently at a loss to where she might go after that for support as Sarah's needs are unlikely to change. At the moment she is unsure about what she will apply for from the Family Fund, thinking perhaps it will be for clothing or a washing machine, it will only be for something that she feels she needs at the time.

## **Recommendations for Improvement**

The family had three suggestions for improving the Family Fund:

- An acknowledgement of receipt of the application would be good, followed by some indication of whether the grant has been successful and how long the grant is likely to take to arrive.
- In most cases the family has had to wait up to 4months for their grant, they believe it would be useful to have a quicker turnaround which would enable them to be able to plan better (especially holidays).
- They felt that alternatives to vouchers would be better to allow more flexibility and give them the opportunity to get more for the money.

# Family 13

## Family Context

The family consists of Jane and her three boys, they live in North Belfast. Her eldest is 17 years old and has ADHD, her second is 15 years old, and her youngest is Peter who is 7 years old and has ADHD and Autism. Peter was diagnosed in 2011, he was being quiet and withdrawn in classes and his primary school teacher advised Jane to see a paediatrician who confirmed the diagnosis. He has since been accepted into a special school. At the moment Jane does not drive and relies heavily on public transport and taxis to attend hospital appointment and do shopping etc. As a result of his autism Peter is set on routine and the unreliability of using public transport can often be a challenge and stressful. Public transport and taxis is also a huge expense for the family, and can be very time consuming.

Jane is the main carer for Peter and does not work. They do not have a social worker as Jane has been told she is not entitled to one due to her perceived ability to cope with the situation she finds herself in. Peter receives the Disability Living Allowance and she receives the Carers Allowance. They found out about Family Fund through someone at Autism NI who was put in contact with Jane following Peter's diagnosis.

## Applications to the Family Fund

Jane has made one application to the Family Fund last October (2011). This application was for driving lessons to help reduce her reliance on public transport. Jane receives a total of 44 hours of lessons with two attempts at both her theory and practical tests. She has passed her theory and is due to take her practical test at the beginning of July. She had no involvement in the organisation of the lessons herself; this was done by the Family Fund and the driving instructor got in touch with Jane directly. Despite not having a real choice in who she could employ as an instructor Jane has been happy with the company and instructor she has been allocated. She also believes that if she had been unhappy she could have talked to the Family Fund in order to change her instructor. She feels that having too much choice in these sorts of situations can be detrimental and was very happy to have the decision taken out of her hands in terms of who to use as an instructor.

Jane found the application process straight forward. She downloaded the form from the website, sent it off and received an acknowledgement relatively quickly. She particularly liked the text number they provided to help her to track where her application might be. If their application had been unsuccessful Jane would have gone without – she would not have borrowed money to cover the cost and driving lessons are too costly for her to save up for. She isn't aware of any alternative charities that she could apply to either.

*'there wouldn't have been any particular change if we'd not received it, we would've just carried on with what we were doing, struggling along'*

## Home Visit

Jane received a home visit within three to four weeks of making her application. The visit lasted for up to two hours and Jane thought the visitor was really lovely and was easy to talk to over coffee. She understood the need for the Family Fund to visit her to ensure she was a genuine case and was not offended by any questions she was asked in order to confirm this. The visitor looked through Jane's paperwork and met Peter and observed, for a short space of time, what family life was like. She was also able to give Jane an indication of whether or not her application would be successful, which was a great weight off her mind at the time.

Jane felt the home visit was an important part of the process on both sides. Not only does it allow the Family Fund to check families are genuine, but it also allows families to put a 'face to the organisation' and feel linked to it somehow. She would offer home visits if she were in charge of the Family Fund.

*'I wasn't worried about the visit – if you've got nothing to hide then why should you be?'*

## Impact

Jane can already see the huge difference having the freedom of their own car will make to her and her family, especially Peter and her mum. The current reliance on public transport, as mentioned above, can be stressful and costly. With her own car she will be able to provide Peter with the stability he needs, she'll be able to take him to his hospital appointments, shopping, and on weekend trips without worrying about how she will get there and back. She will also be able to take her mum to her dad's grave (he recently passed away) and she will be able to visit friends.

## Other Sources of Support

Jane is not in regular contact with any other forms of support other than Peter's appointments with a paediatrician as a result of his ADHD. This is partly due to Peter's recent diagnosis but also the lack of time Jane has had to pursue any additional opportunities for funding. She does intend to look at opportunities for accessing other grants in the near future – but only if she feels she has a need for them. Peter will soon be starting at a special school so he will get additional support there. She is also hoping to get involved in some local groups that support autistic children and their carers; however she is yet to find any locally, having a car will enable her to go further afield.

## The Future

Jane has no plans to apply again to the Family Fund in the near future unless she feels she has to. If there is something that Peter needs that she can't provide then she will apply, however at the moment she had not thought that far ahead and nothing is urgent at the moment.

## Recommendations for Improvement

Jane only had one recommendation for the Family Fund and that was for it to consider its public image, at the moment the perception is that it is for severely disabled children, she was very

surprised when her application was accepted for Peter; support for autistic children certainly wasn't something that she thought she would be able to access.

# Family 14

## Family Context

The family lives in a rural village 20 miles south of Edinburgh. Jo has four children and recently moved up to Scotland from South London to move in with her partner Mark. She brought her three boys from a previous marriage with her, and has a six month old baby boy with Mark. Her eldest son, Joshua, is 15 years old and was diagnosed with Aspergers and Epilepsy at the age of 7. Her other two sons are 12 and 11 years old. Jo is the main care giver for Joshua and works part time so does not receive the Carers Allowance.

Jo finds family life can sometimes be very isolating and stressful. The main pressure for the family, and especially Jo, is managing the dynamics between the children. Jo struggles to get Joshua to understand social communication and how he should behave both with adults and other children. His continuous demands for attention leads the other children to copy what he is doing, and this can cause considerable tension when all children are demanding time and pulling in different directions. Jo finds herself spending a lot of time explaining Joshua's behaviour to the other children. Having Aspergers means that Joshua struggles with change; as a result life has to be structured and predictable, and this too can be challenging to maintain. Joshua is also becoming more aggressive and violent as he gets older. Joshua goes to mainstream school but has additional support in the classroom. Jo found out about the Family Fund through a Google internet search following someone mentioning it at a local organisation offering support to parents of autistic children.

## Applications to the Family Fund

Jo first made an application to the Family Fund when she was a single mother living in London 8 years ago. She had recently divorced and was living on her own looking after her three boys who were 4, 6 and 8 years old at the time. Her first application was for a holiday to Disneyland for the family. She has made two additional applications since; the second for an oven, and the third for a computer for Joshua. While she has had no unsuccessful applications, she has not always been given her first choice.

Jo found the application process streamlined and very easy to complete and did not need any help with the forms. It took between 4 to 6 weeks to receive the grant which was shorter than she was expecting. The family received the first two grants in the form of vouchers. The holiday voucher was for Thomas Cook, she found this quite restrictive and would have preferred to have the flexibility to make her own choices on where to go to book her holiday, she believes she could have got a much better deal and value for money elsewhere. Similarly, she was given a voucher for Curry's with which to buy her cooker. Due to the limitations of the voucher and building regulations at the time in relation to installing the new cooker in her flat Jo ended up spending a considerable amount of money 'topping up' the voucher, which is something that she had not anticipated and which led her to borrowing additional funds. Not having a cooker was not an option as this was her main means of cooking food for her children. Jo believes she could have avoided paying the extra money had she had more flexibility with the voucher. The computer for Joshua she received direct from the manufacturers; she had had no choice of what make or model



of computer Joshua would receive. While it is a good computer she would have preferred to get a higher spec laptop which would have suited Joshua much better. In reality the computer has been a bit problematic and tends to break down a lot. It also comes with Family Fund imposed restrictions relating to the websites that users can access, and when changes are needed it has taken up to two days to sort. The move from London to Scotland also caused problems with the changes to their IP addresses etc. Overall, it has been useful to have a computer for Joshua, however it has brought with it a considerable amount of issues, many of which Jo believes could have been avoided had she had more control over which computer to buy and how the computer's system was managed.

## Home Visit

Jo received a home visit as part of their first application to the Family Fund. The visitor came within two months of the application and she spent an hour having an in-depth conversation about the family's situation, their needs, and what the Family Fund could do to support them and what to expect, she also gave her some useful information on other sources of support. The visitor spent most of her time talking to Jo, but also spent some time talking to Joshua. Jo found it a completely appropriate and useful exchange and recognised the importance of them verifying who she was and why she needed their support. The visit also gave Jo a certain sense of relief that the organisation was not 'just a lottery' and that it had a human element to it. She felt she would have missed out had she not had a visit and believes her faith in the application process would have been compromised without it. She also felt the home visit helped to lessen her perception that the Fund was only for severely disabled children. She would certainly offer one if she were in charge of the Family Fund.

*'The home visit is a great way of getting a better sense of where the money's going and how it is helping families e.g. the difference a dishwasher makes.'*

## Impact

The various items received through the Family Fund have all had a positive impact in some way. The cooker helped to ensure Jo could provide the necessary nutritional care for her children and the holiday provided the children with an experience that they enjoyed and would remember. It has also been useful for Joshua to have a computer. While having access to the Family Fund doesn't necessarily change anything in particular it has made things easier going forward and did help Jo to cope in difficult situations. The issues with the cooker and the computer were not ideal; however Jo was still grateful for the items and the support at the time.

## Other Sources of Support

Joshua is in receipt of the Disability Living Allowance and has regular reviews with specialists every six months. He has additional support at school and they are in the process of organising a social worker – this is largely to do with Joshua's recent increase in aggressive behaviour. They haven't applied to other grants or funds and Joshua is not involved with any local clubs directly in relation to his condition.

## The Future

Jo is very likely to apply for funding again. She believes Joshua spends too much time at his computer and is keen to get him more involved in some form of physical activity, at the moment she is thinking of applying for funding for a tandem bike for her and Joshua.

## **Recommendations for Improvement**

Jo only had one major suggestion for improving the Family Fund and that was in relation to the choice and use of vouchers. She really felt she could have got a lot more value for money out of the Fund had she had more control over how she could spend the grant.

# Family 15

## Family Context

The family lives on the outskirts of Edinburgh in an area of high density social housing. Fiona and Tristan have twin girls aged 4, and Callum, Fiona's son from her previous marriage, is aged 6 and has Autism. Callum was diagnosed with Autism when he was 3 years old; he rarely talks and can just about count to 10. His sentences are no more than 2 words, but his communication has been improving since he started at a school for children with Special Educational Needs just over a year ago.

Over the last few years Fiona and Tristan have had quite a bit of upheaval due to moving house three times. When they first applied to the Family Fund their girls were still very young and they were living in a high-rise flat with a broken lift, they were then moved to another 4-flat property but had trouble with a violent neighbour, so were moved again to their current semi-detached property where they are much happier. They have their own garden and plenty of space, as well as nice neighbours. Fiona is the main carer for Callum, the main pressures she and her family faces are financial and isolation. Callum's behaviour in public can be very challenging, and taking all three children out at the same time is often stressful. Transporting three children using public transport is close to being logistically impossible and often very costly – so Fiona rarely goes out, and when she does she never goes with all three children. As a result Fiona and her children rarely socialise with friends or see her or her husband's family. Tristan works full time and Fiona does not have paid employment; it does not work out financially beneficial for her to claim the Carers Allowance. Fiona was told about the Family Fund by someone at her son's nursery.

## Applications to the Family Fund

Fiona has been the one responsible for their application for the Family Fund and she has made one application to them so far, this was done at the beginning of 2011 and was for driving lessons. Fiona found the application process easy and straight-forward and did not need any help with the forms.

Fiona applied for driving lessons to help ease the stress of travel and to help reduce her family's feelings of isolation. She received the money to pay for the lessons straight into her bank account and was then required to provide receipts and proof of tests etc to the Family Fund. She had two attempts at the theory test and two attempts at the practical test – passing both on the second time. Fiona could choose who it was she had as an instructor which was helpful because it meant she could go with someone local. If her choice had been limited by the Family Fund she would not have been able to take lessons due to the South Edinburgh BSM firm only doing lessons during the day – her husband works during the day, so she would have had no childcare.<sup>9</sup>

## Home Visit

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<sup>9</sup> In this instance the family received the driving lesson grant funding in cash due to the restrictions of the local BSM firm.

Fiona received a home visit approximately two months after she made her application, she was living in the multi-story flat at the time. She thought the meeting went well and they discussed her application, the visitor explained the process and how the Family Fund makes their decisions. She met the children but not Tristan and gave Fiona a leaflet about additional support that she could get from elsewhere. Fiona felt happier after the home visit. It was useful to know that there was someone there that could and would help her if needed, and appreciated the opportunity to explain her situation to someone face to face. She's convinced she would not have been able to articulate it so well had she had to do it over the telephone. Fiona is also not convinced she would have been successful with the application if she had not had a home visit; having the visit gave her some faith in the application process.

*'Sometimes you just feel like a name and number, it's nice to get the personal touch'*

## Impact

Fiona has got her driving licence but has not yet got a car so it is difficult to say what impact the driving lessons have had so far. She is currently looking for a car with her sister and when they have one she is looking forward to being able to go out relatively stress free. She believes the biggest impact will be on Callum, she will be able to take him to different places and to visit his cousins and his dad. He will be able to go to the shops with Fiona and have the opportunity to try on clothes before she buys them. Fiona will also be able to see her friends and family and attend Callum's parents' evenings, something she has not been able to do so far – it currently takes 3 bus journeys totalling 2 hours to get there, in a car it would take 20 minutes.

In the event of an unsuccessful application Fiona would not have borrowed the money from her extended family to take the driving lessons as they do not have the money to lend her, she would also not have taken out a loan to pay for them as her and Tristan are already in debt due to taking out a loan for their wedding. Without the Family Fund support Fiona and her family would therefore still be *'stuck doing nothing'*, spending *'hours on unreliable buses'*, not going out and feeling isolated.

## Other Sources of Support

Callum receives the Disability Living Allowance and is on the low rate mobility. Fiona recently tried to apply for some respite from the local authority but was turned down. They use a point system and she missed the mark by 2 points, with the local authority assessors claiming that she was coping fine and does not need the support. She was disappointed that she was not successful, but has not applied again. Callum does not have a social worker but he gets a lot of support at his school from a range of specialists such as an educational psychologist and a speech therapist. They have recently applied for a placement at a children's holiday scheme and are awaiting a response, however it costs £35 a week so they are still not decided whether they will be able to afford to send him there over the summer. Fiona has had no contact from the Autistic Society since Callum's diagnosis and is not involved in any parent support groups – she feels she has too much to do and her time is better spent with her children.

## The Future

Fiona does not know if she will apply for any future grants. At the moment she is not sure if there is anything else they need and does not want to apply just for the sake of it.

## Recommendations for Improvement

Fiona had a few suggestions for improving the Family Fund:

- Communicate better with applicants and let them know when they change a phone number – Fiona spent almost half an hour on a call trying to get through only to find out the number had changed.
- Not many people know about the Family Fund – maybe there is a way to increase the number of people that know about them, such as advertising it with professionals in touch with children, such as schools and nurseries and health professionals working within them.

# Family 16

## Family Context

The family lives in a detached house in a small town in West Lothian; Zoë is a single mother and has two girls, her eldest is Lucy who is 14 years old, and Sophie is 3. Lucy has a rare condition called Smith-Magenis Syndrome which is a developmental disorder that causes moderate intellectual disability, delayed speech and language skills, sleep disturbances, and behavioural problems. Lucy was diagnosed in 1999 and now attends a special school about 15 miles away. Lucy's condition means that she goes through a lot of clothes which often need changing more than once a day, this is either as a result of her ripping her clothes or from the way she eats and drinks, her medication also means her weight fluctuates. She suffers from night time incontinence and regularly rips her bed-linen. Her unpredictable behaviour means that going out in public, such as restaurants and shopping, can be very stressful for the family. Zoë is her main carer and does not currently have paid employment, while she would like to work Lucy's sleeping patterns means Zoë rarely gets a full night's sleep which makes employment practically impossible.

The main pressures for Zoë is that she can't lead a 'normal life', it is hard to take Lucy shopping due to her behaviour and it is almost impossible to relax when out in public. Zoë doesn't have many friends and family around her so caring for Lucy can be quite isolating and exhausting. She spends a large amount of her time cleaning and mending Lucy's clothes and bed-linen.

Lucy receives the Disability Living Allowance and has recently accessed a personal budget to pay for a carer to take her out once a week during the school holidays. Zoë does not claim the Carers' Allowance as this would impact negatively on the other benefits she is entitled to. Zoë was told about the Family Fund by Lucy's health visitor.

## Applications to the Family Fund

Zoë has been applying to the Family Fund for approximately 8 years, averaging one application a year. Applications have been for clothing and bedding for Lucy, holiday vouchers and white goods. Their most recent application was for a week's holiday to Spain for the family, they had saved up two years' worth of vouchers in order to afford to go (Zoë does not think it is possible to do this anymore), and while the girls enjoyed the holiday, Zoë didn't have much of a holiday herself. Lucy gets very excited about things, and this excitement often overwhelms her and she becomes difficult to control. Zoë spent a lot of the time making sure she didn't escape out of the apartment. Other applications have been for clothing and bedding and a washer/dryer machine. All the applications have resulted in vouchers for various stores, such as Argos, BHS or Thomas Cook. Zoë believes the voucher system is quite restrictive. For instance, the Argos vouchers were for the bedding, but Argos do not stock the bedding that Zoë likes Lucy to have, so they had to make do with what Argos had available, this was not ideal. While she was able to get decent enough clothes with the vouchers from BHS she believes she would be able to find cheaper clothes elsewhere, so again, this wasn't ideal. Zoë had the most problems with Thomas Cook, the holiday ended up costing them a lot more than it was supposed to and Zoë believes that she could have got a much better deal through a family member who works in the travel industry. She really does not think they got value for money with the holiday which was a real shame. Zoë believes that

vouchers are a sensible way for the Family Fund to distribute the money and appreciates their reasoning behind them; however she believes that there should be more flexibility in the approach, at the moment they are too restrictive, nowadays people tend to like to shop around more to get better deals, especially when money is scarce.

Zoë thinks the Family Fund are good at explaining what people are entitled to with the website clearly stating what you can and can't apply for. The first application Zoë found quite challenging, she sometimes struggles to articulate the issues that she has to deal with when caring for Lucy, and writing them down can be difficult – this is compounded by the fact that few people have heard of or understand Lucy's condition. However the later applications she found easier to do as the Family Fund do not require you to repeat information about your child's condition, which is good.

## Home Visit

Zoë received a home visit after her first application; she does not remember much about the visit, it was relatively soon after Lucy's diagnosis so she freely admits that *'it was all new to me and I was too wrapped up in Lucy to take anything in, I was no doubt sleep deprived and an emotional wreck'*. Despite this she remembers that the home visit was a positive experience and she appreciated the face to face contact with the organisation. She acknowledges that it is hard for someone to get a true feel for another person's life in just an hour, however she believed it must be reassuring for the Family Fund to meet the beneficiaries. She also believes it was good for her to have a *'face for the organisation'*.

## Impact

Having the extra support to buy additional clothes and an efficient washing/drying machine has meant that Zoë has avoided going into any additional debt. While she would have bought the items anyway even if her applications had been unsuccessful the detrimental impact on her finances would have been significantly worse. The ability for the family to go on holiday has also been positive for her daughters and she is grateful for that opportunity. She is very conscious to ensure Lucy's condition does not have a negative impact on her younger daughter Sophie, and anything she can do to avoid that she does.

## Other Sources of Support

Lucy gets support from a range of professionals. She sees a social worker every couple of weeks and at school she has contact (depending on her condition) with a psychiatrist, a pediatrician, a speech therapist, an audiologist, and a physiotherapist, she also attends a cleft palate clinic and sees a cardiologist every three years at the local hospital. During the summer holiday Lucy has a day with a carer every Wednesday and attends various activity groups delivered by voluntary sector organisations. Lucy's social worker has recently given Zoë a number of application forms for grants she is entitled to, such as 'Take a Break Trust' and 'Challenge a Child Fund'. Zoë admits that filling out so many application forms can be quite tiring, especially explaining Lucy's condition and outlining income and expenditure. As far as she is aware these applications will not include a home visit.

## **The Future**

Zoë intends to apply for a grant again. It is likely to be for bedding or clothing for Lucy. The Family Fund has been a great help to her and she intends on continuing to apply until Lucy is 17 years old.

## **Recommendations for Improvement**

Zoë has been very happy with her experience with the Family Fund. Her only suggestion would be that it provides some form of sign-posting to other charities that are there to support families with disabled children; it is often very difficult to find out what is available for families so a point in the right direction would be much appreciated.



# Family 17

## Family Context

The family is mum and two sons, Adam (16) and Scott (13) who has learning disabilities and behavioural problems. Scott is borderline autistic and has been statemented as having special educational needs. His education level is around that of a 7 year old and he has autistic traits and symptoms similar to ADHD. The family live in the Borough of Hounslow in West London in social housing.

Mum is the sole carer for Scott and receives carer's allowance; Scott receives Disability Living Allowance. The total family income before tax is between £1,901 - £2,200. They do not receive a personal budget or direct payments. Mum feels that because Scott is not profoundly disabled there is a lack of support and services available. She describes herself as someone who copes and gets by despite the pressures of being a single parent and carer. School provides a helpful routine but the school holidays are particularly challenging. Scott does not meet the criteria for many of the clubs which are for more disabled children but finds it difficult integrating into mainstream activities with other young people. Mum attends a parents' group at Scott's school which she finds really helpful for peer support and information exchange.

## Applications to the Family Fund

Mum was told about the Family Fund Trust once Scott had got a statement and first applied in March 2008. In total Mum has applied three times. The first application was to cover the insurance and tax for her car and for £500 of holiday vouchers. The second grant was awarded for garden furniture and a laptop for Scott and the third most recent grant was for a freezer, a mattress and some clothes for the family. Mum described the application process as very straightforward. She had done it online and it had taken roughly 4-5 weeks for the grant to be awarded.

Mum has always received something from the Trust on each application but not always the full amount. For example, last year she applied for clothes but was not awarded money for these (although she received money for the laptop and garden furniture). Mum says she prioritises carefully which items to ask for in the application and was disappointed not to receive the money for clothes as they desperately needed them.

For the most recent grant mum was frustrated by how the grant was delivered. For the freezer she received a Comet card for £220 but within this was the price of a 5 year warranty which was not optional. The warranty cost £70 which means mum could only get a freezer up to the value of £150 which meant getting a smaller one than she needed as she explained:

*'It didn't give me the option of getting a bigger one which means I can't shop big and that frustrated me. The warranty is a good thing – they cover you in a way you wouldn't cover yourself – but I might have got a warranty for 2 years and then extended it.'*

Mum also felt that if she had been given cash she would have shopped around and got something cheaper from her local white goods store. Equally, with the mattress, mum was given an Argos voucher for £100 but as Scott wets the bed regularly mum had been intending to get him a special

mattress which was plastic-sheeted on one side. This was not available from Argos so mum ended up using Scott's DLA money to buy the mattress that he needed for his medical needs. She offered to return the Argos voucher but was told she could spend it on something else so ended up buying a BBQ as Scott and the family had wanted one for the summer holidays.<sup>10</sup>

Mum understood that there needs to be a clear, auditable system for the grant but that the lack of flexibility in how the money is given means that families may miss out and not really get what they need:

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

Similarly with the clothing voucher, mum would have preferred a voucher for less expensive high street shops such as Primark or Matalan. She explained that having £100 to kit out her two sons - who are now taking adult sizes - does not go far in shops such as Next.

## Home Visit

Mum received a home visit the first time that she made an application to the Family Fund Trust. The visit lasted about 45 minutes and was flexibly arranged around mum's existing commitments and schedule which she appreciated. The advisor had been polite and friendly and mum felt good about the visit.

Mum was positive about the home visit for a number of reasons. Partly it gave her a chance to show she was 'genuine' and for the advisor to see their circumstances. Mum felt like the advisor had gone away knowing who she was and that the need was genuine which she had liked. Secondly, mum had found the advisor helpful as she was given advice on what she could apply for. For example, the advisor had told her about being able to apply to get her car tax and insurance paid. The advisor had also provided help with how to prioritise different things on the application form so mum was more likely to get what she really needed.

The advisor also let mum know that she would be able to get 'pull up' pants for Scott on prescription from the Community Practitioner. This has since been a great help with Scott's bedwetting and has helped to reduce any financial burden of this on the family.

For these reasons, mum felt like the Trust should offer visits for people applying for the first time as the individual might not always know what the application entails and the professional may give them insight into what to apply or what other support might be available.

## Impact

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<sup>10</sup> The Family Fund website advises families to get in touch in case their circumstances change or if they have any funding left over. They will speak to families about the situation and agree appropriate next steps; in this instance the remaining money was spent on a BBQ. <http://www.familyfund.org.uk/sites/default/files/Recreation%20and%20Household%20leaflet.pdf>

Mum conveyed how grateful she was for the Family Fund Trust and what a difference it made being to apply each year for items which would be out of reach financially otherwise for the family. The impact of the grant has been considerable. Having access to capital to buy big, expensive items such as the freezer meant that mum could use the weekly income of the family to pay the rent, bills, the children's pocket money etc. Mum also felt it had stopped her going to loan sharks and ending up paying very high levels of interest.

*'If Provident had knocked on my door I would have said "yes" and ended up paying back £400 for £200 loan.'*

Having the freezer means that mum can bulk buy and fill it up on a weekly basis. This means she is more able to buy better quality meat, capitalize on deals that the supermarkets are offering or treating the children to a takeaway meal with the money saved on the weekly shop.

Having the new mattress has meant that Scott is better able to manage his bedwetting, as the mattress is protected. This means he is more comfortable, less stressed and also has a positive impact on mum and his brother. However, mum had asked for money for additional bedding and a special mattress to help with this as Scott wets the bed several times a week. She felt that being awarded £110 was not sufficient in this instance and that having to go to Argos meant they were not actually able to buy the mattress that met Scott's needs.

*'The mattress was the main priority – it's all about him [Scott] being comfortable. I asked for a mattress and bedding and £110 wasn't enough. He could wet the bed 3 or 4 times in a week and that means constant washing and making sure the bedding is dry.'*

Mum was pleased to have been given some money for clothes and said it was nice that the boys could go to the shops and pick something out for themselves. However, she would also have liked more money for the clothes as they were awarded £100 for the 3 family members which works out at just over £30 each. Mum explained that the boys are in adult clothes now and £30 would barely cover the costs for a pair of trainers.

With the holiday vouchers in a previous year, mum used some of her own money from a car insurance accident pay out to cover the outstanding costs of the holiday and give the family some spending money.

Mum said if the family had not been awarded the grant for the various items they would have either gone without, for example, with the holiday. Or they may have applied for less secure forms of credit and loans to secure items such as the freezer.

## **Other Sources of Support**

The family does not have a social worker or support from Child and Adolescent Mental Health Services (CAMHS) and mum does not think they would meet the threshold for services for these. The only outside support mum and Scott get is from the school mentor at Scott's school who mum says is very helpful.

The other option for grants and credit that mum has used in the past is to obtain an interest free loan from Social Services for items such as a washing machine. The loan is then paid back by

Social Security taking out a fixed amount from the family's benefits each week. The downside of this is that there is less weekly money available for basic provisions.

## The Future

Please include the following info:

- Future intentions regarding the FF
- Any salient points not covered in the above

Mum intends to apply for the Family Fund Trust as long as Scott is eligible and in some ways depends on it for the additional help it provides:

*'It's good to know every year I can apply. It would be upsetting not to get anything because each year you think it will come.'*

Next March 2013, mum intends to apply for a cooker as the thermometer does not work so it only heats up to maximum temperature at the moment.

Mum says the help the Fund gives each year is really helpful for their financially stretched family and with the additional expense that having a disabled child brings. The only downside is not knowing if you can count on the money as you don't know if you'll get anything until you actually apply and this brings a degree of insecurity to it.

# Family 18

## Family Context

Mum is a single parent carer for her 16 year old daughter, Amy, who has 'classic' autism. This means Amy has profound learning disabilities and also behaviour disorders. She finds communicating and social interactions challenging. Mum and Amy live in social housing in the borough of Kensington and Chelsea, London where they have lived all their lives.

The family's monthly income before tax is less than £590 and they are not in receipt of a personal budget or direct payments. The main pressures the family are these tight financial constraints which mean they are largely housebound. Mum holds two degrees and has been employed in the past. However, Amy's behaviour deteriorated when she became a teenager and mum explains that due to this shift she decided to stop paid employment for the time being until her daughter is better established as a young adult. In addition to looking after Amy, mum undertakes a number of voluntary positions such as working as an appropriate adult.

## Applications to the Family Fund

The family has made two applications to the Family Fund Trust. One when Amy was 10 years old for a holiday. After that time mum went back to work and so did not make another application until recently when their financial circumstances were reduced due to her not being in work. Because Amy is in transition from child to adult services, support from Social Services has risen to support this transition. It was therefore the family's social worker which reminded mum about the fund and their eligibility.

The first application involved a home visit (discussed in the next section) and the second time was a straightforward application for a washing machine. Mum found the application form very easy to complete. However, as Amy is profoundly disabled and there is already a social worker involved with the family mum found the process of having to describe and list Amy's impairments as unnecessary and demoralising. She points out that with classic autism the level of need is unlikely to change markedly. If the family is in receipt of Social Security and Disability Living Allowance mum felt like this information could be collated in a central place and could be used to reduce the need for additional information to be given during the application for the Family Fund Trust:

*'You still have to put in the same information each time, it's very trying on parents and reduces their capacity to work because it becomes a full time job explaining the level of need to the different agencies you have to engage with.'*

Mum felt that this duplication of effort was time wasting for families and also for government departments. She recommended a central register of family's needs and type of impairment etc. could be kept by the Department of Education to help with this.

However, on the positive side, mum felt that the application form was 'probably the easiest and most thoughtful of applications.' This was because the form had been constructed and phrased sensitively so you did not feel like you were being tricked or humiliated by filling it in. Most recently for the second application, she had requested a copy on the phone and then filled it in.

This recent time, mum applied for a washing machine as the one in the flat had broken down. However, because the application took over a month to process, mum actually decided to get a loan from income support to pay for the washing machine because she needed it urgently and did not know whether the Family Fund Trust would award her one. The loan approval from income support came through faster than the grant award so mum bought the washing machine. She later found out she had been awarded the money to purchase a washing machine. Mum found this frustrating as the money is coming from government – but just different pots of money. It did not feel like the government was ‘joined up’.

The family received the money for the washing machine as a Comet voucher which is now not needed as they purchased one with the loan from income support. The family also need a new fridge but on seeking advice from the Family Fund Trust, mum was told to send back the voucher and re-do the application because the voucher states it is specifically for a washing machine. On the one hand, mum understands why this is because public money needs to be properly spent and auditable. On the other hand the process seems overly bureaucratic and laborious.

*‘It seems crazy that I have to send it all back in and reapply; but that inconvenience I can live with in one sense.’*

Mum says she would have liked more choice with where to purchase the washing machine and that she would have got a better deal by going to her local white goods store. This way she would have had more choice and possibly got a cheaper or better product. Having a voucher that was redeemable in a wider range of suppliers was also suggested.

## Home Visit

Mum was positive about the home visit which happened the first time that she made an application, six years ago. During the visit she was asked to provide evidence of Amy’s original diagnosis. The advisor met Amy and could also observe the condition of the house and family circumstances. The advisor was helpful in explaining the different items that the family could apply for with the grant. Mum particularly valued the personal touch that the home visit brought to the application process:

*‘The home visit was lovely, it felt very personal. It’s very individualised and it gives you a sense of being cared for. It’s inclusive because some people wouldn’t be able to say what they needed in the same way.’*

Mum felt like the advisor was advocating on her behalf and that the visit was also a way to show that they were ‘deserving’ of the grant.

During the home visit the advisor told mum about the different things that she could apply for under the Family Fund Trust. The advisor also provided information on short breaks and extra financial help although mum cannot remember if she followed these up. However, mum pointed out that information about the grant could be given by a social worker or her daughter’s school and that there were other ways to inform families about what they could apply for such as reading literature. Mum felt that, because of their cost, home visits should be prioritised for families that might particularly benefit from them:

*'Home visits are costly, they are high intensity in terms of resources – to randomly send out people to every single person is a poor use of resources. Home visits are for situations where the need is more complex or expertise or specialist knowledge is required.'*

Mum felt that home visits would be particularly beneficial for families that were 'vulnerable' such as those with complex problems, lower Socio-Economic-Status, substance misuse problems and those at risk of social exclusion. She also suggested that home visits can also guard against fraud or corruption where there are suspicions of this.

## **Impact**

Mum feels that the grant has made a big difference to her child and to herself as well as some difference to the wider family. The first application was for a holiday and that made a huge difference. Amy and her mum went on two holidays for two years running. They chose to go away during the Notting Hill Carnival which is near to their house and is usually a very difficult time of year because of the overwhelming sensory impact on Amy.

At the time of the first grant (2006) mum explains that the Family Fund Trust would give money towards a holiday which they put towards renting a cottage in the countryside near to family. The holiday was really good for both mum and daughter and helped Amy to socialise and build her independence skills:

*'My daughter doesn't deal with change very well, so socializing her skills to other environments is huge. It increases her confidence, independence skills, flexibility and tackles her resistance to change. It also helps her spend time with family.'*

Now mum thinks that you can only apply for Haven or Thomas Cook vouchers which restricts choice and are less suitable types of holidays for Amy's needs. This limited options gave the family less flexibility to stay near family members so that mum got some respite and Amy got to spend time with her wider family. Spending time with the wider family such as aunts and grandparents who live far away was important for both Amy and mum. Mum felt that it helped the wider family to understand the responsibilities of having a child with autism and how they could support her as a carer. It also meant she could share the responsibility of looking after Amy for that week and have a change of environment, which, as a single parent was very welcome.

If the funding for the holiday was not available then they would have gone without it. It has not been possible to benefit from the washing machine as the family used a loan from income support rather than the grant money to pay for this to get it quickly.

## **Other Sources of Support**

Amy goes to respite care once a month for the weekend and this helps to foster her independence and the plan is that this will help her adjust to living away from home which will happen when she becomes an adult. Amy's mum has also just applied to a national charity for her to go away on holiday during the summer break, but she is not sure if this has been successful or not as yet. The process to get support is compared favorably by Amy's mum than other processes which she feels

are more bureaucratic and where there is more emphasis on having to detail all the 'detriments' of the child's abilities.

## **The Future**

Mum intends to apply to the Family Fund Trust in the future for a family holiday. However, applications can only be made up to when Amy is 18 years old. This is considered as a shame by her mum who feels there is a need for more support to be made for young disabled teenagers as they make the transition into adulthood. Mum would like to see a 'transitional branch' of the Trust's funding made available for 18-25 year olds. This would be based less on household support but more targeted support for the individual to help them live independently.

Mum would also like there to be an annual assessment of need, particularly where the family's position is fairly static. This would allow the Trust to then allocate the potential amount of money for the family to apply rather than the less secure process at the moment where family's apply with no surety as to whether they will receive anything. Using other professionals already involved with the family rather than having to evidence the need each time round would also help to streamline the process.



# Family 19

## Family Context

The family live in a social housing complex in central Dundee, they have lived there for over 10 years. Ruth and Greg have two sons, Rory who is 17 years old and has Aspergers, and Ross who is 15 years old. They are a very close family and like to do everything together. The boys go to the local comprehensive school and Ruth and Greg are conscious of Ross's responsibility to look after Rory at school – a responsibility they feel has been challenging for him, but he now copes well.

Rory was diagnosed when he was 3 years old, Ruth and Greg share the caring responsibility for Rory however Ruth has a terminal illness so Greg takes on the majority of the caring role for both Rory and for her. Ruth used to work in a supermarket but is now unable to get paid employment as a result of her illness and is often required to attend hospital appointments, and Greg cannot work due to his on-going caring responsibilities. The nature of Rory's Aspergers means that his ability to live independently is very limited. This is largely to do with his inability to tell the time or to count, as a result he has no comprehension of the concept of time or the value of money – key aspects of everyday life his parents believe are key to living independently and in particular to maintaining paid employment. As he gets older Rory is becoming more aware of his condition and his potential future, he would like to be in the army or the police but is conscious that this may not be possible and is starting to show signs of depression.

The main pressure on the family is financial and they also feel quite isolated. They are very strict and careful with their money so as not to get into debt. Ruth's illness means they rarely go out and this on top of the stress of caring for Rory also puts a strain on their marriage. There is limited support for people with Aspergers in the city and they find that the local community have limited understanding of what it means, Rory is also very conscious of negative images of people with Aspergers in the media. They found out about the Family Fund through a taxi driver friend, he had been speaking to a customer who also had a son with Aspergers and had successfully received a grant from the Family Fund, he took their details and passed them on to Ruth and Greg.

## Applications to the Family Fund

The family made their first application to the Family Fund around 5 years ago. They have applied for a holiday, a bed, and a computer. The holiday application consisted of £550 worth of Thomas Cook vouchers which they used to buy 2 separate holidays, one in Edinburgh and one in London. Their experience with Thomas Cook was really positive; their Thomas Cook representative was able to find them the cheapest deals and gave them lots of choice of destination. Ruth believes that having the vouchers is a good thing as there may be the temptation for people to not spend the money as they should otherwise. For the bed they received vouchers for Blindcraft and were happy with the purchase they were able to make. The computer they received direct from the manufacturer and while a laptop would have been preferable, mainly due to their small house and limited space for a big desktop computer, it has been a 'god send' for Rory and has enabled him to link into social network sites, such as Facebook.

They found the application process straight forward and had no issue with the application forms. They liked the way the Family Fund sent them a text message to acknowledge their application and they received their grants within a matter of weeks. They also had a reminder from the Family Fund to let them know it was time for them to reapply for a grant if they so wished. They felt this 'gave them permission' to make the most of the Family Fund and the support it offers.

## Home Visit

The family received a home visit after their first application. Their experience of the visit was very positive and after the visit it was clear to them that the Family Fund is very much about the *family* rather than just the disabled child, again this helped to really 'give them permission' to enjoy the money as a family, rather than feeling guilty for not spending it all on Rory.

*'you always feel like you're asking for something that you shouldn't really be getting, like you're taking it away from someone else's child who's worse off, the visit helped put our mind at ease about this'*

They felt a lot more relaxed after the home visit, at first they felt nervous about a stranger coming into their home, but the experience was definitely worthwhile for them and they would offer home visits if they were in charge of the Family Fund.

## Impact

The main impact of the Family Fund is that it's helped to keep the family out of debt.

*'it's great that there is someone there when you're at your wit's end'*

Without it they would have struggled, and would certainly not have been able to take their boys on holiday where they were able to have various experiences like quad biking and staying in a London hotel. The computer for Rory, as mentioned above, has been really good to help him connect with his friends and have a little more independence.

## Other Sources of Support

Despite applying for Disability Living Allowance Ruth is not eligible for it, her poor experience of the application process means she will not be reapplying, however there is no way that she can work. They do not claim Carers Allowance as this would have a detrimental impact on the other benefits they claim. Rory receives Disability Living Allowance which he is currently using to pay for driving lessons. The family has never had much contact with voluntary sector organisations in the city, they are not aware that any exist, and get a sense that there's not much of a support network for people with Aspergers in Dundee. They don't have many friends, but are beginning to meet more of Rory's friends' parents and that provides them with a bit more of a social life. Rory gets some support from a social worker at school, but all this support goes through the school and they have limited contact with it.

## **The Future**

The family would love to apply for another grant, they think the organisation is fantastic, however they cannot because Rory is no longer eligible due to his age.

## **Recommendations for Improvement**

The family only had one suggestion for improving the Family Fund and that was to make it more well-known, it has helped them a lot and they want it to be able to help other families like them.

## Family 20

NB: We received a completed questionnaire from this family, who also volunteered to take part in a case study visit to discuss their views and experiences of the Family Fund. When we visited the family, the mother told us that, in fact, her application to the Family Fund had been unsuccessful. We undertook the interview anyway, tailoring our questions accordingly.

### Family Context

Mum and ten year old Ben live in Kent. Ben has ADHD. Without medication Ben is impulsive, angry, can't concentrate, and unpredictable, so they can't go anywhere. Ben has been on medication for 4 years. With medication he is able to control his reactions and channel his energy to concentrate at school and do well. He is very bright but his achievement varies according to whether he can be bothered to try.

Ben can be very demanding, requiring a regimental routine and is obsessed with time. If mum goes out he will constantly ask, 'when is she coming back?' He gets very anxious in crowded places and has to hold mum's hand in the supermarket. Socially he is more like age 6 or 7 – he's not 'streetwise' and can be easily led by older children and get into trouble.

Mum has a partner and other family nearby who help a lot with Ben. Mum works at Ben's school, as breakfast club and lunchtime assistant, because it allows her to look after Ben in the holidays. Mum has very little time for herself, as she also cares for her own father. The family receives Disability Living Allowance for Ben.

### Applications to the Family Fund

Mum heard about the FF from a neighbour whose child has the same condition as Ben and who had successfully applied to the Fund. She applied for money to make the garden secure so Ben could play outside safely (the fence and gate were broken), and for money to install a shower so that Ben could start learning to wash by himself as he gets older. Mum found the form easy to complete, but she thought it was too short so she couldn't put in all the information she would have liked to, to support their application. Their application was rejected because Ben's needs did not meet the Fund's criteria.

Mum was very disappointed. She thought it was not clear enough what the criteria were and why Ben did not meet them. Having had a battle over 9 months to get DLA for Ben, mum did not have the energy to pursue an appeal to the Fund.

### Home Visit

The family did not receive a home visit, but mum thought it would have been a very good idea if they had, so that the worker could have asked for more information to support their application. In addition, she felt that the worker could have offered a fuller explanation as to why their application was unsuccessful.

## **Impact**

Mum paid for the new shower herself with the money she had saved up for Ben's Christmas presents. The garden fence is still broken, although mum's partner has built them a new gate which is a start. Had they been successful, the garden would be safely fenced so Ben could play outside without being scared of next door's Rottweiler getting in.

## **The Future**

Mum has been put off applying again because the application was unsuccessful and she does not understand why, given that her neighbour whose son has the same needs as Ben was successful. However if she thought she would be successful, mum would apply for a holiday, probably to Butlins because Ben wouldn't be able to wander off and there would be lots for him to do. If they go away for the weekend, then mum sees a change in Ben, he's more relaxed and happier. Even on holiday though, mum has to watch Ben all the time in case something happens, e.g. if he is playing football.

Mum would also consider applying for money to decorate Ben's bedroom because it has been left in a poor state following some work done by the council which didn't seal the walls, meaning that the paint is peeling off.

## **Recommendations for Improvement**

Mum would clearer guidance on the eligibility criteria and increased space on the application form to fully describe the family's situation and needs.



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