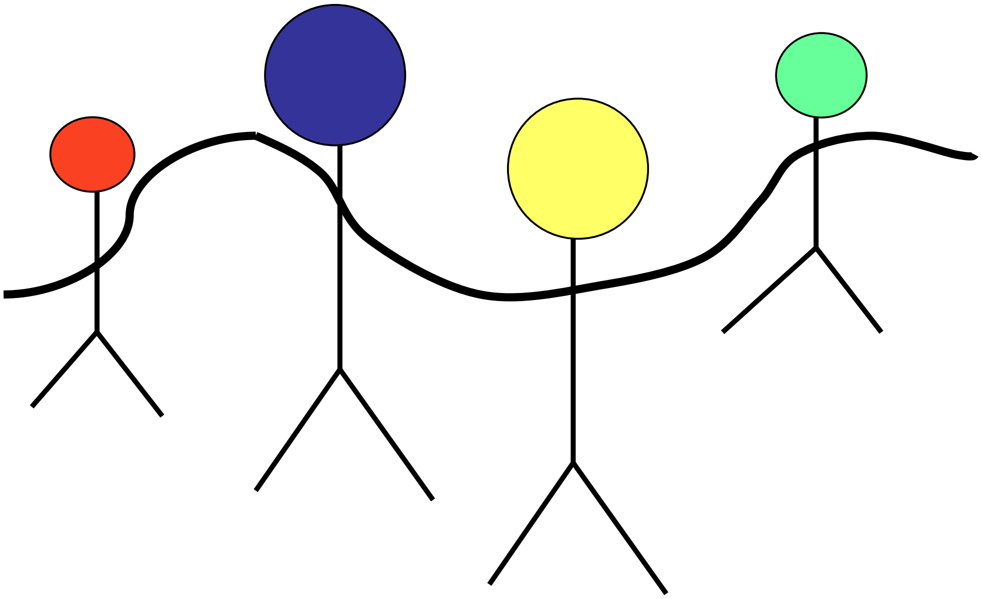
Interim Evaluation Report on Positive Futures' Bangor Families Project



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January, 2007

POSITIVE FUTURES

For people with a learning disability

Executive Summary

Research has repeatedly demonstrated that families who have a child with a learning disability are under considerable strain. This report presents the findings from an interim evaluation of the pilot Bangor Families Project which is delivered by Positive Futures. Postive Futures is a local charity in Northern Ireland which provides support services to children and adults with a learning disability. The Bangor Families Project aims to provide holistic support services to families who have a child with a "significant" learning disability in Bangor, Co Down. This Project began in 2004 and is funded in partnership with the South Eastern Health and Social Services Trust.

At present, 28 families access services provided by the Bangor Families Project. This report details the aims and objectives of the Project, describes the services it delivers and the demographics of families accessing the Project. It paints a picture of the types of everyday emotional, practical and financial challenges that these parents face. For example:

- 25% of Families in the Bangor Families Project are coping as lone parents.
- Many families also have more than one disabled child or are looking after older disabled parents or in-laws, or are themselves ill or disabled in some way.
- 28.8% of families live on "low incomes" (<£16,000 per annum). 39.3% of primary carers left school with O-levels or GCSEs as their highest qualification.
- 21% of the families involved in the Project have 4 or more children living at home. Of these, three families (10.7%) have 4 children, two families (7.1%) have 5 children, and one family (3.6%) has 6 children living at home.
- 89.3% of families received no support from neighbours in the area. 60.7% received no support from friends.

To ascertain the impact the Project has had on their lives, parent's views were obtained using a qualitative methodology. Randomised semi-structured telephone interviews were conducted with 20 parents currently accessing the Project. From this, a number of key findings are presented and key recommendations have been suggested including:

Parental consensus was extremely positive about the pilot Bangor Families Project. Parents expressed high hopes for the pilot to continue

and develop in the future. Many parents referred to the Project as a ‘lifesaver’, ‘blessing’ or a ‘godsend’; saying that they would be ‘completely lost’ without it.

Nearly all parents voiced that, prior to the Families Project, their son or daughter had little or no social outlets outside of their school environment. Parents had typically brought their child out and carried out activities with them.

The Project has positively impacted on the siblings and it has enabled parents to focus more quality time with their other family members.

Additional key themes emphasised by parents included the person-centred ethos of the Project; that Project staff placed the child at the centre of everything; finding opportunities and interests to meet the particular needs of each child.

Parents also reported that their child had made friendships, developed new skills, had their social networks enhanced and even conquered fears. Families expressed delight at the personal milestones that their child had made in developing confidence, being empowered and improving their behaviour or communication skills.

Many parents stated that the Project staff provided vital support by giving timely information, guidance, and advice. Family Workers were often referred to as a type of “confidante”.

Several parents also expressed concerns about the future for their child. New services, such as a Buddy Scheme would be a good way for their teenage son or daughter to have new experiences.

Parents also voiced a desire for more resources provide additional activities, staff and volunteers. Irrespective of their own financial hardship, most parents would be willing to contribute financially to the Project.

A number of challenges remain for families in the Bangor area who are living with a child with a learning disability. Since each family is unique, support is required on many different levels. This Report serves as an evidence-base for current practice and paves the way for future service provision.

Introduction

Research has repeatedly demonstrated that families who have a child with a learning disability are frequently at risk of increased levels of stress (McConkey *et al,* 2006; Roach *et al,* 1999). Higher stress levels within the family unit can affect how these families learn to cope with everyday situations. In turn, stress can also exacerbate health problems and lead to reduced levels of family functioning. In order to facilitate better coping mechanisms, parents and siblings who have a family member with a learning disability require adequate time for respite. Research has also highlighted that social and external support networks have been significant factors in helping families to cope better.

Positive Futures has recently evaluated their Families Projects in the Lisburn and Lakeland areas (Truesdale-Kennedy*, et al*, 2006). These evaluations focussed on the impact of parent carers. The value of a holistic approach to family-based activity support schemes for families with a child with a learning disability has been encouraging. The main findings included:

- Families spoke very highly of the Project and found it of benefit not only to their child, partners, siblings, but to themselves. It opened up opportunities for activities and provided respite breaks for parents.
- Families reported significant improvements on measures of family functioning and had few suggestions for improvement of the Project.
- Families reported that the child with the learning disability had learnt new skills especially in communicating, socialising and independence.
- Most parents valued participating in the person-centred planning approach used by the Project; this helped parents to gain a vision for the child's future.
- Indicators of parental stress and health did not change significantly over time although ratings of family functioning did improve.
- Children who showed more maladaptive behaviours appeared to cause greater stress in mothers.
- The use of informal supports by families did not appear to change. (Previous research suggests that this serves to buffer parental stress).

- We have limited understanding of father's involvement with the child and how a Families Project can assist them.

This interim report provides an overview of another Families Project provided by Positive Futures in Bangor. This Project commenced in 2004 and is funded in partnership with the South Eastern Health and Social Services Trust and Positive Futures.

Aims of the Families Project

The Families Project is based upon a holistic, family-centred approach which provides support to families who have a child with a learning disability. The main aims of the Families Project include:

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

Project Overview

Inclusion criteria for the Bangor Families Project are as follows:

- The child must be aged between 8-19 years
- The child must have a "significant" learning disability or be severely impaired by social or adaptive functioning
- The child's family must reside in the BT10 or BT20 catchment areas

By December 2006, a total of 28 families have been referred to the Bangor Families Project. The Project is currently managed by Tim Parr. There is also one full-time family worker (Jenny Magee) and one part-time family worker (Julia Sloan). In addition, 9 sessional staff are employed as Recreational Support Workers. A further 20 volunteers have been recruited and trained.

The main activities of the Project include the following:

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

Bangor Families Full Evaluation

A full evaluation of the Families Project has been ongoing since 2004. All families, once enrolled in the Project, were invited to participate in the evaluation. Those who decided not to take part were not disadvantaged in any way.

At present, 18 families have agreed to the full evaluation of the Bangor Families Project. Before an evaluation is undertaken, a family carer is required to complete a consent form. A common pro forma of family details is then completed together with the family carer, by a Family Worker. Descriptive information is also gathered pertaining to the child's family circle, schooling, habitation, social and support networks, and healthcare provision.

After these details are captured, the first phase of the full evaluation requires the administration of a series of carefully selected questionnaires. Questionnaires are administered by Family Workers to parents and include the following:

- Social Opportunities (Adapted from Sarason, *et al*. 1983)
- General Health Questionnaire (Goldberg & Williams, 1991)
- Family Functioning (Epstein, Baldwin & Bishop, 1983)
- Parent Satisfaction Questionnaire
- Parenting Stress Index (Crnic, Friedrich, & Greenberg, (1983).
- Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984)
- Aberrant Behaviour Checklist; "ABC" (Aman & Singh, 1986)

For the second phase of the evaluation, the same questionnaires will be re-administered 12 months after the initial series. These are completed with parents by a Research Officer who is not involved in the delivery of the Project. Once complete, comparisons between a number of measures will be drawn between the two time frames in the family's life. This will enable the evaluator to ascertain the impact of the Project on the family carers, and other family members. As the full evaluation is currently at the midway stage, a comparison of measures cannot be drawn. Therefore they are not included in this current report.

Instead, a baseline analysis has been conducted using pro forma data collected from all 28 families registered with the Project. This information was subsequently used to create profiles of all the families involved. In addition, 20 parents were selected at random and interviewed over the telephone. This enabled parents to describe their feelings towards the Project and to speak freely about how the Families Project had impacted not only on their lives, but on those of the Project child and the wider family network.

Characteristics of Families

All families enrolled (N=28) in the Families Project will now be described.

Every family involved in the Project is from a white ethnic background. Twenty families (71.4%) are reported to be two parent families, 7 (25%) are lone parent families, and 1 family (3.6%) has a parent-partner arrangement.

In the majority of families (96.4%), except for one, the mother is the primary carer. In 12 of the families, the main carer is aged between 30-39 years of age, and in another 12 families, the main carer is aged in the 40-49 age group. Only 4 families (14.3%) have a primary carer in the 50-59 age group. Of the primary carer, the majority (N=11; 39.3%) had left school with O-levels or GCSEs, and 5 families (17.9%) had left school at the age of 15. Ten of the primary carers (35.7%) had acquired higher education qualifications. In 23 families (82.1%) a main wage earner was reported. 28.8% of families live on low incomes of less than £16,000 per annum.

In terms of living arrangements, 24 families (85.7%) own their own home, whereas 4 families (14.3%) do not; they currently rent their house from the Housing Executive. The average length of stay in the current family home is 7.3 years, however this period ranged from only a few months to 20 years.

In addition, 14 families (50%) have 2 children (including the Families Project child) living at home. A number of families (N=4; 14.4%) also have either one or three children living at home. Three families (10.7%) have 4 children, 2 families (7.1%) have 5 children (of which one is a lone parent), and one family (3.6%) have 6 children living at home. There were no other dependents reported to be living in the home. Nevertheless, 16 families (57.1%) reported that they had relatives living within the area. Ten families (35.7%) did not have relatives living nearby. Two families (7.1%) did not provide this information.

Child Characteristics

Twenty-eight children with a variety of mild to severe learning disabilities are currently enrolled in the Bangor Families Project. All children (N=28; 100%) live with their natural parents. The majority of children are male (N=17, 60.7%), compared to 11 (39.3%) children who are female. The children are aged between 8 and 18 years of age. Their average age is 12.

A name has been given for the majority of the children's conditions. These are described in Table 1 below.

Nature of condition	**No. of Children presenting**	**%**
Autism Spectrum Disorder	9	32.1
Asperger's Syndrome	1	3.6
Downs Syndrome & Autism	3	10.7
Downs Syndrome	1	3.6
ADHD	2	7.1
Tuberous sclerosis and Epilepsy	2	7.1
Global Developmental Delay (GDD)	5	17.9
Speech & language problems	1	3.6
Hydrocephalus	1	3.6
Dyspraxia & GDD	1	3.6
Sensorineural deafness	1	3.6
Coffin Lowry Syndrome	1	3.6
Total	**28**	**100**

Table 1. Nature of child's condition in the Bangor Families Project

As can be seen from Table 1, most children enrolled in the Project have Autistic Spectrum Disorder. Six children (21.5%) have Global Developmental Delay (GDD), with one child having GDD and Dyspraxia. In addition, fifteen children (53.6%) have some type of behavioural problem, 13 (46.4%) do not. Six children (21.4%) have a visual impairment and 4 children (14.3%) have a hearing impairment.

Five (17.9%) children attend mainstream school, whereas 23 (82.1%) of the Project children attend special schools and have a statement of special educational provision. The majority of children (N=14) attend Clifton Special School in Bangor.

Support Networks

Families were also asked if they received informal support. Seventeen families (N=60.7%) said that received support from children and grandparents in the family. Eleven families (39.3%) did not receive any support or help from children in the home, or grandparents.

Furthermore, 25 families (89.3%) did not receive support from neighbours in the area. When asked if they received support from friends, the majority 60.7% (N=17) said no. Twenty families (71.4%) had not received support or attended a parenting group.

Practical Supports

Parents were asked to report on whether or not they received any financial benefits, made any adaptations to their home or received any transport for their child/family. Twenty-six parents (92.9%) were in receipt of financial benefits, 2 families (7.1%) were not. Eight families (28.6%) were reported to have made adaptations to their home, and 9 families (32.1%) reported that they had received transport assistance for their child/family.

Other Service Supports

Parents were asked about the contact that they had with named professionals in the previous 12 months. All families had been in contact with a wide range of Allied Heath Professionals. Professionals that parents were most in contact with were teachers, dentists, social workers, and doctors. These are described in more detail in Table 2 overleaf.

Professional	No. of families	Percentage
Teacher	28	100
Dentist	28	100
Classroom Assistant	27	96.4
Social Worker	27	96.4
GP	27	96.4
Speech & Language therapist	18	64.3
Hospital/community doctor	16	57.1
Clinical Psychologist	14	50.4
Community Nurse	12	42.9
Behavioural Support Worker	11	39.3
Educational Psychologist	10	35.7
Occupational therapist	9	32.1
Physiotherapist	8	28.6
Overnight Respite Worker	8	28.6
Domiciliary Worker	5	17.9
Heath visitor	2	7.1
FE college tutor	1	3.6

Table 2. Professionals in contact with families in past 12 months

Leisure/Recreation Organisations/Groups

Parents were also asked about leisure and recreational organisations, or groups that their child had attended. A summary of these findings is detailed in Table 3.

Organisation/group	No. of children involved	No. of children NOT involved
Summer Scheme	13 (46.4%)	15 (53.6%)
Church Group	7 (25%)	21 (75%)
Uniformed Organisations	5 (17.9%)	23 (82.1%)
Youth Group	6 (21.4%)	22 (78.6%)
Sport/leisure clubs	5 (17.9%)	23 (82.1%)
All Year Scheme	8 (28.6%)	20 (71.4%)
Any Other activities	1 (3.6)	27 (96.4%)

Table 3. Frequency and type of leisure activities for Project children

Reactions to the Families Project

The following information was obtained from structured telephone interviews[1] with 20 of the participating families. To mitigate potential biases, families were telephoned at random.

All parents mentioned at least 1 way in which the Project had benefited their child. This is documented in Table 4 below.

Benefits to the child	**Number of mentions**
Socialising with others outside family	8
Confidence/independence improved	7
Meeting child's needs	6
Activities provided	5
Well looked after	5
Stimulation and Support	3
Structure	3
Outside interest for the child	2
Respite	2
Organisation	1
Organisation	1
Consistent –familiar faces	2

Table 4. Benefits for taking part in the Project for the child

Among the comments that parents made were:

It has helped N enormously to express herself, it has broadened her horizons no end. Her helper has encouraged N to do lots of things that we wouldn't have thought she could have done. She has been encouraged to pursue her own interests- and has since progressed extremely well with a musical instrument. She has also become very good at complex jigsaw puzzles-we just can't believe it.

Ns medication has meant that recently he prefers to be on a one-to-one basis. Positive Futures have recognised this and sent someone to be with N on a one-to-one level. They have been a very personal service to N.

N has become more independent from us, as before we would have been his 'security blanket'. He has also developed a very strong bond with his helper.

N has autism and the physical activities, like swimming, means that he is keeping healthy and getting fit and this keeps his mind active. Before he would have been about the house, getting bored and frustrated. N likes 'solid play' and the activities are broken down so that he can understand. It's tailored perfectly for him.

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[1] Telephone interview questions are attached in the appendices and more detailed information is available on request.

Love the fact that it's given N huge confidence that she didn't have before. It's wonderful especially at the moment when they are off school. N needs routine and this is provided by Positive Futures.

Parents also showed enthusiasm for the range of activities offered to their children. The main activities mentioned are in Table 5.

Activities	**Mentions**
Swimming	12
Saturday Outings – day trips/meals	7
Arts and crafts	6
Dance	5
Cinema/theatre	5
Horse riding	5
After schools club/summer scheme	5
Parties – Christmas, Halloween	4
Trampolining	3
Specific visit – e.g. law centre, airport	3
Special Olympics	3
Drama	2
Football	2
Ten pin bowling	2
Leisure centre/gym	1
Drama/dance	1
Fishing	1
Campaigners	1
Shopping	1

Table 5. Type of activities children were involved in

My child never had anything like this before. We have always been very restricted by what we can do with her in terms of opportunities outside of school. I can't say enough how fantastic the service has been in giving my child such an outlet…and the pleasure is written all over her face when she comes home.

Opportunities before the Project were much more sporadic. It gets N into a regular routine, gives her a focus and gets her out of the house…she loves that.

The Saturday trips are great for N. She has learnt so much and it gets her excited. The staff are so good to them. She tends to join in more and come out of herself when I'm not around. I can see her getting more confident.

She loves horse riding and talks about it all the time. We see a big difference in how she cares for animals a lot more now. N has since taken some responsibility for our animals at home-and is more affectionate toward them; the cat… she even feeds the fish.

All parents interviewed were able to name at least one way in which the Project had benefited their child. This is summarised in Table 6.

Perceived help	**Mentions**
Learn new skills	5
Socialising/mixing with others	5
Improving child's independence	4
Improved communication skills	3
Improved child's self esteem	3
Enjoyment	3
Provides structure	2
Improves family dynamics on child's return	1
Community integration	1

Table 6. Parents perceptions on how activities have helped child

Of all the services we have availed of, this is the only one that has made such a difference to all of our lives. There is a saying "disabled child, disabled family". Positive Futures has really empowered our son, and personalised everything so it's relevant to him.

It is wonderful to see my child get opportunities. …Dance, drama, cinema trampolining…it's been fantastic. I'd be lost without them.

It gives N a focus. He looks forward to the activity days and during the week he will ask what day it is and get excited- it's helped us to get him out of the house and onto the school bus in the morning, which used to be quite an ordeal.

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 too, 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.

N has grown so much. Her communication skills have improved tremendously. Nowadays she uses far more eye contact and listens to me more.

Positive Futures' Families Project has given her a social life outside of school. She enjoys going to crafts and she has become more self-assured. I don't want N to be a burden on her brothers and sister, and I know I won't always be around forever. That's always been a big worry for me.

I hate the water and Positive Futures are great because they bring N swimming. I couldn't do that for N.

Benefits to Parents

Benefits	Number Mentions
Respite	9
Time with other children	7
Practical support	4
Knowing child is stimulated	4
Knowing the child is safe/no worries	3
Knowing someone is there	3
Emotional support	3
Information	3
Reliable service	3
Can visit/go out with family	2
Get to socialise with other parents with a similar child/new circle of people	2
Seeing the child happy	2
Time to cool down	1
Its independent from home	2
Knowing there are other families in same situation	2
Go shopping	2
Time for study	1

Table 7. summarises the main benefits to parents

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

I can close the door, and have time to switch off. This is a 24 hour job and I can't leave her, even to go for milk at the shop. I need and appreciate the space.

Positive Futures have always been consistent. Other domiciliary schemes we have been involved with before have cancelled on us and frequently let us down. I don't have time to keep (tax) books and Positive Futures take all that worry and responsibility away from me. They are a godsend.

We get to relax in a less-stressed family environment. We interact and have family time with each other without pressures of things that could upset N, like what seat we sit in at the dinner table. It's unusually a very controlled environment.

I know my daughter is with people I trust, they are familiar faces to her. I don't have to worry. She is collected from the front door and brought home safely. The environment she is in gives me complete peace of mind.

My mother in law is disabled and my own parents live abroad. The information and the extent of support we have received from the Key-worker has been invaluable. I get a lot of good advice. Any time I need anything I just lift the 'phone.

I have my hands full with other children, and I am a lone parent. I haven't much time to get practically involved. But the support I get from Positive Futures takes a huge burden of worry off me.

They (staff) are very good at working around us and the Family Worker will get in touch ahead of time to let us know if something is happening or even if something is being sent to us. This gives us more time to prepare.

Parents further highlighted some key benefits that the Project had afforded the child's other siblings. These are now listed below.

Benefits	**Number Mentions**
Quality time with parents	6
Get peace and quiet	4
They attend a siblings group	3
Don't have to compete for mums attention	3
Activities/trips	3
Work experience (volunteer)	2
Know they are not alone	2
They get a break	2
Know they are not alone	2
Don't have to live by a schedule	1
Know that the child is out enjoying themselves	1
Know they are not alone	2

Table 8 Benefits to child's other siblings.

N has started to participate with her brother on the computer together, playing games whereas before that simply wouldn't have happened. It's great to see them becoming closer.

My other daughter got the opportunity to go to a sibs group…She used to get very embarrassed about Ns behaviour. Thank goodness there are these programmes are on offer to support other members of my family too.

I can plan to do something one-to-one with my other child. It's hard to do that when N is around as there is a big age difference and they have very different interests.

Willingness to Help in Developing the Project

How willing would you be to:	**Yes, willing**	**Yes, (willing but could not do so at present)**	**No, not willing**
Make a financial contribution to the Project	12 (60%)	8 (40%)	0 (0%)
Volunteer to help in activities	8 (40%)	11 (55%)	1 (5%)
Transport your child/children to activities/events	14 (70%)	5 (25%)	1 (5%)
Join a management/steering group for the Project	12 (60%)	7 (35%)	1 (5%)

Table 9. Parents' willingness to contribute to the Project

Improvements and Recommendations to the Project

Parents had a number of suggestions for improving the Families Project.

- The overwhelming consensus from the families interviewed was that the Families Project should continue and expand. In order to achieve this recommendation, additional funding is required. In turn, even more activities could be made available, with more variation for parents regarding the choices and timing of activities that suit them and their child.
- An additional pool of volunteers is needed in order to support the growing number of families accessing the services. These volunteers could accommodate both children who prefer one-to-one support and those who prefer group-based activities. More staffing resources would be needed to assist in volunteer recruitment and training. It is also important that volunteers get the opportunity to meet parents and vice versa.
- More effective communication channels should be put in place between Family Workers, volunteers and families. For example, a reminder call system which confirms activities, locations and times, one day in advance would minimise miscommunication. It has also been suggested that parents get the opportunity to meet with each other.
- A "buddy scheme" should be established for children in their teenage years to enable them to experience more age appropriate activities and to develop new friendships with their non disabled peers.

Improvements	**No. Mentions**
Seeing it grow/expand	8
Funding available for it to continue	7
More staff volunteers	5
More hours	4
Provisions for older/younger people	2
More activities	2
Youth Club	1
Parents class	1
Activities spread out over week	1
More involvement of non disabled children	1
Source employment for older children	1

Table 10. Parents' suggestions for improvements

If I could change anything I would give Positive Futures a huge budget and lots more publicity and recognition for the great work the folks down there do!

My daughter is at a difficult age between being a child and an adult. It's hard to mix activities with much younger aged children. She loves music, like most teenagers. I would love to see her up dancing at a disco, this would really keep her stimulated. But there is virtually nothing out there for kids with learning disabilities at that stage in their life.

My child does 2 activities after school for 2 days back to back. I think that has been brilliant. Its not a complaint, but I would love to see her activities spread out more - a couple of days apart, or a bit later in the evenings as my child needs time after school to do their homework.

A little bit more feedback. Also in terms of a reminder call about pick-ups and collection; say…on the day before, would be really useful.

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. These types of Projects will help governments save money in the end. I wouldn't want this Project to stop. But it does need more funding and more volunteers.

A Wish List?

Parents were also asked about other activities or classes, if given a magic wand, that they felt would be a great experience for their child to do, which is currently unavailable to them. Overwhelmingly, the majority of responses from parents echoed the view that the Bangor Families Project had already achieved so much to help realise the needs and desires of their child. Nevertheless, some parents offered the following suggestions;

- Basic level cookery class
- Musical instruments class; especially looking at and listening to different types of music, such as jazz and percussion
- Saturday morning or afternoon youth club – combining fun activities and practical information (e.g. on bullying)
- Computer class – IT training / Computer gaming
- Discos and activities geared towards teenagers
- Ballet
- More board games
- Visiting specific places of employment e.g. factory, office
- Transport; airports, trains; motorbike rally – Formula 1
- Skills training for managing money and time

And for parents, individuals suggested that parenting courses on issues like challenging behaviour, sexuality and life changes, and coping with bullying would be useful. Another parent suggested more family activities to be able to get the whole family together, and to give them all an opportunity to get to know the volunteers. In addition, a parent suggested a resource guide containing relevant information for their child's future would be extremely helpful. A male parent also commented that, as a father, he also had feelings and emotions, and wished that there were more ways to help fathers to open up.

Finally, a number of parents added their thoughts on the Project overall.

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.

We would love to see it continue. A few years down the line when N leaves school I would love to take up a care package, if it was available with Positive Futures. I would happily pay for someone to take her out, because at 19, a day centre will not be the answer. Although they have their benefits N needs more stimulation and more 1-on-1.

I would definitely without hesitation recommend the service to other people. I know a mother from Newtownards who has 2 children and is desperate for a support service like the Families Project. I know how lucky we are.

I would love to put something back into the service- it's been super for N – keep up the great work!

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

Key Findings

A majority of families involved in the Bangor families Project (N=20; 71.6%) were interviewed for this interim evaluation report.[2] Parental consensus was extremely positive about the Project. Parents expressed high hopes for it to continue in the future. Countless parents referred to the Project as a 'lifesaver', 'blessing' or a 'godsend'; saying that they would be 'completely lost' without it. All but a few parents voiced that, prior to the Families Project, their son or daughter had little or no social outlets outside of school. Typically, before the Project, it was the parents who brought their child out and did activities with them.

Additional key themes emphasised by parents included the person-centred ethos of the Project; that Project staff placed the child at the

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[2] 4 of these families are lone parents, 1 family have a parent-partner arrangement. The remaining 15 families interviewed are 2 parent families.

centre of everything; finding opportunities and interests to meet the particular needs of each child.

Through participation in the Project, parents claimed that their child had made friendships, developed new skills, had their social networks enhanced and even conquered fears. It is apparent the extent in which the programme has enriched many of their lives. Furthermore, some families expressed sincere delight at the personal milestones that their child had made with regard to developing confidence, being empowered and improving their behaviour or communication skills.

Many parents stated that the Bangor Family Workers provided both vital support and timely information, often referring to them as a type of confidante. Families also identified a range of supportive benefits to the wider family circle including siblings and partners.

However, parents also voiced a desire for more resource allocation to supplement additional activities, staff and volunteers. Further improvements and recommendations were also noted.

Conclusions

Families who have a child who has a learning disability require more support mechanisms to help them to cope with life's everyday stressors. This report outlines a number of the challenges that families in the Bangor area face in terms of living with a child with learning disabilities. It illustrates that there are a relatively large number of families (N=7; 25%) in the Bangor Families Project who are coping as lone parents. Certain families also have more than one disabled child, or are looking after older disabled parents or in-laws. Support is required on many levels and each family is unique. The interim evaluation not only demonstrates the efficacy and holistic nature of the Families Project, but also advocates as an evidence-base for future service developments.

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Appendices

Sample questions from Positive Future's Families Project Telephone Interview.

PART 1

1. Overall what do you like about the Project?

2. Are there aspects of the Project that you are not happy with or wish were different?

PART 2: Activities

1. What activities has your child been involved in with the Project? (which community/specialist)

2. How does this compare in relation to number and type of activities before you your child was involved in the Project?

3. Is there anything that you would like to see changed in relation to the activities e.g. are there activities that you would like provided that are not at present?

PART 3: Involvement & Support

1. How involved do you feel you are with the Families Project? (probe: staff, activities, shaping the service etc.)

2. Does this apply to your partner also? If 'yes' has this support been tailored to meet the needs of your family?

3. Has the Project provided opportunities for N's siblings to explore/discuss their own issues and feelings? (Probe: could you please give examples)

PART 4: Benefits

1. What are the main benefits, if any, that you as carers, personally get from using the services provided by the Families Project? (Probe: could you please describe)

2. What are the main benefits, if any, your other children in the family get from using the services provided by the Families Project? (Probe: could you please describe: Record *not applicable* if only child)

PART 5: The Future of the Service

1. How would you like the service to develop in the future? (Probe: is there anything else if they mention continuity of the service)

2. Would you recommend this service to other families such as yours?