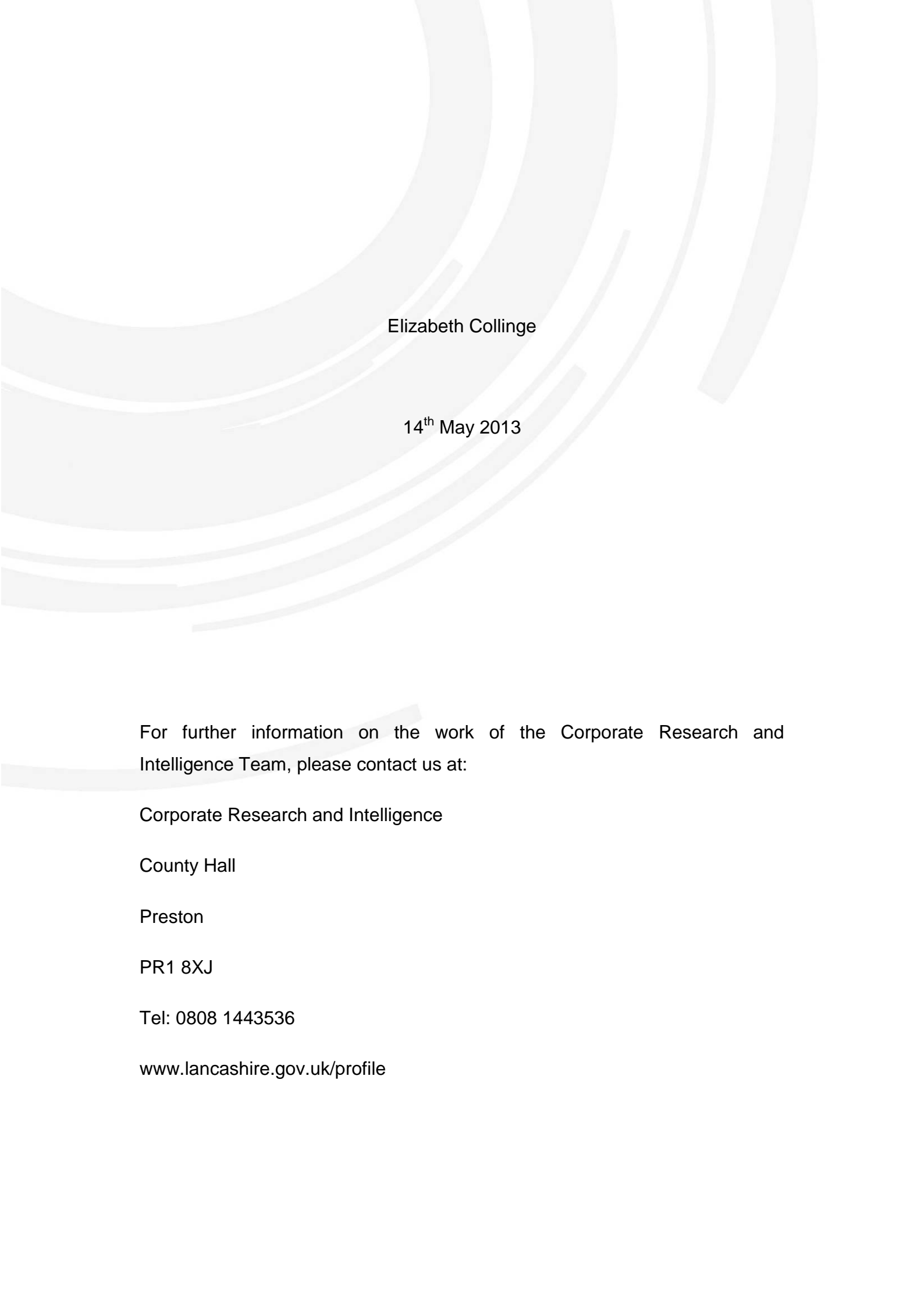


Shared Lives Day Support Service -  
Customer Experience Report



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14<sup>th</sup> May 2013

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## Executive Summary

The Shared Lives Day Support Service offers one-to-one daytime care to customers with learning and physical disabilities. This research assesses the experience of customers and their full time carers, the impact of the service on their lives and the benefits it brings to them. Eight customers and their full time carers were interviewed.

## Main findings

The main findings from this research are:

- A majority of customers and their full time carers were happy with the service
- One customer and their full time carer were very unhappy with the service
- A majority felt it was a flexible service which catered to their needs
- A majority of customers and their full time carers felt that the service had made a positive impact on their lives
- The service helped customers to
  - Reduce social isolation
  - Make social connections
  - Increase their confidence
  - Increase the variety of experiences they have
  - Break the monotony of daily life
  - Increase their physical and mental wellbeing
  - Feel a sense of freedom and autonomy

- The service gave family and other full time carers
  - A break from the hard work of caring
  - A sense of freedom
  - Improved wellbeing
  - Peace of mind for the future
- Finding the right carer for the customer is key to customer satisfaction. Factors in successfully matching carers to customers include
  - Similarity in age, or perceived age
  - Shared interests
  - A carer willing to fit around the customer's needs and desires
- A majority of both customers and full time carers would recommend the service to others

### Recommendations

Not all recommendations are within the power of the service to deliver. For more details please see 'Conclusions and Recommendations' at the end of the report.

- When recruiting carers, pay attention to the overall profile of carers to gain a range and diversity that can match the demographics of the customer base
- In cases of multiple failures of customer - carer matching, investigate this and re-assess the customers' needs and suitable carers in light of this.
- Ensure customers eligible for care services who do not already have contact with Adult and Community Services are able to access the Shared Lives service

- Conduct a customer experience review when the service has been running for longer; the participants here had not used the service for long
- Introduce a regular feedback mechanism
- Increase the amount of hours of care available
- Increase the length of time a customer can use the service in one go
- Increase the amount of travel expenses included. This could take the form of an occasional exception to the allowance for special day trips or similar
- Identify full time carers with low respite availability and/or low wellbeing and initially target funding for extra hours there

## Introduction

The Shared Lives Service launched the Daytime Support Service (from now on referred to as 'the service') in November 2012 following a pilot in Lancaster and Morecambe. Adults with disabilities, older adults, and adults with early stage dementia are supported by a Shared Lives carer in the manner of a family carer, for example going shopping or doing leisure activities. The service is available in blocks of up to 6 hours per week. The service provides an alternative to Domiciliary Agencies, Residential Support or Older Peoples' Day Services.

The Shared Lives Service is now in a position to widen the project to the whole of Lancashire and offer daytime support to a wider target audience. In order to better the service and give an evidence base on which expansions of the service can be made, the service wished to gain evidence of the impact of the service on customers and to learn from their experiences.

This report documents the findings of research carried out with customers and their family members or other full time carers in Central and East Lancashire.

## Research objectives

The objectives of the research were to gain evidence of:

- customers' experience of the Daytime Support Service
- the impact of the Daytime Support Service on customers
- the experience of family members or other full time carers, as customers of the Daytime Support Service
- the impact of the Daytime Support Service on family members and carers of customers

## Methodology

Participants were interviewed confidentially in their own homes. The interview took the form of a guided conversation, with the researcher having pre-prepared specific questions and areas to cover, in line with the objectives of the research.

Interviews were recorded and then notes taken in an anonymous form. The researcher analysed the views of the participants to identify themes and patterns.

## Participants

The eight participants were adults with disabilities (from now on referred to as customers) and their family members who cared for them, or other full time carers. Seven customers had some form of apparent learning disability and some of these were accompanied by physical disabilities. One customer had no apparent learning disabilities and multiple physical disabilities. A range of conditions and difficulties were represented in the groups although all were mobile. The ages of participants ranged from 24 to 82 years old and included six males and two females. The customers had been using the service for between three weeks and six months and used the service for between four and six hours a week.

The family members interviewed were the customers' carers. Two of the customers lived with full time carers, in a set-up akin to fostering, and received some hours of extra day time support. For the purposes of this research, there is no distinction made between family members and other full time carers.

## Limitations

The sample size was small. The Shared Lives Service provided details of thirteen customers and their full time carers, of which eight customers agreed to be interviewed.



7 out of the 8 customers interviewed had a form of learning disability. They had varying levels of comprehension and communication. The two main effects of this were 1) in some interviews the researcher was unable to obtain responses covering all the question areas and 2) the researcher found it difficult in some cases to gain responses from open questions; these had to be substituted with more direct and potentially leading questions.

The service is very new. This means that there is no long-term perspective on the service, which could affect what benefits and problems the report is able to identify.

## **Main research findings**

7 out of 8 customers have had a positive experience of using the service. There was a high level of consistency in responses from these seven customers. One customer, Customer 3, and their family carer have had a negative experience of the service. I will first detail the majority experience and then move on to detail the negative experience of Customer 3.

### **Customers – The Majority Experience**

In this section I will lay out the experiences of 7 out of the 8 customers interviewed. They gave highly consistent responses and so I will not quantify the number of customers who mentioned each point.

#### **Experience of Daytime Support Service**

Customers had experienced different types of previous care, which varied and included residential care and day centres. Customers felt the main differences between those care services and the Shared Lives Day Service were that the Shared Lives Service was more tailored to the individual, allowed the customer to have more choice over activities, and provided one-to-one attention, which for many customers makes it easier for them to engage.

Customers liked

- Spending time with other people
- Doing different things to their usual routine
- Having choice and input over activities
- The flexibility of when they can use their hours
- That it breaks the monotony of their daily routine

All the customers get on with their current Shared Lives carer and enjoy spending time with them. A strong theme in conversations was the need for the carer to be well matched with the customer.

Most customers did not have direct contact with the administrative side of the service and so did not have much comment on this. One customer particularly mentioned that the approval process for carers seemed to take a long time.

The customers did not dislike anything about the service but did suggest some improvements;

- More hours of care being available
- Longer periods of time available e.g. full day trips
- Social occasions with other customers

Customers would like to continue using the service and would recommend this service to others.

### **Impact and Benefits of Daytime Support Service**

The main reason cited by customers for wanting to use the service was to get out and about, get into the community and reduce isolation; the 7 respondents felt this need was met. Many of the customers' family carers had their own health problems or were older people who struggled to keep up with the customers. This means they are not as able to take them out regularly and so the service helped to fill this gap. The follow-on benefits for customers of getting out and about were

- Reduced social isolation
- Increased confidence
- Increased variety of experiences

- Increased mental and physical well being
- Increased opportunities to make new social connections

Other benefits which were strongly mentioned by the customers were

- More freedom in their lives
- A feeling of safety when out of the house

One customer said that the service has helped them recover from depression and helped them through bereavement by replacing activity they used to do with a family member who died.

The service has a considerable positive impact on the lives of customers, not only in the immediate experience but also in longer lasting and more profound effects which continue into their daily lives.

## **Family Members and Other Full Time Carers – The Majority Experience**

In this section I will lay out the experiences of 7 out of the 8 family or other full time carers interviewed. They gave highly consistent responses and so I will not always quantify the number of customers who mentioned each point.

### **Experience of Daytime Support Service**

6 out of the 7 full time carers found out about the service through existing contact with Adult and Community Services, either through social workers or existing Shared Lives contact. One carer found out about the service via a third party charity.

Family members and other carers liked

- The flexibility of the hours
- That the carers usually came to pick up and drop off customers
- The one-to-one nature of care

The blocks of care include an allowance of ten miles of travelling expenses, after which mileage must be paid for by the family. Family members and other carers disliked this limit and felt it restricted the options available for activities to a limited geographical area.

Most family members and full time carers were happy with the administrative side of the service, many mentioned that they would feel happy to call or email if they had a problem. Most felt that communications from the service were clear.

Improvement suggested by family and carers are

- More hours of care being available
- Longer periods of time available e.g. full day trips
- Increased recruitment of carers
- Greater allowance for travelling expenses
- Social occasions with other customers

### **Impact and Benefits of Daytime Support Service**

The two main reasons family members and other full time carers wanted to use the service were to get some respite from caring and to get the customers out and about and into the community. These needs were met for the seven family members and other carers.

Some customers are unable to be left alone and all carers spoke of the physical and mental strain of caring. Family members and other carers all expressed a need to

have a break from the responsibilities of caring. Many of the family members and carers received no other regular respite. The reported levels of wellbeing in full time family carers correlated strongly with the amount of respite they received from caring. The family carers with the least support, either from other family or care services, had lower reported levels of wellbeing.

The follow-on benefits for the family member or carer of getting respite from the service are

- A physical and mental break
- Freedom from responsibility and worry for a few hours
- Improved mental and physical wellbeing
- Improved mood

The carers wanted to use the service to get the customers out and about and felt that the customers received follow-on benefits from this including

- Improved mental and physical wellbeing
- Improved mood
- Improved social skills

The carers were also happy that the customer has an enjoyable experience using the service. One of the carers said the service allowed them to continue working part-time, which gave them another source of wellbeing and allowed them to be economically productive.

Many family members mentioned that the increased social skills customers gained gave them peace of mind that the customer would cope living in different situations when the family member was no longer around.

The family members and other carers would like to continue using the service and would recommend the service to others.

### **Experience of Shared Lives Day Support Service – Customer 3**

Customer 3 and their family member reported a very different experience of the service to all other customers. The customer liked the idea of the service, especially the one-to-one care, and wanted to use it to get out and about with other young people. However, the customer found that the two carers they were previously placed with were not suitable for their needs or age. They felt that they had to fit in with what the carer wanted to do, and didn't enjoy doing certain things. This included going to church, which the family carer felt was 'pushing religion' onto the customer. Unhappy previous experiences make this customer reluctant to go out with a Shared Lives carer again, although they have enjoyed the short time they have spent with their new carer.

Customer 3's family member found out about the service through a web search. They wanted to use the service to provide respite; they are the sole carer, they feel very isolated, they would like to have some time to themselves, and some time to spend with their other child. The customer does not receive any other support. The family member felt that the service could provide good respite if it was with a well matched carer and if the customer and family member were listened to properly. The family member said that a carer not listening to them had led to the customer being left alone, which was not safe. The family member also reported that the current carer had not listened to instructions and had given the customer inappropriate food and made them ill. The family member says that this meant that the care had actually provided no respite as the customer needed extra care and attention on their return. The family member felt the focus of the service was on the carer's needs and not the customer's.

The family had used other very similar care services in another part of the UK. They had a very positive experience of that and feel that the current service does not live up to that.

The customer and their family member would like to see more of a focus on the needs of young people, a better variety of carers and for carers to listen better to what the customer and their family say. They would currently not recommend the service to others.

The carer reports that the service did respond to complaints about the service and unsuitable carers, however the family member feels that they have still not got it right for this customer. The carer acknowledges that the service has improved, however the main reason that they are continuing to use it is because they have no other respite care and no other family to help them.



## Conclusions and Recommendations

### Main Findings

The main findings from this research are:

- A majority of customers and their full time carers were happy with the service
- One customer and their full time carer were very unhappy with the service
- A majority felt it was a flexible service which catered to their needs
- A majority of customers and their full time carers felt that the service had made a positive impact on their lives
- The service helped customers to
  - Reduce social isolation
  - Make social connections
  - Increase their confidence
  - Increase the variety of experiences they have
  - Break the monotony of daily life
  - Increase their physical and mental wellbeing
  - Feel a sense of freedom and autonomy
- The service gave family and other full time carers
  - A break from the hard work of caring
  - A sense of freedom

- Improved wellbeing
- Peace of mind for the future
- A majority of both customers and full time carers would recommend the service to others
- As demonstrated by the experiences of both Customer 3 and all other customers, finding the right carer for the individual customer is key to customer satisfaction. Both the positive and negative experiences related here have often come from the same source; the customer – client relationship and the dialogue they build. Factors in successfully matching carers to customers include
  - Similarity in age, or perceived age
  - Shared interests
  - A carer willing to fit around the customer's needs and desires

### **Recommendations**

My recommendations are split into two parts; those which can be actioned by the service (I), which I offer for their consideration, and those which cannot (II).

#### **Recommendations I**

The following recommendations are for consideration by the service

- When recruiting carers, pay attention to the overall profile of carers to gain a range and diversity that can match the demographics of the customer base
- In cases of multiple failures of customer - carer matching, investigate why the relationships were not able to be built up or have broken down. Assess if there

were factors missed by either side in the matching process and re-assess the customers' needs and suitable carers in light of this.

- Ensure customers eligible for care services who do not already have contact with Adult and Community Services are able to access the Shared Lives service
- Conduct a customer experience review when the service has been running for longer; the participants here had not used the service for long
- Introduce a regular feedback mechanism

### **Recommendations II**

The following recommendations are not within the power of the service to consider, as they relate to the commissioning of the service or the distribution of budgets to individual customers. I include them as they are strongly suggested by the wishes of the customers and the findings of the research.

- Increase the amount of hours of care available
- Increase the length of time a customer can use the service in one go
- Increase the amount of travel expenses included. This could take the form of an occasional exception to the allowance for special day trips or similar
- Identify full time carers with low respite availability and/or low wellbeing and initially target funding for extra hours there

## Appendix 1 – Customer Interview Guidance Questions

- 1) How did you hear about the Shared Lives Service?
  
- 2) Does it give you what you need for day time support?
  - What specifically does it give you?
  
  - Is there anything it doesn't give you?
  
  - Do you think it could meet your needs with some adjustments?
  
- 3) What are the strengths and weaknesses of the service?
  
  
- 4) What do you like/dislike about having a Shared Lives carer?

5) Have you ever used any other care services, like someone coming to your house to help or residential or respite care?

6) If yes, what is different about the Shared Lives service?

7) If yes, what is the same or similar about the Shared Lives service?

8) In terms of what you like/dislike, how would you compare them?

9) What made you want to use the Shared Lives service?

10) When the service contacts you, is what they are saying clear? And how easy is it to contact the service when you need to? (When starting with the service and during)

11) Have there been any benefits to you from using the service?

- If yes, what are these?

12) (Family member) What effects has the service had on you as a carer? For example, in giving you respite.

13) Do you want to continue using the Shared Lives service?

14) Is there anything missing from the service, in the caring or administration, what else should it be offering?

15) Would you recommend the service to others?