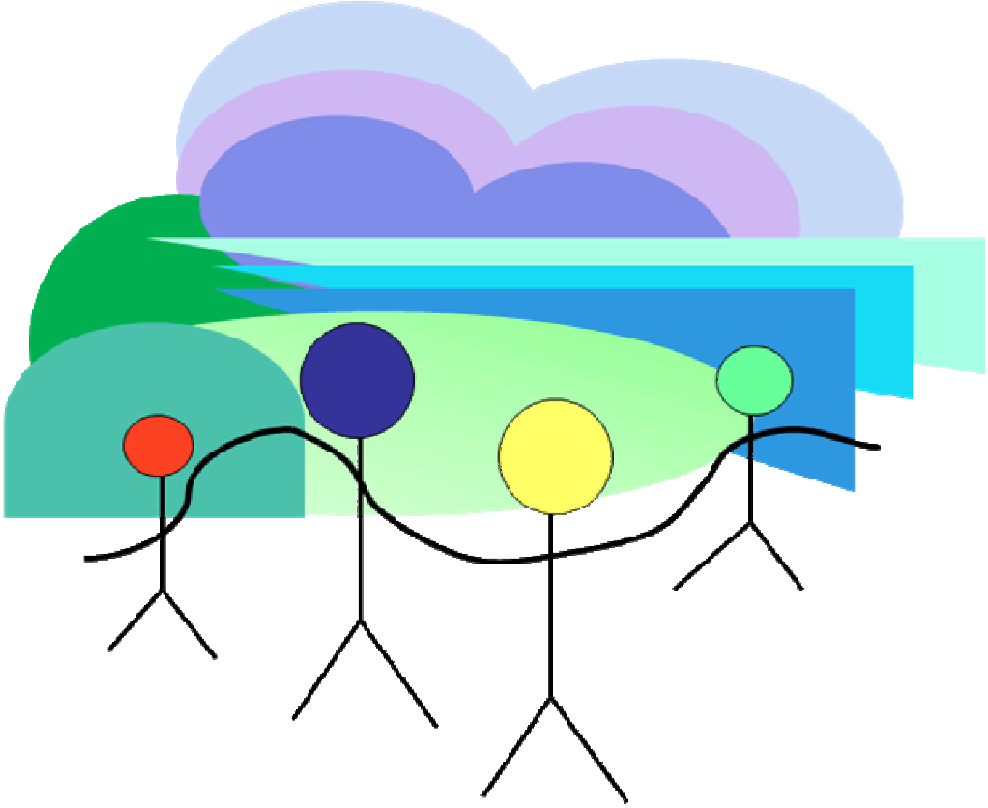
"LifeLines"

An Evaluation Report of the Impact of the Families Services delivered by Positive Futures in Rural and Urban Areas of Northern Ireland.



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8th October 2008

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Acknowledgements

Warm thanks to all those that helped in making this report possible. In particular, thanks to all the parents and stakeholders who were so willing to share their stories and views about the Service.

Further information on the findings of the Report are available online at: http://www.positive-futures.net/publications.asp

Executive Summary

There are at least 9,000 children with a learning disability who are known to statutory services in Northern Ireland. Research has demonstrated that families who care for a child with a learning disability are under considerable stress. Therefore, family-centred approaches to service delivery which focus on the needs of the child and the whole family are widely endorsed.

This Executive Summary provides an overview of the findings from an evaluation of Positive Futures' Families Services. Positive Futures has been providing support services to children with a learning disability and their families since 1999. The evaluation was conducted over a 3 year timeframe (2005-2008) across 3 service locations, namely Bangor, County Down; Lisburn, County Antrim; and "Lakeland", south east County Fermanagh. Comparisons could thus be made between rural and urban areas.

The Families Service is delivered using an innovative model which offers children and young people with a learning disability opportunities to realise their aspirations and to lead full and valued lives. Tailored programmes offer regular social and leisure opportunities and provide each child with the opportunity to make new friends. They enable the child to be included in the community and to participate in activities that increase their sense of worth, and their mental and physical well-being.

The model also offers families much needed respite, emotional and practical support from dedicated Family Workers, and specific group projects such as Siblings Groups. In addition, partnership working with statutory organisations, community and voluntary groups has enabled a variety of successful initiatives to be developed to better meet the families' needs.

The purpose of the evaluation was to assess the efficacy of the Families Service Model and to report the impact and outcomes that it has on the lived experiences of families. The *Lifelines* evaluation report contains 3 elements. Firstly, a profile of the families gathered through a census exercise. This is followed by the results of a longitudinal research study investigating the impact of the Service on the carer's well-being and their opinions about their experience using the Service. Finally, the views and experiences of key stakeholders including volunteers, staff, social and community workers and children with a learning disability are reported.

The census data provides essential demographic and socio-economic information about 104 families who access the Families Services. It highlights the emotional, practical and financial hardships and the type of support these families receive. Key findings reveal that:

- Nearly one quarter of families are coping as lone parents and have children with multiple needs. One fifth of families also have more than one disabled child, are caring for older disabled parents or in-laws, or are themselves ill or disabled in some way. 60% of carers are over 40 years of age.

- 82% of children with a learning disability accessing the Service attend special schools. Most have a least three additional medical or physical conditions and some of these needs are very complex. One third of the children have a physical disability. A similar number exhibit challenging behaviours. Many have specialised dietary and medical needs. 20% of children using the Service cannot communicate using speech. 45% of the children have an Autistic Spectrum Disorder.

- Half of all the families live in relative poverty. Many find it difficult to ‘make ends meet’, particularly larger families, since one quarter of those on low incomes have at least 4 children living in the family home. The same is true for the high number of lone parents. The Service in south east Fermanagh (the Lakeland Service) has the greatest number of families living on low incomes. Using the Multiple Deprivation Measure index, the Lakeland Service has higher levels of social deprivation in terms of access to services and child poverty than its urban sister Services. This Service also has the highest number of families with no reported wage earner.

- Of those primary carers that are employed, the majority are in low paid “tertiary” sector roles. Many others are unable to work because of their child’s needs. One third of carers left school with no formal qualifications.

- Families receive low levels of informal support. Support mainly comes from members of their immediate family. 65% of carers receive no support from friends and only 27% receive support from neighbours.

Moreover, families whose child has multiple needs have even lower levels of informal support. Those supported by the rural based Lakeland Service were particularly isolated in terms of their informal support networks. Families across the three Services received high levels of support from Allied Health Professionals indicating that the needs of the child were high.

- Prior to receiving support from Positive Futures, children were involved in few activities and had little opportunity to integrate with non-disabled children or the wider community. With the introduction of the Service, a number of opportunities to participate were made available to children e.g. holiday schemes, after schools clubs, and weekly activities. These activities are facilitated by paid staff and volunteers. On average, the children's levels of social activity increased from virtually zero to 2.5 activities per week, and in many cases exceed that of their siblings.

- The Services support children in a wide range of ways including sporting activities such as swimming, horse riding and football. In conjunction with local schools, a variety of recreational after-schools projects are available including computer skills, cookery and arts and crafts. Partnerships provide opportunities for the children to be included in local youth clubs. Children in Bangor and Lisburn have also participated in a number of courses and theatre productions in association with the KIC Drama Project. Buddy groups enable the children to choose their own programme of activities, such as going to an ice hockey match or out for a meal. Team-building and social and life skills are also developed through the Duke of Edinburgh Scheme and other courses such as First Aid.

The report also documents the results of a longitudinal research study designed to assess the impact of the Service and any positive outcomes this may have had for 48 of the carers. Carers completed a number of initial questionnaires and were re-interviewed 12 months later to enable comparisons to be made. In total, over 800 questionnaires were completed. The main findings were as follows:

- In general, carers health was poor. Nearly half reported that they felt “run down and constantly under strain”. Many felt exhausted and exhibited low self-esteem. Over one third had felt unable to cope because “everything was getting on top of them”. Three carers admitted having regular suicidal thoughts. Stressors such as the challenging behaviours of the child, the limited support available and marital disharmony impacted on the carers' mindset and physical well-being. A number of carers are on medication for depression and anxiety. 9% were due to have surgery and this left them anxious as to who would assume the caring role for their child when they were in hospital. Many carers whose scores indicated extremely poor health at the first stage had improved health scores when they were re-interviewed.

- Opportunities for socialising were rare for carers. However, during the two timeframes, the number of 'weekly' and 'monthly' social opportunities for carers increased, suggesting that the Service may have freed-up more time for them to socialise. Few carers took time for themselves; 23% undertook regular exercise and 10% were studying a course to give them an outside focus. Many carers admitted that they were the last person they considered in the family as their efforts were mainly focused on other family members. One quarter also spoke poignantly of being excluded from family get-togethers or social events with friends. Carers believed that as a family, they were not accepted by society, often reporting experiences of discrimination.

- For parents, the opportunity to spend time together as a couple was limited by the difficulties associated with organising childcare from trusted sources. Older siblings and grandparents frequently stepped in. However, not all families could depend on older siblings and in many cases, grandparents were infirm or deceased. Carers were grateful for the flexibility the Service offered in facilitating breaks so that they could spend quality time with other offspring and their partners, or enabling them to attend social events.

- Results indicate reasonable levels of family functioning, however disparities did exist. Carers had higher levels of stress than the general population. All found the parenting role challenging and 90% reported that they were giving up more of their life to meet their child's needs than they had ever expected to. Nevertheless, half of the 'parenting satisfaction' scores improved between the two timeframes demonstrating that these carers had become more positive about their parenting role. There was also a significant improvement in the child's behaviour indicated by their adaptive and aberrant behavioural scores. This may be attributable to the intervention of the Service which focused much energy on developing the children's social and practical skills. The improved behaviours of the children may help to explain the increase in parenting satisfaction levels in the follow-up analysis.

- Carers commented about their experiences of using the Service, its delivery and the impact it had on their child. The consensus was extremely positive in all Service locations and carers cited multiple benefits for the child and family. Families spoke highly of the Service, its uniqueness and how grateful they were for the support it offered. The main benefits reported were the increased opportunities for their child to experience and learn new skills and the extended social networks for both child and carer. In addition, families expressed delight at the personal milestones their child had achieved; the Service had indeed transformed many lives. It opened up a whole new world for the children and carers no longer felt like they were alone.

- Carers also commented on the professionalism and genuine care shown by staff and volunteers and the reassurance they felt knowing their child was safe and with people they trusted. Others reported that initiatives such as the 'Sibs group' provided a supportive environment for siblings to experience opportunities and helped them to realise that they were not coping alone. Likewise the 'Women Carers Project' enabled mothers to meet together and embark on an emotional and empowering journey of personal development.

- Additional key themes emphasised by carers included the person-centred ethos of the Service. This way of working also, for the first time, helped many parents to look to the future. Carers expressed high hopes for the Services to continue. Many referred to it as a 'lifeline', a 'blessing' or a 'godsend'. The consensus was that carers 'wouldn't be able to cope without it'. Irrespective of their own financial situation, carers were willing to contribute either financially or practically to the Service to ensure it continued.

The final section of the report outlines the views of a number of key stakeholders obtained through semi-structured interviews and focus groups. Staff, community workers and volunteers reported that the Service 'filled a huge gap' in the lives of these children and helped to educate and raise awareness in the wider community. Their views echoed those of carers; that the Families Service is essential! Children with a learning disability reported that they enjoyed the Service; the activities, the fun, and the new friends they made. Very few stakeholders had anything negative to say about the Service. In fact, the vast majority commented on how rewarding their involvement had been. The commitment of volunteers and staff was evident, and many had gone to great personal lengths to make sure that the children received the best possible service. Other partners also reflected upon the positive working relationships. However, there was evidence that there should be more joined-up working between the Families Service and the statutory sector. In spite of funding limitations, stakeholders advocated that the Service brought tremendous value. Based on the evaluation findings, a series of recommendations are presented in Chapter Seven.

Chapter 1: Introduction

The aim of this report is to present the findings of an evaluation of the Families Services delivered by Positive Futures, a regional charitable organisation that was originally established in 1995 as ‘United Response Northern Ireland’. The organisation specialises in providing a range of community based support services to local children and adults with a learning disability and their families. Currently, Positive Futures has over 300 staff and 200 volunteers working in a variety of settings to support people with a learning disability.

Positive Futures established the first of its three Families Support Services in the city of Lisburn, County Antrim in 1999. Since then, sister Services have also been rolled out in Bangor, Co Down and in “Lakeland” - south east County Fermanagh. Each Service is funded in partnership with the local Health & Social Care Trust.

Report Structure

Chapter 1 introduces the report and describes the Families Service Model. Chapter 2 provides information about the evaluation methodology. Chapter 3 presents the findings from the census data which profiles 104 families availing of Positive Futures Families Services. Chapter 4 continues by discussing the types of supports these families receive. This is followed in Chapter 5 with the results of the research study. Chapter 6 focuses on the qualitative perceptions of key stakeholders including Social Workers and the children themselves. Chapter 7 concludes with a summary of the findings and provides recommendations for future Service provision.

Profiles of three children using the Services are then documented to illustrate the benefits of the Service. Two partnership projects, namely the KIC integrated drama project and the Women Carer’s project are also profiled.

Rationale

Very few services exist which support families who have a child with a learning disability in a holistic manner. Positive Futures strives to provide services to meet the needs of families and people with a learning disability. There is an onus to gather evidence that such services are effective as well as discovering how they can be improved to better meet the needs of the people they support. Positive Futures have previously evaluated their

Families 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 the families concerned. Overall, the findings demonstrated that, despite funding limitations, the services provided were mutually beneficial to the parents and their children. Overwhelmingly, families reported that they did not know how they would cope without the support provided by Positive Futures.

Report Aims

The aims of this report are manifold:

- To produce a detailed profile of the characteristics and needs of the young people with a learning disability and their families who receive services from Positive Futures.
- To describe the person-centred Families Service Model and assess its impact on carers.
- To assess measures of coping and well-being in primary carers by conducting a longitudinal study.
- To obtain the reactions to the Families Service by those who accessed them.
- To provide an evidence-base to illustrate the impact of the Families Services on the lives of children with a learning disability and to help clarify the contribution that Positive Futures can make to children's services within Northern Ireland.
- To obtain the views of Service staff and other external stakeholders, such as community development workers, who may be involved in the lives of families who have a child with a learning disability.
- To highlight areas of unmet needs.
- To present information to Service Commissioners on service outputs measured against running costs using an analysis matrix.

- To make recommendations for future development and improvement of the Services based on the experiences reported by those using the Service. This will also help to inform strategic service delivery/planning.

- To publish and disseminate the evaluation findings.

What Other Research Tells Us…..

There are approximately 9,000 children with a learning disability known to statutory services in Northern Ireland. However many more remain unaccounted for. Children and young people with a learning disability may find themselves with limited opportunities to make friends and to fully experience meaningful social activity. Research tells us that children and young people with a learning disability are more vulnerable to developing difficulties with their mental health and emotional well-being than their non-disabled peers (Emerson, 2007). They are also more likely to experience greater levels of discrimination, bullying and social exclusion (Black & Devine, 2008). In order to give children and young people a better quality of life supportive relationships, regular social and leisure opportunities and the chance to experience success and achievement are all important. These “protective factors” are known to increase their resilience and ability to ‘bounce back’ from stressful or challenging life situations. Fortunately, with the right support, resilience is a characteristic that can be taught and learned.

Having a child with a learning disability also places a huge burden on the family in terms of their relationships with each other (Brown *et al*., 2006). Research demonstrates that these families experience a lack of support and fewer opportunities. Such factors increase their risk of stress (see Turnbull *et al.,* 2007). Stress is also compounded because many families with a child with a learning disability are living in poverty, which often results from the financial burden associated with being a carer (Datta *et al.,* 2002). Families living in isolated rural areas also lack the support and access to services they need. In addition, a number of carers are coping as lone parents. Caring for a child with challenging behaviours or limited communication also increases the strain on the family unit. These stressors are known to exacerbate mental and physical health problems (Kersh *et al*., 2006). Furthermore, mothers and fathers in these situations are thought to cope differently (Wang *et al.,* 2006).

Families with a child with a learning disability need effective social support networks and regular respite breaks. Family-centred approaches to service delivery which focus on the needs of the child and the whole family are widely endorsed (King *et al.*, 2003). Positive Futures aims to counteract some of the negative stressors described above by delivering support, opportunities and respite through its innovative Service Model.

Service Overview:

The 3 core aims of Positive Futures' Families Services are to:

i. 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. support families with their unique and individual needs, using person-centred tools.
iii. adopt a Community Development Approach in local areas to raise awareness and meet the needs of young people who have a learning disability.

Eligibility Criteria

The eligibility criteria for the Family Support Service are as follows:

- The child is aged 8-18+ years at the time of referral.
- The family reside in a designated geographical area.
- The child has a severe learning disability and meets the Health & Social Services Trust's requirements to receive the Service.
- The Service provided by Positive Futures will end when the young person transfers to Adult Services.

Family Service Model

All three Families Services are based upon person-centred approaches which are designed to offer *holistic* support to families who have a child with a learning disability (Sloper, 1999). New families are referred to the Families Service by Social Services. The Families Service is based upon a model which is presented in Figure 1 overleaf. 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 inclusive community groups (youth clubs, churches, community groups)
- After school activities, homework support
- Easter, Summer and Christmas holiday schemes
- Targeted groups: Siblings group, Fathers group, Advocacy group.
- Themed parties: summer BBQ, Halloween, Christmas.
- Co-ordination of support staff and volunteers

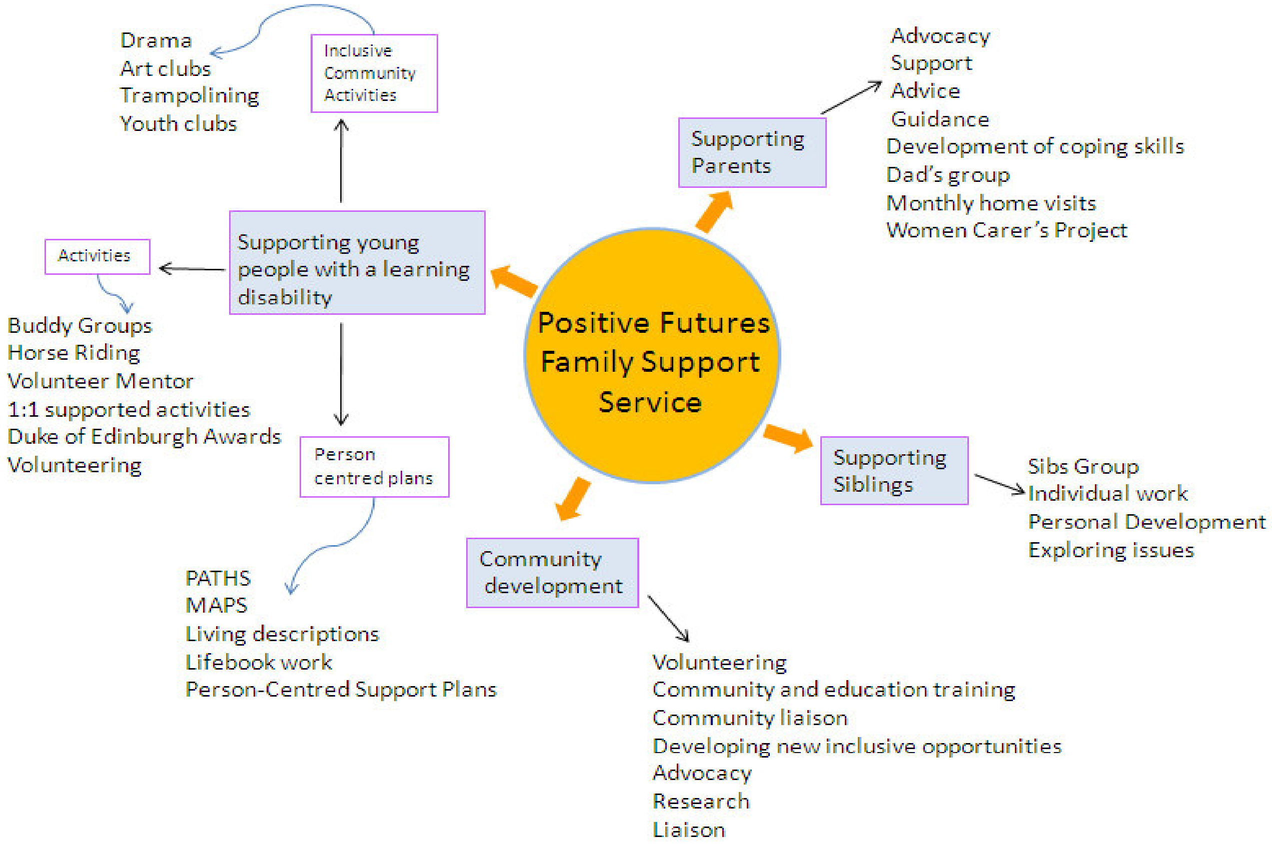


Figure 1. Positive Futures Families Service Model

Within this model, a designated Family Worker is identified for each new family accessing the Service. The Family Worker acts as an individual contact for practical support and advice, and they also advocate on behalf of the family with health professionals and other agencies. Family Workers visit the family on a monthly basis (more frequently when needed), and this is complemented with regular telephone support when required.

The role of the Family Worker is also to support each family to identify their needs, and to match the child to a range of activities of preference using person centred-planning approaches. Family Workers consult with the child and their families in order to develop a PATH or MAP (Sanderson, 2000) which helps to identify the child's goals and aspirations by including all the key people in the child's life in a *circle of support*. From this, Plans are developed to enable the child to participate in new opportunities that help them to develop their own interests and interpersonal skills. The Plans also help the family to plan positively for the child's future.

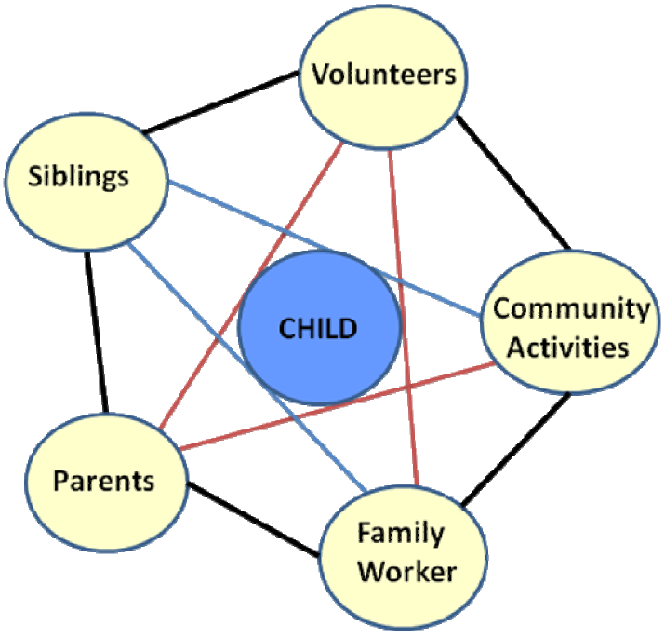


Figure 2. Networks around the child

Activities include a wide range of leisure and recreational activities that accommodate different interests, including one-to-one support, group activities like sports and games and creative activities such as art and drama. Activities are held at various times: after school, during weeknights, at weekends and longer residential breaks which take place during the school term time and in the Easter, summer, and Christmas holidays.

In addition, 45 volunteers have been recruited to provide support to children in "Buddy groups" and on a one-to-one "mentoring" basis. When joining the Service, all volunteers are subject to enhanced police checks and are required to provide two references. Volunteers receive an induction program and relevant ongoing training including First Aid, child protection and challenging behaviour. Volunteers can offer varying time commitments, from a few hours per week to longer timeframes for residential schemes or Duke of Edinburgh Award expeditions.

Enabling the child with a learning disability to attend social and leisure activities also provides much needed respite to parents and siblings. Specific projects and events for mothers, fathers and siblings are offered so that the family's needs are taken into account and catered for in a holistic way. Positive Futures staff also provide training and advice sessions about disability issues to local community groups, schools and youth clubs through the delivery of a 'Valuing Differences' program. These sessions aim to raise awareness in the local community about disability issues and inclusion.

Partnership-Working

A core part of the Families Service Model involves community development via partnerships with local community projects in order to champion more inclusive community-based activities. Partnership working is a fundamental aspect of the Families Service strategy. Positive Futures has established an extensive range of positive partnerships with statutory, private, voluntary and community organisations including youth groups, schools, church groups and local councils. It is through these close working partnerships that new links have been formed and other ventures have been successfully developed.

Partnerships have also benefitted parents, children and volunteers. For example, the Lakeland Families Service has been able to gain free access for families to participate in activities at the "Share Centre" on Saturday mornings. Families 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 together, and it also enables them to meet other families on a more social basis. Lisburn Families have teamed-up with Lisburn Borough Council in a 'Buddy Card' initiative which enables volunteers to avail of free entrance into both the local leisure and Civic Island centres when supporting a young person with a learning disability from the Service. In Bangor, the children are able to visit the Ulster Folk and Transport Museum free of charge. Such initiatives can help minimise the financial burden on the families.

This Chapter has outlined the aims of the report and presented an overview of the key barriers that impact on children with a learning disability and their families. It also provides details of the Families Service Model provided by Positive Futures which is designed to meet many of the families' individual needs.

Chapter 2: Service Evaluation Methodology

Before the Service evaluation commenced, a number of research methods were considered. It was decided that the research methodology should include a mixture of qualitative and quantitative approaches. Mixed-method approaches are increasingly recognised as essential in gaining a deeper understanding of complex issues. Combining methods in this way is known as 'methodological triangulation'. This technique is used to overcome the deficiencies inherent in single method studies by exploring multiple methods that counterbalance each other (Olsen, 2004). In turn, the research presented in this report adopts a three tier approach:

1. Census profiling the families using the Service (N=104)
2. Comparative study including a 12 month follow-up (N=48 families)
3. Qualitative data obtained from semi-structured interviews with key stakeholders

Ethical Considerations

Ethical approval was granted by Positive Futures' Research and Development Committee. Formal ethical approval was not sought as this evaluation was considered to be a service audit rather than pure research. At the time of first accessing the Services, parents or guardians were formally invited to participate in the research evaluation. Those in agreement completed consent forms and each family was guaranteed that their information would remain confidential. Families who declined to participate were informed that they would not be disadvantaged by the Services in any way. Families could also withdraw from the evaluation at any time if they desired.

To gather an overall assessment of the Service both internally and externally, the Researcher also interviewed a number of stakeholders including:

- Positive Future's staff (Service Managers, Family Workers)
- Social Work staff from a Health and Social Care Trust
- Volunteers
- Independent Community Workers (church and youth club schemes, Drama Project, Women's Carers project staff)
- Children with a learning disability accessing the Service
- Non-disabled children from an inclusive summer scheme

Verbal consent to participate in the research was obtained from the key stakeholders. In total, 67 semi-structured interviews were conducted. This format was chosen because it enabled participants to talk freely about issues of particular interest to them or in which they have great personal experience. The interviews allow for subjectivity and enable comparisons to be drawn between responses, based on a relatively standard, but not limiting, set of questions. This method is considered more suitable than open-ended interviews because the latter may yield less specific information (Searle, 1998). Moreover, the research results would not be limited by the interviewer's framework of reference (see Bryman, 2004).

In addition to the interviews, 5 focus groups were completed. This afforded respondents an opportunity to express what they thought was working well in the Service and to suggest areas for improvement. Focus groups were chosen because they can be completed in a less intimidating environment in which participants, especially children, can relay their views. A rich set of information can also be obtained from a reasonable number of participants.

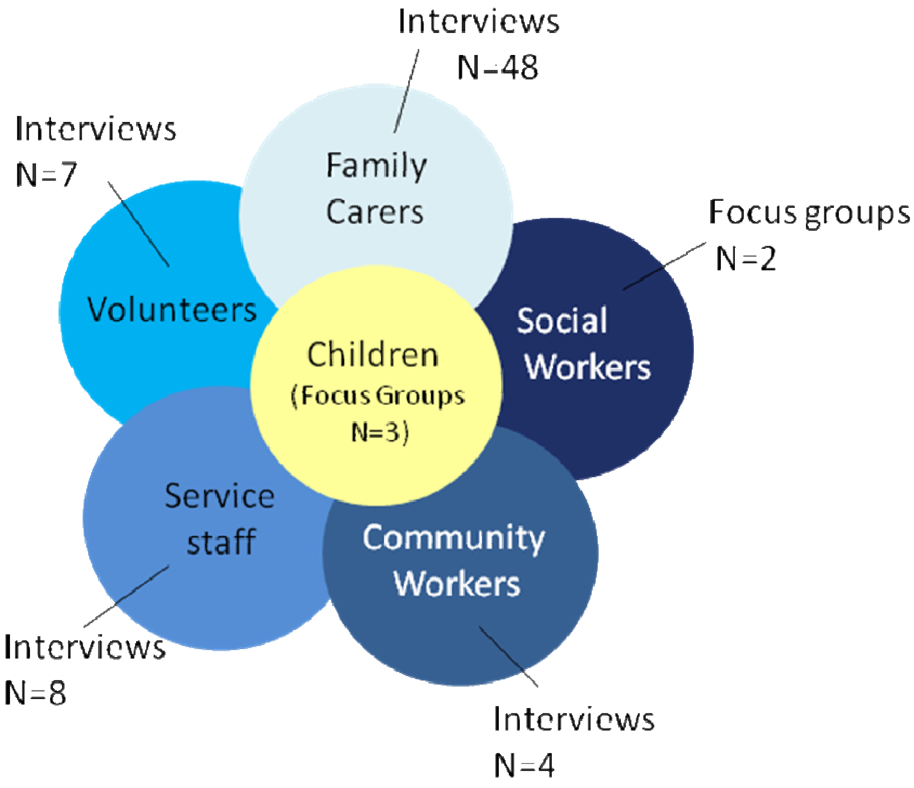


Figure 3. Research conducted with key stakeholders

This Chapter has provided a brief overview of the research methodology adopted to evaluate the Families Services.

Chapter 3: Census

In order to better understand the needs of families who have a child with a learning disability, this Chapter presents the main characteristics of families accessing Positive Futures' Families Services. This was achieved by using census information collected on each family. It also highlights demographic differences between these families in rural and urban parts of Northern Ireland.

Background

The census provides information on 104 families using the Families Services on 1st January 2007. This presents a snapshot of the types of families within the three Service locations, information on their socio-economic status and the various support networks they utilise in daily life.

The data for the census was obtained by administering a standardised proforma. This was completed with the primary carer within the family and their Family Worker in the carer's home. The information received was then collated by the Researcher using SPSS Version 15. Crosstab and chi-square analysis enabled multiple variables to be compared within the different service locations in order to delineate trends and assess any levels of significance within the results. The characteristics of the families are now presented.

Characteristics of Children with a Learning Disability

All children in the Service are from a white, English-speaking ethnic origin. There are more male (62%) than female (37%) children using the Services and this trend is evident in each of the three Service locations. As of 2007, the largest Service is Lisburn N=41 families (39%), followed by Lakeland with N=32 (30%) families and Bangor with N=31 (29%) families respectively.

At the time of the census, the average age of the children is 12.6 years (age range 6-19; SD 3.3). Children were grouped into two age categories, those aged between 6-12 years old and teenagers aged 13-19 years old. The majority (54%) of the children are aged between 13-19 years, whereas 46% of children are in the pre-teen age group.

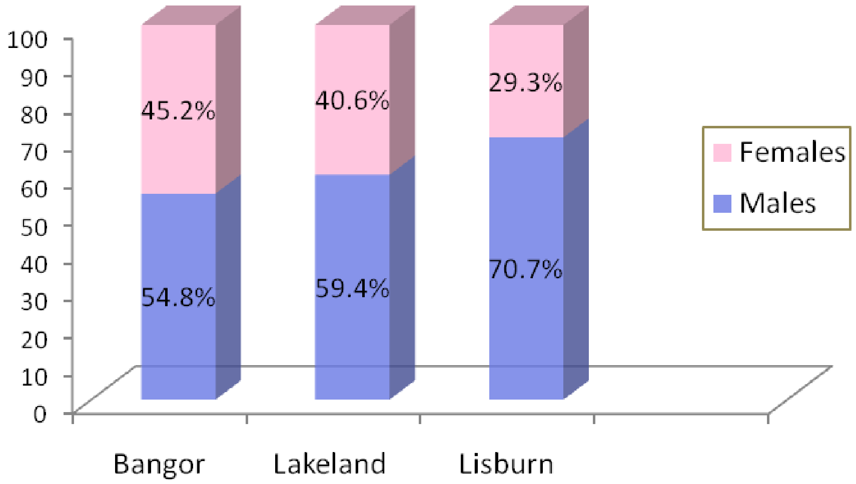


Figure 4. Breakdown of Service children by gender and location

Regarding schooling, 97% of the children have a statement of special educational needs (SEN) and 82% attend special schools. Children attend a total of 27 different schools. The Lakeland Service has the highest number of children relative to its sample who go to mainstream schools. The Lisburn Service has the highest percentage of children in its sample (87%) attending special schools, followed by Lakeland (78%) and Bangor (71%). Bangor has the highest percentage in its sample attending special units (9%). Two children across the three Services are not attending any school; one child suffered bullying whilst another child was pursuing an "Applied Behaviour Analysis" programme.

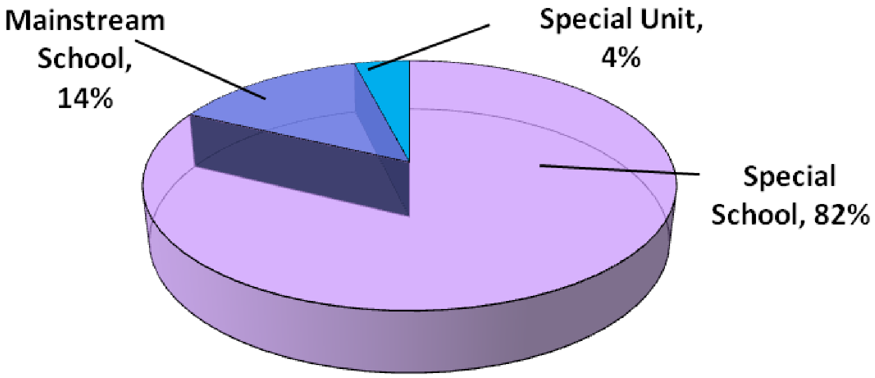


Figure 5. Overall percentage of types of school attended

Nature of the Child's Disability

89% of children have a severe learning disability. However, several children (11%) do not have a diagnosis; some of them are awaiting a diagnosis, whilst others have been referred to the Service because of challenging behaviours.

Location:	**Yes**	**No**	**Total**
Bangor	29 (93%)	2 (7%)	31 (100%)
Lakeland	28 (87%)	4 (13%)	32 (100%)
Lisburn	36 (87%)	5 (13%)	41 (100%)
Total	**93 (89%)**	**11 (11%)**	**104**

Table 1. Children with a significant learning disability by Service location

A number of children have been given a specific diagnosis. The most frequent condition recorded is Autistic Spectrum Disorder (N=47; 45%) which is more common in males (79%) than in females (21%), and is most prevalent in the Bangor Service (N=17; 53.1%). Down's syndrome is also common and it has its highest incidence in Lakeland. Overall there were slightly more females (N=10; 58%) than males (N=7; 41%) with Down's syndrome.

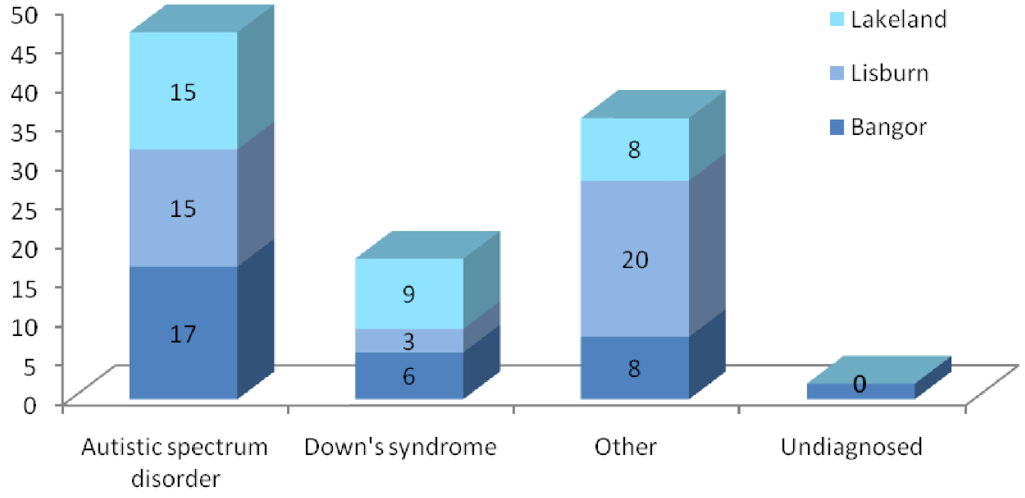


Figure 6. Classification of child's condition by location

Conditions in the ‘other’ category include Fragile X syndrome, Attention-Deficit Hyperactivity Disorder (ADHD) and Coffin Lowry syndrome. Only male children have a dual diagnosis of Autism and ADHD (6%).

50% of children across the three Services have a medical condition in addition to their learning disability. The most frequent medical condition recorded is epilepsy (24%). Five children (4%) have asthma, and four children (3%) have cerebral palsy. Two children have Type 1 diabetes. Other children in the Service have specific medical conditions such as congenital heart disease, Pitt-Hopkins syndrome, Milroy’s disease, and hydrocephalus, amongst others. Nearly one third (27%) of the children have a physical disability. The Bangor Service has the highest number of children with a physical disability its sample group (35%).

The children also have a range of other disabling conditions as shown in Table 2.

Condition	**Yes**	**No**	**Not known**	**Total**
Physical disability	29 (28%)	75 (72%)	0	100%
Challenging behaviour	36 (35%)	67 (65%)	1	100%
Visual impairment	19 (18%)	84 (82%)	1	100%
Hearing impairment	10 (9%)	93 (91%)	1	100%
Medical condition	52 (51%)	51 (49%)	1	100%

Table 2. Other types of disabling conditions presenting in the children

Over one third (35%) of the total population sample exhibit challenging behaviours. Approximately 40% of Bangor and Lakeland Service children were recorded as having challenging behaviour.

There are a number of families coping with a child who has what could be considered very complex needs. One family in Lakeland have a child with 6 recorded conditions; and just over one quarter (26%) of all families are coping with a child with 4 or more conditions.

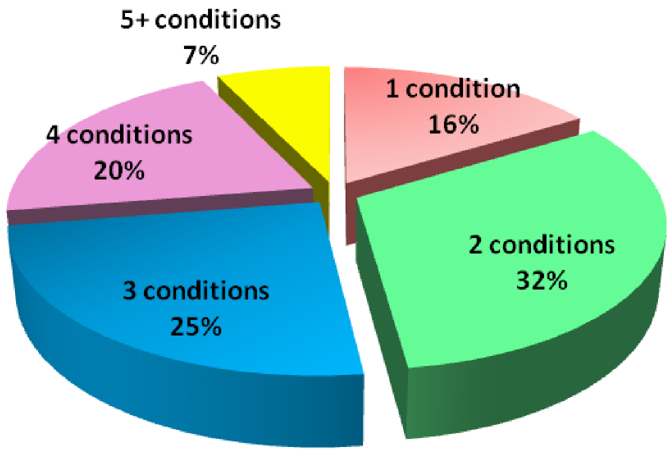


Figure 7. Number of conditions per child

Most children are able to communicate using speech. However, 17% of the total sample are unable to communicate using speech and this is also thought to add to the stress of rearing a child with a learning disability. Some children are learning to use assistive technologies like PECS. Within the individual Service samples, Lisburn has the highest number of children without speech (21%), followed by Lakeland (18%) and Bangor (10%). In the overall sample a further 12% of children have very limited speech.

Family Structure

78% of families are two parent/guardian families, whereas nearly a quarter of the sample (22%) are one parent families. One family in Lisburn and one family in Lakeland are living with dependents (e.g. grandparents or foster children). In two families the primary carer is a grandparent.

Carers

A variety of descriptive and demographic information regarding the child's carers is now described. With regard to family set-up, Table 3 provides a breakdown of the different types of guardianship. As can be seen, two thirds of the children (66%) live with both of their natural parents. One fifth live with the maternal lone parent (19%). Three children (3%), all in the Lisburn area, live with a foster or adoptive family.

In the majority of cases (84%), the mother is the primary carer. In seven families (7%), both parents report that they share the caring responsibility equally.

Guardianship	**Bangor**	**Lakeland**	**Lisburn**	**Total**
Natural parents	20 (65%)	21 (66%)	28 (68%)	69 (66%)
Lone natural parent (mother)	7 (23%)	8 (25%)	5 (13%)	20 (19%)
Lone natural parent (father)	0 (0%)	0 (0%)	2 (5%)	2 (2%)
Natural parent (mother) & non-parent partner	4 (12%)	3 (9%)	0 (0%)	7 (7%)
Natural parent (father) & non-parent partner	0 (0%)	0 (0%)	1 (2%)	1 (1%)
Grandparents	0 (0%)	0 (0%)	2 (5%)	2 (2%)
Foster or adoptive family	0 (0%)	0 (0%)	3 (7%)	3 (3%)
Total	**31 (100%)**	**32 (100%)**	**41 (100%)**	**104**

Table 3. Summary of the child's guardianship and family set-up

Lone Carers

There are 23 lone carers supported by the Families Services. Relative to their individual populations, Lisburn have the lowest number of lone parent families (19%), followed by Bangor (22%) and Lakeland who have the highest percentage (25%). Two families in Lisburn have a male lone carer. Nearly one quarter (22%) of all lone parent carers are coping with a child with at least 4 or more conditions.

"I have my hands full with the children and I am a lone parent. I haven't much time to get practically involved with the Service. But the support I get from Positive Futures takes a huge burden of worry off me. I dread to think how I would've been able to cope."

Age of Primary Carers

The ages of the primary carer are presented as follows:

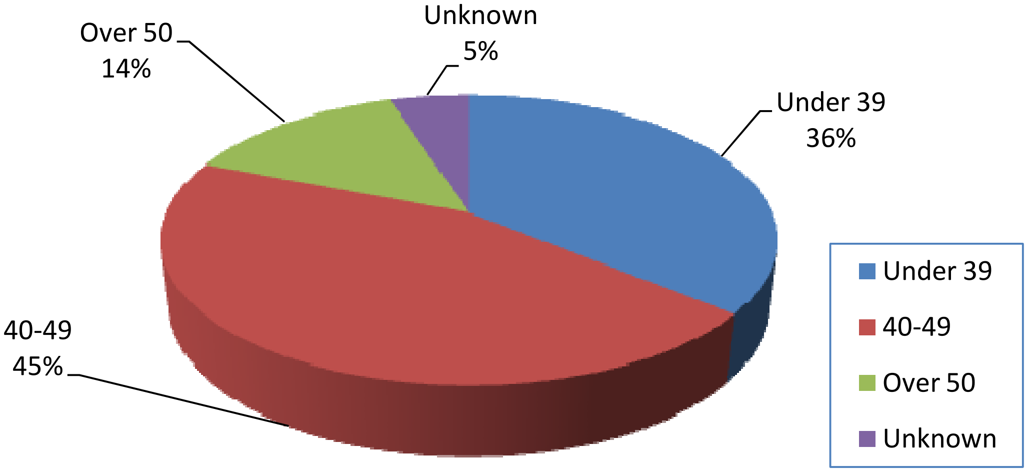


Figure 8. Age range of the child's primary carer

As can been seen from Figure 8, nearly half of the primary carers are in the 40-49 age group (45%). Two primary carers are under the age of 30, and four are above the age of 60. The spouse/partner ages were similar. However, a number of their ages were not recorded due to changes in family set-up as a result of marital breakdown.

Offspring

The total number of offspring living at home across the three Service locations is presented in Figure 7. The size of families varies considerably. The average number of offspring per family is 2.6 (min 1, max 8; SD 1.3). In 8% of families, the child with the learning disability is an only child. In 40% of cases, the child with the learning disability is the youngest family member. Six families have twins. In all twin sets, at least one child has a learning disability. In Lakeland, there are two families where both twins have a learning disability.

3 families are coping with another child in the family with a serious medical condition including cerebral palsy, leukaemia, and one child has a tracheotomy. Five families have more than one child with a learning disability. One family in Lakeland have four children with a learning disability.

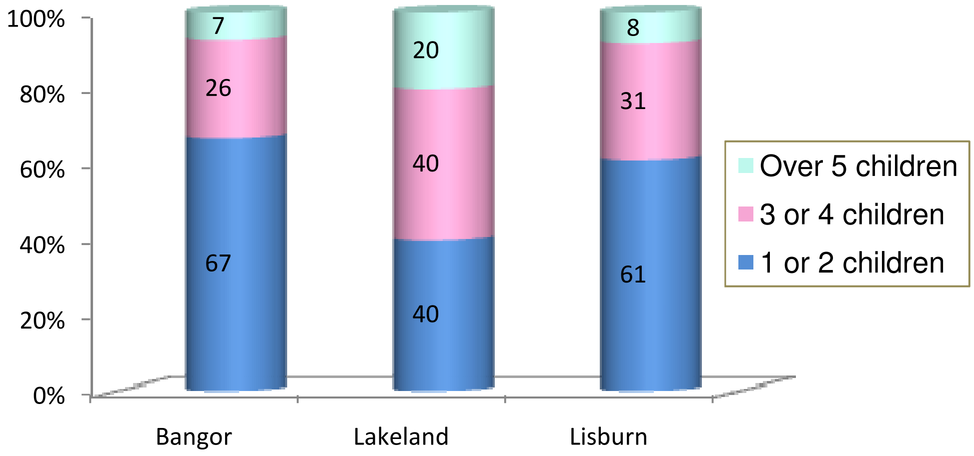


Figure 9. Percentage of children living at home by location

The majority of families have 2 or 3 children living at home (58%). One quarter of families have 4 or more children at home and one family in Lisburn have 8 children living at home. Lakeland has the highest percentage of families (6%) with 5 or more children still living at home.

Siblings

Both Lakeland and Lisburn Services support families with more than one child with a learning disability as shown in Table 4. Lisburn has the highest number of additional children with a learning disability in the family being supported. In addition, 25 siblings are also being supported through a tailored programme provided by Positive Futures called the "Sibs" groups.

Location	Number of families with more than one child with a learning disability is supported	Number of families where other siblings are supported
Bangor	0	8
Lakeland	1	7
Lisburn	6	10
Total	**7**	**25**

Table 4. Details of siblings being supported by the Families Services

Socio-economic status

Family's socioeconomic status (SES) is 'implied' through selected social class indicators, as discussed below.

Education

Table 5 summarises the highest educational attainment of the primary carer. One third of carers left school with no qualifications. About one third (36%) of primary carers have a third level qualification. A further 9% are educated to A-level standard. A similar pattern is reflected for their spouses or partners.

Bangor has the highest number of primary carers relative to its population sample who have attained a third level educational qualification and the lowest number of primary carers who left school at 15 (23%). The Lakeland sample has the highest number of primary carers who left school at 15 or with GCSEs (68%) and the lowest number who attained a third level qualification.

	Left school at 15	GCSEs/A-level	Higher Education	Total
Bangor	25%	23%	41%	31 (100%)
Lakeland	34%	34%	31%	32 (100%)
Lisburn	32%	32%	35%	37 (100%)
Total	**31**	**33**	**36**	**100**

Table 5. Educational background of the primary carer by location

Income and Deprivation

Households in the UK with a total annual income of less than £16,000 are considered to live in 'relative poverty'. Family income was ascertained using two categories i) annual income above £16,000 and ii) annual income below £16,000.

Location	Income above £16,000	Income below £16,000	Total per sample
Bangor	61%	38%	31 (100%)
Lakeland	43%	56%	32 (100%)
Lisburn	63%	36%	38 (100%)

Table 6. Income levels above and below £16,000 per annum

Overall, nearly half (44%) of all Service families are living in 'relative poverty' with an annual income of less than £16,000 per annum. Respective of individual samples, the Lakeland Service has the greatest number of families in its sample living on a reported income of less than £16,000 (56%). Since one quarter of those on low incomes also have at least 4 children living at home, this could make it more difficult for larger families to 'make ends meet'. Daily living may also be financially challenging for the high number of lone parents in the Services. The Lakeland Service has the highest number of lone parent families (21%) with an income less than £16,000. Lisburn has the highest number of families (63%) with an income of more than £16,000, and this is closely followed by Bangor (61%). Lisburn have the highest number of families who are caring for four or more children whilst on incomes of less than £16,000.

Location	Income <£16,000 + lone parent per sample	Income <£16,000 + more than four children at home per sample
Bangor	16%	19%
Lakeland	21%	16%
Lisburn	14%	7%
Total	**18**	**15**

Table 7. Comparisons of lone parents and larger families on low incomes

Multiple Deprivation Measures

The Northern Ireland Multiple Deprivation Measure 2005 (MDM) is based on the small area geography of Super Output Areas (SOAs) and is a widely accepted methodology for measuring spatial deprivation. It ranks all geographical areas in Northern Ireland on a scale from 1 (most deprived area) to 890 (least deprived area). Figures have 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.

Using the MDM, it is possible to calculate areas of deprivation for those accessing the Families Service. Families using the services come from a diverse range of socio-economic backgrounds. Out of the three localities, the families in the Lakeland Service area have the highest levels of social deprivation in terms of access to services and child poverty. The average rank of the MDM in Lakeland is 377 (min 158; max 691). This is a much lower figure when compared to the average overall MDM rank for Bangor (659: min 144; max 884) and Lisburn (568: min 117; max 875) families.

	Number of families	Total sum of SOA ranks	Lowest SOA Rank in project area	Highest SOA Rank in project area	Average rank per area total ward
Bangor	31	20456	144	884	659
Lakeland	32	12094	158	691	377
Lisburn	41	23291	117	875	568
Average	34	18613	129	816	535

Table 8. Summary of deprivation measures by location

Bangor in North Down is one of most affluent areas of Northern Ireland. Interestingly Lisburn (the city) is, on average, nearly 100 points below Bangor. Lisburn also has a family living in the lowest SOA rank (117). The highest and lowest 25% of the MDM was used as a threshold to indicate how many families are at either end of the deprivation measures scale. There was a very significant difference between families that lived in the top and the lower end of the scale. In terms of families being in the top 25% MDM (i.e. most affluent SOA's ranging from 668 to 890), Bangor was highest with 19 (61%) of its families living in these areas. Lisburn had N=17 (41%) and Lakeland had only one, suggesting many families in more rural areas are likely to live in less developed, less affluent places.

Regarding the bottom 25% of the MDM (ranks ranging from 1 to 222), out of the three sample areas, Lakeland had the highest number of families in its population living in this range (31%), followed by Lisburn (10%) and then Bangor (6%). Families residing in Lakeland also have less access to good infrastructure and transport links when compared to Bangor and Lisburn which are both in close proximity to Belfast.

Tenure

Three quarters (74%) of families own their own home (either as a mortgage or outright), whereas 26% do not. Lisburn has the highest percentage of respondents who do not own their own home (34%). The average length of stay in the current accommodation is 8.9 years (min 1; max 40). Over half of all families (54%) live in detached accommodation, with 22% living in semi-detached accommodation. 15% live in Housing Executive accommodation and there are more families living in Lisburn (7% of total) in this accommodation than the other 2 areas.

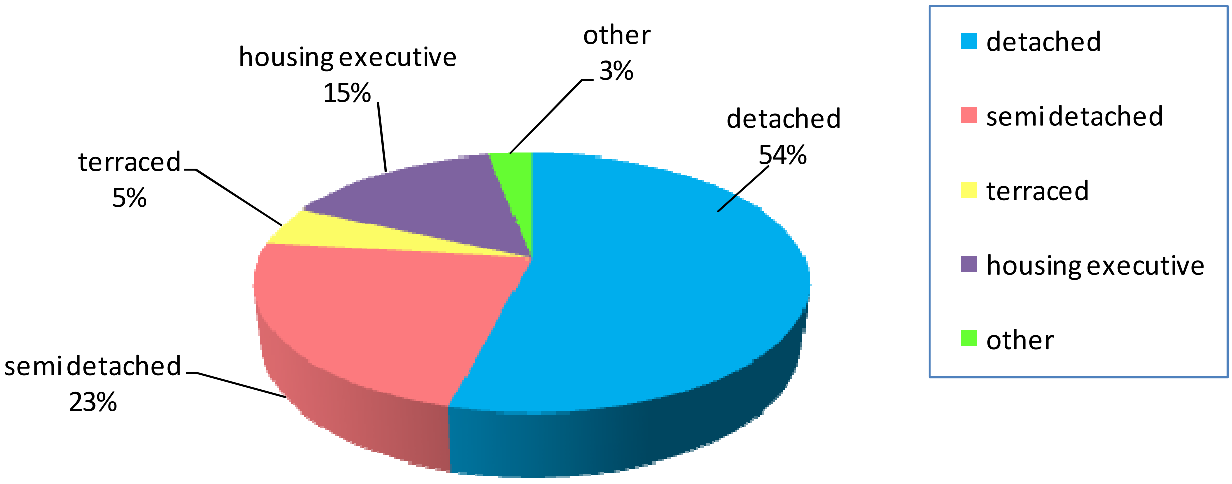


Figure 10. Accommodation type for all families

	Detached	Semi-Detached	Terraced	Housing executive	Other
Bangor	15%	11%	2%	4%	1%
Lakeland	20%	4%	0%	4%	1%
Lisburn	19%	8%	3%	7%	1%
Total	**54%**	**23%**	**5%**	**15%**	**3%**

Table 9. Type of residential accommodation by location

Employment

Overall, in 20% of the total sample, no main wage earner (either the primary carer or their partner/spouse) is reported. Relative to its population sample, the Lakeland Service has the highest number of families without any reported wage earner (28%). Again, this could be linked to the rural geographical spread of families, and the lower levels of opportunities for employment in such areas when compared to urban areas. By contrast, Bangor has the highest number of wage earners in its sample area (87%). In Lisburn, there is a wage earner in 81% of families.

Primary Carer Employment

Regarding the employment status of the primary carer, 48% are in some form of employment, whereas 52% do not work. There are more carers in part-time work than in full-time work. In lone parent families, 3 carers work full-time and 6 work part-time. Over half of all lone parents are not employed. 52% of all carers do not work.

The primary carers who work are to be found in a variety of employment sectors ranging from professional to tertiary occupations. Job roles include sales executives, teachers, hairdressers, and secretaries. Job roles have been classified into three occupational categories (OC1-OC3) and are presented below.

i) OC1 - professional and managerial occupations (18%)
ii) OC2 - semi-professional (33%)
iii) OC3 - sales and ‘other’ tertiary occupations (49%)

Fewer carers work in semi-professional or professional job roles (OC1 or OC2). Two primary carers work from home (OC2). The majority work in the “tertiary” sector (OC3). Many of these jobs are less well paid. Occupations such as nursing auxiliaries, sales advisors, waitresses, and domestic assistants are included in this sector. Limiting factors for carers in the progression of their careers may include their caring role, but may also be the high number (55%) who left school at 16.

This Chapter has presented a breakdown of the characteristics of families and their socioeconomic backgrounds. It highlights the diverse range of needs of children and the levels of deprivation within families. The Lakeland Service is providing support to the most deprived areas when compared to its sister Services.

Chapter 4: Family Supports

Support networks for families are vital. This Chapter presents information about the types of informal and formal supports that families across the three Services receive.

1.Informal Supports

The results indicate that 71% of families had relatives that were living as neighbours nearby. Within their sample, Lisburn had the highest number of families with relatives living nearby (81%) followed by Lakeland (68%) and then Bangor (61%).

Families were also asked whether or not they received support from any of the following ten 'informal' types of support:

In receipt of Informal support from:	**Yes**	**No**
Adults in household	79%	21%
Children in the household	64%	36%
Grandparents	49%	51%
Other extended family	43%	56%
Friends in area	37%	63%
Other families who have a similar child	34%	66%
Friends not close by	21%	79%
Neighbours (non relatives)	27%	73%
Parent support group	28%	72%
Regular childminder	13%	87%

Table 10. Types of informal support received

Out of a possible maximum of 10 types of support, the average number of informal supports was 3.8 per family (min 1; max 8; SD 1.9). These supports were categorised into 3 levels: low support (1-3), medium support (4-6) and high levels of support (7+). Most families (45%) have low levels of support. Of these, 8% reported having only one type of informal support. 36% of families have medium levels of informal support while only 16% have relatively high levels of informal support (7+). Only one family had 8 informal supports.

Interestingly, most lone parent families also had low levels of informal support (45%). Only 18% of all lone parent families had high levels (7+) of support. Within each location sample, Bangor had the highest percentage of people receiving low levels of informal supports (51%) followed by Lisburn (47%) and Lakeland (38%). The Bangor Service had more of its families (22%) receiving 'high levels of informal support', when compared to Lakeland (16%) or Lisburn (12%). Each type of informal support are discussed below.

Family support

Carers received most support from within their own families. 10% were not receiving any form of support either from children or adults in the household.

79% of respondents received support from adults within the family (namely spouses, partners and grown-up children). In one fifth of families (20%) there was no form of adult support and this could be linked to the number of one parent families (N=23). Carers in Bangor had the lowest level of support from adults in the household (67%), whereas Lisburn had the highest (87%). The most frequently cited type of support from the adults was shared support with daily tasks (65%), and emotional and practical support (12%).

The most common types of support carers received from children in the household included help with daily tasks such as housework, babysitting or playing and reading with the child with the learning disability. Two offspring supported their families financially. Lisburn had the highest levels of support from children in the family (72%), whereas the Lakeland Service had the least (51%). Over one third of all families (35%) did not receive any support from other children in the family. This may be due to factors such as having very young children or likewise, children that have grown up and left the family home. Other families have only one child. In addition, as previously highlighted, some families have more than one disabled child and this may limit the ability of siblings to give support when needed.

Many of the families utilised their own parents or in-laws for support. However a number of families did not because their parents were ill, deceased, elderly, or living outside of Northern Ireland. Primary carers frequently expressed that they *"do not want to burden parents or in-laws*". Lisburn had the highest number of families receiving support from the child's grandparents (59%) closely followed by Bangor (51%). Lakeland had the least informal support from grandparents (34%). Grandparental support came in the form of both practical and emotional support, such as collecting the child from school, childminding and respite breaks.

Support from extended family varied between locations. Over half (56%) of all families said that their extended family were not involved in any type of informal support. *"None of our relatives would think to pick up the 'phone or call in, it's very much a 'that's your own problem' attitude."* Many felt that this was due to a lack of understanding, fear, or ignorance of the nature of the child's disability. Lisburn had the highest percentage of informal supports from extended family, whereas Bangor had the lowest. Those who did have extended family support named practical (13%), babysitting (13%), and emotional support (8%) as the main types of help. One family also received financial support from their extended family.

In summary, families in the Lisburn Service received the most support from family, whether adults, children, grandparents or extended family members.

Carers were also asked about other informal supports that came from outside of the family circle.

Neighbours

Lisburn had the highest number of families receiving support from neighbours in its sample (34%), whereas Lakeland had 31% and Bangor had much less (16%). Overall, nearly one third of the families across the three Services (27%) received some type of support from neighbours.

Friends

The number of families receiving support from friends is similar across the three Service locations (around 35%). One carer in Bangor commented *"It's one way to find out who your true friends are when you have a child with a learning disability. No-one will take N after school to play with their children. Many people don't live in the real world, they worry about trivial things about their own children, not things that are important."* More families had support from friends living in the same area (37%) compared to friends that lived further afield (21%). One family in Lakeland utilised *care-sharing* support. Perhaps, because of the rural location, Lakeland had the highest number of families receiving support from friends that were not close by (34%), whereas both Bangor and Lisburn had much lower percentages (approximately 15%). Support from friends not living nearby included 'emotional' support such as 'sounding off'.

Parents with a similar child
Overall, 21% of families found support in the form of 'other families with a similar child' mainly through peer support or in practical terms via respite. Lakeland has the highest number of families using this as a support (71.9%), Lisburn have 69% and Bangor 53%. Due to its rural locality and more limited social opportunities, it could be said that carers in Lakeland meet and maintain links with more people through their child with a learning disability.

Parent support group
Just over one quarter of Service families were receiving support from a parent support group. Lisburn had the lowest number of families (17%) attending such groups whereas Lakeland had the highest number in its sample (43%). The higher percentage of those in rural areas receiving this support could be as a result of the lack of access to other social support networks available to when compared to those living in urban areas. The different types of support groups that carers attend include PAPA (11%), the Down's Syndrome Association (4%) and other groups such as the Aspergers Network, Homestart, and PHAB.

Childminder
Only 13% of families have support from a regular childminder. Childminders were all called upon for respite support. Many voiced that they would like a regular childminder so carers could go out and do practical tasks, for example, going shopping or more social activities. However, recruiting someone they trusted with the expertise to care for the child's needs proved challenging. For those in rural parts of Lakeland, this was also more difficult. Out of the total sample, Bangor had the highest number of families receiving support from a childminder (9%).

2. External Supports: Formal & Professional

Families were also asked to comment on the number of formal and professional supports they were in contact with concerning their child's needs over the past year. These were listed from twenty possible professional roles which are detailed in Table 11.

Professional (contact within past year)	Yes	No
Teacher	97%	3%
Dentist	96%	4%
GP	92%	8%
Social Worker	90%	10%
Classroom Assistant	71%	29%
Speech & Language Therapist	56%	44%
Hospital/Community Doctor	42%	58%
Clinical Psychologist	30%	70%
Educational Psychologist	30%	72%
Occupational Therapist	39%	61%
Physiotherapist	28%	72%
Domiciliary Worker	22%	78%
Other Professionals	22%	78%
Community Nurse	21%	79%
Behavioural Support Worker	20%	80%
Overnight Respite Worker	14%	86%
Health Visitor	11%	89%
Further Education College Worker	8%	92%
Vocational Trainer	8%	92%
Trust Support worker	8%	92%)

Table 11. Types of formal support received

The number of formal or professional supports ranged from 1 to 16 (average 8; SD 2.6). Formal and professional supports were grouped into low (<5), medium (6-10) and high levels (11+) of external support.

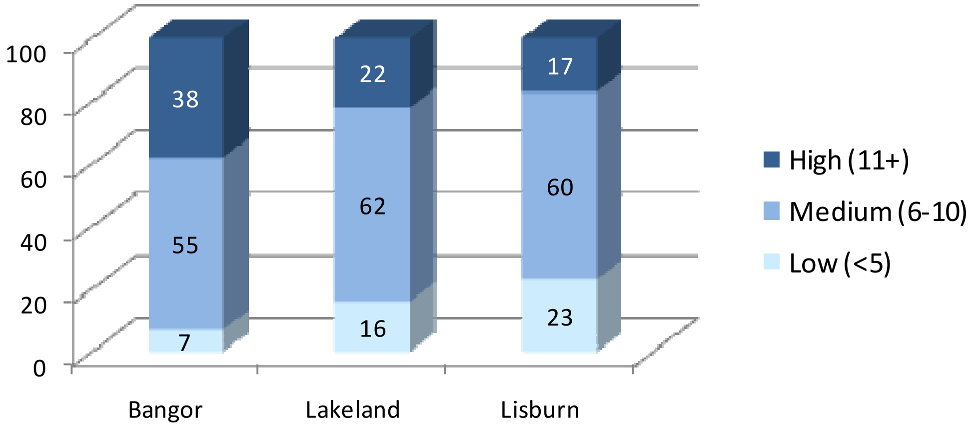


Figure 11. Levels of professional contacts families utilised

Very few families (7%) had less than 4 types of professional contacts within the past year. Overall, only 16% of families across the three locations had professional contacts in the ‘low’ range. Most families fell into the ‘medium’ category (61%) and the ‘high’ category (25%), suggesting the needs of the children were great. Bangor has the lowest number of families in the ‘low’ professional contact category and the highest number in the ‘high’ category (39%), indicating that many of their children had more complex needs. One family in Bangor has been in contact with a staggering 16 different professionals in the past year.

The most common professional contact/support came from teachers, Dentists, GPs, and Social Workers. There was a significant correlation between high levels of professional contact and the number of impairments relating to the child. When cross tabulated with the informal supports, 23% of the families that had few informal supports (1-3) had been in contact with at least 11 professionals, suggesting that these children have multiple needs yet the family has to cope with few informal support levels from the people around them. The sheer number of formal contacts further illustrates how difficult it must be for parents to manage different appointments and ensure effective communication between various health professionals. *“The most frustrating thing about caring for N is not the complexity of his needs, it’s getting service provision for him…getting them to acknowledge the level of his needs. You get weary of fighting for everything.”*

Financial Supports/Benefits

Guardians were also asked if they received any financial benefits, such as Disability Living Allowance (DLA) from the Government. Overall, 95% of families are in receipt of this. All families within the Lakeland Service (100%; N=32) receive some type of welfare benefit, whereas three families in Lisburn and two families in Bangor receive no benefits. The most common type of financial support received was Disability Living Allowance (DLA) (90%).

Carers were also asked if they had made any adaptations to their home to better accommodate the needs of their child. Over half of all families (57%) had not. 43% had made adjustments to their house or garden. Modifications included adapted areas such as roof space conversions, extensions, walk-in showers, and Perspex windows. Two families had built new houses and one family had moved to a more appropriate single story house (bungalow).

Families were also asked if they received assistance with the transportation of their child. 30% families were in receipt of such assistance. The Lisburn Service received the highest level of transport assistance (41%), followed by Bangor (32%) and then Lakeland (15%). Types of assistance included Mobility Vehicle (N=16; 65%), and transport to school and activities hosted by Positive Futures.

Supports for Children: Recreation and Leisure

Prior to accessing the Families Service, the majority of the children with a learning disability had little or no social activity outside of their school environment. Children mainly attended events or activities with other family members. Since 82% of children attended Special Schools, many rarely had the opportunity to mix with other non disabled children outside of the family unit.

Types of Activities Before Joining the Service

The most common type of activity that children attended before accessing the Service was ‘summer schemes’. These were provided by the child’s school, or by charitable organisations such as Mencap and the Down’s Syndrome Association. Only one child attended a local council summer scheme, highlighting that involvement in inclusive opportunities with non-disabled children was low. It also illustrates that due to the seasonal nature of summer schemes, families did not have a consistent, year-round activity for their children to go to. Only a handful of children attended ‘sport and leisure’ activities. These included, for example, swimming and the Special Olympics. Four children attended ‘Gateway’ clubs and two were members of a martial arts club. Another two children were involved in the local Youth Forum, one child was a member of NICCY, and one child was a member of a music band. 19% of the children went to church activities, commonly in the form of Sunday school classes. Very few attended uniformed organisations like Cubs, Campaigners, or the Girl Guides.

Activity Levels During Service

As part of the Family Support Service, children and their families are given the opportunity to participate in various activities. These opportunities include holiday schemes, after-schools clubs, buddy groups, weekly activities, and one-to-one support with volunteer mentors who act as role models in the young person’s life. Children are also able to meet new people, form friendships, be involved within their local community, participate in activities they enjoy, learn new skills and take regular exercise. All of these opportunities are used as a platform to bolster self-esteem and promote positive mental health in the child.

Demand for activities was high and well-attended. After accessing the Service, the average number of activities children were involved with increased from virtually zero to 2.5 activities per week and in many cases, exceeding that of their siblings.

Activities Offered

A wide range of activities are provided as part of each Service. Examples of sporting activities offered include swimming, horse riding, basketball, racquet clubs and dance classes. In conjunction with local schools, a variety of creative after schools projects were available including computer skills, cookery, 'fun in the gym', arts and crafts and drama.

Partnerships between the Services and other organisations enabled the children to attend local youth clubs. 'Buddy groups' made it possible for the children to choose their own programme of activities such as going out for a Chinese meal or watching an ice hockey match. Social and life skills were also developed through the Duke of Edinburgh Award Scheme and courses such as First aid and 'learning to use money' were also available. Personal activities tailored to the children's interests such as going to football matches, fishing, and to the theatre were also supported.

Person Centred Planning

Person-centred plans (PCP's) have been developed with all of the children using the Services. These person-centred support plans helped parents and their child to decide the most appropriate activities for them. Risk assessments were carried out with all children participating in activities. Person-centred thinking tools (http://www.helensandersonassociates.co.uk, for example) were used to evaluate unmet need and to document personal progress. This also helped parents to think about planning for the future.

Service Leavers

This year, 18 children will no longer access the Families Services as they will be making the transition into adulthood. This is a serious concern for families as many believe they will lose the regular emotional and practical support that they depend upon from the Families Service. Follow up research should be conducted on young people making the transition into Adult Services to assess the impact that this has upon their lives.

This Chapter has highlighted the low level of informal support families received and the dearth of social opportunities that their children experienced before they accessed the Families Service. It also provides a synopsis of the type of activities children participated in and the person-centred approaches that the Service adopts to meet the individual needs and aspirations of the children.

Chapter 5: Longitudinal Research Study

This Chapter presents the findings from a longitudinal research study that was conducted to discover the impact of the Families Services on the families who were accessing it.

Research Methodology

Data for the study was collected between 2005 and 2008. Once consent was sought and obtained, participating carers were interviewed at home on two occasions approximately 12 months apart. On the first occasion (Times 1) they were asked to complete a baseline proforma followed by a number of standardised Likert-scaled questionnaires. Each questionnaire had proven reliability and validity. Carers rated how they felt according to a number of possible statements. Response typically ranged from "strongly agree" to "strongly disagree" on a 5 point scale. The questionnaires administered are outlined below (further details are provided in Appendix 1):

- Basic Details Performa of baseline child and family data (Times 1 only)
- Social Opportunities Questionnaire
- Family Functioning Questionnaire
- Parenting Stress Index
- Parent Satisfaction
- General Health Questionnaire
- Vineland Adaptive Behaviour Scales – Interview Edition
- Aberrant Behaviour Checklist
- Pen Picture (Times 2 only)

At Times 2, the carer was interviewed by a Researcher who was independent of the Service. The Researcher re-administered the same questionnaires and a "pen picture" was also created which described the family's life at that time and the carer's experiences of the Service. In total more than 800 questionnaires were completed in this process. The results from the Times 1 and Times 2 questionnaire data were contrasted to ascertain any direct impact the Service had on the family and to determine any differences between the experiences of families living in rural and urban areas in terms of supports, coping strategies, barriers faced and Services received.

In addition to the quantitative information derived from the questionnaires, the Researcher also administered a semi-structured questionnaire. This enabled parents to talk in more detail about their experiences of using the Service, to identify its strengths and weaknesses and also to relay their perceptions of the impact of caring for a child with a learning disability. These qualitative findings were transcribed and thematically categorised using constant comparative techniques (see Lincoln & Guba, 1985: 347). In addition, a 'pen picture' was completed on each family. These provided a valuable insight into each carer's perspective of own life and family circumstances at that particular time.

Participants

At Times 1, N=54 (52%) of all families using the Service agreed to take part in the evaluation. At Times 2, a number of families (N=6) withdrew from the evaluation for various reasons, for example marital separation, family crisis or the child was no longer availing of the Service. At Times 2, around half of the total number of families using the Families Services N=48 (46%) had participated in both the Times 1 and Times 2 evaluations. For consistency and comparative reasons, only families who completed Times 1 and Times 2 data are included.

General Characteristics of Participants

The Lakeland Service had the highest number (N=20; 41%) of families participating in the research study. The Bangor Service had N=19 (39%) and Lisburn had N=9 (18%) participants. All families are from white, English speaking ethnic backgrounds. In general, the characteristics of these families did not differ greatly from those in the census. Informants in all but one case were female.

Children

There are 30 males (63%) and 18 females (37%) included in the evaluation. At Times 2 the average age of the children was 12.8 years (min 8; max 18). Over one third (35%) of children have an Autistic Spectrum Disorder and one quarter have Down's syndrome. Other children have conditions such as Global Development Delay, brain injury or Attention Deficit Hyperactivity Disorder (ADHD). The average number of conditions per child is 3.5 (min 1 max 7, SD 1.5). One third of families have a child with more than 5 conditions which is indicative of complex needs. Seven families (15%) have a second child with either a learning disability or a serious illness. All the children in the research study have a statement of special educational needs. The average number of leisure and recreation activities each child participated in was 2 (min 0; max 6).

Carers

Across the three Services, 19% of families are lone parent carers. Over one third (37%) of carers had completed third level education and 83% were owner-occupiers. 45% of informants were in either full time or part time employment, and 38% had an annual income of less than £16,000. In 83% of households there was a main wage earner. Two thirds of families (62%) were over the age of forty. The average number of contacts with professionals in the last 12 months was 8 per family. Most families could name 4 informal types of support. However 42% of families had low levels (1-3) of informal support.

In terms of deprivation, Bangor is the least deprived area with a mean MDM of 687, followed by Lisburn at 518. The most deprived area is Lakeland which has a MDM of 326.

Analysis

For the analysis, data was anonymised and each family was assigned a unique code to identify them. Statistical analyses techniques (both descriptive and inferential) were used to calculate frequencies, percentages, and measures of central tendencies using SPSS software (Version 15). Any items that were not completed in the interviews were treated as missing data. Data was cross-tabulated in order to assess levels of significance and differences between the Services in rural and urban areas. Non-parametric tests (Wilcoxon Signed Ranks Tests) were used to compare the results of the questionnaires over the two time frames.

Findings

1.General Health

The General Health Questionnaire (GHQ) consists of 28 items and is commonly used to assess psychiatric morbidity within the community. The questionnaire is divided into four subscales: somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. Carers rate how they have felt over the past 12 months. A score of 8 or greater, is indicative of health problems.

Almost 50% of carers said they felt "run down and constantly under strain". Nearly a quarter reported having pains in their head. 50% also reported losing sleep over worry. Over one third had felt unable to cope because they felt "like everything was getting on top of them". One fifth felt unable to enjoy their everyday activities and 10% felt that "life was hopeless" and "felt worthless". Three carers had contemplated suicide.

At Times 1, the average GHQ score was 5.1 (SD 6.4). One quarter (N=12) of carers showed signs of health problems. Three individuals had very high scores which were over 20. At Times 2, the number of carers scoring above the threshold had increased to N=17 (35%). The average score was 6.2 (SD 5.9). However, there was only one carer scoring over 20 at Times 2 and despite the slight average increase, a number of carers scores either stayed the same (N=10) or decreased (N=14), suggesting that in several cases, levels of health had improved over the past year.

Carer's health could have been impacted for a number of reasons. Chronic stressors, for example the constant 'fight' for support services, having other family members that were ill, and more general pressures associated with having a child with a learning disability. Financial constraints or managing challenging behaviours could also be linked to their poorer health. These stressors had impacted on the carers mindset and physical well-being.

"I've got fibromyalgia and arthritis. I'm slow on my feet and I don't drive anymore. I get little sleep and am constantly on painkillers."

A number of carers mentioned they were on medication for depression and anxiety and self-blame was frequently mentioned. Some described themselves as having low self-esteem. Others expressed physical weariness and exhaustion. Four carers were due to have surgery in 2008 and several mentioned they had suffered illness in recent times.

"Both my in-laws are ill, one is recovering from cancer. But they don't really understand about N. I feel so alone. My own family live a few miles up the road, but they never make an effort to see us…society has such unrealistic expectations. My husband works long hours and I have a young baby to care for too. N doesn't sleep at night and I have to watch her all the time for fear that she will self-harm. These demands have left me completely exhausted and I often feel like I can't cope, life is so stressful and it all gets on top of you. I have no choice… but to get on with it."

2. Social Lives of Carers

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

The average number of responses between the two timeframes shows that most primary carers seldom get the opportunity to do things on a regular basis (Figure 4). The most common response was the 'occasional' opportunity to participate in social outlets. Overall, the results indicate these primary carers would be deemed 'low socialisers', compared to the rest of the population, most likely because of the constraints of their caring role.

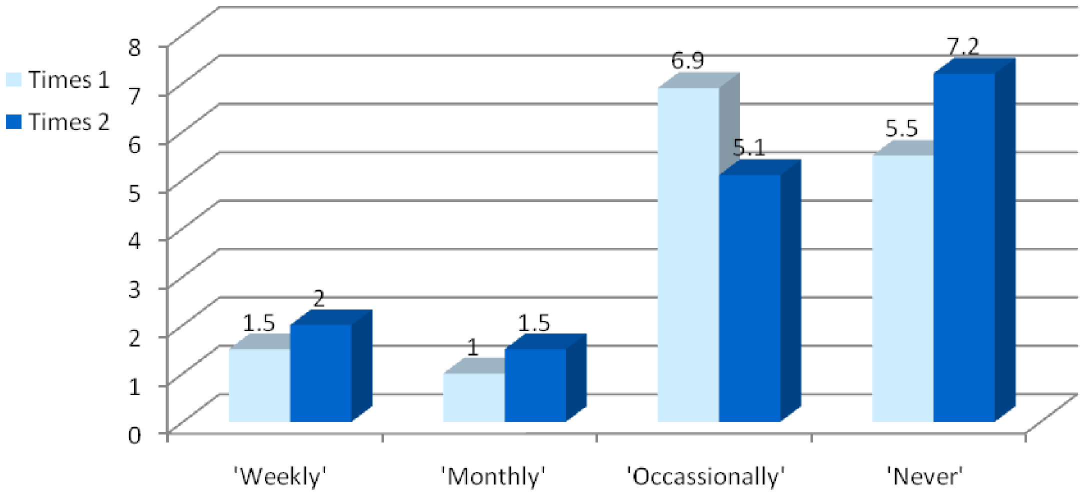


Figure 12. Average social opportunities of Carers at Times 1 and Times 2

As can be seen, the number of 'weekly' and 'monthly' social opportunities have increased slightly between Times 1 and Times 2. This could be as a result of the Families Services freeing up more time for the primary carer to do more things when their child is involved in activities. The most common weekly activities included 'having friends or family come to the house' (38%), 'church related activities' (35%) 'evening classes or training' (33%) and 'sports or exercise' (23%). There were a number of carers (10%) who were studying in tertiary education and this was used as a mechanism to strengthen confidence and gave carers an outside focus. Others reported that they were taking vocational courses such as aromatherapy and driving lessons.

Many mothers admitted that they were the last person they consider in the family, as their efforts were mainly focused on other family members. One quarter of informants also spoke poignantly of being excluded from social events like family get-togethers or dinner parties with friends because of the lack of understanding by both relatives and the wider society.

"We have no close family support. We are isolated. We can't get out to the cinema or for a meal as a family because of N's needs. Our neighbours and family circle have rejected and forgotten about us. Like last week…. I received an invitation to a wedding and everyone in this family was invited except N. People don't realise how hurtful they can be."

Family holidays were infrequent. Parents spending time together was also limited by the difficulties associated with organising childcare from trusted sources who understood the needs of their child. Older siblings and grandparents frequently stepped in. Nevertheless, not all families were able to depend on older siblings and in many cases grandparents were infirm or deceased. Lone parents tended to rely on extended family or support from older children in the family. Many carers said they didn't get the time or the opportunity to take part in physical exercise and because of these restrictions, many enjoyed the convenience of walking as a means to 'get their head showered'. In families where children had more challenging behaviours, routine activities like going to church or going shopping were done separately by the parents/guardians, as this was perceived as less disruptive for the family. In the Lakeland Service the isolation felt by carers exacerbated their ability to carry out everyday tasks.

"Being in the country…not everything is on your doorstep and even getting the shopping involves planning well in advance. Although the location is better suited and safer for N, it does have its downsides for the rest of the family, especially socially for his sisters and us."

3. Family Functioning

This scale asks carers about the decision-making ability of the family unit, communication between family members and support during crises. There were no significant differences in family functioning between Times 1 and Times 2. The mean score at Times 1 was 36 (min 24: max 44; SD 3.9), and 35 at Times 2 (min 25: max 42; SD 3.1). Generally, there seemed to be reasonable levels of family functioning. Overall, most families felt that they were cohesive and communicative although disparities do exist. For example, some carers indicated that they try not to talk about their present situation or the sadness they may feel about having a child with a learning disability. 20% said they found it difficult to express feelings to each other. Two families have partners who are away from the family home during the week with their work and this may also have placed pressure on the coping strategies of the primary carer. 23% reported there was “bad feelings in their house”. Often, getting their male partner to ‘open up’ about their feelings was a struggle for mothers. Many carers recounted the first few years of the child’s life being spent in hospital; constantly travelling to and from hospital and this had added to the pressure of the family unit. Others felt this had brought them closer together. *“We didn’t have anything like Positive Futures back in those days!”* one carer exclaimed.

One fifth of families did not feel accepted by wider society. Many recollected hurtful experiences of discrimination and ignorance. 30% of families found planning activities challenging. Knowing what was best or suitable for the child and taking into consideration the needs and feelings of other siblings in the family appeared difficult to balance. Some experienced issues with rebellious teenagers in the family; other siblings wanted to bring their friends to the house but felt embarrassed because of their brother or sister’s behaviour or condition. Many parents felt that their other offspring may have felt neglected because of the constant demands and attention placed on the child with the learning disability.

“When N is with Positive Futures I can plan to do something together with my other child, and it’s important we have that time so that he doesn’t feel forgotten about. It’s hard to do that when N is around as there is a big age gap and they have very different interests.”

Despite this, most siblings were described by carers as being very protective of their brother or sister.

4. Parent Stress Index

The purpose of the Parent Stress Index (PSI) is to produce a diagnostic profile of perceived child and parent stress. The PSI is based on the theory that total parental stress is a function of child and parent characteristics, as well as situational variables. The total stress domain measures the level of stress in the parent-child relationship. The child domain measures the child’s distractibility/hyperactivity, adaptability, reinforcement of the parenting experience, demandingness, mood, and acceptability. The remaining seven subscales make up the parent domain and measures: competence, isolation, attachment, health, feeling of role restriction, depression, and spousal support.

The results of this questionnaire reveal that these carers are “significantly” more stressed than the general population, with many total scores being in the highest percentile (85-100). When asked how they rated themselves as parents, most carers (39%) rated themselves as ‘average’ parents. 9% admitted they had some trouble in the parenting role. *“If I am out with N and he is hitting out, people stare and I feel they judge me as a bad parent.”* Others commented on the vulnerability of their child *“N treats everyone the same - she is very trusting and would speak to anyone and believe whatever they tell her. I worry about her being ridiculed, bullied or worse.”*

Carers were asked how they coped with the demands of their caring role and most replied *“you have to, you just do. No-one else is going to do it for you… you get used to it and keep going, one day at a time.”* Another commented, *“you get the strength from somewhere. You have someone who is totally dependent on you, you don’t allow yourself to be exhausted.”*

Parents were asked to think about the number of behaviours that their child exhibited that bothered them (for example dawdle, refusal to listen, hit out). Carers described a variety of mannerisms and behaviours. Most carers stated that their child did about 4 or 5 things that bothered them. *“N will self-harm, and because he can’t speak, I get so distraught trying to work out what he needs. I know he’s not doing it for badness - he’s frustrated.”* One quarter felt that their child had 8 or more behavioural tendencies that bothered them.

“Life is determined by N, we put him before all of us. N has no speech and can be intolerant of noise. He can be demanding and a nuisance in some ways – one minute he will be fine and the next he will have nail varnish everywhere; he wouldn’t know about “stranger danger” or that things like bleach are dangerous. He bites his hand and he can slap his head. It’s like having a puppy in the house ... relentless..... a constant risk, running after him and checking he is safe. N can have periods of sleeping well, but if he is tired, he can be very challenging, even a cold can really upset him and make him miserable. The summertime can be a nightmare.”

63% of informants found it harder than they expected to ‘get their child to do something or to stop doing something’. 90% of informants reported that they found themselves giving up more of their life to meet their child’s needs than they had ever expected. 80% of carers felt their child made more demands on them than most children, one commented *“it’s a 24 hour job…he needs constant supervision”.* A similar percentage believe that their child reacted very strongly when something happened that the child didn't like and 78% felt that their child found it difficult to get used to new things. Many also said that they felt their efforts were not often appreciated. *"There have been times when I wonder what it's all about and I question everything."* 63% of carers had problems with their child's eating and sleeping patterns. *"If he starts to eat the wrong thing, like sweets or anything with artificial colours, it's like a person on drugs, he starts to chew the furniture".* Almost half (46%) revealed that having a child with a learning disability had caused problems in their relationship with their spouse or partner.

5. Parenting Satisfaction

There were no significant differences between Times 1 and Times 2 for parenting satisfaction. However, between Times 1 and 2, 50% of carers parent satisfaction scores had increased indicating that they had become more positive about their parenting role. The majority of carers scored slightly higher than the midway point at both intervals and despite the difficulties, most carers reported a great feeling of accomplishment in caring for their child. Carers spoke of the love they had for their child. *"I wouldn't swap N for the world."* However, this was also tinted with some sadness. Acceptance of the child's disability was a difficult issue for some. *"It's like grieving for the child you never had. I see a child who was born in the same hospital on the same day as N, around town. She will be dating boys and learning to drive and I know N will never be able to do that."*

96% of carers believe that their child provides them with a challenge. A similar level of agreement was found when asked if having a child with a learning disability had led the carer to develop new skills or abilities. 90% also thought that their perspective on life had increased for the better. For example, 77% of carers felt that they had become more compassionate as people. "*N is so loveable….she's my life, I am blessed by what she can do rather than what she can't."* Nevertheless, 48% felt that their spirituality had decreased since having this child. 27% felt that their social and community networks had not increased and 11% of carers poignantly felt that, their child did not give them love or affection.

6. Vineland Questionnaire

This scale enables an assessment to be made about the behaviours of the child and is useful to illustrate the different levels of the children's development. The scale consists of 297 items and is divided into five domains concerning the child's development (communication, daily living skills, socialisation skills, motor skills and maladaptive behaviours). It is acknowledged that there was a wide range of variation between the children scores because of the diversity of the children's abilities, and this is reflected in the results.

In general, no development was made by the children in the daily living skills area; the data suggests that the children have regressed one year on. By contrast, the children's socialisation and motor skills have significantly improved, more than would be expected by the passing of time. This could arguably be because it is these issues that the Service tended to focus on and develop. Communication scores are similar in Times 1 and 2. In sum, the results indicate an overall improvement in their raw scores. Descriptive statistics are shown in Table 12.

Vineland Totals	N	Mean	Std Dev	Min	Max	25th	50th	75th
Times 1 Communication	45	45.5	20.5	19	109	28	44	53
Times 1 Daily Living Skills	45	55.9	17.3	20	106	48	53	64
Times 1 Socialization	45	40.0	21.1	19	92	19	36	54
Times 1 Motor Skills	45	70.4	27.3	19	113	46	73	92
Times 1 Maladaptive Behaviours	45	24.9	13.7	1	59	14	27	35
Times 1 Total Score	45	237	68.1	101	409	186	231	275
Times 2 Communication	48	47.2	23.5	19	114	29	43	58
Times 2 Daily Living Skills	48	39.8	22.6	19	101	19	38	55
Times 2 Socialization	48	57.1	22.1	19	112	43	55	71
Times 2 Motor Skills	48	81.9	27.6	19	113	55	88	111
Times 2 Maladaptive Behaviours	48	24.6	15.0	1	61	10	25	37
Times 2 Total Score	48	250.8	72.7	95	422	208	252	290

Table 12. Summary of Vineland Scores at Times 1 and Times 2 intervals

Aberrant Behaviour Checklist

Finally, the Aberrant Behaviour Checklist (or ABC) was administered to carers. This questionnaire examines in further detail the behaviours of the child. Again, while there were no significant differences between Times 1 and 2 and some scores had remained similar, nearly half (47%) of the children's total scores had decreased. This indicates that overall, behaviours had improved between Times 1 and Times 2. This is likely to be linked to the positive impact the Service has had on their aberrant behavioural tendencies.

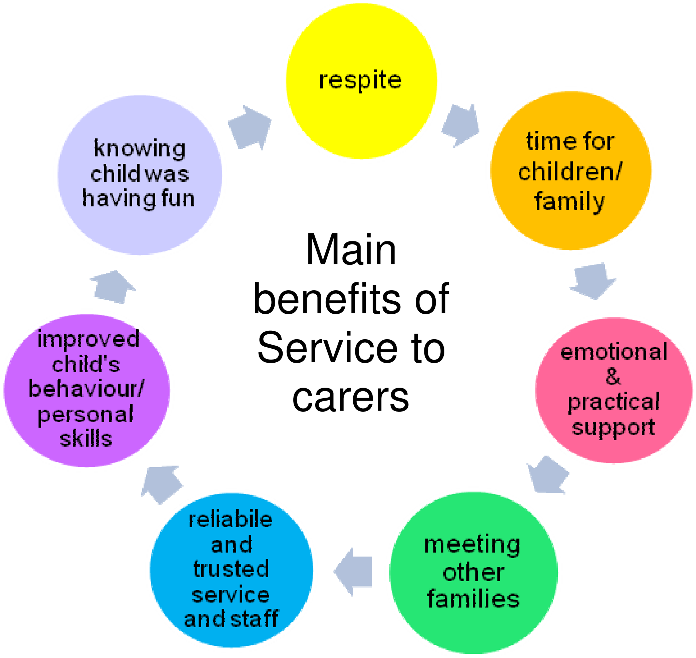
"When N is with people similar to him all day, his behaviour mimics that of those around him. But when you put N with "normal" people, his behaviour improves dramatically. By being with others he is learning how to behave in a more socially appropriate way."

Semi-Structured Interviews

Semi-structured interviews were also conducted with the 48 carers who participated in the research study. The purpose of the interviews was to delineate carers perceptions of the Service and to highlight areas for further development or improvement. Consensus was extremely positive across all three Service locations and carers cited multiple benefits and outcomes for the child and their families. The main themes are now presented.

Service Beneficiaries: Carers

Carers spoke very highly of the Families Service and how they believed that there was 'nothing else that was like it'. In spite of the resource limitations of the Services, carers commented how grateful they were for the support provided. The most frequently cited benefits to carers are highlighted below.



A number of carers reflected on how challenging and stressful life was but that they felt fortunate to receive the Service as it relieved some of their stress and worry.

"My husband and brother both have serious illnesses. Although my other four children are a big help and very accepting of N, it has been really difficult for me to get any help from Social Services. Before Positive Futures I felt like I had no back-up"

"I know how lucky were are, there are many families nearby who don't get anything and yet are also in great need of support."

"I get a break…It's really filling a need, and I hope it continues. I have got to know others through the Service. It makes me realise I am not alone."

"I used to dread the holidays coming around in the past. Now we all look forward to them. It's a lifeline for our son. Thank you so much Positive Futures!"

Carers also commented on the professionalism and the genuine interest staff and volunteers had for them and the reassurance they felt knowing their child was safe and with people they trusted.

"She looks the same as other kids to you and me, others wouldn't know she has a learning disability by looking at her. You just wouldn't know who would take advantage out there, especially because N can't verbalize her feelings…Staff are brilliant, they're vetted and they know N's temperament …they're always there as an ear to listen too. I can't fault them."

"The Family Workers regularly check to see how we are all doing and to offer advice. They are extremely professional when issues arise. They're helpful too in other ways, always looking for new things that N could try or might enjoy."

"The staff and the volunteers are terrific! They have a great skill in being able to include N and persuade him to try new things and to go to activities even when he adamantly doesn't want to participate in something. His brother is also involved in football run by Positive Futures and that's given him a new lease of life too."

Other carers who lived in more rural locations appreciated the lengths the Service had gone to in making activities possible for their child.

"It was a complete answer to prayer! We are so thankful. Because we're so far out in the country it had been really stressful driving the dark roads in the winter to take N anywhere. Now I don't have to worry... she gets picked up from the door and brought back safely. If it wasn't for Positive Futures, N would be sitting at home, bored. There's no doubt that it's transformed her life."

The person-centred ethos of the Service was also a common theme of comments from carers; that staff placed the child at the centre of everything.

"It's all about N. It's given her the chance to do things, things that are not connected to school. It gives N a life. No other service is like it."

"N loves swimming but I am afraid of the water. Positive Futures are able to bridge this gap and do the things for my child that I can't do for him. That's a huge weight off my mind. I know he's happy."

This way of working also, for the first time, helped many parents to look to the future, something that many confessed they didn't want to think about.

"I find it hard to think about the future…I know we won't be around for N forever. I don't want N to be a burden on her brothers, I want them to be able to have their own lives when they're grown up. Its scares me what might happen as I know no-one will be able to look after N the way I can."

"I don't want my son to go to Day Care. Positive Futures have shown everyone what he can do and I know he would really enjoy working in part-time employment. He's become really good on the computer and is great with his hands. Positive Futures break the mould and challenge others' expectations."

Carers expressed high hopes for the Service to continue. Many referred to it as a 'lifeline', a 'blessing' or a 'godsend'. Overall consensus was that carers 'wouldn't be able to cope without it'. Many had become reliant on the break it provided.

"Positive Futures have always been consistent. Other domiciliary schemes we have been involved with before have cancelled on us and frequently let us down. Positive Futures take all that worry away from me."

Others felt that initiatives such as the 'Sibs group' had provided a supportive environment for siblings to experience opportunities and had helped them to realise that they were not coping alone.

"My other daughter got the opportunity to go to a "Sibs group" as before she felt left out…She used to get very embarrassed about Ns behaviour. Thank goodness these programmes are on offer to support other members of my family too."

Likewise the 'Women Carers Project' (see page 64) had enabled mothers to meet together and embark on an emotional and empowering journey of personal development.

Irrespective of their own financial circumstances, carers were willing to contribute either financially or practically to the Service to ensure it continued. Many families had asked other family members to help out too.
"My husband and other son are heavily involved in volunteering with the Service. We really believe in it."

Children using the Service

Carers also identified a number of positive outcomes for their child. The most common responses from carers related to the activities the children participated in.

“He can’t wait until the next outing and always asks about it. The range of activities he does is fantastic.”

Many felt that the Service had opened up a whole new world for their child.

“It is wonderful to see my child get opportunities - dance, drama, cinema, trampolining…it’s really been fantastic, in fact, life changing. I’d be lost without Positive Futures”

“You have to engage with N to bring the best out in him- just like you would with the elderly, he needs people to take time and to interact with him, that’s what the Service does. It’s amazing to see how he has come on.”

In particular, the opportunities to participate in new and inclusive opportunities had notably increased interpersonal skills and improved behavioural patterns in the child. These included increased confidence, improved communication and social skills – such as eye contact, listening skills and reduced aggressive tendencies, better sleep patterns, and improved co-ordination.

“It helps N to be less aggressive and hyper. He loves all the sports and that helps release all his energy and frustration. There’s nothing on offer for teenagers like N, no-one else will take responsibility for my child, that’s why Positive Futures have been so good.”

“It’s the best thing that’s ever happened to N and the rest of the family. He’s grown so much as a person and “come out of his box”… his confidence, interaction and communication skills have soared.”

“My child is getting the chance to be involved in things that we never thought he could be. It’s giving him independence from us so that N can establish relationships without us being there. His behaviour has also improved; he is mixing with more people and learning to adjust his temperament.”

The social aspect of the Service was also seen as a huge benefit to the children. Others felt that the Service was keeping their child fit and giving the child opportunities that wouldn’t be as beneficial if the parents were present.

"It's great for N to meet people that aren't her school friends."

"Having the volunteer to take N out means that N is able to do things with someone who is at a similar stage in life, rather than us old ones. That's important."

"Before Positive Futures N had no real friends. He wouldn't know how to form relationships and he liked his own space. He tends to join in more and come out of himself when I'm not around. I can see him getting more confident."

"N has autism and needs routine. The physical activities, like swimming, means that he is keeping healthy and getting fit and this keeps his mind active. Activities are broken down so that he can understand. It's tailored perfectly for him."

Carers commented about the reliability of the Service, that it was something that they could rely upon in spite of other upheavals. The consistency and structure it brought to the child's life and the peace of mind knowing that their child was in safe hands were also repeatedly mentioned.

"I can close the door, and have time to switch off. This is a 24 hour job and I can't leave her for a minute. The Service takes the pressure off me and I need and appreciate the space."

Carers also spoke of personal milestones and increased competence that their child had achieved through their involvement with the Service.

"He always comes last in sports in school, and being involved with Positive Futures and the Special Olympics gives him great happiness and goals to aim for. It has also given him a huge social network and has helped him to develop interests….helped his communication skills and taught him to share and support others who need more help than him."

"I wouldn't be without Positive Futures …all the family are so proud of what N has been able to achieve with the help of the Service."

"The Service has highlighted things for us about N that we didn't know he liked or could even do."

Some carers also identified how Services like Positive Futures may be able to help the government in the longer-term.

"The Government needs to rethink its strategy and provide more money to children with learning disabilities so that in the end we aren't draining resources down the line. Such Services will help governments save money in the end. I wouldn't want it to stop. But it does need more funding and more volunteers".

Overall, findings revealed that that 96% (N=46) of carers interviewed were completely happy with the Families Service and would recommend it without hesitation to other families in similar situations. Two carers in the Lakeland Service were less satisfied. One felt that despite the benefits that the Service brought, she felt that her family lived in too remote a location for the time it took to get her child to and from activities to be of benefit. Another carer, whose child had been with the Service since its inception, felt that the Service had grown so much that it had become less tailored to meet the needs of her child.

Carer's 'Wish List' for the Service

Carers were asked about other activities in the Service that they felt would benefit their child. Overwhelmingly, the majority of responses from parents echoed the view that the Families Service had already achieved so much to help meet the needs and wishes of their child through its person-centred approach.

"I wouldn't change a single thing! The times that are available and the choice of activities is all very convenient, and not too far from where we live. Before joining we had no outside support… especially when N was under 10 and there are no other families with a child with Autism in the area. N has very few school friends and there were many times when he would be left deliberately out of activities with other children, and sent home from other people's houses…so cruel. It would have been wonderful to have Positive Futures back then too."

"For us, Positive Futures is the caring partner who will look after our child's best interests. We don't need to be there in the shadows checking she is alright. We simply can't get enough of it."

"If I had a million pounds I would give it all to Positive Futures. I can't thank them enough for what they have done for my granddaughter."

Carers were also asked, if given a 'magic wand', what more would they like to see made available for their child in the Service. A number of suggestions, some of which are Service-specific, were made:

• Golf/driving range • Line dancing • Saturday Youth Club • Visits involving farm animals • Horse-riding • Board games • Yoga for teenagers • Soft play • Laser-quest • Gymnastics • Safe space for child to ride bike	• Outdoor-based activities e.g. abseiling; canoeing • Practical activities - e.g. mucking out at farm • Part time work experience e.g. at dog kennels, in a kitchen. • Discos and activities geared towards teenagers • Musical instruments class; especially different types of music, such as jazz and percussion • Computer games or club/IT training

Table 13. Carers' "Wish list" of future activities for Service

Other key recommendations by carers included:

- Longer timeframe for activities
- Difficult for some carers to get their child to attend activities during weeknights as children can be tired
- Increased number of weekend breaks/activities
- More inclusive activities with non-disabled peers
- Increased recruitment of volunteer 'mentors' for teenagers
- Some carers have to stay with child at activities and this may defeat the purpose of letting them have a break.
- More suitable venues in Fermanagh as some were not as convenient due to the infrastructure; time taken to and from venues can be lengthy.

It was also evident than more support is needed for carers. Since their lives are primarily taken up by their caring role, many suffer from poor health, low self-esteem and few social support networks. Carers need increased respite, in addition to flexible, responsive support services. Some suggested that they would like better information about services and support networks and more help with paper work/form filling. Carers with children who have no speech or challenging behaviours suggested that aromatherapy or massage courses would be useful so that they could provide this to their child to help settle or relax them. Person-centred plans for carers should be adopted.

This Chapter has presented the findings of a longitudinal research study involving carers of a child with a learning disability. The study highlights the high levels of stress, poor health, and the range of family functioning, social opportunities and parenting satisfaction of carers. It also provides an overview of the diverse range of behaviours and development levels of the children within the Services. Carers also gave their views on the Service and the consensus was that it had made a very significant difference in the lives of the families. Carers no longer felt like they were coping alone. In addition, they expressed delight at the personal milestones that their child had reached and the interpersonal skills they had developed. The Service has indeed proved to be an invaluable lifeline which had transformed many lives.

Chapter 6: Views of Stakeholders

The final part of the evaluation sought to take into account the views and experiences of stakeholders. These were obtained via 19 semi-structured interviews and 7 focus groups. Details of these methods are presented below.

I. Focus groups were conducted with 2 cohorts of Social Workers from the one Health & Social Care Trust. One focus group also included staff from Positive Futures.
II. 3 focus groups were also conducted with children attending an inclusive summer scheme; 2 groups were with non-disabled children and 1 group was held with children with a learning disability who were supported by the Service.
III. In addition, 19 semi-structured interviews were conducted with other key stakeholders; volunteers (N=7), community development workers (N=4), and Service staff (N=8).
IV. Finally, to gather a more complete view of how the Service operated, the Researcher also observed children interacting with staff and their peers at two activities during their summer scheme in 2008. This included a trip to the 'ARK' farm and a games day.

Views of the stakeholders are presented and several recommendations are also presented.

Social Workers

In general, Social Workers in both focus groups expressed an incomplete understanding of the remit and purpose of the Service. Many thought that its main purpose was the provision of activities for children rather than a holistic family centred service. Several commented on the potential duplication of work around the Service Plan and the visits to the family each month. Person-centred working was also queried as the Trust uses this way of working for specific purposes, such as at transition. Others suggested that some parents did not associate the partnership link between the Trust and the Service. One Social Worker commented, *"when one service doesn't know what the other is doing, it provides some families with the opportunity to "play us off" against each other in terms of service provision."*

Recommendations:

- Initial family referral visits should be held jointly with the family, their Trust Social Worker and Positive Futures' Family Worker to ensure a clear understanding and good working relationship from the start.
- Decisions on support should be made explicit from the initial visit.
- To increase accountability and governance, regular, meaningful and 2-way communication and information sharing between the Trust and Positives Futures should be happening across all Service locations. This will help to minimise duplication of work.
- To encourage more positive working relationships, quarterly meetings are advocated as a means for both partners to update each other and to share best practices/learning.

Children and Young People

While attending an inclusive summer scheme, the Researcher conducted 2 focus groups with non-disabled children and 1 focus group with children with a learning disability who were supported by the Service. The average age of the children in the focus groups was 10.9 (min 9: max 11).

The 2 focus groups with non-disabled children comprised of 7 males and 7 females. They were asked about what they liked about the summer scheme, and more specifically what they thought about having children with a learning disability at the scheme. Many of the children had attended the summer scheme for a number of years and looked forward to it as it gave them something enjoyable to do during the summer months.

Generally the children thought that the summer scheme was very good as there were no other clubs like this in the area. Three children suggested that people with disabilities are often considered "different". One commented, *"it's important that we treat them like us"*. However, two younger children did not fully understand what a learning disability was and thought that people with learning disabilities should look physically different. Others suggested that it had helped to raise their awareness about disability. *"It's great ... it includes children with disabilities, they don't feel different; there isn't much they can't do here, they're just like us really."* Another said "*it brings everyone together, it's something for us and now something for them too. We are all friends."* The non disabled children also reported that they had become more considerate. Many demonstrated ways in which they had been helpful, *"I like helping them when they get stuck, opening doors or if they can't do something"* and another said, *"I have learnt to be more tolerant and kind"*. Four children identified that the leaders were very supportive in helping the children with a learning disability. Eight also commented on the behaviours of the children with learning disabilities, such as, *"some don't understand personal space, they just come right up to you. I don't say anything to them...I have learned to be patient, speak more clearly and slowly so that they understand. I would never shout if they did something wrong."* Others identified how sad they felt that some children were limited in their ability, *"some can't join in the physical games and I feel guilty that I can."* Concerning their feelings about inclusion none of the children would prefer a separate club for those with a learning disability *"it's good for them to be here - there would be no other clubs for them and a separate club wouldn't be as interesting for us."*

A focus group was also held with 5 children with a learning disability supported by the Service who attended the summer scheme. Each child mentioned how they enjoyed the scheme and what their favourite activity was. They had all made new friends and it gave them something enjoyable to do; before joining they did not know any of the non-disabled children. One said *"it's fun"* and another commented *"I get to do stuff I don't get to do at home."* Two also mentioned how helpful the leaders were. When asked what the children had done before they started the summer scheme they replied *"watching TV, playing in the garden."* Outside of the summer scheme there appeared to be little interaction with non-disabled peers, except with their siblings. All children agreed that they preferred coming to the scheme than being at home.

Recommendation:
Both the disabled and non-disabled children have valued the experience of attending inclusive activities such as summer schemes. More opportunities for inclusive schemes should be made available not solely during the summer months but throughout the year, helping to break down barriers and the social exclusion young people with a learning disability currently face in society.

Community Development Workers

Semi-structured interviews were also conducted with 4 community development workers (2 males and 2 females). This included the Director of an integrated drama project, 2 Youth Co-ordinators of integrated youth clubs, and a trainer from a Women's Carers Project. All had worked closely in partnership with Positive Futures.

Each informant spoke enthusiastically of the wide range of benefits of the Service and how it was meeting the needs of children and their families. The most common benefits mentioned concerned inclusion and community participation. Informants also commented about the safe or trusted environment. One reflected *"not only are the children mixing and coming out of their shells, but they're having their peers tell them to wait in line like everyone else and to share, and that's really positive. They get treated like everyone else."* Another said *"it completely challenges the norm... what we are doing, so that the environment the children are in* ***becomes*** *the norm. It has taught me and my own staff to think more about inclusion and how they treat others. The youth club is very flexible so if a child doesn't want to join in they don't have to. It also empowers children to go on and become young leaders."* One recommended that these initiatives should be extended and more widely available to raise awareness in younger generations.

Volunteers

Volunteers provide crucial support in each of the Families Services. As part of the evaluation the Researcher interviewed seven volunteers (4 males; 3 females, age range 21 to 50) across the three Services. Their average length of involvement with the Service was approximately 2 years. Volunteers support children at group activities and some work with specific individuals in a "mentoring" role. They come from a diverse range of backgrounds and each volunteer shared their story about how they had become involved and what they thought about the Service. The key themes that emerged included:

- Being involved with the Service had given children a 'fuller life' and brought awareness to the wider community
- Volunteers main reasons for involvement were to help others; 'feel good' factor and personally rewarding, felt valued by Service and families
- Dedication to the Service was high
- All had learnt new skills and seen it as mutually beneficial
- Good levels of training and support from staff reported
- More people should be made aware of the Service as volunteers take some of the resource pressures off staff
- Service was limited by funding restrictions; far more support could be provided with additional resources, for example a mini bus would greatly aid services in regard to transporting children to and from activities

Recommendation:
Evidence indicates that communication needs to be stronger between staff and volunteers. It would also be useful if a “volunteer buddy card” initiative could be made available in all Service areas so that volunteers could support children when using council facilities (e.g. swimming pool) without any financial costs to volunteers, parents or to the Service.

Positive Futures’ Staff

Paid staff including 3 Service Managers, 2 Family Workers and a Volunteer Co-ordinator were also interviewed. Their views on the Service were also encouraging. Staff valued the teamwork of their colleagues and the positive relationships that they had built up with parents. Many felt the service was not just ‘tick boxing’ but very much serving the needs of families. However, they also reflected on the limited capacity for the Service to extend to other families in need and to families whose child had reached 19 years of age. Staff recommended that more volunteers and support staff were required. Time invested in these resources was deemed vital, along with additional secure funding.

Chapter 7: Recommendations & Concluding Remarks

Providing support to families who have a child with a learning disability is a multifaceted and complex process. This report has highlighted some of the many challenges faced by families who care for a child with a learning disability in Northern Ireland. Each family supported by Positive Futures' Families Service has a diverse set of needs. Likewise, many of the families are dealing with very stressful circumstances. The report demonstrates that the Families Service Model is equally effective in meeting the support needs of families living in urban and more rural areas. The evaluation indicates that while families in the three locations have similar needs, the needs of those living in the Lakeland area are exacerbated by the rural location.

Although there were no significant differences between the carers' responses between the two study intervals, all carers indicated their appreciation of the Service. Findings indicate that carers suffered from stress and felt "exhausted" and this impacted negatively on their physical and mental well-being. For them, the Families Service has helped buffer family dysfunction and provided 'lifeline' support both in day-to-day life and at times of crisis. Carers appreciate that the Service is not simply giving them a break but that it is also providing their child with opportunities in which to experience interesting and fun activities. On joining the Service children had increased opportunities for social outlets. With the notable improvements in the children's behaviours and their social skills, the Service has contributed to the promotion of resilience and positive mental health within the family. These outcomes are the essence of the Family Support Services model. As a result of these factors carers social opportunities and satisfaction with their parenting role increased over the study duration. This demonstrates that the Service positively impacted not only on their child's quality of life, but on the carers' lives as well. Carers trust the professionalism of the Service and many would be lost without it as it gives them a much needed rest, and time to focus on other members of their family. Stakeholders also endorsed the benefits of the Service. The engagement of the children within their communities had undoubtedly broken down barriers of social exclusion and helped to educate peers and the wider community.

As a result of the findings in the evaluation, a number of recommendations are proposed:

- The current geographical and age limit criteria for eligibility to access the Service should be revised to allow the Service to expand, not only in the current localities, but right across Northern Ireland. In order to achieve this recommendation, accurate demographic and diagnostic information regarding children with a learning disability and additional recurrent funding is required.
- Partnerships have been key to the success of the Service in championing community-based initiatives. Further development of such partnerships is recommended to achieve more inclusive opportunities for children with a learning disability.
- Carers are very grateful for the range of supports they receive from the Service; however the majority have identified the need for additional respite. Additional recurrent funding should be secured to enable the Service to meet this need.
- Families Services should seek to align the range of support services they provide to young people more closely to the expressed aspirations of parents.
- Families Services should endeavour to better meet the identified support needs of primary carers. One way of doing this might be by developing person-centred plans for mothers.
- Lone carers, families with a child with complex needs, and those with more than one child with a learning disability require additional support from the Service.
- More support is needed during the long summer holiday period as the break in routine can be difficult for families to manage. Different agencies working together to co-ordinate the provision of their activities throughout holiday periods would be of greater benefit to families.
- Staff are an expensive resource. Services should strategically seek to recruit and maximise their use of volunteers to support the growing number of families accessing the Services. In order to achieve this, additional staff resources will be needed to assist in volunteer recruitment, training and support.
- Age appropriate supports should be developed for children in their teenage years. Many carers would like a volunteer mentor to support the young person to develop new friendships with their non-disabled peers and to participate in age appropriate activities as they approach adulthood. Such activities can also provide opportunities to strengthen the young person's involvement within their community and help them to lead more inclusive lives.
- Carers would like a 'sitting service' to be established so that they can call upon a register of people with appropriate skills to look after their child when needed. This was particularly evident for families in south east Fermanagh as many of them are isolated and lack social opportunities.
- This year 18 children will no longer access the Families Services as they will be making the transition into adulthood. Their parents are particularly anxious about the future because many feel the vital 'lifeline' support they desperately depend on from the Families Service will be lost. The Families Service and statutory services should work together to address parental concerns and ensure that the transition into Adult Services does not result in a reduction in the support families receive.
- Follow up research should be conducted on young people making the transition into Adult Services to assess the impact of this upon them.
- There is evidence that the Service and the Trust should work in a more joined-up way with regular feedback and communication. This should include joint referral

visits, improved communication and the development of systems to minimise the duplication of work.

- The Families Services in urban areas should consider how the geographical eligibility criteria and the prioritisation of referrals impacts on access to the Service by families from lower socio-economic backgrounds.
- Finally, the Service should consider other ways of working, such as getting parents as the "experts" to 'link in' with each other to share experiences and offer mutual support.

As with all research there are weaknesses in the study which must be acknowledged. For example, the 12 month interval between administration of the Times 1 and Times 2 questionnaires is arguably too short a timeframe to ascertain the impact the Service has had on carers and children. Additional follow-up could possibly yield more significant results at a Times 3 stage. Another important aspect that the study omitted was a control group of families who did not obtain support from the Service. In this case, a comparison could be drawn between the two sample groups of those 'with' and those 'without' the support from the Families Service.

Conclusion

This report provides an evidence base that paves the way for the development of future service provision for families who have a child with a learning disability. The Families Service Model provided by Positive Futures focuses on the unique needs of each family and as a consequence it is highly valued. It is a preventative model that serves to mitigate some of the stress factors which impact on families caring for a child with a learning disability. The Model is transferable between urban and rural areas. Before the Service existed, families had little in the way of support. Whilst the Service is only reaching about 1% of these families in Northern Ireland, it has made a major positive impact upon the quality of their lives. However this also means that 99% of families living locally with a child with a learning disability are without access to this "vital lifeline". It is the families hope, and ours, that the Service continues and that the barriers to other families accessing the Service are overcome so that all families can have better life chances and opportunities, today and in the future.

Profile: KIC Visual Theatre Project

KIC is a professional visual arts theatre company that is directed by Dave Calvert. The ethos of KIC comes from its influence of having worked in disadvantaged areas across Northern Ireland which have limited access to the arts.

KIC has been working successfully in partnership with Positive Futures for the past 6 years. KIC's work is all about making theatre with young people by connecting with them. KIC have produced several inclusive drama projects involving children and teenagers with learning disabilities alongside non-disabled young people. The company adopt a non-traditional way of teaching; there is no learning prose from set scripts. Instead, KIC mix together methods like dance, games, physical stories, music and lighting effects in a safe environment where individuals' imaginations are able to run free. As Dave comments:

"We do very challenging unconventional drama. The work very much comes from them, it's spontaneous, alive, and they act as the catalyst for ideas."

KIC students have performed to the public, showcasing their work and talents in venues around Northern Ireland. Dave also reflected on how much the drama is 'a release' especially for children and teenagers with learning disabilities:

"The beauty of these children is that they are not encumbered with what they think they should do or say. It is raw and honest. Their motivation levels are phenomenal; they'll have a go at anything. They like the fact that someone is paying them attention. There are a variety of capabilities and behavioural levels too and that adds to diversity of characters within the group dynamic…Its very exciting stuff."

In terms of outcomes, there have been many positive changes in the behaviour of some of the children.

"Many of these kids live in their own world; a fantasy world. This project enables them to act out the world they live in and tell me what they see. They see things that I can't see and it's fascinating. It fits with their reality. But that's not to say these children don't feel just the same things and angst that other young people do.

Many of Positive Future's children are from very sheltered backgrounds and this project gives them the opportunity to express themselves and to flourish in a way that they have maybe never had the chance to before. It also enables them to develop their social interaction skills and personal development. The training is intensive, but I have seen many gradually overcome huge milestones. The mainstream children have a lot to learn from mixing with their peers."

KIC workshop groups usually comprise of a maximum of 10 children. Dave feels very privileged to be working alongside young people with a learning disability who bring a whole new set of ideas and concepts to the world of theatre. Dave thinks he has changed his way of working for the better.

"I met some of the first Positive Futures children when they were 13 or 14 years old, now those children are young adults and really comfortable on the stage. When they come week after week, I know they are getting something out of the experience. The relationships that have been established between the children and ourselves have been incredible. Many have multiple and profound disabilities, communication limitations, low social skills. Through the project many have grown and developed into their own. They have learnt to work as a team, patience, negotiation, listening skills, compromise, the list goes on. One of the students from Positive Futures is going on to study media."

When asked about his views on what the children's parents felt, he replied:

"Three of Positive Future's parents sit on the management committee of KIC. They help to drive it. There's a real sense of pride when they come and watch their child on stage. They hardly recognise the transformation in them."

Since KIC began, the drama program has really evolved. Recently it secured long term funding with Positive Futures.

"Positive Futures do extraordinary work. I can see not only what it gives to the children but the bigger picture, what it is doing for their families and how complex that is to deliver. I am full of respect for them."

Dave has big plans for the future to continue to provide a platform for disabled and non disabled young people to come together and express themselves creatively through the medium of theatre.

Profile: Women Carer's Project

The Women Carer's Project is a one year initiative funded by the Training for Women Network based in County Fermanagh. The Project is co-ordinated by Elisha O'Callaghan. Its aim is to enable women carers to develop confidence, interpersonal and work based-skills. There have been very few courses aimed at mothers who care for a child with a learning disability.

The first Women's Carers programme began in March 2008 and ran once per week on a Wednesday morning for 4 months. The model for the program focuses on group work with weekly themes such as positive attitudes, stress management, personal appearance, time planning, setting goals etc. As Noreen Kettyles, one of the Trainers from the programme reflects:

"…one week we studied the theme 'acceptance' - coming to terms with being the carer of a child with a learning disability. The group all gave their views and it was a great mutual learning environment. The project also offered one-to-one mentoring, recreational classes, like salsa dancing and skills courses such as accountancy."

Person-centred plans were developed for each of the carers to work towards. Positive Futures also arranged for support for the children so that mothers could attend classes. Noreen commented how appreciative mothers were because it actually enabled them, many for the first time, to think about themselves.

"For many of the mothers, the program seems to have come at the right time for them in their lives. Many appeared to have lost touch with themselves; low self esteem stemming from being constantly in the caring role; poor health, family and relationship issues, facing the constant battle for support and respite for the child (and the bureaucracy that goes with that) other illnesses in the family, isolation because of the rural location."

Through the course of the program, various issues came to the fore. Noreen described it as:

"an emotional rollercoaster of self-reflection…. It took quite a few weeks to break down the barriers, but it was highly therapeutic and quite a few tears were shed. There were many issues such as mental health problems and family crises that had impacted on the carer who was also having to cope with the demands of a child with a learning disability." "Mums are just so grateful for any support they can get from Positive Futures… I think they don't want to burden the staff. They have gotten used to coping

alone and they are very strong and resilient women when you consider what they have been through. They were able to draw strength from each other."

One of the main benefits of the project was that the women were able to share some of their most personal information in very trusted environments with likeminded people who could relate to each other. Before this, many of the mothers didn't know each other, or only knew each other to see. Over time the relationships grew, and a common bond and support network developed. Since the group's inception, they have all become friends. Noreen has felt privileged to be a part of the journey.

"For most it has been life changing. Because we had a budget to be able to meet some of their needs, we were able to equip them with help and life skills…whether counselling, literacy skills, kinesiology, training or leisure activities. We started with 10 on the course and through word of mouth ended up with 15 because momentum grew so strongly. We are now running a second course".

Because the course was only 12 weeks in duration, many of the carers were anxious about what to do when it ended as it had become such a 'lifeline'. These mothers have now gone on to develop their own group called "The Escapists". They have assumed roles of responsibility within their group and have developed a programme which utilizes their own talents or skills to do things collectively: like Nordic walking, reflexology, and massage. They have also been out for meals together and this social aspect of the group has been invaluable.

"It has also given them a brighter and more positive perspective on life. It is a model that works and we would love it to keep going as there is so much need out there for mothers in similar situations."

Profiles of Children Using the Services

Bangor Service

Ben "...funny, bright spark, happy, entertaining!"

Ben is now ten years old and has been with Positive Futures Bangor Families Service for 2½ years. Before he joined the service, he was very unsettled and unsure of a world he did not really know or understand. He kept to his room a lot and avoided communication with people, preferring his own company.

Thankfully all that is past and Ben has discovered a whole new side to life. Through a process of getting to know Ben and understanding him, Bangor Families have been able to gently expand his horizons, giving him new experiences and the courage to explore. With a new-found confidence he started to build relationships beyond his own four walls with both those who are supporting him and more importantly, his peers. Ben is a changed boy! He looks forward to his activities, such as swimming and trampoline, but especially his special time on a Saturday where he meets his friends in their buddy group and indulges in the things that interest them. When he gets home, he is full of what he has done, happily talking about what happened and who was there.

His parents are delighted. They feel that Ben has matured and developed a lot over the last couple of years and his personality has flourished. He no longer lives in his own wee world but has become so much more sociable both with themselves and with everyone he meets. They never imagined it could be like this. They felt that they would always be in the "hard zone" with him but all that is history and Ben just puts a smile on their faces each day!

Ashleigh

"...loveable, sociable, creative"

Ashleigh is a young lady who is 15 years old who has spent significant periods in hospital due to illness. She is limited in the opportunities available to her due to mobility difficulties and medical needs. The dark times have been difficult for Ashleigh and her family.

Ashleigh has made great friends with the help of Positive Futures volunteers in Lisburn, a team of 5 young women who support her at home and at local community events. They have lots of laughs together and have lifted her spirits. On Saturdays Ashleigh's volunteers will visit and chat, they bake together or go for a walk to her favourite pet shop. The fun times have meant so much to Ashleigh and her family.

Over the past year, Ashleigh has attended craft workshops at the local Arts Centre on Saturdays. She has made crafts for Valentine's Day, Fathers day and a kite! She is also a member of Positive Futures' Buddy Group and has gone shopping and enjoyed local community performances. She enjoys the company of the other girls in the Buddy Group and the fun and friendship of the volunteers. Positive Futures have recently enabled Ashleigh to attend the Holiday Summer Scheme. She was able to go to the Planetarium, a local farm, and other group outings. Ashleigh's sister sometimes joins in too as part of the Siblings Group.

This summer Ashleigh took part in a Fun Run. Afterwards, Ashleigh, her volunteers and the family went together to a coffee shop. This highlights how the link between volunteers and the family has enriched the lives of everyone involved. Ashleigh thrives on the company and interest of everything going on around her and Positive Futures have continued to make the difference in Ashleigh's life.

Colm *"…gentle, kind, thoughtful"*

Colm is 17 and lives in rural County Fermanagh with his mum and brother. He enjoys socializing with his peers and spending time with his family. Colm has been with Positive Futures for a number of years. Through this, he has been involved in the Duke of Edinburgh Scheme and is due to receive his Bronze Award soon. Recently Colm participated in 2 overnight residentials in Cladagh Glen where he was also involved in doing fun team building activities. Colm has also undertaken community work and became a volunteer at the Share Centre, helping staff to paint the playground. Colm also participated in physical activities through Positive Futures including basketball, football and athletics on a weekly basis. To his mum's delight he has also learned two new skills: using a mobile phone to text and basic First Aid.

Colm also took part in the 'Volunteering For All' project with Positive Futures where he obtained work experience in a local café. There, he was supported by a member of staff from Positive Futures and he continues to do this. He has really grown in confidence and has become part of his local community through this experience. Another part of the service supports Colm to be involved in the buddy group which takes place on a monthly basis. This group of volunteers and young people come together to do what the young people decide… things like cinema or bowling. It has been a great success!

One-to-one work was also carried out with Colm and staff member Lorraine in relation to the sad and untimely death of his father. Lorraine completed life story work with Colm and he now has a book of memories to look back on. This has helped Colm come to terms with his father's death and also has helped his mother Margaret in the grieving process.

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Appendix 1: Research Questionnaires (Carers)

Questionnaires used in Times 1 and Times 2 Study.*

- Basic Details Performa (Baseline data of child and family including formal & informal supports-Times 1 only)
- Social Opportunities Questionnaire
- Family Functioning Questionnaire (Epstein, Baldwin & Bishop, 1983; 12 items)
- Parenting Stress Index (Crnic, Friedrich, & Greenberg, 1983; 36 items)
- Parent Satisfaction (14 items)
- General Health Questionnaire (Goldberg & Williams, 1991; 28 items)
- Vineland Adaptive Behaviour Scales – Interview Edition (Sparrow, Balla & Cicchetti, 1984)
  - -Communication domain (67 items),
  - -Daily living skills domain (92 items),
  - -Socialisation domain (66 items),
  - -Motor skills domain (36 items),
  - -Maladaptive behaviour domain (36 items).
- Aberrant Behaviour checklist (Aman & Singh, 1986; 58 items)

*Semi-structured interview questions used for stakeholders are available by contacting the authors.

Appendix 2: Service Budget and Staffing Details

Data pertaining to human resources and financial information required to maintain the services was also collected.

Resource	Bangor	Lakeland	Lisburn
Service Cost per annum*	£86,844	£88,679	£94,033
Number of children in service	31	32	41
Year Service Commenced	2003	2003	1999
Manager	0.5	0.5	1
Family Workers	1.5	1.5	1.5
Administration Staff	0.5	0.4 (15hrs)	0.4 (15 hrs)
Sessional Support Workers	9	21	6
Volunteers	20	5	20

*Standardised Costs for Financial year 2007-2008

Table 14. Summary of human and financial resources for each Service

As can be seen from the table above, the Families Services are managed with limited staff resources. Much Service provision is dependent upon the work of Family Workers and the vital contribution of paid sessional support workers and volunteers.

Matrix Cost Model

Positive Futures have developed a method of analysing and comparing the practical outputs delivered by each of the Services against their individual total budget using a ‘Matrix Cost Model’. The model is based on standardised costs which removes the variances between each of the Services. The total service cost has been achieved by calculating expenditures associated with staff salaries, activities, travel, volunteers and training. It then provides a detailed breakdown of the total number of hours delivered through the various types of supports in each service. By dividing the annual number of support hours per Service by the total Service cost, it is possible to estimate the cost of each Service on an hourly basis.

According to the Matrix Cost Model, the three services hourly costs range from £7.58 in Bangor, £9.67 in Lakeland to £11.40 in Lisburn. A breakdown of each service is now provided.

Bangor

The standardised cost of the Bangor Service in the financial year 2007/08 is £86,844 per annum. The total number of service hours (11455) per annum is divided by the total service cost. In turn, this model estimates the running cost of the Bangor service is £7.58 per hour. Each family receives an average of 8 hours of support per week.

Type of Service Support	**Total no. hours per 4 weeks**	**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	510	6630	18.9
No. of hours at family visit per month	42	546	1.6
Follow-up: liaising with professionals & agencies	70	910	2.6
Self help group hours - sibs and advocacy	16	208	0.6
Self help group hours – parents	10	130	0.4
No. of holiday support hours	98	1284	3.7
Hours for volunteer support (induction and training)	39	509.6	1.5
Hours for community development	39	509.6	1.5
No of hours of administration	56	728	2.1
TOTAL	**881 hrs**	**11455 hrs**	**32.6 hrs**

Table 15. Matrix Cost Model: Bangor Service

Lakeland

The standardised cost of the Lakeland Service in the financial year 2007/08 is £88,679 per annum. This equates to £9.67 per hour.

Type of Service Support	**Total No. hours per 4 weeks**	**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	250	3250	8.6
No. of hours at family visit per month	45	585	1.6
Follow-up: liaising with professionals & agencies	66	864	2.3
Self help group hours - sibs and advocacy	77	1001	2.7
Self help group hours – parents	8.5	111	0.3
No of holiday support hours	91	1188	3.1
Hours for volunteer support (induction and training)	58	754	2.0
Hours for community development	60	780	2.1
No of hours of administration	48.5	630	1.7
TOTAL	**705 hrs**	**9164 hrs**	**24.3 hrs**

Table 16. Matrix Cost Model: Lakeland Service

Lakeland dedicates approximately 9,164 hours per annum to the running of the Families Service. Each family receives an average of 6 hours support per week. Most hours are spent on activities and the least amount of support hours are spent on self-help groups for parents.

Lisburn

Lisburn Families Service runs on a slightly different model which is funded in association with Parents For Opportunities (PFO) - a parents advocacy group. PFO consists of an additional 19 children whose families actively raise funds so that all children (including the 41 full service children) can participate in activities.

Type of Service Support	**Total No. of hours per 4 weeks**	**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	166	2158	4.0
No. of hours at family visit per month	45	585	1.1
Follow-up: liaising with professionals & agencies	28	364	0.7
Self help group hours - sibs and advocacy	140	1820	3.4
Self help group hours - parents	10	130	0.2
No of holiday support hours	108	1415	2.6
Hours for volunteer support (induction and training)	73	949	1.8
Hours for community development	20	260	0.5
No of hours of administration	43	559	1.0
TOTAL	**633 hrs**	**8240 hrs**	**15.4 hrs**

Table 17. Matrix Cost Model: Lisburn Service

Based on the Matrix Cost Model, Lisburn has the largest standardised Service costs at £94,033. This translates as approximately £11.40 per hour. Each family receives on average 3.7 hours of support per week.

Out of the three services, Bangor provides the most activity hours and overall total number of hours are greater in the Bangor service than in Lisburn or Lakeland. Interestingly this service, according to the Matrix Cost Model is the most cost effective. Lisburn has a high percentage of time apportioned to volunteering because of a dedicated Volunteer Family Worker which neither of the other two Services possess. The limited staff resources also limits the number of hours the Lisburn Families Service can dedicate to each family, because they have more families.

In sum, the Matrix Cost Model demonstrates the cost effectiveness of the three services in both rural and urban areas. As Services continue to expand, it will be challenging for Positive Futures to meet the growing number of families joining the service and their needs on such restricted budgets.