

Review of the **Lakeland Families Service**

provided by Postive Futures



Darragh McCullagh and Professor Roy McConkey
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Fermanagh District Council



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It is like a 'Christmas present' moment to be offered this opportunity in the knowledge that childcare is in safe hands.

Parent, LKFS

Foreword

Over the past 15 years the Fermanagh Trust has successfully supported hundreds of community and voluntary initiatives across County Fermanagh. The Trust's goals include being a community catalyst; enhancing people's lives and promoting the sustainability of communities and life in County Fermanagh and beyond.

Later in 2010, following public concerns regarding the decision to no longer provide statutory funding for the Lakeland Families Service and the resulting groundswell of support against this decision, the Fermanagh Trust was approached by users and advocates of the Lakeland Families Service requesting guidance and support. Following subsequent discussions with a range of stakeholders the Fermanagh Trust recognised the need to research the background to, and the impact of the decision not to support this Service in Fermanagh in the future.

Fermanagh District Council was also concerned about the withdrawal of the support to the Lakeland Families Service and the impact this would have on users of the Service. The Council welcomed the Fermanagh Trust's initiative to research the implications of the decision to withdraw funding from the Lakeland Families Service and supported the Fermanagh Trust with financial support towards the cost of the project. Professor Roy McConkey from the University of Ulster was commissioned to complete research on the impact of the Lakeland Families Service. This work included facilitating and encouraging people to speak for themselves, about their experiences and the impact of the Service on their lives and the potential impact of the decision not to provide funding for the Service in the future.

Helping support people in rural areas is a challenge, helping support people living in one of the most rural areas of Northern Ireland is very challenging; helping support those with a learning disability and their carers and support

network is extremely challenging. Positive Futures rose to this challenge in 2003 with the establishment of the Lakeland Families Service centred in Lisnaskea.

This report outlines how Positive Futures has successfully reached this rural community and provided a valuable mechanism which is having an extremely positive impact on people's lives. In this report we hear from the community about their needs.

It is important to note that the N.I. Executive, through the offices of the Department for Social Development, is currently preparing a Concordat between the Voluntary and Community Sector and the NI Government with a view to working together as social partners to build a participative, equitable and inclusive community in Northern Ireland. Hopefully the learning disabled, the families and the wider community which benefits from the Lakeland Families Service can benefit from this approach.

Let's not sell our community and those most in need short. Let's ensure we support people by listening to their needs and work with them to address these very needs. This report tells us this Service is working, the challenge for those with a statutory remit is to ensure we all build on the positive impact of these endeavours to date and ensure this continues to be the case.

Lauri McCusker,
Director, Fermanagh Trust

Background to the Review

In 2003, Positive Futures¹ commenced the Lakeland Families Service. The model of service had been developed and evaluated in association with the former Down Lisburn and Ulster Community & Hospital Health and Social Services Trusts. Likewise a later Review confirmed the ongoing value of these services to families and the significant improvements in the quality of life outcomes for the children and families concerned (Black et al 2008)².

Following the cessation of the time limited DHSS&PS funding for these new style of services, the Lakeland Families Service continued to be part-funded by the Western Health and Social Care Trust (WHSCCT), with significant additional monies being invested by Positive Futures from their reserves and fundraising, including funds raised by the families. In 2009, owing to financial pressures, the WHSCCT advised Positive Futures that it could no longer make a financial contribution to this Service and hence the Service faced closure in March 2010.

Owing to the success of continued fundraising by Positive Futures and the families, including contributions from Positive Futures' reserves and a significant grant by the Henry Smith Foundation, the Service was able to continue for a further six months but with a reduction in provision. As the closure date came closer, and in view of the significant loss which families were anticipating as a result of the imminent closure of this Service, families organised themselves into a strong lobbying group which eventually resulted in a decision being made by the regional Health and Social Care Board to continue to fund the Service on an interim basis until March 2011. In allocating this funding the regional

HSC Board acknowledged the valuable role Positive Futures plays in supporting children with a learning disability, many of whom have complex needs and gave a commitment to working with Positive Futures and all those with an interest in the Service, to develop the most "optimal future arrangements" for caring for children with a learning disability. It is against this background that the present Review of the Service has been undertaken, led by the Fermanagh Trust.

This Review had three main aims:

- To confirm the impact the Service had on children and families and to ascertain parental preferences with respect to future provision.
- To specify the variety of discrete Service inputs that the Service offered to young people and families.
- To examine the broader socio-demographic characteristics of the County; the numbers of children with moderate and severe learning disabilities and the funding provided for learning disability services in the WHSCCT.

¹ Positive Futures is a leading provider of support services to children and adults with a learning disability and their families across Northern Ireland. Since its inception in 1995, the organisation's work has been characterised by its capacity to develop and deliver innovative, individually tailored approaches to meeting identified need. <http://www.positive-futures.net>

² Black, L-A., McConkey, R., Roberts, P. & Ferguson, P. (2008) Developing a person-centred support service for families caring for children with significant disabilities in rural and urban areas. *Journal of Intellectual Disabilities*, 14 (2), 111-131.



A Steering Group was appointed for the Review consisting of representatives of Fermanagh Trust, Fermanagh District Council and Positive Futures along with two parents who used the Service. Professor Roy McConkey, University of Ulster was commissioned to complete the Review as he had been involved with the previous evaluations of Family Support Services in Northern Ireland. He was a former Trustee of Positive Futures and holds a joint appointment with the Health and Social Care Board. Darragh McCullagh was appointed as Research Associate to assist with data gathering and analysis. He holds a Masters degree in Applied Psychology from the University of Ulster.

This report summarises the information gained from this Review; identifies the cost-benefits of this model of support to families and argues for the continuation of funding based on four main considerations.

1. The Service is in line with the DHSS&PS vision for modern services and embodies the vision outlined in the Bamford Review.
2. The Service has responded to the needs of the whole family and is their preferred option. If it were to cease, there are no adequate alternatives available to support families.
3. The Service has attained cost benefits that provide an exemplar for other social services in the WHSCT and elsewhere.
4. Local provision needs to be developed in Fermanagh in order for families and children with disabilities to have equitable access to support services.

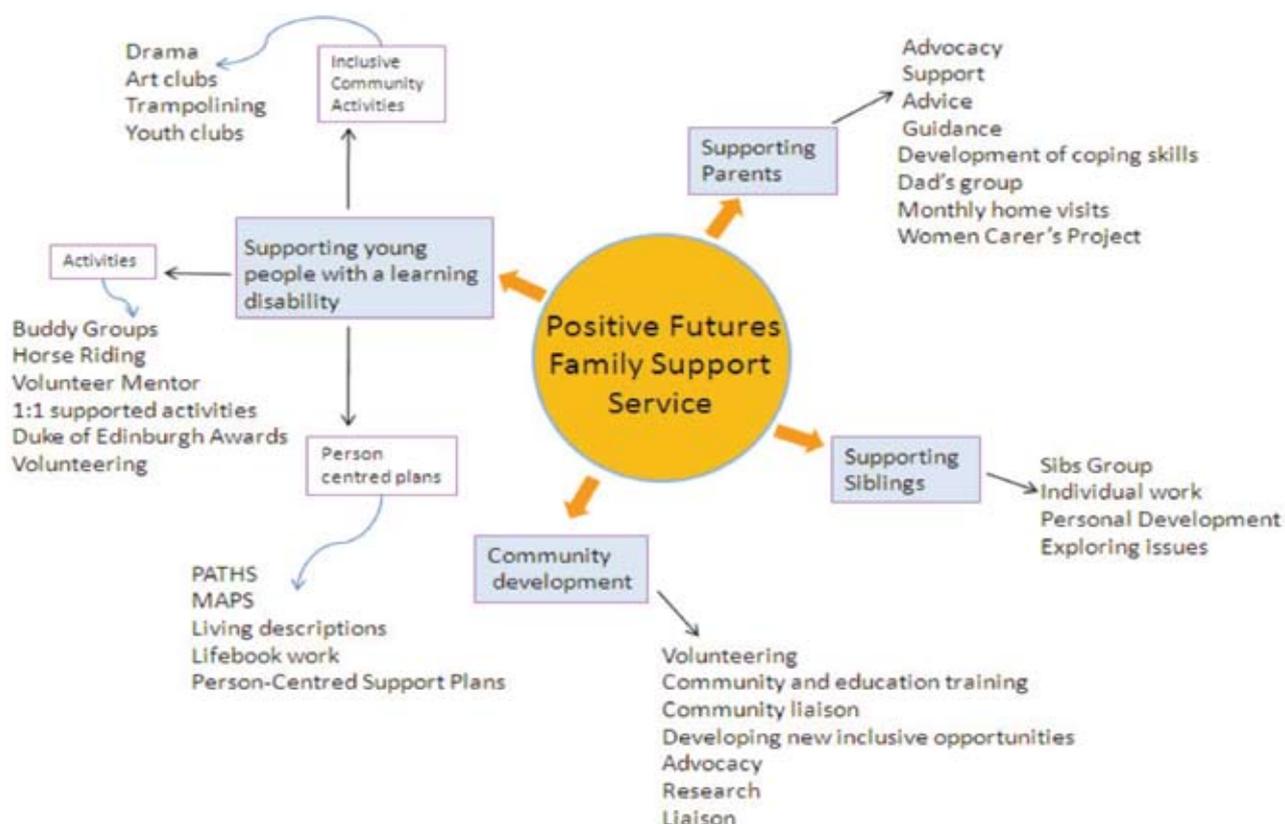
Section 1:

Overview of the Lakeland Families Service

“The main benefit for me is seeing (my child) improve and have further opportunities. Also having a point of contact myself if I have any queries or questions, otherwise I would have no support... Positive Futures have been a lifeline and that’s not an exaggeration. I would hate to see them go. If I didn’t see N going out with her friends on a Friday night it would break my heart. With Positive Futures alleviating some stress, its improves general family life” *Mother*

The Lakeland Families Service aims to provide holistic, local, family-centred support to parents whose children have learning disabilities and complex needs. As the Figure shows it operates on a number of dimensions:

Figure 1: The Lakeland Families Service Model



- It provides opportunities for children and young people with a learning disability to get involved in their community through inclusive activities or ones specific to their interests.
- It supports parents through advocacy, advice and guidance provided to groups or during individual home visits.
- It enables brothers and sisters to enjoy fuller family and social lives.
- It utilises community development approaches involving training and volunteering to enable the young person with the learning disability and their family as a whole to experience significantly enhanced quality of life outcomes.

How the Service operates

During the period that the WHSCT financially contributed to the Service, new families were referred to the Service by Trust Social Workers. 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 also advocates on behalf of the family with health professionals and other agencies. Family Workers visit the family on a regular basis, and this is complemented with regular telephone support when required.

The Family Worker supports each family to identify their needs and to match the child to a range of activities of preference using person-centred planning approaches. With each family an individual plan is devised that identifies the child's goals and aspirations by including all the key people in the child's life. The plan identifies new opportunities for the child to participate in so as to develop their own interests and assist with the development of new life, social and interpersonal skills. The plans also help the family to plan positively for the child's future.

Hence the key activities undertaken by the Service include:

- Person Centred Planning with and for the family and for the child with special needs.

- Family support, including practical and emotional support, information, advice and regular monthly contact.
- Support to attend inclusive community groups (youth clubs, churches, community groups) during weeknights and at weekends.
- Provision of after-school activities and homework support.
- Support for carers, personal development and activity programmes for mums and dads.
- Easter, Summer and Christmas holiday activities, trips and parties including residential breaks which take place during the school term time as well as at holiday times.
- Targeted groups, such as Siblings group, Fathers group, Advocacy group.
- Co-ordination of support staff and volunteers.

Further details of the Service staffing, hours of support provided and the costs are provided in Appendix 1.

Conclusion

The Lakeland Families Service is much more than 'respite' for families. Of course, it does provide parents with short breaks from their caring responsibilities but the Service explicitly addresses the needs and interests of the children through a person-centred plan. Moreover, supports are offered to the wider family – mothers, fathers and siblings - as well as efforts to promote the children's social inclusion within the wider community. This Service is a prime example as to how the first objective outlined in the Bamford Review of Learning Disability Services (Equal Lives) can be met:

"To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society" (p.35).

Section 2:

Impact of the Service on children and families

“He is a different child with Positive Futures ... They didn’t see his disability they seen his ability and were able to bring the best out of him. He would have been withdrawn before but with Positive Futures he has become more assertive and is interacting a lot better.” *Mother*

Introduction

The Lakeland Families Service has supported 42 families since it started (details of the children and families are given in Appendix 2). Due to time constraints, a sample of 24 families was interviewed by telephone. Within this sample there were families who are still using the Service (N=18), those who had used it during the full funding period but who can no longer avail of the Service (N=2) and those whose children can no longer be supported but either or both parents still attend the relevant carer group (N=4). The interviews were conducted by an external person (DMcC) and parents were assured of confidentiality. A structured interview schedule was used that focussed on perceived changes within their child and themselves as well as obtaining their views on future service provision.

This information can be supplemented by that obtained in another study carried out within the same Service in 2007 (Black et al 2008³).

Perceived changes in the children

Parents were asked to rate the changes they had observed in their child in seven areas (see Table 1) using a five-point rating scale: “much improved, improved, same as before, worse or unsure”. For clarity, these were grouped into three categories as shown in Table 1. The majority of children were reported to have improved on five out of the seven variables since their involvement with Positive Futures. The variables with the greatest improvement were socialising (getting on with others), communication (verbal and non-verbal) and independence.

The parents were also asked to describe in their own words the changes they had seen in their child. Their responses could be grouped into the themes shown in Table 2 along with the number of parents mentioning each theme. Again the dominant themes were mixing with others and becoming more independent.

Table 1: Changes in Child (%) since support from Service (N=24)

	An improvement	Same as before	Worse
Socialising	95.8%	4.2%	0%
Communication (verbal and non-verbal)	75.0%	25.0%	0%
Independence	70.8%	29.2%	0%
Physical Health	54.2%	45.8%	0%
Contact with friends	54.2%	45.8%	0%
General Behaviour	45.8%	54.2%	0%
Inclusion in community	45.8%	54.2%	0%

³ Black, L. A., Roberts, P. & McConkey, R. (2008) “Lifelines”: An Evaluation of the Impact of the Families Services Delivered by Positive Futures in Rural and Urban Areas of Northern Ireland’. <http://www.positive-futures.net/publications.asp>.

Table 2: Changes in child reported by the parents (N=24)

Change in Child	Number of Mentions
Mixing with friends / Socialising	12
Independence	7
Gets to try new activities	3
Duke of Edinburgh Experience	3
Learned new life skills	2
Communication / Speech	2
Self-Esteem	2
Behaviour Improved	2
Academic improvement	2
Good Routine	1
Support in safe environment	1

Example comments included:

"PF (Positive Futures) opened N's eyes a lot and gave her a better understanding of the world. It broadened her horizons and helped her understand how people with different special needs cope."

"N is now very confident, her speech has improved in leaps and bounds. She would have got 'down' before but PF kept her stimulated as I was getting older and couldn't keep up. She would never have achieved anything without PF. N would have been in tears leaving Duke of Ed as she had such a good time with her group. PF have made a life for N."

Impact on Parents

The parents were asked to rate perceived changes to themselves using a similar five-point ratings scale but these were reduced to three categories shown in Table 3. The majority of parents felt better able to cope, had a better quality of life, were in better health and felt less stressed. Only one third reported increased support from family and friends.

Again parents were asked to state in their own words the main benefits they personally had derived from the Service. Their responses are summarised in Table 4.

Table 3: Changes in parents (%) (N=24)

	An improvement	Same as before	Worse
Feeling able to cope	79.2%	20.8%	0%
Overall quality of life	66.7%	33.3%	0%
Physical Health	62.5%	37.5%	0%
Levels of Stress	58.3%	41.7%	0%
Family getting on with one and other	50.0%	50.0%	0%
Support from friends and other family members	37.5%	62.5%	0%

Table 4: Benefits to Parents (N=24)

Parents' Comment	Number of mentions
Gives me a break / relieves stress	7
Women's carer group allowed me to meet other parents in a similar situation	7
Less restriction / better social life	5
PF's staff are able to offer support /guidance and advice	4
Personally develop e.g. confidence / self esteem	3
Peace of mind when my child is with PF staff	3
Staff are flexible to meet my needs	3
I couldn't manage without PF	2
Now easier to manage my child	1
I enjoy seeing my child have fun	1

Example comments included:

"I have seen what PF have done for N and has brought me great joy. I could never keep up as I'm getting older. PF have made a great change in N and I don't need to put in as much time. It's a real miracle and it's all thanks to PF who planted the seed that has grown ever since."

"I have come on really well. I suffered severe depression before PF came on board and the 'all about me' program has helped so much and I feel a huge weight lifted off my shoulders."

"I went back and done my hair dressing course in the South West College through PF's funding. They paid for my fees my hairdressing kit and my exams. This allowed me to graduate in June 2010 and I now work two days a week. This has been great and would never been possible without PF... it gave me confidence that I never had before."

"I really enjoyed the Women's Carer Group as I got guidance on various things, such as forms that I needed to fill out, from other parents and it was great confidence boost speaking to other parents in similar situations."

Impact on other children

Parents were also asked for their perceptions as to how the Service had benefited other family members. Their responses were grouped by themes and the frequencies of the response are detailed in Table 5.



Table 5: Benefits to other children

Benefit for other Children in the family	Number of mentions
Spend more time with other children	10
Sib too old / young to benefit	4
Helps sib understand N and their learning disability	3
Gives sib a break	3
Enjoyed sibs group	3
Increased confidence	2
Met new friends	2
Days out / new activities	2
Sibling volunteered with PF	2
Met other sibs in similar situation	2

An example of some of the parents' responses to the benefits of the Service to other family members are given below:

"She enjoyed the sibs group...and meeting other sibs who had similar family circumstances. She has also helped out as a 'young helper' at the Duke of Ed. Her knowledge, understanding and acceptance of learning difficulties have improved greatly for a child her age."

"I am able to spend more time with my other children. My daughter would ask questions about why N wasn't attending any other groups or going out as she never understood, but now he can do these things with PF."

"Sibs group gave N's brother help to realize that he was not the only person with a sibling with a learning disability. He met new friends and increased in his confidence."

"We are a lot happier as a family. We didn't know where to turn before PF, we had never heard of them until my social worker informed me that the Service was available. PF are always available to speak too otherwise I'd have no one to turn to and staff are extremely helpful. [Provider X] are too far away in Enniskillen. I would be absolutely devastated and gutted if PF Service was lost. We, as a family, have met lots of people with similar issues as ourselves. We wouldn't be able afford the swimming without PF funding."

Conclusions

The parents interviewed are clearly convinced of the benefits the Service has brought to their child with the disability, to themselves as carers but also to other children within the family. This confirms what previous evaluations have found of similar services in Lisburn and Bangor. Moreover these outcomes are commonly reported in studies elsewhere into effective 'respite' breaks for families⁴:

"There is now more emphasis on the needs of the actual disabled child and the importance of meeting their needs, as well as those of the parents. A further development is the greater recognition of the impact of a child's disability on siblings." (p.365)

⁴ Harris, H. (2008) Meeting the Needs of Disabled Children and their Families: Some messages from the Literature. Child Care in Practice, 14, 355-369

Section 3:

Parental views of future service provision

“What’s the point in going away overnight? I don’t need respite. (My children) are not a problem at night. I’d prefer them to be out and about doing activities.” *Mother*

Introduction

In line with the requirement by DHSS&PS to ascertain the views of service users in the planning of future provision, parents were asked to state their preferences for how support services for families should be provided in the future. In particular, they were consulted on the proposal made by the WHSCT that families would have access to the overnight short breaks (respite) facility based in Omagh if the Lakeland Families Service had to close.

Parental preferences for future provision

During the individual telephone interviews parents were asked to describe the services they would like to see being made available for their child and family in the future. The responses from the parents were grouped together and their frequencies of mention are detailed in Table 6.

Table 6: Services that parents would like in the future (N=24)

Services parents would like in the future	Number of mentions
Present Services continuing	14
Additional Service when child reaches 18	6
More organised summer scheme	2
Follow on group from current Duke of Ed group	2
More 1 to 1 support	2
More Duke of Ed places	2
More variety in activities	2
Continuing flexibility	1
Extra support in summer	1
Emergency PF in family home if needed	1
Keep football going	1
Bring back horse riding	1

Example of comments included:

“I would love to see present Service continuing and if possible to have it expanded. Without funding staff can’t plan ahead which is very important when working with children with a learning disability. This could affect staff morale.”

“...perhaps a more organized summer scheme, e.g. one week summer scheme for 5 days in one week instead of 1 day every 5 weeks. Maybe a bit more variety in activities instead of continuous bowling or swimming.”

“I would love to see current previous support continue. Perhaps a back up Service where in an emergency PF staff would be available for support N at home...I would really like a transition Service available for the time when N is moving from school into adulthood e.g. supported employment and supported living.”

“We don’t get that much support now that N is over 18. I have to think long term about N’s future but this isn’t really available so some support in line with this would be good. There are eight children who completed the Duke of Ed, it would be great if they could continue meeting up as it would be a shame to see that group folc

Other options available to the families

A question was included to find out what other options were available to the families if Positive Futures’ support was not available. Only three families were able to name an alternative: some support from Cedar Foundation, Downs Syndrome Youth Club and use of direct payments.

Use of overnight breaks

Parents were asked about their prospective use of overnight breaks in Omagh, or if a similar service was to be offered in Enniskillen. They were given three options originally but during the interviews a number of parents felt there should be an additional option “Yes – in an emergency but would prefer evening / weekend support.” The responses are detailed in the Table 7. Only around one in eight parents would use the Omagh service and that would be in an emergency and up to one third would use such a service if based in Fermanagh. Two-thirds of parents interviewed preferred evening and weekend support.

Table 7: Parents’ views on proposals relating to overnight respite in Omagh and Fermanagh

Use of overnight respite facilities	Percentage use if based in Omagh	Percentage use if based in Fermanagh
Yes – On a regular basis	0%	13%
Yes – In an emergency only	4.3%	8.7%
Yes – in an emergency but prefer evening / weekend support	8.7%	13.0%
Prefer evening / weekend support only	87.0%	65.3%

Comments from parents included:

“I think that PF should be all over Fermanagh and not just the rural areas around Lisnaskea. Although C gets the respite facility he doesn’t enjoy it and is not too fond of leaving home. I personally hope that PF gets funded again because we really do need the support.”

“Respite Service no good as what use is one overnight stay? I used to save all my monthly direct payments to pay someone to stay over one night which was at least flexible whereas Trust respite may only be available when they say so. Also the travel between Omagh and Enniskillen is not ideal. We need to have some hope that there will be funding for Lakers group as we have been cut off completely compared to Lisnaskea area.”

Conclusions

Parental preferences are clearly for continuation of the present arrangements. Attending to their aspirations has clear benefits as a recent evaluation of a Short Breaks scheme concluded⁵ :

“There is clear evidence from the evaluation that better outcomes are achieved in terms of short breaks that meet family wishes, are more inclusive and meet the widely varying need and wishes of children and young people if there is significant investment in mechanisms that involve families at all levels of commissioning and provision.” p. 82.

⁵ Grieg et al. (2010) Short Breaks Pathfinder Evaluation, Research Report DFE-RR062. London: Department of Education

Section 4: The Socio-Demographic Context

Introduction

The Lakeland Families Service also has to be seen in the context of the County and Trust area in which it is located. Hence this section brings together information regarding the likely numbers of children with a learning disability, the socio-demographic characteristics of the County and the monies expended by the WHSCT on learning disability services in comparison to other Trusts.

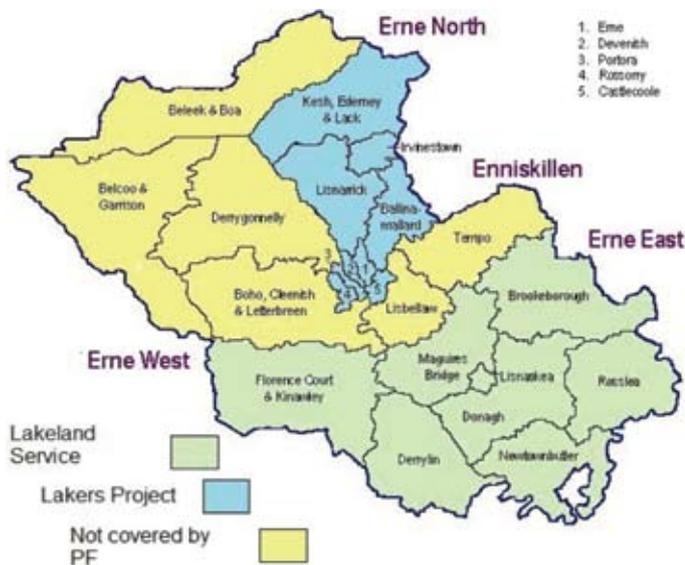
Numbers of Children

The WHSCT supplied the numbers of children with a moderate to profound learning disability recorded on Module V of the Child Health System in County Fermanagh (see Table 8). The prevalence rates are shown as a ratio per 1,000 of the total child population estimated at 2009. These rates vary across the age bands as more children tend to be identified during the school years.

Table 8: Number of children with a moderate to profound learning disability recorded on Module V of Child health System in County Fermanagh

Age Bands	Total LD	Estimated Child pop	Ratio per 1,000
0-4	11	4,163	2.64
5-9	40	3,885	10.2
10-14	78	4,295	18.16
15-19	54	4,079	13.24
Totals	183	16,422	11.14

These figures can be further broken down into the numbers living in wards in which the Lakeland Families Service operated (N=54 children) and those living in other wards (N=129) – see Figure.



At present, the reduced Service has 25 families participating in it which is less than half of those resident in those wards who are known to the health and social care services.

Also there are many other children in the County who could potentially benefit from the Service in other parts of the County. Previously the Lakers Project operated around Enniskillen with an additional 15-20 families but this had to curtailed when funding was cut.

Hence there are many other families who could potentially benefit from this Service in County Fermanagh.

Socio-demographics of Fermanagh

Fermanagh is among the most socially deprived Council areas in Northern Ireland on certain indicators, notably in terms of proximity to services. It seems ironic then for the Trust to further reduce services that have been established in the County and then expect families to use services outside of the communities where they live.

Also of the 26 Local District Councils in Northern Ireland, Fermanagh ranks fourth in terms of the highest percentage with Statements of Special Education Needs

(Stages 1 to 4) and 14th in the provision of free school meals.

When intra-county comparisons were made between the wards that were covered by the Lakeland Families Service and those that were not (see Figure); there were higher proportions of children with free school meals and stage 1-4 statements of special educational needs in the wards served by the Service although these differences were not statistically significant from the other wards in the County (see Table 9).

Table 9: The percentage of children with SEN statements and receiving school meals in the Fermanagh wards covered by the Service

		% SEN Statements	% Free school meals
In wards covered by the project	Mean %	21.5	18.9
	Number wards	14	14
	Std. Deviation	4.6	10.5
Not in wards covered by the project	Mean %	20.7	12.8
	Number of wards	9	9
	Std. Deviation	3.2	6.4
Total for county	Mean %	21.2	16.5
	Number of wards	23	23
	Std. Deviation	4.0	9.5



Health and Social Care Funding

Table 10 summarises the amount of money spent by four HSC Trusts in Northern Ireland on mental health and learning disability services taken from their latest Annual Reports. (This

information is not provided by the Northern HSC Trust). Only the South Eastern Trust provides a breakdown between mental health and learning disability and this is half to each).

Table 10: The amount (in millions) spent on Mental health (MH) and Learning Disability (LD) services in four HSC Trusts.

HSC Trust	Total spend	Amount MH and LD	% MH and LD
Belfast	£993.6 m	£94.5 m	9.5%
Western	£540.7 m	£55.8 m	10.3%
South Eastern	£427.0 m	£59.8 m	14.0%
Southern	£487.7 m	£86.5 m	17.7%

Although the Belfast Trust spends the highest amount on Mental Health and Learning Disability services, the proportion is reduced probably due to the higher concentration of acute hospitals in that Trust. The Southern HSC Trust however spends over 50% more on Mental Health and Learning Disability Services than does the WHSCT.

The discrepancies across Trusts may also result from inequities in past funding. Future allocations should take account of this. From data provided by the Western Local Commissioning Group, the spend in 2010/2011 within the learning disability programme of care is budgeted at almost £32 million: 6.8% of the WHSCT total funding. This figure included £1.061 million of planned Service developments in learning disability.

Hence the amounts provided to fund the full Lakeland Family Service (@£125,000 per annum) represents a very small proportion of present and future spend within the WHSCT on Learning Disability Services.

Availability of Services

A further comparison can be drawn between the services available to families in Fermanagh and those provided in other parts of Northern Ireland. Two comparison areas were chosen: Derry City Council area (as this falls under the Western HSC Trust) and South Down Council

area which is in a different HSC Trust (South Eastern) but has a somewhat comparable rural population. Neither of these locations has a Family Support Service.

As far as possible we traced all of the services that were currently available to children with learning disabilities and their families other than schools. These were obtained from a variety of sources and cross checked individually to ascertain that they were still functioning. However we were not able to obtain accurate information as to the numbers of people availing of each service. Nonetheless the information gathered suggests that there are fewer service options available in Fermanagh compared to these two other parts of Northern Ireland. This confirms parental reports noted earlier as to the lack of alternative services available to them in Fermanagh. (Full details of the identified services are available on request.)

Conclusions

Families in Fermanagh who have a child with a learning disability could be considered disadvantaged in various ways in comparison to similar families in other parts of Northern Ireland and even in the WHSCT area. There is potential for these disadvantages to be further compounded by the removal or reduction of existing services within the County.

Section 5: Conclusions.

The trigger for this Review was a decision by the WHSCT to withdraw funding from the Lakeland Families Service as part of the cutbacks they were required to make. Although Health and Social Care budgets are constrained and reductions in funding are necessary, this particular decision seems to be counter-strategic as the information in this report illustrates. The Steering Group for the Review would respectfully note the following conclusions.

First, the Service is fully in line with the vision for Family Support Services contained in the Equal Lives Review of Learning Disability (Bamford Review) that has been endorsed by the DHSSPS. Moreover parents were able to identify a range of specific benefits that the Service had brought to their children and also to themselves and other siblings. It seems strange for a Trust to be closing a model of service that has been particularly commended for future service provision and which results in demonstrable gains for the child and other family members which have been documented in two previous Reviews of these Services (Black et al, 2008; Truesdale et al., 2005) as well as in the present Review. The Bamford Implementation Group and more especially the Bamford Monitoring Group of the Patient-Client Council might be consulted on this issue as the Trust's decision would have wider ramifications for the implementation plans associated with the Bamford Review.

Secondly, the Service responded to current financial stringencies by reducing the support hours it could provide to families. Although the numbers of families availing of the Service has had to be reduced, the Service was reconfigured so as to maximise the direct support made available to families and their accounts testify to the value they continue to derive from the Service. Moreover the costs per service user hour are considerably less than overnight respite provision which the Trust appears to be advocating as an alternative⁶. It would seem odd then to reward greater cost efficiency by the withdrawal of all

further funding. The Board members of the WHSCT might be interested in using the Lakeland Families Service as an exemplar to the Trust and its sub-contractors as to how efficiencies can be improved within Social Services.

Thirdly, the families have clearly stated their preferences with regards to the supports that they would find beneficial. Given the emphasis in Health and Social Care services on consulting with the consumers and engaging with them in service planning and provision, it would seem curious that the Trust would ignore their expressed opinions and offer instead an alternative service that the majority of families feel they would not use. The Health and Social Care Board might wish to adjudicate on this issue and in consultation with the Western Local Commissioning Group.

Fourthly, there is evidence that families in Fermanagh are particularly disadvantaged in comparison with other areas of the Western Trust and with Northern Ireland more generally. Parents reported a lack of alternative services available to them. This is further exacerbated by the rural nature of County Fermanagh which places significant additional pressures on these families, not least in terms of access to whatever services might be available. Political representatives have an important role to play in ensuring that any reductions in services do not further disadvantage their constituents.

The Steering Group are happy to have a dialogue with any and all parties in advocating their case for the retention of funding for the Lakeland Families Service.

⁶ NEF (2009) The social and economic value of short breaks. London, New Economics Foundation.

Appendix 1

Details of the Lakeland Families Service

This Appendix gives further details of the Lakeland Service in terms of staffing; hours of support time provided and the costs of providing the Service. This information is provided for the 'Full' Service when it was fully resourced (up to 2007/08) and for the present the support available under the 'Reduced Service' (April 2010 to September 2010).

Staffing

In the Full Service, the staff establishment was 0.5 FTE (18.75 hours) Service Manager, 1.5 FTE Family Workers, 0.4 FTE (15 hours) Administrative support and 0.6 FTE (22.5 hours) sessional support staff.

In the reduced Service, the Service Manager post was removed and it is now managed by an Operations Manager who spends approx 0.2 FTE (7.5 hours) with the Lakeland Families Service. There is currently no administrative support time within the reduced Service. In summary, the reduced Service includes 1.5 Family Workers and 0.6 sessional support staff. It should be noted that as the 0.5 Family

Worker was on maternity leave during April – September 2010 and the underspend on this salary during this leave was used for additional sessional support hours.

Table A.1 summarises the amount of support hours that service personnel provided per month to the families when the Service was fully funded and with reduced funding. When children took part in group activities the support hours were multiplied by the total number of children participating by the length of the session, for example if four children attended a two hour group session, this was counted as eight support hours.

As the Table shows most of the support hours are devoted to the children and young people as these have reduced by nearly 70% most notably through buddy groups, after-school activities and summer schemes. However some new forms of support have developed such as Special Olympics Football, Duke of Edinburgh Gold and a Girls group.

The support hours provided to families have also dropped by 24% and support to siblings has halved. The small amount of time given to community development has remained with a focus on volunteering.

Table A.1: The number of support hours provided per month in the four main activity areas in the full and reduced Service.

TASK	Activity Hours Delivered Full Service	Activity Hours Delivered Reduced Service
1. Supporting Young People with Learning Disability		
Buddy Groups	348	84
After School Support	372	0
1 to 1 supported activities	40	32
2 to 1 supported activities	24	48
Homework Support	24	0
Summer Schemes	1900	456
Special Olympics Football	0	64
Girls Group	0	36
Duke of Ed Bronze	96	56
Duke of Ed Gold	0	112
Sub-Total	2804	888
2. Supporting Parents		
Advocacy	8	2
Support	6	4
Advice and Guidance i.e phone contact	12	20
Development of Coping Skills	4	2
Support for Dads / Male Carers		48
Monthly Home Visits	44	8
Support for Mums / Women	140	80
Sub-Total	214	164
3. Supporting Siblings		
Sibs Group	120	56
Sub-Total	120	56
4. Community Development		
Volunteering	8	20
Community Liaison	8	0
Developing new Inclusive Opportunities	4	2
Sub-Total	20	22
Total Hours per Month	3158	1130

Service Funding

Table A.2 provides details of the expenditure of the Service. This is provided for an equivalent six-month period for the full Service and the reduced Service.

Table A2: Expenditure for six months in the full and reduced Service

	Full Service*	Reduced Service
Salary Costs	£48,282	£28,643
Travel and Subsistence	£4,331	£3,315
Training	£523	£361
Administration Costs	£1,863	£1,241
PWS Costs	£6,492	£5,791
Sundry Expenditure	£12	-
Depreciation and Replacement Charges	£1,152	-
Total Expenditure	£62,655	£ 39,351

* These are for the financial year 2007/08

The per hourly cost of the Service can also be computed by dividing the monthly Service cost by the number of support hours provided. In the full Service, the per hour rate is £3.31 per hour but this has risen to £5.80 in the reduced Service. This reflects the economy of scale that the full Service was able to offer.

Income

The HSC Board has committed to make a contribution of £40,000 to enable the Service to continue to 31st March 2011 with the balance of monies coming from Positive Futures' reserves.

It should be noted that although the WHSCT did not provide any funding towards the reduced Service from April 2010 – September 2010, the Trust has made two discrete spot purchases from the Service; a contract to provide weekly support for a young person with complex and significant disabilities and

the provision of summer support to a number of specific children with complex needs during August 2010. The financial information relating to these spot purchases is not included in the above Table.

It should also be noted that within this six month period of the reduced Service, there was very successful fundraising by the parents in relation to raising funds for the Duke of Edinburgh Gold Award. As sufficient funds have now been raised to complete this project, similarly high levels of fundraising would not be anticipated for the second half of the financial year 2010/11. It should also be noted that similarly high levels of fundraising by parents could not be expected nor would be sustainable over a long period of time.



Donations in kind

In addition to the funding that the Service has been able to secure through fundraising and specific grants, the Service has been very successful in partnership working with other organisations to secure additional benefits for families supported. A prime example of this has been in the partnership with MeUnltd, a local Community Interest Company that supports carers through personal development programmes and the development of sustainable support groups. In a recent cross-border project, core funded by the DFA (Department of Foreign Affairs) and jointly run (April – December 2010) by Positive Futures, Enable Ireland (ROI Disability Charity) and MeUnltd, a range of personal development programmes was run for male and female carers on both sides of the border. As part of this project, a Give-a-care scheme, operated by MeUnltd in partnership with Positive Futures, was in place that enabled local businesses, organisations and

individuals to donate time and resources to benefit carers e.g. free access to leisure and health activities for discrete periods of time, free access to counselling and therapeutic support. Under this scheme, just over £9,000 worth of support in kind was available to the carers involved in this cross-border project. As a result of all of the personal development programmes that the Service has run in partnership with MeUnltd over the last few years, just over £35,000 of support in kind has been donated under the Give-a-care scheme to provide additional support for carers involved in these programmes.

Hence the project has levered funding from other sources that would not otherwise have been available to families in Fermanagh.

Appendix 2: Characteristics of the children and families who have used the Service

There are currently 42 families that either are still supported by the Service or were supported during the full Service. The current Review interviewed 24 parents including those who were still using the Service (N=18), those who had used it during full funding and no longer can avail of the Service (N=2) and those whose children can no longer be supported but either or both parents still attend the relevant carer group (N=4).

Throughout this section there will be comparisons to another study carried out within the same Service in 2007 (Black et al 2008). At this time (2007) there were N = 32 children

included in the research and information was available for all the families using the Service in that year.

The average age of the children within the present sample is 14.75 years. In the Lifelines report, the three Family Services within Positive Futures were included and the average age in this research was 12.6 years. Left is a comparison of the gender differences between the 2007 sample and the 2010 sample.

Table A2.1: Gender differences (%)

	Male	Female
2007	59.4%	40.6%
2010	50%	50%

Table A2.2 indicates the percentages of children who either attend mainstream school, special school or who have left school. At the time of the first report all of the children were still attending school, however, some children who were supported by the Service had left school by 2010 which is reflected in the Table A2.2.

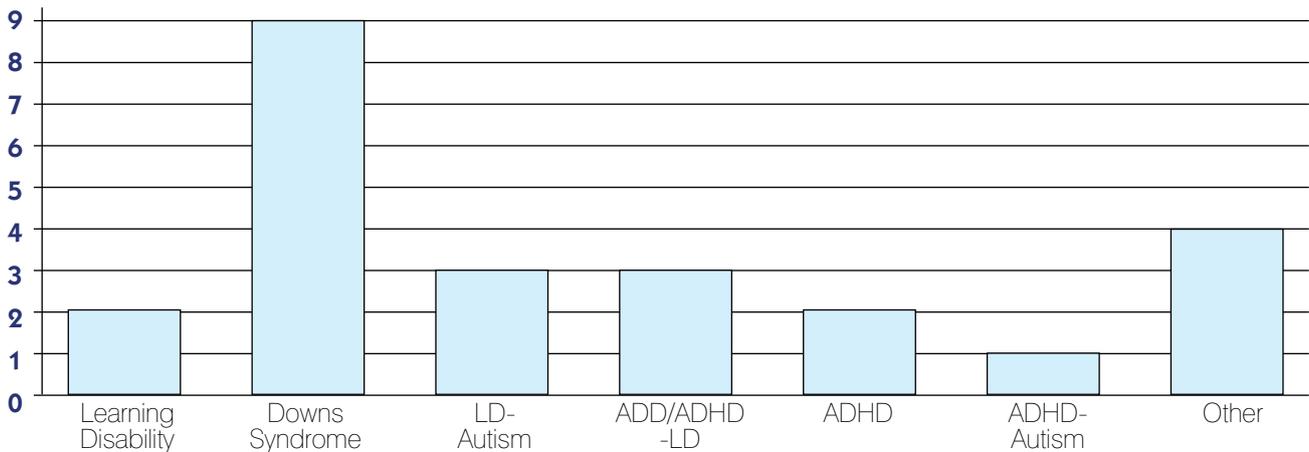
Table A2.2: Schools Attended %.

	Mainstream	Special	Left School
2007	22%	78%	N/A
2010	10.7%	62.5%	12.5%

Figure A2.1 summaries the different types of disabilities among the children within the current Service. Only two children were diagnosed as having a single learning disability and there are a total of nine children with Downs Syndrome (3 boys and 6 girls) and three children with a dual diagnosis of a learning disability and autism. There are also three children with a

dual diagnosis of ADD/ADHD and a learning disability and one child with both ADHD and autism. There are four children who have a condition that would be described as 'other', for example; Prader-Willi Syndrome.

Figure A2.1: Types of Disability



Services Children and Families Used

This section details the particular activities accessed by the children and family members within the Service. This is presented in Table A2.3 which details the activities that were accessed by the children and families during the full and reduced Service. There are some

instances where there is no data entered for a particular activity as it may not have been available when the Service was either at reduced or full capacity e.g. the work with fathers has developed in recent years and was not happening in 2007.

Table A2.3: Number of people accessing activities per month

Activity	Number Availing of Service Full Funding	Number Availing of Service Reduced Funding
Support for Mums / Women’s Carers	25	14
Buddy Group	29	7
After Schools	31	N/A
1 to 1 support	13	4
2 to 1 support	2	5
Swimming membership	3	3
Sibs Group	15	7
Summer Schemes	38	19
Duke of Ed	8	14
Homework Support	3	N/A
Support for Dads / Male Carers	N/A	11
Special Olympics Football	N/A	4
Girls Group	N/A	3
Volunteering with PF’s	N/A	4
Total	167	95

Table A2.3 indicates that many more children and families were able to access support and activities during the full Service (167) compared to the reduced Service (95). In total there was an overall

reduction of 43.1% in services accessed from the full to reduced Service. There was a 50.4% reduction in the activities availed of directly by the children from the full to reduced Service.

A further question examined what other support services are the families receiving from the WHSCT or any other organisation. The responses are detailed in the Table A2.4:

Table A2.4: Other Services used by families

Service Used	No of Parents whose family use the Service
No other support	13
Direct payments to employ staff	5
Down's Syndrome youth club	2
Respite	2
1 : 1 support from WHSCT	1
Cedar Foundation	1
Social Worker support	1
Community Nurse	1
Autism NI	1

Over half the families interviewed indicated that apart from Positive Futures they had no other support available. The most common form of additional support was direct payments from the Trust that enabled parents to employ carers on a part-time basis to support their child/children.



Appendix 3: Case Studies





Darragh "... clever, caring, honest and so endearing"

We, the Cassidys, have been involved with Positive Futures for the past six years. The whole family collectively and individually, have been involved at different stages over that period. Darragh primarily, has taken part in many activities and courses improving his social skills, meeting new friends and providing a form of respite for the rest of us. All this has helped him to grow into the social butterfly that he is. He has been involved in sports and the Special Olympics and is now able to work with a range of people. He has been exposed to a wide range of opportunities from horse riding and canoeing to mountain trekking and internet surfing!! This young man is always going somewhere!!

Over the past three years, Darragh has taken part in several Duke of Edinburgh Expedition's. Initially, Darragh set his sights on achieving a Duke of Edinburgh Bronze Award. While he enjoyed the expeditions, at times, it was quite difficult and distressing for him and others involved. We began to think that this may not be achievable for Darragh at this point in time. However, we sat down together with staff from Positive Futures and explored all the options available to us, focussing on the positives, Darragh's strengths and how we could

help him to achieve what he intended. Each expedition brought new challenges for Darragh, new learning for us and the staff, but also new achievements for Darragh.

At the planning stages, using a person centred approach, the 4+1 tool and in view of the risk assessments, Positive Futures increased the staff support for Darragh to a 2:1 ratio and on the few occasions when that wasn't an option, either his Dad or I came along as added carer support. This ensured carers stayed in Darragh's tent at night. Darragh also had the opportunity to bring along his personal belongings such as his ipod, portable DVD player, books, folders, food, lamp and a lead blanket to use during difficult periods in order to de stress. Each expedition Darragh went along to, he went off packed and prepared with a detailed structured programme of what was to happen during his time there. Darragh's motivation was clear throughout and we all felt a great sense of achievement watching his delight at receiving his bronze award. The amount of effort, planning and organising that went into each leg of this journey with Darragh has been nothing short

of commendable! We as a family have been blessed to work with people who are so committed to Darragh's progress. We and Positive Futures all recognise with pride, the major undertaking and achievement this has been and that Darragh's success in achieving his Bronze, has made it all worthwhile.

Since then, Darragh has also achieved his Silver Award and the fab photo at the top of this article was taken at Queens University on the very proud day that it was presented to him.

Darragh is now nearing completion of his Gold award and we have no doubt he will achieve this also. We are all so proud of Darragh's achievements to date and no doubt will see many more in the future.

In addition to all that Ciaran, Darragh's brother, has attended the Siblings group where he has a wee circle of friends, who all live in a house like ours. This gives him a safe space to air his frustrations and other emotions. It also allows him to participate in a range of activities that are fun based and are entirely 'sib-focussed'. He thoroughly enjoys this group, has formed some good wee friendships and he looks forward to meeting up with them each week. Gemma, Darragh's older sister also attended the Siblings group in her day and has many happy memories of her sessions there and the friendships she shared along the way. She is now attending College and more recently has worked voluntarily, in the Lakeland Office doing

administration duties. Liam, my husband has attended the courses for the male carers and he regularly attends their outings and activities. He looks forward to and enjoys his time out with the group, whether it's going for a trek, a pint or action packed combat. He thoroughly enjoys the banter that goes on within the group, amidst the man fun stuff!

And then there's me Mary, last, but unlike years ago, no longer least!! I have undergone the 'Its All About Me' course for carers and advanced levels, enabling me to explore my own journey of personal development. Now rather than only facilitating the lives of my loved ones, I value and appreciate that my life too, is for living. I achieve a better balance and am much less isolated, as I have formed a fantastic circle of friends and a valuable support network based on positivity and gratitude. This makes me stronger and helps me to continue meeting my daily caring demands. I also hugely contribute, voluntarily to my community.

Finally, in summary, the impact of Positive Futures on the lives of our family, both collectively and individually, has been immense. It is impossible to pinpoint any one part of the service that was/is more or most important because as the main carer in our family, I see the benefits of each and every particle involved and the impact on the recipient family member and on the family unit as a whole. Each bit, however great or small, fits together, like a family jigsaw and every piece is equally important, every person is truly valued.

By: Mary Cassidy



Laura "...bubbly, kind, thoughtful"

Laura and our family have been involved with Positive Futures for a number of years now. Laura attends a local youth club with her peers each week with support from Positive Futures, where she enjoys meeting new people and sharing stories.

This has been particularly important to Laura as she is a sociable and very bubbly and capable little girl who would dearly love to socialise with her friends outside of school time, but would not always get the opportunity. Laura was first introduced to Special Olympics through Positive Futures and then progressed to become a member of the Lakeland Special Olympics club; she recently obtained silver and gold medals, competing for Ulster in the Ireland games and all with the biggest smile on her face, a true inspiration to all. Laura's experiences on days out with Positive Futures gave her the confidence to travel with and stay with her team for the Ireland games and, from what we can hear, she kept the squad entertained throughout! Laura is an active member of the St Michael's Scout unit and has already achieved a number of merit badges. Laura's initial introduction to the Unit

was supported by Positive Futures; their liaison with the Scouting leaders gave the leaders the knowledge and confidence to welcome Laura into the unit and to facilitate her in gaining a full and positive experience from her role as a Cub scout. Laura has attended the Swimability programme at the Lakeland Forum over a number of seasons and has achieved her 25m swimming badge to her and our absolute delight; we can just imagine the fun she will have now on her outings to the pool with her buddy group.

Through all of these experiences Laura's confidence has grown immensely and she always looks forward to any new opportunities that arise; it is our hope that the opportunities continue to come!

Laura's sister Emma has also been involved in Positive Futures sibling group, getting together with others from similar backgrounds to have fun and also discuss their feelings about having a sibling with a learning disability. This opportunity came at a particularly important time for the family and for Emma, who does not have the benefit of extended family to offer the emotional support that a sibling can require. Emma has also helped out at residential as a Positive Futures' young volunteer; she is a natural in this role, bringing the fun, warmth and empathy to the role that she shows to her little sister.

We, Paul and Fiona, Laura's parents, have both been involved in carers' courses facilitated by Positive Futures. The courses were a vital and enjoyable opportunity to meet other parents and professionals, sharing information and advice, to be supported in developing resilience and coping strategies, as well as being involved in a few pampering and fun activities along the way; time out from busy family life!

As a family, we have benefited immensely from the support, activities and courses provided by Positive Futures and we hope to be involved in many more as we continue to support Laura in leading a full and active life and achieving her dreams.

By Fiona Keenan

Shaun, his siblings and his carers have been supported by Positive Futures very soon after they became established in Lisnaskea.

Shaun availed of pick up from school, taken to participate in activities which were geared to support his individual needs, and was coached in basketball, botcha, and other sporting activities. His siblings were able to join him many of these activities and were able to meet other young people who were also carers and had siblings with a learning disability. His siblings also benefited very much from individual programmes designed to support siblings explore their feelings about their disabled sibling and the effect it had on their life and that of their family.

Positive Futures were a great support to me as a carer in often trying times for our family. Their knowledge of my son's disability offered great comfort to me that he was being cared for by excellent staff and volunteers. I truly admire the many young people who volunteer with Positive Futures and give so generously of their time to care for our children.

Another way that I was supported by the service was by involvement in the carers personal development programme. This gave me the opportunity to meet and learn alongside other carers who had children with disabilities. It is so important that carers can think about themselves and look after themselves so they can look after their family – it is about benefiting the whole family.

Shaun's greatest achievement in his life has been the achievement of his Bronze, Silver and Gold Duke of Edinburgh Awards which could not have happened without Positive Futures staff and volunteers. This achievement stretched Shaun in every possible way; he learned to look after himself, he was challenged to share bedrooms and tents with others with a learning disability (something he finds very difficult to do), he fended for himself in the great outdoors sharing cooking, cleaning, hiking and many

other activities with others. He learned new skills, volunteered and was challenged to improve himself in many ways.

Positive Futures currently offers Shaun a work placement on Friday morning therefore enabling him to put to good use the skills he learned as part of his Duke of Edinburgh Award, namely typing, filing and other office duties.

Positive Futures are a very important part of Shaun's life in very many ways and continue to support him and many other children in the Lakeland region where services are very limited. It is an excellent model for caring for children and young adults with learning disabilities and needs to remain and indeed expand in order to support the many families who so desperately need their help. The service is about supporting families and not about crisis intervention. Families do not want to get to the point of crisis, we need the support before this happens.

By Angela Lynam



Mark Joseph is the youngest of four siblings, living in Lisnaskea, Co Fermanagh and he attends the Erne School, Enniskillen. He has Down's syndrome and a learning disability as well as having some health problems. Mark Joseph was 10 years old when our family first became involved with Positive Futures in 2004. This is Mark Joseph's life journey.

Today, as a 16 year old teenager, Mark Joseph is an avid Liverpool supporter and along with this, enjoys getting every opportunity to have a kick about demonstrating his football skills and his passion for the game. He attends the Special Olympics Football club each Saturday with his friends from Positive Futures. Mark Joseph is a very sociable young man who likes to mix with others whilst attending his local youth club and gym in Castlepark, going swimming with his school, going to scouts and visiting his neighbours to name but a few.

As his parent, I initially highlighted the need for Mark Joseph to get support to use local resources in the community, which would encourage integration and help build relationships as well as giving our family some respite. The team at Positive Futures then introduced the family to Person centered tools. From the use of such tools it was clear that Mark Joseph loved the outdoors, loved to help others and socialize as much as possible. It was at this time when Mark Joseph began his Duke of Edinburgh Bronze award. He had the opportunity to be supported in several volunteer roles including conservation work at Florence court and helping out at the local scouts group. Currently, Mark Joseph has a volunteer placement in Barnlee where he helps to water plants, collect eggs from the hens and chat to the residents. He loves this role and has become part of the team there, he has been invited too barbeques and parties with the staff and residents. Mark Joseph feels very much part of the local community and feels so grown up as he talks to family about 'going to work.' Through this award Mark Joseph learned lots of new skills, attending computer courses, mobile phone training and first aid training. The part that Mark Joseph enjoyed most was getting away for expeditions with his peers, having fun and getting away from mum and dad for a while! Mark Joseph has grown as a person and his

independence has shone through. As a family we are so proud of his achievements and to date Mark Joseph has completed both the Bronze and Silver Awards and is currently completing his Gold Award. These achievements have taken us to Stormont and Queens University in recognition at the fantastic effort and commitment Mark Joseph has put into getting his Awards.

Positive Futures has also given us support as parents, both myself and my husband have been involved in carers' programmes, meeting with other parents for personal development and also just some time out, meeting for lunch, walks or some pampering. These groups have given us the chance to make new friends and talk about the challenges in life as well as looking at the Positives.

Overall, the opportunity for Mark Joseph to complete his Duke of Edinburgh Gold Award has been such a great highlight in our lives. Mark Joseph has loved every minute of the experience, he has made so many friends and he has become so independent. We have seen pictures from the expeditions and the challenges he has faced, what an achievement! The staff at Positive Futures see the potential in the young people they support and we are so grateful for their support through the years, they are like an extended family to us.

By Bernie McCaffrey



*Mark Joseph Mc Caffrey
"...Friendly, fun loving, great craic"*



Through all of these experiences (her)..confidence has grown immensely and she always looks forward to any new opportunities that arise; it is our hope that the opportunities continue to come!

Parent, LKFS



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