Positive Futures Interim Project Report

“They ask and they listen and they act and they care.”

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30th April 2014
Executive Summary

In 2011 Positive Futures produced “The Careful Plans Report” which focused on the needs of older carers of people with a learning disability and identified a number of key recommendations as to how these needs can be met. In response to these recommendations, Positive Futures was successful in obtaining a grant from the Big Lottery ‘Reaching Out, Connecting Older People Fund’ to develop a three year Pilot Project. The Better Futures Project targets older family carers, caring for a relative with learning disabilities focusing on their physical, mental and social well-being needs.

This Report summarises the interim evaluation findings of the Project at the end of year 1. A final evaluation report will be completed at the end of this Project.

Methods: In total 27 families, made up of 30 family carers, were supported by the Project over this twelve-month time frame; all family carers were offered the opportunity to engage in a formative evaluation of the Positive Futures’ Project, conducted by the University of Ulster. The family carers were aged 60yrs plus and were all caring for a relative who had a learning disability. There were two parts to this evaluation. Stage 1 involved the family carers completing two standardized questionnaires about their health (GHQ-28) and their caring difficulties (CADI) prior to commencing the project (Baseline / Time 1) and one year follow-up (Time 2). Of the 27 families who took part in the Project, 19 family carers consented to complete the questionnaires prior to commencing the programme: a 70% response rate. Secondly, seven family carers participated in a focus group to explore the benefits of the programme at the end of year 1.

Results

Stage 1: Both the older family carers and their relative with a learning disability were involved in a range of activities throughout this Project. The support staff and volunteers have been working directly with the family carers offering: short breaks / respite; practical and emotional support; transport; the provision of various peer-to-peer and professional support groups; development of Person-Centred-Plans and emergency plans. They have also been involved in facilitating and enabling family carers to meet with the appropriate Health & Social Care personnel, political representatives and other key individuals and agencies to lobby for their rights. Some parents have become part of the Project’s advisory committee. Likewise, the staff and volunteers have been supporting the adults with a learning disability to engage in a range of community activities that have afforded them a number of opportunities to develop their skills and independence.

Just less than a quarter of the family carers (22%) scored above 8 on the GHQ-28 prior to the commencement of the Project, indicating a potential mental health problem. When this was re-assessed at Time 2, this figure had increased to 35%.
The majority of these family carers reported caring to be physically demanding (CADI). The family carers reported that their relative with a learning disability presented them with many demanding personal care challenges: these figures slightly increased at Time 2. These findings may reflect the effects of the ageing process upon the family carers, and also the demands this places upon them as their relative with learning disabilities also ages. Many family carers reported their ‘emotional well-being suffering’ as a result of caring and they constantly worried about this caring role. These figures had reduced slightly at Time 2 thereby suggesting that the Project has provided these carers with some emotional support and practical assistance with this caregiving role.

**Stage 2:** A focus group was conducted which consisted of seven family carers and one adult with learning disabilities. The carers unanimously agreed on the positive impact of the Project and stated the following benefits: ‘provision of flexible respite support / short breaks; practical information / training / support; emergency / future planning; and building resilience to continue to care’. All expressed overall satisfaction with the Project. Not only did the family carers gain from this Project, their relatives / loved ones with learning disabilities also gained from ‘participating in a range of social activities, developing social and life skills and independence’. Throughout the focus group all of the family carers spoke very highly of the calibre of staff and volunteers, including their friendliness and genuineness and their willingness to ‘go the extra mile’, commenting on the induction and training that Positive Futures provides its staff and volunteers.

**Conclusion:**

This Interim Report clearly shows that the aims and objectives are well on the way to being met. Reports from the family carers illustrate the success and lifeline this project has offered them.
How we carried out the study

**Design:** This study employed a mixed methods design. Stage 1 used a number of questionnaires to collate information on the family carers' health and demands of caregiving across two time points (Time 1 / Baseline) and Time 2 (one year into the Project). Stage 2 undertook a focus group with seven family carers to explore the benefits and challenges with the Positive Futures' Project.

**Sample:** In total 30 adult family carers were involved with the Positive Futures’ Project during 2012/13, 19 of these family carers consented to completing the questionnaires at Time 1 (Baseline) with a further 14 family carers consenting to complete the questionnaires at Time 2 (one-year follow-up). There were a number of individual demands and pressures ongoing with families such as ill-health and family crises that were given as reasons as to why they did not wish to participate in having the questionnaires re-administered at Time 2.

For Stage 2, purposeful sampling was employed to identify family carers who had been involved in the Positive Futures' Project for one year. Positive Futures' staff invited the family carers involved in the Project for their availability to attend a focus group a short-time after the questionnaires had been administered by the University staff. This was to explore what the family carers and adults with learning disabilities were involved in during the Project and the benefits of the Project for the family carers. Taking part in the focus group was impacted upon by a number of factors that are common to the majority of activities the Project organises. Carers have so many demands put on their time and when their loved one is in day-care, their time is very precious to them and needs to be utilised to maximum effect. Reasons given to Project staff for not attending were that they had recently spent 1 to 2 hours with University staff completing Time 2 questionnaires and discussed the benefits that they perceived during this time and they had other pressing needs such as hospital appointments for themselves.

A total of seven family carers and one adult with learning disabilities took part in the focus group. The focus group lasted 50 minutes and took place in a community hall. The focus group was audio-taped and all were informed that the interviews were voluntary and they could withdraw at any stage. Of the seven adult family carers, six were mothers, one was a father and there was one son with learning disabilities present.

**Data collection**

**Stage 1:**
The general health questionnaire (GHQ: 28) (Goldberg & Williams, 1991) is a 28-item questionnaire recommended for the assessment of mental health in the community. In addition to the overall score, this version has four subscales, each containing seven questions which cover: somatic, anxiety and insomnia, social dysfunction and severe depression.
Difficulties in caregiving were assessed with the Carer’s Assessment Difficulties Index (CADI) (Nolan et al., 1998). This instrument was created to provide a detailed profile of carers’ difficulties in providing care. The scale has 30 items based over six domains (care-dependent relationship, physical demands of caregiving, family problems, restricted social life, financial consequence and poor professional support) and total stress score. Some of the items focused on ‘my sleep is affected’, ‘it is physically tiring’ and ‘professional workers don’t seem to appreciate the problems carers face’. The scale uses a three-point Likert scale (not stressful, stressful and very stressful). Llewellyn et al. (2010) in a study of 64 older parent carers of people with learning disabilities in Australia reported the Cronbach’s alpha of the subscales to range from 0.72 to 0.9.

**Stage 2**: An interview schedule was developed to explore what the family carers and adults with learning disabilities were involved in during the Project and the benefits of the Project for the family. The focus group lasted 50 minutes and took place in a community hall. The interviews were digitally recorded and participants were informed that the interviews were voluntary and they could withdraw at any point.

In order to ensure the truthfulness and consistency of the focus group, a range of *a priori* methods were employed. Firstly, the focus group was recorded and transcribed to ensure consistent and accurate accounts of the carers’ experiences. Secondly, the data was subjected to a thematic content analysis using Newell and Burnard’s (2006) framework. Thirdly, to authenticate the key themes and sub-themes, as identified by the interviewer, peer validation was employed whereby members of the research team reviewed the transcript.
Results

Stage 1

Demographics

Of the 30 family carers involved in this project, completed questionnaires were returned from 19 family carers at Time 1 and 14 family carers at Time 2. The majority of family carers were mothers caring alone; there were a few fathers caring alone; four siblings (three sisters and one brother) were the main carer; one carer identified themselves as an aunt of the person with learning disabilities and there was a set of grandparents providing care. Thirteen of the family carers reported their age: 6 carers were aged between 60-69 years, 6 were aged between 70-79 years and one carer was aged 80 yrs plus. Over two-thirds of the participants were lone carers whereas a third of family carers were dual carers (two carers actively involved in the caring role and engaging with the Project in the same household).

Activities family carers were involved in during the Project

The family carers and the person they cared for with learning disabilities were involved in a range of activities. Figure 1 below shows that all the family carers received home visits from a support worker (100%), visits from a staff team member (100%), Positive Futures’ staff were in regular contact with families to ensure the smooth running of the Project (100%) and the Organisation also lobbied for them on various issues (100%). The majority of family carers had developed an emergency plan (via Message in a Bottle) (89%); likewise many were in the process of developing a Person-Centred-Plan (77%). A major component of the Project was to provide respite / short breaks and transport for the family carers to attend a number of the groups that were delivered by the Organisation such as ‘Mutual Carers Support Group’ (70%), ‘Get Up and Go Group’ (44%), ‘Cosy’ (37%) and meetings with different Trust personnel (60%): this also included information sessions (60%) with solicitors, etc.
Figure 1: Activities family carers were involved in during the twelve months of the Project

- Loan of technology
- Attend COSY Group
- Attend other groups
- Respite
- Influence policy
- Advocacy service
- Information Sessions
- Carers support network
- Transport
- Development of PCP
- Emergency planning
- Lobbying
- Consultation about prog
- Regular phone contact
- Befriending service
- Home Visits
**Carers’ Mental Health**

Table 1 shows the carers’ self-reports on their mental health using the GHQ 28. The mean score for this group of carers at Time 1 was 4.5 (range 0 to 19: maximum possible 28): four family carers (22%) scored above 8 which is taken as the cut-off for screening purposes as indicative of psychiatric morbidity. The mean score for the carers at Time 2 was 5 (range 0 to 12): five family carers (35%) scored above 8.

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<th>Time 1 (N= 18)</th>
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<td>Total Score</td>
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**Carers’ difficulties in caring**

Figures 1 and 2 below illustrate that for the majority of these family carers they reported caring to be both physically and emotionally demanding. Just less than three quarters of the family carers (61%) reported caring to be ‘physically tiring’ and this increased to 70% at Time 2. Just less than half of the family carers (41%) reported that their physical health had suffered. Approx. a third of family carers (30%) also reported that their ‘sleep was affected’ as a result of their caregiving. The findings at Times 2 may reflect the effects of ageing on the family carers and the increasing demands this placed upon them as they and their relative with learning disabilities also ages.

The family carers further reported that over a third of the adults with learning disabilities ‘demanded a lot of their time’ (41%) and over one fifth of family carers also reported that the person needed ‘a lot of help with personal care’. As can be seen from Figure 1 these reports had increased respectively at Time 2, again this may result from a combination of the effects of ageing on both the person with learning disabilities and the family carers.
Figure 1: Carers report on the physical demands of caring (CADI)

Figure 2 below illustrates that just less than half of the family carers reported their ‘emotional well-being suffering’ (49%), this figure had reduced to 26% at Time 2; over a third of the participants reported being ‘helpless and not in control of the situation’ (36%), and approx. a third reported that they could not ‘relax because of worrying about caring’ (30%) at Time 1 – this had reduced to 20% at Time 2. However, these figures had reduced at Time 2 with 26% of family carers now reporting that their ‘emotional well-being was suffering’ and 20% of carers could now not being able to ‘relax because of worrying about caring’. Numbers might be quite small as there were only 14 families who completed the Time 2 questionnaire.
Figure 2: Carers report on the emotional demands of caring (CADI)

![Graph of emotional demands of caring]

Figure 3 below illustrates how half of the family carers found caring to ‘restrict their social / outside interests’ (49%), caring ‘putting strain on family relationships’ (49%) and that 36% of family carers ‘could not have a break’. However, these figures had reduced at Time 2 with 34% of family carers now reporting that caring ‘restricts their social / outside interests’, 34% of carers reported caring to ‘put a strain on family relationships’ and 27% of family carers ‘could not have a break’. Over a third of family carers at both Time 1 and Time 2 reported that formal supports (i.e. professional workers) did not recognise and provide enough support to the family carers as shown by the bar chart.
Figure 3: Carers report on informal and formal supports

- It restricts my social/outside interests
- It can put strain on family relationships
- I cannot have a break or take a holiday
- Professional workers don’t seem to appreciate the problems carers face
- I don’t get enough help from health and social services

T1: Very/Stressful (N=16)  T2: Very/Stressful (N=14)
Stage 2

Four themes emerged from the data: ‘benefits for the family carers, benefits for the adults with learning disabilities, quality of the support / volunteer staff and strategic involvement’. The themes and sub-themes identified are presented below and are supported with evidence in the form of narrative accounts expressed by the family carers.

**Theme 1: Benefits for the family carers**

In this theme the family carers identified five sub-themes ‘respite and flexibility, practical information / education / support, emergency / future planning, resilience to continue to care and overall satisfaction with the Project’.

**Respite / flexibility**

Part of the Project involved offering short breaks / respite in the form of a volunteer / support worker linked to a person with learning disabilities who engaged in various activities such as attending shows, swimming, shopping, etc. This offered the family carers the short breaks / respite they needed to ‘charge their batteries’ and this was ‘beneficial’. All of the family carers agreed that this form of short break / respite was responsive and met their needs at the time when they requested this. One family carer stated ‘the volunteer comes and stays with my daughter… she comes round about 7pm, she doesn’t go home until 10.30pm’ (P.9). Likewise, the family carers stated that other services were not quick to respond and to offer a respite service, a service that listened and acted upon the needs of the family carer and the person with learning disabilities:

‘Nobody ever came to say do you and asked do you need an hour off or what about your daughter or your son, nobody.’ (P. 1)

‘So that kind of quick response is lovely, you just couldn’t put a value on it, it is that good’. (P. 8)

'I have never known support workers who would come to your house and they never look at their watches or the clock... Positive Futures is an exceptional organisation.' (P. 6)

It appears that this family centred approach to planning is very much valued within the Positive Futures’ Project; it is a core strength of the Organisation as stated by the following two carers’ statements:

‘Positive Futures seem to know what you need and be able to help you, until I heard from Positive Futures, there was never one rang that phone to say, do you need any help, you are getting on in years, and that is all very
important to you because you do know then at the end of the day there is somebody who really cares about you.' (P. 9)

'I think one of the really positive things is that Positive Futures is an organisation that has been on the go for a long-time but they are always asking how they can improve services. At the strategic planning day that they had, they totally involved family carers in terms of voting with dots for our preferences for how they go forward. Now you very often find that with other organisations, that the top brass make all those decisions and they don’t really consult and they don’t certainly on a regular basis ask how could we do things better. Positive Futures always does that and I think that is a huge, huge benefit for everybody. They never sit on their laurels and I think it is a model that the statutory organisations should seriously look at.' (P. 6)

**Practical information / education / support sessions**

Another part of the Project was the facilitation of regular opportunities for the family carers to come together so they can listen to each other and in so doing offer emotional support for these carers. ‘Pampering sessions’ and massage were also offered. Part of these groups also included a range of invited guest speakers who provided practical information on a number of topics. There was consensus among all of the family carers that this information, education and practical and emotional support was very valuable as stated by the carers:

‘As a carer it is a lonely experience anyway and it gets probably lonelier as you get older. It is really important that we have each other for support. As regards to the whole group, the fact that they sit and listen to your story and it is terrific, I enjoy every meeting I go to, I really enjoy it.’ (P. 9)

‘We are not just a lone voice trying to make the services listen, because we didn’t even know who to approach; now we as a group can approach the right people.’ (P. 7)

**Emergency / Future planning**

As part of these sessions and continuing support within the family home, Positive Futures’ staff also focused upon journeying with the carers to explore and develop both emergency and future plans. Identifying family and siblings, as well as other support networks, to be part of these plans was explored. One carer stated that it was ‘very helpful and really important for staff from Positive Futures to encourage people of our age group to think ahead and to plan.’ (P7).

A number of the family carers highlighted the sensitive nature of this topic given the diminishing support networks that these families have as they age, but also that they did not want to burden their other adult sons/daughters with taking on the future carer role. However, many older family carers have not, up to now,
included the non-disabled siblings in such discussions about future plans. This can be summarized by the following two accounts:

‘This project made us think about what would happen if we had been written off in a car crash, we hadn’t shared our thoughts or our hopes and fears and what we certainly would want and wouldn’t want, with anybody, not even his two brothers. Our boys said thank goodness you are including us and asking us, we didn’t want to put any sort of pressure on them but they were glad to be asked. So it made us think, you do need to write things down this is really important.’ (P.6)

‘My son and his wife they have enough. They are working full-time and are bringing up two children. It would not be fair; I think they have enough, more than enough that they would have something helpful to contribute to the discussion of trying to tease out what the options might be best for our daughter.’ (P. 1)

Invited speakers held classes on exploring housing options and ensuring financial security for the person with learning disabilities (i.e. wills and trusts).

‘I have now created a discretionary trust, which I wouldn’t have known to do...I carried it through and I have that done now and have even went further, I have went on and had my own funeral arranged.’ (P.9)

Resilience to continue to care
A number of the family carers strongly stated how the Project provided them with the appropriate and prompt respite, information / education, practical and emotional support, and companionship to face planning for the future in a sensitive and compassionate manner. Likewise, the support staff and volunteers developed a friendship with the person with learning disabilities, further reassuring the family carers of how their loved one’s needs were also being met. The family carers highlighted that this bond and responsiveness, evident in all aspects of the Project, and the staff and volunteers had positively impacted on their resilience to continue in the years ahead.

‘Actually if they looked at it logically, it is very foolish to let it go because the more support we get the longer we can keep on going.’ (p.1)

‘Our chances of maintaining the caring role are now much improved because of the Project has brought in the facility of someone coming to look after our son to take him to places and that is respite for us. I would say that is equally important that we have been alleviated to a very good extent, so the things that the project do for us personally is that it gives us the respite that means we can recharge and we are much more likely to be able to stay in the long run.’ (p. 8)
‘The chances of people of our age being able to continue in caring have been much improved because of what the project has done. If that goes then we suffer definitely straight away.’ (P. 6)

Overall satisfaction with the Positive Futures’ Project
There was total agreement among all seven of the family carers and also the person with learning disabilities that the Positive Futures’ Project was invaluable and achieved positive outcomes for all concerned:

‘I think it is absolutely the best thing that I have come across, it is very helpful, very positive.’ (P. 1)

‘We really have enjoyed it.’ (P. 4)

‘I am eighty-two years of age, I have a heart condition and I am the sole carer. Nobody ever listened to me until I met up with Positive Futures.’ (P. 9)

To summarize how the Positive Futures’ Project works differently from other services:

‘They deliver, in one word they deliver. I remember saying at one stage that they ask and they listen and they act and they care. To me that summarizes it all because other people may ask you what your needs are, you know in a carer’s assessment and maybe eventually a couple of things might happen but immediately Positive Futures’ find a way. They just find a way to try to meet your needs and it is terrific.’ (P. 6)

The family carers also worried about what happens when the project finishes if no other support options are offered:

‘I certainly think that the Positive Futures’ project is bound to be really good value for money. The benefits that we have got out of it compared to the costs of the statutory support workers, their managers etc, and the Positive Futures’ volunteers who are fantastic; I mean I don’t know what costs but I know that the voluntary sector which Positive Futures is, is much better value for money than the statutory sector, just because of the salary scales alone. So I just think it is fantastic value for money and it will be hard on us all when it ends.’ (P. 7)

‘Well my worry is almost that, I suppose you could say expectations have been raised through this Big Lottery funding. We have all benefited massively and it is going to be extremely detrimental when the funding runs out. It could be detrimental to everybody’s health around this table, never mind their loved ones, because we have been given what we
probably should all have had many moons ago from the statutory sector. And to take that away now is not good for our health.’ (P. 6)

‘Just to reiterate, it has been particularly beneficial for the older carers. The loss to all the carers would be more significant than for others who are say a generation younger. You are much more resilient when you are younger and our resilience is reducing with time. If we lose the benefit then that would be a pretty swift decay curve I feel.’ (P. 9)

**Theme 2: Benefits for the person with learning disabilities**

In this theme the family carers and also the person with learning disabilities highlighted the benefits of the Project. Three sub-themes were identified: socialising, learning / independence and trustworthiness / confidence.

**Socialising**

All of the family carers described the activities the adults with learning disabilities were involved in with the volunteers / support workers during the week; and more so in the evenings and weekends when little support was offered by other statutory agencies. These included sitting services with their loved ones; watching the TV with companionship and / or doing activities at home, swimming, going to the theatre, etc. One family carer stated ‘our daughter never gets out of the house unless we take her out, so this is a great opportunity for her, she loves it.’ (P. 8).

**Learning / independence**

Some of the family carers reported that the volunteers / support workers also supported the person with learning disabilities to learn and develop new skills. These included sewing, learning to use a mobile phone, learning to use the bus and train, and this has increased the individuals’ independence. This is highlighted by the following quotes:

‘She is more independent now’. (P. 8)

‘He is a much more outgoing and interesting individual now.’ (P. 7)

‘The volunteer who has been with my son has tried to very, very gently to increase his independence, like learning how to use a mobile phone. They have taught him how to take a couple of other bus routes and how to go on a train and look out, not just sit there but to look out for every station on route and know where the final destination is. Obviously they are always with him but the point is that it is almost a teaching role.’ (P. 6)
**Trustworthiness / confidence**

A number of carers stated that one of the strong benefits of the support staff and volunteers is that when they are out with the person with learning disabilities you feel very assured that your son / daughter is ‘safe’.

‘You know they are safe, you know they are out, you know they are safe and you know they are enjoying it.’ (P. 5)

**Theme 3: Quality of the volunteers / support staff**

This one theme identified the friendliness and the training of the staff and volunteers involved with the Positive Futures’ Project. The family carers repeatedly commented on the high quality of the training and induction the volunteers and staff received that provided them with a clear understanding of the varying needs of the adults with learning disabilities but also the needs of the older family carers. This is demonstrated in the following quotes:

‘I think that the training that both the support staff and the volunteers get is very important. I mean they understand all of the ranges of disabilities and they really do care. There have been other carers that have been involved with our son in the past and you get the feeling that it is a bit half hearted, whereas you get the feeling from Positive Futures’ staff that there is a real caring ethos and everybody is there because they really understand and want to do their best.’ (P. 4)

‘The staff and volunteers are always bubbly, you would think they have been with us all their lives and they haven’t, we have only known them now over a year. It has been the most wonderful thing.’ (P. 5)

‘The volunteers are full of joy you don’t feel that they are strangers coming into your home.’ (P. 9)