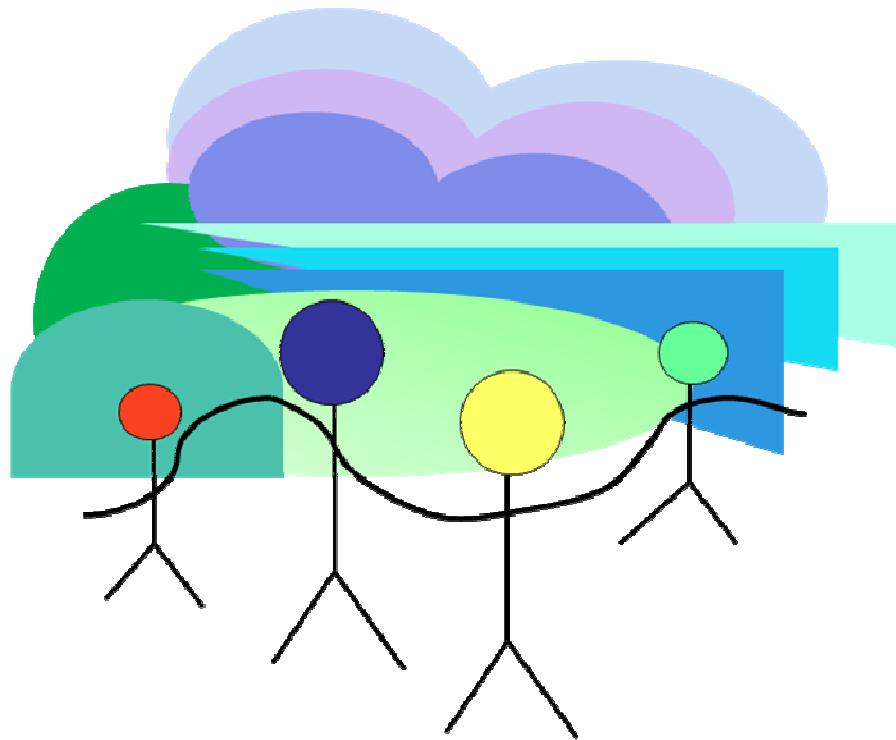




## **Evaluation Report: Lakeland Family Support Service**



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## Contents

	Executive Summary .....	3
1.	Introduction .....	5
2.	Service Overview .....	5
	Aims of the Lakeland Families Service.....	5
	Number of Families Participating .....	6
	Eligibility Criteria .....	6
	Family Service Model.....	6
	Service Staff .....	7
3.	Census .....	7
	Characteristics of the Families Using the Service.....	7
	Children using the Service: Profile .....	7
	Children’s Age Range .....	7
	Nature of Child’s Disability .....	8
	Service Leavers .....	9
	Siblings Profile .....	9
	Parent/Carer Profiles .....	10
	Family Structure.....	10
	Age of Carers.....	10
	Parental Education, Income & Employment Background .....	10
	Living Arrangements .....	11
	Deprivation Measures .....	11
4.	Support Networks .....	12
	Informal Supports.....	12
	Professional Supports.....	12
	Child’s Leisure & Recreational Opportunities .....	13
	Families Service Support Overview .....	14
	“Training for Women” Initiative .....	15
5.	Research and Evaluation Study .....	15
	Methodology .....	15
6.	Findings .....	16
	Social Lives of Carers .....	16
	Statistical Analysis .....	17
	Qualitative Responses .....	17
	Benefits for the Child.....	18
	Benefits for the Parents.....	19
7.	Improvements to the Service .....	20
	Parent’s ‘Wish List’ for the Service .....	21
8.	Social Matrix Model – Service Costs .....	21
9.	Conclusion .....	22
	References .....	23
	Appendix I: Research Study Questionnaires.....	24
	Appendix II: ‘Family Portraits’ – The Lives of Primary Carers.....	25

**Special thanks to Professor Roy McConkey for his help in the drafting of this report.**

## Executive Summary

This report presents the findings from an evaluation of the Lakeland Family Support Service which is delivered by Positive Futures. Positive Futures is a local charity which specialises in supporting children and adults with a learning disability. The Lakeland Families Service aims to provide support services to 37 families who have a child with a significant learning disability in Fermanagh. The Service began in 2003 and is funded in partnership with the Western Health and Social Care Trust.

The report provides a detailed overview of the types of families and children accessing the Service. It presents a wide variety of everyday challenges that parents as carers face with regard to emotional, practical and financial needs. Some of these are highlighted below:

- One third (34%) of the Service families have a least 4 children living at home.
- Over a quarter (27%) of families are caring as lone parents. Two of the lone parents are caring for 5 children in the family home.
- Nearly half (46%) of the Service children have at least two additional impairments or medical conditions in addition to the learning disability.
- 11% of families also have more than one disabled child.
- The area covered by the Lakeland Service is the most deprived of the 3 Positive Futures Families Services in Northern Ireland, according to the average NINIS Multiple Deprivation Measures. Many families have limited access to services because of their rural location.
- Over a quarter (27%) of families have no wage earner in the family.
- Nearly half (48%) of families live on the poverty line (on low incomes <£16,000 per annum).
- The majority (54%) of primary carers left school with O-levels or GCSEs as their highest qualification.
- Each family has on average 8 professional contacts (e.g. allied health professionals), but only 2 informal supports (e.g. friends, neighbours, extended family) in their lives. This illustrates that they are caring for children with significant needs, but have few day-to-day supports to help them cope emotionally and practically.

The report also discusses the impact of the Service on the lives of these families. Prior to involvement with the Families Service, each child had few social outlets outside of school. Since the majority of families live in rural, isolated locations, this meant that mixing with other children or participating in activities was difficult. Before their child joined the Service, each child participated in approximately 1.5 recreational activities. At that time, 24% of children were not involved in any activities outside of school. Since joining the Families Service, children now avail of approximately 3.3 activities.

In order to ascertain the impact and efficacy of the Service, parent's views were obtained using semi-structured interviews and questionnaires. These were conducted by

a Researcher with 17 parent carers. Although there were no significant changes, responses show that carers are extremely stressed, exhausted and these factors have often impacted on the way the families function together as a unit.

Findings overwhelmingly indicate that there were positive reactions by families about the Service. Many parents referred to the project as a 'lifeline', or a 'blessing' saying that they would be 'completely lost' and 'unable to cope without it'.

The Service has opened up a wealth of experiences and opportunities for the children. Whether doing activities as a team with non-disabled peers, being creative through art and crafts, individualised homework or one-to one support, service staff place the child's needs at the centre of everything. Several key themes emphasised by parents included the person-centred ethos of the service and enhanced quality of life. Parents also claimed that their child's interpersonal skills had increased, their social networks had broadened, and that they had achieved new milestones. The Service has also promoted family cohesion and togetherness. For example, it enables families to go swimming together, provides support to siblings and a 'Training for Women' Initiative to help women carers gain important work-based skills.

The Service also supports carers by giving them time-out from the demands of caring. Carers could focus more on quality time with their other family members or catch-up on practical tasks. Many parents stated that the Family Workers gave vital emotional support, practical advice and help with form-filling. Family Workers, Support Workers and volunteers were seen as reliable people who worked seamlessly together as a team.

Several parents also expressed concerns about the future for their child. Seven children will be due to leave the Service over the coming year because they will turn 19. Many parents are extremely anxious about the future as the Service supports will end for their family. Initiatives such as Buddy Mentor Schemes would be a good way for their teenage child to have continued experiences that could be carried on into later life.

Nevertheless, a number of other challenges still remain for the Service and these families in the Lakeland area. Parent consensus strongly voiced a desire for more resource allocation to supplement additional activities, staff and volunteers. The logistics of getting to and from activities in rural Fermanagh can be difficult. The majority of parents, despite their own constraints, would be willing to contribute to the Service either financially or practically through volunteering.

In sum, this report acts as an evidence-base to show the value of the Lakeland Families Service and the unique needs of the people it serves. Parents expressed strong wishes for the Service to continue and develop in the future. It is hoped that this report describes the Service as an exemplar in terms of best practice for future service provision.

## **Introduction**

Literature has frequently highlighted that families who have a child with a learning disability are at increased risk of experiencing stress (see Feldman *et al.*, 2002). Stressors occur at different times and can be triggered by a variety of factors. For example, families may experience both a lack of social support and fewer opportunities for respite breaks because of the demands of their caring role; they may have to manage challenging behaviour, or, they may live in poverty as a result of the financial burden associated with being a carer. Such factors impact on a family's ability to cope and adapt to everyday life, their relationships with each other, and the sense of family cohesion. In order to facilitate better coping mechanisms, parents and siblings who have a family member with a learning disability require effective support networks and regular respite breaks.

Positive Futures Families Services support over 120 families across Northern Ireland. These are located in Bangor, Lisburn and Lakeland. Positive Futures recently evaluated their Family Support Services in Lisburn (Truesdale-Kennedy *et al.*, 2006) and Bangor (Black & Roberts, 2007). These evaluations described the services delivered and the impact that they had on families. The findings demonstrated that these services provided by Positive Futures were mutually beneficial to the parents and their children. Many families reported that they simply did not know how they would cope without these services.

## **1. Service Overview**

This report provides an overview of the Lakeland Families Service. The Lakeland Service is currently provided by Positive Futures in partnership with the Western Health & Social Care Trust in south east Fermanagh. It began in 2003 and was originally part-funded by the Department of Health, Social Services and Public Safety. Like its sister services, it is based upon a person-centred approach which offers *holistic* support services to families who have a child with a learning disability.

### **Aims of the Lakeland Families Service**

The three core aims of the Service are:

- i. to support children and young people who have a learning disability to become more involved in their local community and to lead fuller and more valued lives.
- ii. to support families with their unique and individual needs, using person-centred tools.
- iii. to adopt a Community Development Approach in local areas to raise awareness and meet the needs of young people who have a learning disability.

## Number of Families Participating

In January 2008 there were **37** families being supported by the Service. **25** of these families were receiving a full service, while an additional **12** children were accessing the 'Lakers' Project. This is provided in partnership with Autism NI, Mencap and the Share Centre, and is funded by Oak Housing. Children accessing the Lakers Project are able to avail of some of the activities and after schools clubs that the Families Service provides.

## Eligibility Criteria

The Eligibility criteria for the Lakeland Family Support Service are as follows:

- Child must be aged between 8-19 years
- Child must have a "significant" learning disability or be severely impaired by social or adaptive functioning, and they must be listed on the WHSCT Register.
- Family must reside in the South East Fermanagh area.

## Family Service Model

The Lakeland Families Service is an innovative family model of family support service which is presented in Figure 1 below.

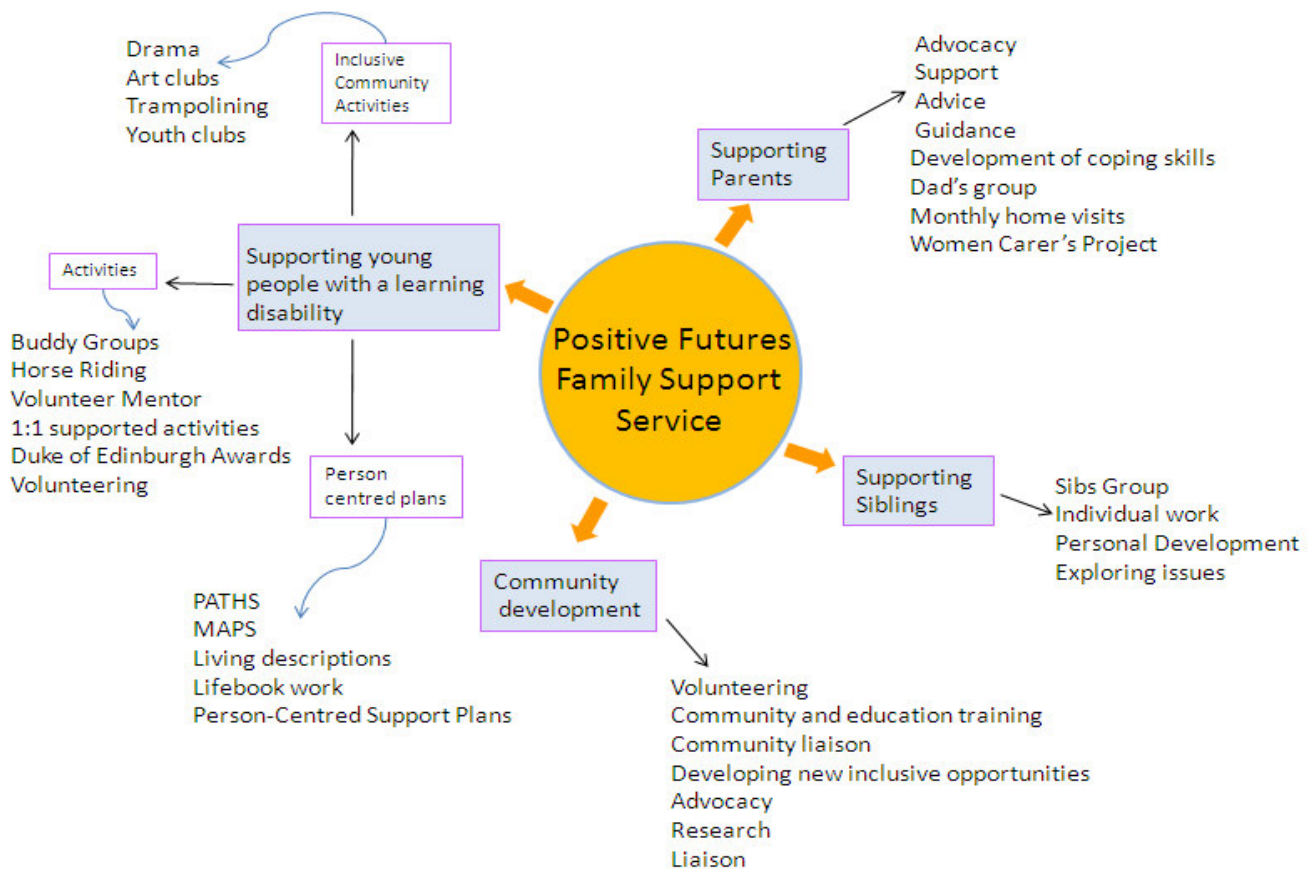


Figure 1. Positive Futures Families Model

Key elements of the model include:

- Person Centred Planning
- Family support, including practical and emotional support, information, advice and regular monthly contact
- Support to attend mainstream community groups (youth clubs, churches, community groups)
- After school activities, homework support
- Easter, Summer and Christmas holiday schemes
- Targeted groups: Siblings group, Dads group, Advocacy group.
- Themed parties: summer BBQ, Halloween, Christmas.
- Co-ordination of support staff and volunteers

## **Service Staff**

At present, the Service is managed by a Service Manager (18.3/4 hpw) and there are 2 Family Workers (37.5 and 18.3/4hpw). There are also 21 Sessional Support staff (22.5hpw) employed to help with activities. Five volunteers have been recruited and trained to support the children in a variety of situations. In addition, the service currently has one Trainee Social Worker and one student Social Worker.

## **2. Census**

### **Characteristics of the Families Using the Service**

This section provides a brief overview of the 37 families involved in the Lakeland Families Service. All children and families in the Service are from a white ethnic origin. Census data for the Service has been collected for each of the families via a standardised proforma. This has been completed by the child's primary carer together with the Lakeland Service Family Worker and/or a Researcher from Positive Futures.

### **Children using the Service: Profile**

Every child lives with at least one natural parent. 34 children (91.8%) have a significant learning disability. The 3 children who do not, are currently registered with the *Lakers* Project. N=34 children (91.9%) have a statement of Special Educational Needs. 29 (78.4%) children attend Special Schools while 8 (21.6%) attend mainstream schools. Children attend a total of ten different schools in the Fermanagh region.

### **Children's Age Range**

The children's ages range from 6 to 18 years. The average age is 12. When divided into 2 groups (teens and pre-teens), the majority N=25 (67%) of children are aged 12 or under.

## Nature of Child's Disability

The most common type of condition recorded is an Autistic spectrum disorder (N=16:43.2%), followed by Down's syndrome (N=11; 29.7%). As can be seen in Table 1, Autistic spectrum disorders is far more prevalent in males than in females. Examples of disabilities in the category labelled 'other' include: undifferentiated learning disability (N=3), brain injury at birth (N=1), and Fragile X syndrome (N=1).

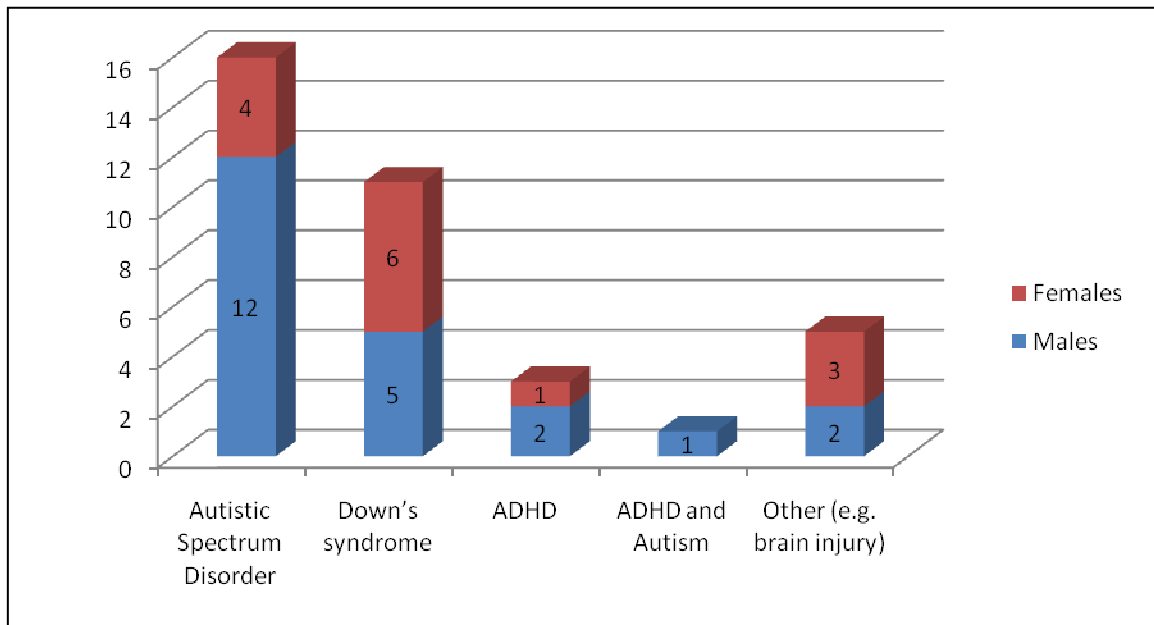


Figure 2. Types of disability by gender

A number of the children (N=12; 32.4%) also have other impairments and medical conditions in addition to their learning disability. These include epilepsy (N=5), asthma (N=2) and less common medical conditions, such as neurofibromatosis (N=1). Children also have a number of disabling conditions which are categorised in Table 1.

Condition	Yes	No
Physical disability	5 (13.5%)	32 (86.5%)
Behavioural problems	17 (45.9%)	20 (54.1%)
Visual impairment	7 (18.9%)	30 (81.1%)
Hearing impairment	5 (13.5%)	32 (86.5%)
Medical problem	12 (32.4%)	25 (67.6%)
Other	4 (10.8%)	33 (89.1%)

Table 1. Additional disabling conditions of children in the Lakeland Families Service

When considering the additional conditions and impairments, 7 children (18.9%) do not have any additional conditions. However, 13 children have one, 13 children have 2, and three children have 3 additional conditions. One child has four disabling conditions and



also uses a wheelchair. These figures are outlined in Figure 3. This demonstrates that the majority of families in this Service are coping on a daily basis with a child with a variety of complex needs.

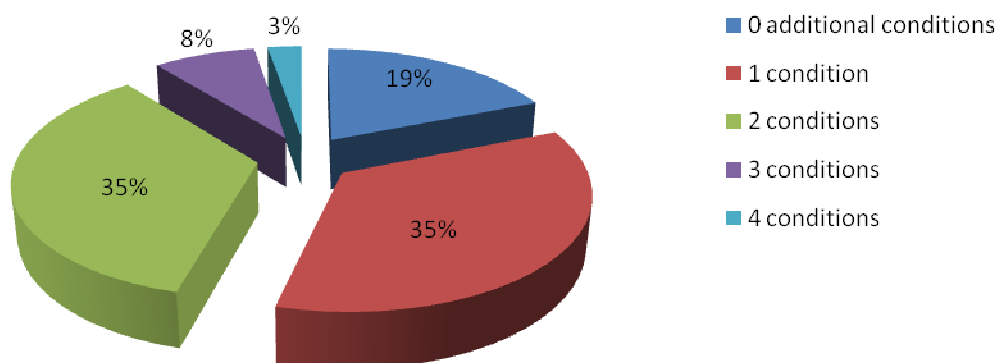


Figure 3 Percentage of Service children with additional disabling conditions

Most children (N=28; 75.7%) have speech, however, 7 (18.9%) children have no speech, and 2 children (5.4%) have very limited speech. The mothers with a child without speech reported that this was a huge barrier to their ability to cope. In particular, mothers explained how difficult it was to determine their child's likes or dislikes, and whether or not their child was in pain. Although some of the children used assistive technology or gestures to communicate their needs, others were completely unable to communicate in any recognisable way.

### Service Leavers

There are 7 children who will soon be no longer able to access the Lakeland Service as they will become 19 years of age within the next 12 months. This was a concern for these families and many mothers when interviewed admitted that they are 'trying not to think about it'. Many felt anxious about their child's future, as in many instances, the Service has been a lifeline for the families involved.

### Siblings Profile

The majority of families (54%) have either 2 or 3 children living at home. However, some families are larger. Six families (16.2%) have 5 children living at home (including the disabled child). Another six families (16.2%) have 4 children living at home. Five families (13.5%) have only one child living at home.

Three families (8.1%) have twins. In one of these families, one twin has a learning disability and in the other two other families, both twins have a learning disability.

Two families (5.4%) also have additional child in their family with a serious chronic illness. In 9 (24.3%) families the child with the learning disability is the eldest child. In fourteen families (37.8%) this child is the youngest.

## Parent/Carer Profiles

A variety of descriptive and demographic information regarding the child's carers is outlined below.

### Family Structure

With regard to the family structure, 10 families (27%) are 1 parent families, and N=27 (73%) are two parent families. Of the ten families who are lone parents, 1 mother is a widow. In the majority of instances (N=36: 97.3%) the mother is the primary carer. However, in one family both of the parents share the primary carer responsibility.

### Age of Carers

The ages of the primary carer and spouses are as follows:

Age range	Primary carer	Partner/Spouse
Under 30	2 (5.4%)	0
30-39	15 (40.5%)	7 (18.9%)
40-49	17 (45.9%)	16 (43.2%)
50-59	3 (8.1%)	6 (16.2%)
60+	0	1 (2.7%)

Table 2. Age range of the child's primary carer and their spouse.

As can be seen from Table 2, most of the children's carers are in the 40-49 age range. There are very few carers under the age of 30 (N=2) and only one person (a spouse) is over 60 years of age.

### Parental Education, Income & Employment Background

The educational background of the primary carer and their spouse is documented in Table 3. From this, we can see that both the majority of primary carers and their spouse/partner's highest educational attainment is either GCSEs or that they left school at 16. Although the data suggests that more primary carers (N=14: 37.8%) have achieved a higher number of third level qualifications than that of their spouse or partner (N=8; 18.9), this is difficult to ascertain because there are 9 missing values for the spouse/partner. In these instances the mother is a lone parent and the spouse/partners details were not recorded. In five lone parent families, the mother has acquired a third level qualification.

<b>Educational background description</b>	<b>Primary carers highest educational attainment</b>	<b>Spouse/partner highest educational attainment</b>
Left school at 16 or with GCSEs	20 (54%)	21 (56.7%)
A-levels	3 (8.1%)	0
Third level qualification	14 (37.8%)	8 (18.9%)
Not applicable/ missing	0	9 (24.3%)
<b>Total</b>	<b>37</b>	<b>37</b>

Table 3. Educational background of the primary carer and spouse/partner

When asked about family income, 19 families (51.4%) reported an income above £16,000 per annum, whilst 18 families (48.6%) reported an income of less than £16,000 per annum. This suggests that day-to-day life and providing for the family might be rather difficult, especially since several families using the Service are relatively large (12 families (32.4%) have more than 4 children at home). These findings are in line with previous research that indicates that families with a child with a learning disability are more likely to live in poverty (Emerson, 2003).

In 27 families (73%) there is a wage earner in the family and in nearly one third of families (N=12; 32.4%) the mother is employed. Of these, 8 mothers are employed part-time and 4 are employed in full-time work. Their job roles range include secretarial, crèche and classroom assistants, to nursing jobs.

### **Living Arrangements**

In terms of living arrangements, N=27 families (73%) own their own home, while N=10 (27%) families do not. Five families (13.5%) live in privately rented accommodation and five families (13.5%) are living in housing executive accommodation. Interestingly, and perhaps because of the rural location of many families, most N=24 (64.8%) live in detached accommodation. Two families (5.4%) have at least one of their own parents or in-laws living with them. The average length of time that families have been living in their present accommodation is approximately 13.5 years (minimum 1: maximum 29).

### **Deprivation Measures**

Out of the three regions served by Positive Futures Families Services, the Lakeland area has the highest levels of social deprivation regarding aspects such as access to services and child poverty. The average rank of the multiple deprivation measure (MDM)<sup>1</sup> in Lakeland for the families concerned is 362 (min 158; max 691). This is a much lower figure when compared to the average overall MDM rank for Bangor (659) and Lisburn (568) families. The MDM scale ranges from 1 (most deprived area) to 890

<sup>1</sup> This figure has been calculated via the NINIS Social Deprivation indices using each family's postcode. These postcodes are assigned to geographical 'wards' of the families involved in the Service.

(least deprived area) and accounts for all wards in Northern Ireland. As much of the Lakeland area is rural, this impedes the transport of children to activities as getting to and from venues can take far greater time as the transport infrastructure is more limited when compared to other parts of the province. For example, a number of families using the Lakeland Service have children that require medical attention and some of these families are making at least one weekly commute to either Belfast or L'Derry to access hospital facilities.

### 3. Support Networks

Supports networks for families who have a child with a learning disability are vitally important. Parents were asked about the contacts they had had with a number of both formal and informal support networks over the past 12 months. The findings demonstrate that these supports varied and depended upon factors such as the number of children and parents in the family, where they lived, and the seriousness of the child's disability.

#### Informal Supports

The informal supports most families received were from immediate and extended family. Apart from immediate family members, on average, carers only received support from 2 outside sources from the list presented in Table 4. Very few families receive either practical or emotional support from either their neighbours, other families with a disabled child, or child minders. N=22 families (59.4%) do not have relatives living nearby, nevertheless, only N=15 (40.5%) families have relatives living nearby, so for them, relying on the support of relatives is limited. Again many families are living in rural areas and are not in close proximity to their extended family.

Receiving support from:	Yes (%)	No (%)
Adults living in the household	30 (81.1%)	7 (18.9%)
Children living in the household	16 (43.2%)	21 (56.8%)
Grandparents	14 (37.8%)	23 (62.2%)
Other extended family	18 (48.6%)	19 (51.4%)
Friends living in the area	12 (32.4%)	25 (67.6%)
Friends not close by	11 (29.7%)	26 (70.3%)
Neighbours	10 (27%)	27 (73%)
Parent support group	15 (40.5%)	22 (59.5%)
Other families who have a similar child	10 (27%)	27 (73%)
Regular child minder	4 (10.8%)	33 (89.2%)

Table 4. Types of informal support received by the Service's parents

#### Professional Supports

Families were also asked about the number of professional supports they have been in contact with over the last 12 months. These are presented in Table 5.

<b>Professional</b>	<b>Number of families receiving this type of support</b>	<b>Families not receiving this support</b>
Teacher	37 (100%)	0
Dentist	35 (94.6%)	2 (5.4%)
Classroom Assistant	28 (75.7%)	9 (24.35)
Social Worker	33 (89.2%)	4 (10.8%)
GP	33 (89.2%)	4 (10.8%)
Speech & Language Therapist	22 (59.5%)	15 (40.5%)
Hospital/Community Doctor	14 (37.8%)	23 (62.2%)
Community Nurse	3 (8.1%)	34 (91.9%)
Behavioural Support Worker	5 (13.5%)	32 (86.5%)
Psychologist	10 (27%)	27 (73%)
Occupational Therapist	14 (37.8%)	23 (62.2%)
Physiotherapist	9 (24.3%)	28 (75.7%)
Overnight Respite Worker	6 (16.2%)	31 (83.8%)
Domiciliary Worker	6 (16.2%)	31 (83.8%)
Health Visitor	6 (16.2%)	31 (83.8%)
FE college tutor	1 (2.7%)	36 (97.3%)
Other	9 (24.3%)	28 (75.7%)

Table 5. Types of formal support received by the Service's parents

On average, most families had contact with 8 professional contacts (min 4; max 12). Seven families (18.9%; SD 2.3) are in touch with a hefty 11 or more professional contacts. This is most likely due to the complexity of their child's needs. These figures suggest that parents experience considerable demands in terms of managing appointments and maintaining communication between the various professionals involved with their child.

### **Child's Leisure & Recreational Opportunities**

Parents were also asked about leisure and recreational activities, or groups that their child attended, *before* they joined the Families Service. Out of the 8 possible activity types listed, on average, each child was involved in 1.5 activities outside of the school context (min 0; max 6). Some 9 children (24.3%) were not involved in any sort of activity outside of school. Sport and leisure activities (N=9) were the most popular leisure and recreational activities attended, whilst church group activities were attended by the least number (N=3). Summer schemes were mostly provided by the child's school, or by organisations such as Mencap or the Down Syndrome Association. The types of activities children participated in included Scouts, badminton, and football. Two children were involved in the local Youth Forum, and one child was in a member of a music band. A summary of these findings is detailed in Table 6.

<b>Organisation/group</b>	<b>No. of children involved</b>	<b>No. of children NOT involved</b>
Sport/Leisure Clubs	9 (24.3%)	28 (75.7%)
Summer Scheme	8 (21.6%)	29 (78.4%)
Uniformed Organisations	8 (21.6%)	29 (78.4%)
All Year Scheme	8 (21.6%)	29 (78.4%)
After Schools Club	5 (13.5%)	32 (86.4%)
Youth Group	4 (10.8%)	33 (89.2%)
Church Group	3 (8.1%)	34 (91.9%)
Any Other Activities	3 (8.1%)	34 (91.9%)

Table 6. Types of activities children attended before accessing the Service.

### **Families Service Support Overview**

The introduction of Family Support Service has given children and their families an number of opportunities to participate in activities, and be supported in a variety of ways. Below is a summary of the main types of support that families and children currently access through the Service.

<b>Type of Support</b>	<b>Number of children</b>
Holiday schemes, youth club, leisure activities and themed parties	N=32
After schools clubs	N=31
Monthly home visits	N=25
Volunteer project	N=7
Buddy group	N=6
Siblings group	N=8
Training for Women Initiative	N=6
1 to 1 support	N=5
Homework support	N=3

Table 7. Breakdown of current types of support provided by the Families Service

With the added benefits of being introduced to new faces and the chance to try out new things, these children are involved in more activities now than before they had joined the Service. By calculating the average number of activities per child, children using the Service are regularly participating in approximately 1.8 additional activities. Each child is also interacting and integrating with their community peers and their friends within the Service.

Families are also encouraged to participate in activities together. For example, this Service have been able to negotiate access for families to the Share Centre free of charge on a Saturday morning. All members of the family can have complimentary access to the steam room, the pool area and tea or coffee in the lounge afterwards.

This offers a worthwhile incentive for the whole family to be involved, and it also enables them to meet other Service families on a more social basis.

### **“Training for Women” Initiative**

In addition to the practical support and respite that the Service provides to parents and siblings, 6 mothers (16.2%) using the Lakeland Families Service are also involved in the Women Carer’s Project. This is a one year initiative funded by the Training for Women Network. The Project aims to enable women carers to develop confidence, interpersonal and work based-skills. The Project offers a number of courses, for example, personal development, stress management, accountancy and recreational classes, like salsa dancing. Person-centred plans for these carers have also been developed.

## **4. Research and Evaluation Study**

In addition to the census data, 17 out of the 25 families using the full Lakeland Families Support Service agreed to participate in a research and evaluation study of the Service and its impact on families. This is part of a larger 3 year study involving the 3 Positive Futures’ Families Support Services. This research is briefly presented here, and a full version of the research report is due for publication later in the year.

### **Methodology**

The first phase of the evaluation involved the administration of a series of standardised social science questionnaires about family life, the primary carers health, levels of stress, family functioning and the behaviours of the child (details of these can be found in Appendix I). This was completed initially by the Family Worker when the family first joined the Service (Times 1). Primary carers rated how they felt according to a number of possible responses on a Likert scale. These ranged from “strongly agree” to “strongly disagree”. A follow-up study (Times 2) was then completed by a Researcher<sup>2</sup> who administered the same questionnaires to the primary carer twelve months later. A comparison was able to be drawn about the quality of the carers life, and to assess any changes since they had joined the Service.

In addition to the quantitative information derived from the questionnaires, the Researcher also used a semi-structured questionnaire. This enabled parents to talk in more detail about their experiences of using the Service and to identify its strengths and weaknesses. It also allowed families to raise any issues that they did not like about the service and to suggest improvements. In addition, a ‘pen picture’ was completed on each family. These provide a valuable description of each family’s life at that particular time, and are based on the carer’s perspective. For illustrative purposes, three of these ‘family portraits’ have been anonymised and are presented in Appendix II.

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<sup>2</sup> The Researcher is not involved in the delivery of the Service.

## 5. Findings

The questionnaire was analysed using a statistical package so that comparisons could be made at Times 1 and Times 2.

### Social Lives of Carers

The Social Opportunities questionnaire relates to the social outlets of the primary carer. The questions ascertain how regularly the respondent participates in a number of recreational activities, for example, going to the gym, cinema, shopping with friends, or taking a college course. The primary carer was asked to rate their level of participation from a choice of four responses from 'weekly, monthly, occasionally, and never.'

The average number of responses from the first and second interviews shows that most primary carers rarely get the opportunity to do things on a regular basis (Figure 4).

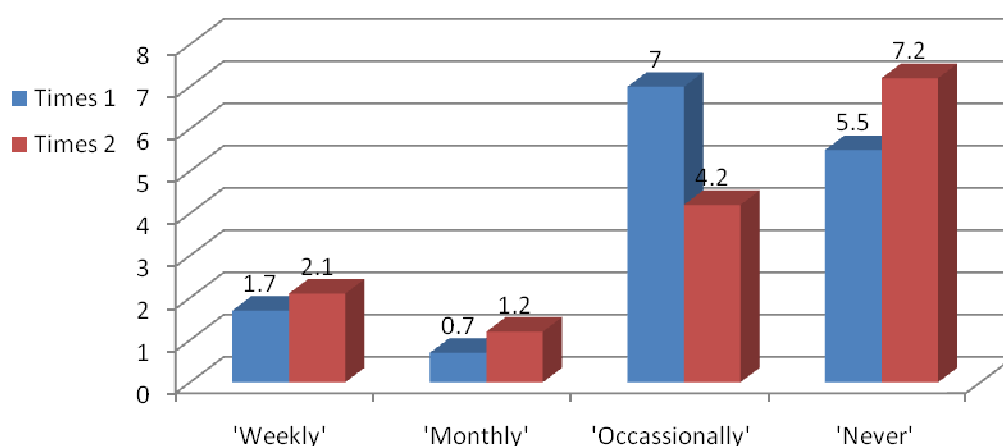


Figure 4. Social opportunities of Primary Carers at Times 1 and Times 2 intervals

Weekly and monthly social opportunities have increased between the first and second interviews. This may be because the project has freed up more time for the primary carer to do things they like when their child is at activities. However, the amount of time the carer 'never' gets to do things has also increased by the second interview. Overall, the results show that these primary carers would be deemed 'low socialisers', most likely because of the constraints of their caring role. Many mothers admitted that they were the last person they consider, as their efforts were focused on everyone else in the family. It would also be interesting to determine if the spouse or partner has as few social opportunities as the primary carer.

Three families also spoke poignantly of never being invited to functions (such as weddings, family get-togethers) because of the child's behaviour and lack of understanding by relatives. In families where children had more challenging



behaviours, things like going to church were done separately by the parents, so that both could attend.

In Parent Stress Index questionnaire the carer was asked about being able to enjoy themselves if they went to a party. The majority of carers responded “what party!” as it is such a rarity for them to be able to go out for an evening. What was even more striking was the lack of opportunity for parents to spend time together. It appeared to be more difficult for them have this type of break because they would need to get a child minder with the appropriate skills. Usually one parent had to be in the house (unless there was a sibling old enough to care for the other children) and this also seemed to impact on the sense of cohesion in the family.

### Statistical Analysis

Due to the small sample size, a non parametric test<sup>3</sup> was used to compare the results of all the questionnaires over the two time frames. Overall, there were no statistically significant differences in the families between the two time frames. This may be because of the small sample size and the relatively short period of time between the two interviews.

Nevertheless, two measures are nearing significance levels. These are for ‘parent/child dysfunctional interaction’ and for ‘difficult child’. These score averages at Times 2 suggest that mothers gave increased ratings for ‘dysfunctional interaction’ but lower ratings for ‘difficult child’. Although these are only trends, it is possible that the Service has reduced the stress experienced mothers by having additional help with their ‘difficult child’, although this did not help their stress levels when interacting with the child.

### Qualitative Responses

During the interviews with the 17 families, the Researcher asked the carer to name the types of activities that their child was involved in with the Service. These included therapeutic and creative activities like music, arts and crafts, and more physical activities such as basketball. In addition, a number of children have had the opportunity to participate in personal development and life saver courses and to obtain swimming badges. Many of the carers with an Autistic child noted the benefits that swimming had brought to the child. The main responses were categorised accordingly in Table 8.

Activity	Mentions
Swimming	9
After schools club/summer scheme	6
Basketball	6
One on One support	4
Arts and crafts	4
Day trips – e.g. Armagh Planetarium	4
Parties – Christmas, Halloween	4

<sup>3</sup> Wilcoxon Signed Ranks Test

Sibs groups	3
Football	3
Cinema/theatre	2
Personal development course	2
Homework support	2
Leisure centre/gym	2
Out for a drive	2
Drama	1
Athletics	1
Badminton	1
Rowing	1

Table 8. Activities children participated in

### Benefits for the Child

All parents interviewed were able to name ways in which the project had benefited their child. These are summarised in Table 9.

Benefits for child	Mentions
Socialising/friendships	6
Have fun	5
Gets the child out of the house	4
Learn new skills	3
Enjoyment	3
Provides structure	3
Meeting new people (that are not in same school or class)	3
Community integration/mixing with others	3
Relieves boredom	2
Therapeutic	2
Sense of achievement	2
Good exercise	2
Reduces aggression/hyperactivity	2
Improved communication skills	1

Table 9. Parents perceptions on how activities have helped child

*The person-centred planning approach the Service take is excellent because it's all about N. They [staff] listen and take the time with us. I just wouldn't be without them. All the family are so proud of what N has been able to achieve and her quality of life has greatly increased because of the opportunities and goals she has reached. They [staff] helped N with homework, were able to get her some part time work in a local shop. They also made her dreams come true when they arranged for her to meet her favourite pop band Westlife.*

*The Service lets N get out and about, and it gives him the opportunity to meet other people. He has made many new friends. He has done so much, like basketball,*

days away and arts and crafts. Its increased his confidence and independence no end. He has gone on to do things by himself that we thought he never would be able to.

Without knowing it, N is so vulnerable and unpredictable and I would worry about letting her anywhere. But with Positive Futures I know she is in a safe environment with well trained staff. I only wish there was more of it.

It gives N that vital structure that he needs in his life. It's like having a puppy in the house...relentless....a constant risk assessment, running after him. Positive Futures give him high energy things to do so that when he comes home, he is more relaxed and he sleeps better..therefore we all do.

He gets to be his own person and do things without us. He lights up when we even mention Positive Futures. We have seen great changes in his behaviour, its transformed him.

## Benefits for the Parents

Parents also discussed how the project had helped them.

Benefits for parents	Mentions
Respite/a break	11
Personal support from staff (emotional and practical)	8
Time to spend with other family members	5
Convenience	5
Reliable service	4
Knowing child is with trusted and vetted staff	4
Time to do daily chores/housework/shopping	4
Knowing its good for the child and seeing the personal rewards	3
Time for farm/business	2
Meeting other families	2
Not having to drive on the roads on the dark nights	1
Seeing improvements in child's behaviour/seeing them develop	2
Share problems – relieve the burden	1

Table 10. Benefits for the parents

*I've always had to fight for every bit of support. Now that I am on my own I sometimes just don't know how to cope. Positive Futures have taken a lot of the worry away and they have become my extended family. Nothing is too much for them.*

*[Staff] are brilliant, they are always there for me as an ear to listen. They check in with us regularly to see that we're doing OK. Recently they arranged for someone from Positive Futures to come out for an hour and help N with her homework. The service has given N a new lease of life and I wouldn't change a thing about it- it's fabulous. N's brother goes to the sibs group and to the basketball with his sister. He loves it and gets a lot from it...meeting new people too, other folk with and without learning disabilities. That's important because he knows that there are others in his situation and that he is not alone.*

*I have very little outside support. I had no support when N was under 10 and there are no other families with a child with Autism in this area. N has very few school friends and he was often left deliberately out of activities by other children. He lived in isolation. There was nothing I could do, I felt helpless. Positive Futures has changed us as a family for the better. Its the best thing that's happened to us. I just wish we could have had access to the service before the last 2 years.*

*We live so far out in the country, and it was always been stressful for me at my age driving the dark roads in the winter to take N anywhere. It benefits N to be involved in new things, meet new people and it enabled us to get to know other parents. If it wasn't for the Families Service at Positive Futures, N would be sitting at home bored. It gives me and her dad a break, and we know that she is in safe hands.*

*I know just how lucky we are to have all this support from the Families Service. There are lots of other families in the Kesh area that are desperate for the type of support we get.*

*What's great is the chances it gives to my son. My partner and daughter volunteer with the Service so it's a real family affair. I have peace of mind knowing that he's in safe hands. It also gives me quiet time in the house to catch up on the housework. Now and again I get time to get out for a walk and get my head showered.*

## **6. Improvements to the Service**

Of the 17 parents that were interviewed, N=15 (87%) were completely happy with the Service. All carers commented positively on the dedication and teamwork displayed by the staff.

However, one carer felt that the Service had become 'watered down' since her child was one of the first to join in the days when it was much smaller and more individualised. Another carer felt that many activity locations were inconvenient to where she lived.

*It would take me an hour to get my child to some activities and it just doesn't leave me with any spare time to get anything done.*

When asked what else could be done to improve the Service, the consensus seemed to indicate more funding to expand the service and thus more respite opportunities.

Suggestions for improvements included:

- More funding resources for the Service
- Increased respite opportunities
- Babysitting service especially during in summer months.
- Wider range of activities available in the summer
- Logistics of getting to activities; time and transport- more activities closer to home
- Increasing the length of time to do activities
- Parent group that meets regularly for coffee
- More one-to-one
- More volunteers

When asked about sustaining the Service, carers were happy to support the Service in ways they felt they could. Some families already actively volunteer in the Service, and several others (N=5; 29%) said they would like to volunteer if time permitted. N=11 (63.8%) of carers would be willing to make a financial contribution to the Service.

### **Parent's 'Wish List' for the Service**

Parents were also asked about other activities or interests that they felt would be a new experience that their child would like to try. Overwhelmingly, the majority of responses from parents echoed the view that the Lakeland Families Service had already achieved so much to help realise the needs and desires of their child. Nevertheless, some parents offered the following suggestions;

- Golf/driving range
- Line dancing
- Youth club
- Horse riding
- Computer games/IT training
- Visits or activities with farm animals
- More outdoor-based activities e.g. abseiling; canoeing
- More weekend opportunities
- Volunteer Buddy Mentors

Interestingly 4 parents of teenage disabled children (10.8%) felt that they would like a buddy mentor. This is someone that can take their child out on a regular basis who is independent from the family. Volunteer mentors play a vital role and help the child experience the same types of things that other young people like to do. One mentor recently accompanied one of the Service teenagers to her first formal.

## **7. Social Matrix Model – Service Costs**

Table 11 presents a method of analysing the practical outputs delivered by the service against the total cost. This model provides a detailed breakdown of the total number of hours delivered by the various elements of the service.

Type of Service Support	Total No. of hours per 4 weeks	% of total support	Hours per 4 weeks x 13 for the year	Average no. hours per family per 4 weeks
No. of individual and group activity support hours	204	35%	2658	8.5
No. of hours at family visit per month	36	6%	468	1.5
Follow-up: liaising with professionals & agencies	57	10%	747	2.4
Self help group hours - sibs and advocacy	45	8%	585	1.8
Self help group hours - parents	7	1%	91	0.2
No of holiday support hours	93	16%	1210	3.8
Hours for volunteer support (induction and training)	46	8%	598	1.9
Hours for community development	46	8%	598	1.9
No of hours of administration	44	8%	572	1.8
<b>TOTAL</b>	<b>579 hours</b>	<b>100%</b>	<b>7528</b>	<b>24.1</b>

Table 11. A breakdown of support hours delivered by the Lakeland Positive Futures

The cost of the Service in the financial year 2007/08 is £95,000 per annum. Using this model it is possible to determine an estimate of the cost of the outputs of the different elements of the Service delivered by hour (7528 per year) by dividing this by the total service cost. This model estimates the cost of the service at £12.67 per hour of activity provided. This model does not take account of the support that the service provided by volunteers and other non-staff.

## 8. Conclusion

This report highlights the value of the Lakeland Families Support Service and documents some of the challenges facing families who have a child with a learning disability in Fermanagh. It also provides details of the unique Families Service Model that has been adapted to each family's needs. Children in the Service have many conditions and multiple needs. Likewise, many of the families are dealing with very stressful circumstances such as poverty, lack of access to services, and few practical and emotional supports. Living in such rural, isolated locations is also difficult. The Families Service is mutually beneficial for children and their parents. It provides children with increased integrated social outlets and experiences. It benefits parents by giving them a break and timely support when they need it. Families were very appreciative towards the Service and many sang the praises of staff members and volunteers alike. They also acknowledged that they would like increased funding so that the project can be sustained. It is their hope that the Service develops so that their families have continued access to better life chances and opportunities, now and in the future.

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## Appendix I: Research Study Questionnaires

Questionnaire	Overview of questionnaire
Social Opportunities (Adapted from Sarason, <i>et al.</i> 1983)	Designed to rate how regularly the respondent is able to participate in recreational activities.
General Health Questionnaire (Goldberg & Williams, 1991)	Asks the respondent a variety of questions about the state of their health.
Family Functioning (Epstein, Baldwin & Bishop, 1983)	Used to assess how well the family interact and get along with each other.
Parent Satisfaction Questionnaire	Ascertains how much the respondent enjoys bringing up their child.
Parenting Stress Index (Crnic, Friedrich, & Greenberg, (1983).	Delineates how stressed the parent is according to a range of questions about the behaviour of their child.
Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984)	Quantifies the adaptive behaviours and development of the child according to their actual age.
Aberrant Behaviour Checklist; "ABC" (Aman & Singh, 1986)	Scales more complex behaviours of the child.



## Appendix II: 'Family Portraits' – The Lives of Primary Carers

### Family A, Lakeland.

Mrs A lives in a rural bungalow in County Fermanagh. Mrs A has 5 children aged 21,17,15,13,and 11; 4 boys and one girl. Her youngest child, Jack has profound and multiple learning disabilities. He is double incontinent, cannot walk or talk, and communication with him is very limited. He has to be fed a special carb-free diet. He take fits and requires constant attention. He also has very poor sight and hearing. When I asked Mrs A if Jack would know her if she came into the room, she said that she would have to be close to him, and that he might recognise her perfume. She feels that it's really difficult as his mother to know what he likes or dislikes because he cannot verbalise it. "For me it's heartbreaking", she said.

In addition, Mrs A and her husband have been travelling every week to Belfast. Her husband has bowel cancer and is receiving his treatment there. Mrs A has to go with the him in case something happens with his Colostomy bag on the journey. Getting the household up and out in the morning, in between caring for Jack, and her sick husband, is truly hectic for Mrs A. Family A also have a number of cattle and sheep which Mrs A works on during the day whilst the children are at school. Much of the work she does is manual, lifting hay and so forth. She feels that this is an additional responsibility and very time consuming, but it also acts as a coping mechanism for her. She realises she is the only one fit to do it. When they can, her sons drive the tractor for her, but she knows she will have to learn to do this in the near future, as they will grow up and lead their own lives. Mrs A feels that the other children in the family are very accepting of the fact that they do not receive as much attention as Jack.

In terms of her own social support networks, Mrs A has virtually no back up; her brother has leukaemia and cannot help. Mrs A gets very little time for herself, nor much sleep. She has attended massage and aromatherapy classes at the local college and sees this as a time to "get a break and to have an outside interest on other things". She feels that what she has learnt at the courses will be of benefit to Jack to help him with his conditions.

Jack has been with Positive Futures for almost 3 years now. He regularly goes swimming. Mrs A says that he loves this and that it is very therapeutic for him. He needs a lot of one-to-one support. Staff from Positive Futures have come to the house on numerous occasions and sat with Jack if Mrs A and her husband are late getting back from hospital appointments, or if Jack is off school on appointment days. She feels that Positive Futures staff will go "completely out of their way to help. I 'can't sing their praises enough, they are a lifeline. I would be really stuck without their support." Mrs A thinks that staff have also been excellent at giving her advice on a personal level. "All the volunteers and Family Workers are wonderful. Recently Social Services could not give me any first aid advice for Jack. When Positive Futures heard about this, they were able to bring me to one of their own training courses for first aid. They have been a rock for me."

## Family B, Lakeland.

Mrs B has recently separated from her husband. She has 5 children aged 19,18,17, 14 and 11. Mark is the second eldest, and he is her only son. Mark has behavioural problems. He can be noisy, restless and sometimes aggressive. He has also shown evidence of having bowel problems, although he is fully toilet trained.

Mrs B feels very alone. With the recent break-up of her marriage she is finding it difficult to cope. Mrs B has a busy job in a nursery- "life's busy!" she exclaimed. She feels her work keeps her sane, gives her focus and purpose outside of the home life. She feels the work is very rewarding. Her faith has also been an important element in helping her to cope. None of Mrs B's family live anywhere nearby and she would rarely go out socially.

Regarding Positive Futures, Mark goes to Athletics on a Tuesday. Mrs B feels that the staff are very good at getting Mark out of the house as he may complain on the way to an activity that he does not want to go. He always ends up having lots of fun and he likes the routine. He especially loves the sports, particularly the swimming. He has also attended a Personal Care course with Positive Futures. Mrs B proudly commented about Positive Future's summer scheme when last year Mark went sailing. "He's very strong and he really took to it. They did a fabulous job working with him. He was really good at the rowing and he had a real sense of achievement having been given that opportunity."

Mrs B thinks that the Positive Futures staff are simply fantastic. She described them as "wonderful, my life-savers". She explained that they have recently formed a buddy group in Positive Futures. She also mentioned that for Mark's 18<sup>th</sup> birthday, 2 support workers arranged a party for Mark. For this, they brought 5 supported people and Mark to the park. Afterwards they went for a celebratory meal and the cinema. "It was great to see everyone together, they had a ball". The Service also enables the children to take trips of interest; recently Mrs A reported that Mark went to the Armagh Planetarium. She feels that the Service gives Mark opportunities that his mother simply cannot give to him. When asked what else Positive Futures could provide for her family, Mrs B suggested taking Mark to a driving range to try golf.

Mrs B has also opted for Direct Payments which she says has been super in giving her the freedom to choose times for support. "It's flexible and because Positive Futures Staff are involved and familiar to Mark and vice versa... it's a weight off my mind. I trust them and they know Mark". This time is important to her for doing chores and getting the shopping "living in the country is difficult and not everything is on the doorstep". Her other daughters are very good with Mark too and will also babysit him. They have been involved in a sibs group which has helped them to understand their own situation, and given them the chance to meet other young people in similar circumstances. Mrs B hopes that in the future Mark will not go to Day Care Services. "He has many skills and talents and is very good on the computer. I would love him to be able to get a part-time job in computers in supported employment."

## Family C, Lakeland.

I interviewed Mr and Mrs C in the Royal Victoria Hospital for sick children in Belfast. They have 3 children, Jacob (11), Jenny (8) and David (4). David, their youngest child, was diagnosed last year with leukaemia and the family have been accompanying him to hospital for follow-up chemotherapy treatments. They travel from Fermanagh to Belfast at least twice a week for this. David has had major surgery and they will be attending the hospital for the next 2 years. At one stage they were at the hospital so often, that they were even given a bed there. They are well known by all the hospital staff.

In addition to David, Jacob, Mr and Mrs C's eldest child, was brain damaged at birth. In the past he would take up to 15 seizures per day. Jacob takes 12 medication tablets per day. He is also partially blind in one eye. Mrs C used to work as a nurse, but had to give up her career to care for her children. In the early days, no-one in the house got any sleep at all. "The body just gets used to it," Mr C explained. We thought the exhaustion and despair would never end. When Jacob was born we were basically sent home and told that our son would be a vegetable, he would never walk and never talk. We were told to love him and do our best for him. It was agony." Despite the odds, Jacob attended the British Institute for Brain Injured Children (BIBIC) in Somerset. Slowly, he began to make improvements and today he can walk, talk, and play sports. He has achieved far more than his parents ever imagined.

Nevertheless caring for a learning disabled child and another with leukaemia has been exhausting. "We never get to spend any quality time together. There just aren't enough hours in the day and the shops aren't open at 2am." The older 2 children also have to be stripped of their clothes and put on a disinfectant coating when they come in from school to protect the youngest child, David from potential risks of infection from other two children because they may have picked up germs at school.

Mrs C copes by taking a couple of walks each day. Financially life is quite a strain too. Mr C used to drive a fork lift vehicle, but he had also been involved in a serious car accident involving a drunk driver, that ended up in a wheelchair for 6 months. Mrs C also had a tumour removed from her throat in 2002, so life has certainly dealt them many challenges. Despite them both having large extended families, they receive very little support from them. "Except for my [Mrs C's] sister; people don't understand or know how to deal with us". They feel that their own relatives "would never phone or call by... it's very much 'that's your own problem'".

Positive Futures have been a "blessing" for the C Family. Jacob's behaviour has really improved. The support they offer has meant that Jacob goes on day trips, swimming, and attends art and craft classes. Positive Futures have given him "an increased sense of confidence, and the ability for independence- to go and do things without the rest of us." When asked if there was anything else Positive Futures could do for Jacob they replied "it would be great for him, at his age, to have a male buddy for him to take on walks, or to football matches, even if it was just once a month. When Jacob is with disabled children like himself all day, his behaviour mimics them because that is what

he knows. But when you integrate Jacob with mainstream people, his behaviour improves dramatically. We would love more mainstream activities for him. We cannot complain about the Service at all but that would be an added bonus for us.” Regarding other aspects of the service, Mr C commented that family worker visit is useful and keeps them informed, “they lend an ear when we need it. They have been the only organisation to care about us.”

Despite everything they have been through, the C family were completely open and very calm people, even though they have multiple stressors in their lives. “We do go to church – it has been very supportive our lives. We aren’t religious people, but our faith has increased with everything we have been through. It is things like Positive Futures that we are most thankful for.”