

Evaluation of the ‘Better Futures Project’:

Supporting older carers of people with learning disability to care for now and plan for the future

‘Better Futures works!’

(Words of an older family carer)



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Executive Summary

Background

Within Northern Ireland, there are no community-based services that have specifically targeted the needs of older family carers of people with a learning disability. In 2011 Positive Futures produced “The Careful Plans Report” which focused on the needs of older family carers of people with a learning disability and identified a number of key recommendations as to how these needs could 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 the ‘Better Futures Project’; this was a 3 year Project which was extended by a further 1 year following receipt of additional funding from the Big Lottery.

Aims

There were 2 key aims of the ‘Better Futures Project’:

1. To develop and evaluate a range of support options designed to meet the needs of older family carers of people with a learning disability and
2. To enable older family carers to have the capacity to create emergency and future plans with their extended family and to share these with the South Eastern Health and Social Care Trust.

How we carried out the study

In total the ‘Better Futures Project’ provided direct support and interventions to 81 family units composed of 115 carers who cared for 88 dependent adults with disabilities (203 people in total). All family carers were offered the opportunity to engage in a formal evaluation of the ‘Better Futures Project’ conducted by Ulster University.

There were 2 parts to this evaluation. Stage 1 involved the family carers completing 3 standardised questionnaires about their psychological distress (GHQ-28), their caring difficulties/stresses (CADI) and how they managed/coped with caring (CAMI) prior to the commencement of the Project (Baseline/Time 1) and approximately 12-24 months follow up (Time 2). Of the 81 families who took part in the Project, 64 family carers consented to complete the questionnaires prior to commencing the Project (a 79% response rate) and 42 family carers completed the questionnaires at time 2 (a response rate of 65%). In addition, a series of focus groups were held with a representative sample of family carers from years 1, 2 and 3 of the Project, as well as focus groups and face-to-face interviews that were conducted with Positive Futures and Trust staff.

Only 42 family carers completed the questionnaires at time 2, a response rate of 65%. Many similar studies with older family carers reported difficulties in identifying, recruiting and engaging with older family carers of adults with a learning disability and evaluation is no different. There were a number of demands and pressures ongoing with families (such as ill-health, family crisis and exhaustion from the demands of the caring role). This meant that taking time to complete the questionnaire and attend focus groups could not

be prioritised which meant that some of these family carers could no longer participate in the research element of the evaluation. It must also be recognised that the majority of the research activity took place during the day when many of those being cared for were in day services meaning that the carers were getting a much needed break from caring.

Results

Stage 1: The family carers' problem solving skills on the CAMI were found to significantly increase from Time 1 (41.3) to Time 2 (46.2) ($p < 0.05$), highlighting that the Project has enabled and empowered these older family carers to access information, ask for help from family and professionals, and articulate how they feel and are coping. This can be evidenced by the words of one family carer: ***'Positive Futures has actually empowered me to open my mouth, to stand up for myself.'***

Half of the family carers (51.6%) scored above 4 on the GHQ-28 prior to the commencement of the Project, indicating they were experiencing psychological distress. When this was re-assessed at Time 2, this figure had decreased to 40.5%, although this was not statistically significant, these results do suggest the Project has had some impact upon diminishing the burden these carers were experiencing.

The majority of these carers reported ***'caring to be physically demanding'*** at Time 1 (CADI), although there were no significant differences found at Time 2. This 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 age. The difficulties of caring can be heard from the strained words of one older family carer: ***'I am not getting any younger and I don't have the same energy anymore, my husband is not well either... it's very difficult.'*** Many family carers reported their ***'emotional well-being was suffering'*** as a result of the long-term impact of caring, and that they constantly worried about this caring role and their greatest fear was ***'what would happen to their relative with learning disabilities when they were no longer around.'***

Stage 2: Three focus groups were conducted with representative samples from a cohort of family carers from each of the 3 years of the Project ($n=27$). The other focus groups and face-to-face interviews were held with 20 Positive Futures and Trust personnel. Six key themes were identified from the family carers, Positive Futures and Trust staff's narratives. All the participants highlighted that the ageing process and long-term caring especially for lone carers impacted on the carers' physical, emotional and social well-being. One carer emotionally stated: ***'caring emotionally wears you down your physical well-being suffers too.'*** There was a clear consensus among the family carers, Positive Futures and Trust staff that the accumulated supports and activities of the Project (i.e. respite/short breaks, support groups, practical information, emotional support, knowledge, information sharing, signposting, emergency and future plans) have alleviated the physical, emotional and social isolation that these families encounter. They reported that the Project connected them to their peers and communities. This can be clearly heard by the warm words of a lone carer: ***'I was part of the carers' Cosy group; I could discuss things with other carers... it made me feel less isolated.'***

Many of the participants reported that older family carers were not a priority and therefore their needs were not always proactively addressed, and that statutory services waited until a ***'crisis'*** occurred before responding. In contrast the 'Better Futures Project' had a more holistic ethos, proactively working with families by building ***'trust'***, putting in ***'appropriate respite when we needed it'***, ***'marvellous respite'***, developing ***'emergency plans'*** and ***'future plans'***; thereby supporting people with a learning disability to continue to live with their families. In each focus group all of the family carers spoke highly of the calibre of the support staff and volunteers including their friendliness, genuineness and their willingness to ***'go the extra mile'***.

Although a sensitive and emotional topic, many of the families developed emergency and future plans. Of the carers that completed these, they reported being fully supported by the Project staff to work through this process. One family carer described: ***'I completed my future plan, I was away overnight... I could have cried... I was so happy that it worked.'***

Initially there were mixed responses about involving siblings in discussions about future planning, however through dialogue with Project staff another carer testified: ***'I was encouraged to speak to my son, I did, and he has agreed to manage her finance and overall care... that's a great relief off my mind.'*** Having a future plan in place has also had the effect of providing some family carers with a new found confidence and reassurance for a time when they can no longer provide the support and care at home.

All of the family carers spoke abundantly of the ***'lifeline'*** that the 'Better Futures Project' brought to them and their families. This support came in the form of respite/short breaks, the dedication of the support workers/volunteers, the support groups, the activities, the practical information and signposting, emotional support and overall commitment of Positive Futures. One carer clearly articulated this view: ***'they (Positive Futures) deliver, in one word they deliver... they ask and they listen and they act and they care.'*** One family carer poignantly summarised how the Project had a dramatic impact on her thoughts and worries: ***'I can see a light now, where I am not just as set in thinking my son should go (die) before me.'*** Despite such success in the Project, some carers expressed concern about what services and supports would be available after the Big Lottery funding ended.

Conclusion

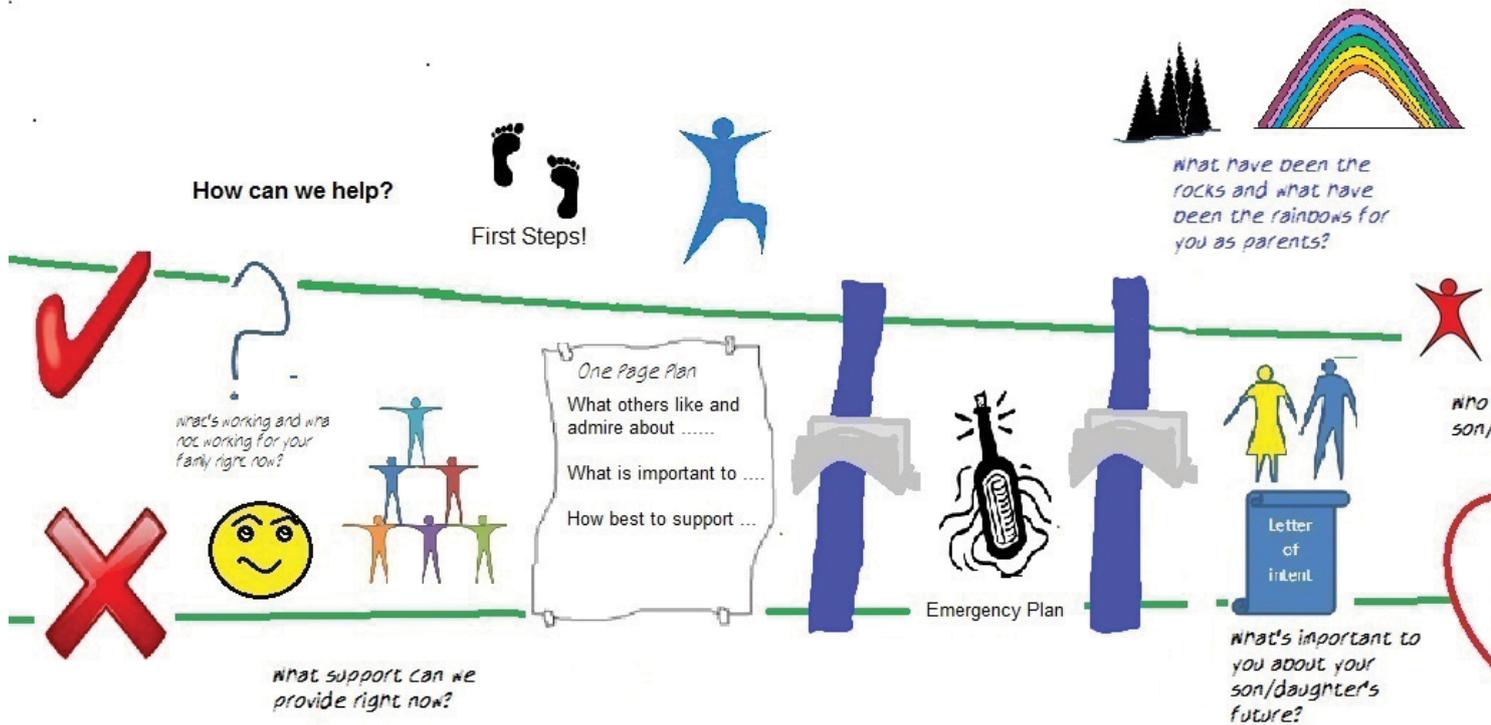
This report shows that the aims and objectives of the 'Better Futures Project' were not only achieved but clearly exceeded expected outcomes. The 'Better Futures Project' developed a bespoke array of family services (i.e. respite/short breaks, support groups, practical information, emotional support, knowledge, information sharing, signposting, emergency and future plans) that have clearly met the specific needs of each of these families caring for a relative with a learning disability. Narratives from the family carers, Positive Futures and Trust staff all highlight the achievements and ***'lifeline'*** this Project has offered these older carers to continue to support and care for their relatives with learning disabilities within their family homes.

At the heart of the 'Better Futures Project' is the holistic ethos and values espoused by the entire Positive Futures organisation and staff ***'they are there for all of us... finally, our isolation has been broken and we have contact again with the outside world.'*** Positive Futures have successfully developed a family centred model operating in one area of Northern Ireland. The Project model has focused on a number of elements in its design. It has responded to the current support needs of the carer and their loved one, thus allowing more capacity for thinking about and looking to the future. It has enabled these older family carers to continue to care for their relatives with learning disabilities within their own homes for as long as possible. 'Better Futures Project' staff have sat down with and worked through the options, and spent time planning with the family carers and their loved ones, for emergency situations and for the future when the carer can no longer provide the care.

It can be argued that the 'Better Futures Project' offers a low-cost support package to each family that can provide opportunities to support these families without large increases in overall spend. This evaluation report evidently shows the substantial benefits that the 'Better Futures Project' has made to this vulnerable group of older carers and their families, as well as the person with a learning disability. This is a community based model that could be replicated and act as an 'exemplar' in other settings across the country and beyond.

Evaluation of the 'Better Futures Project':

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Better futures for All!

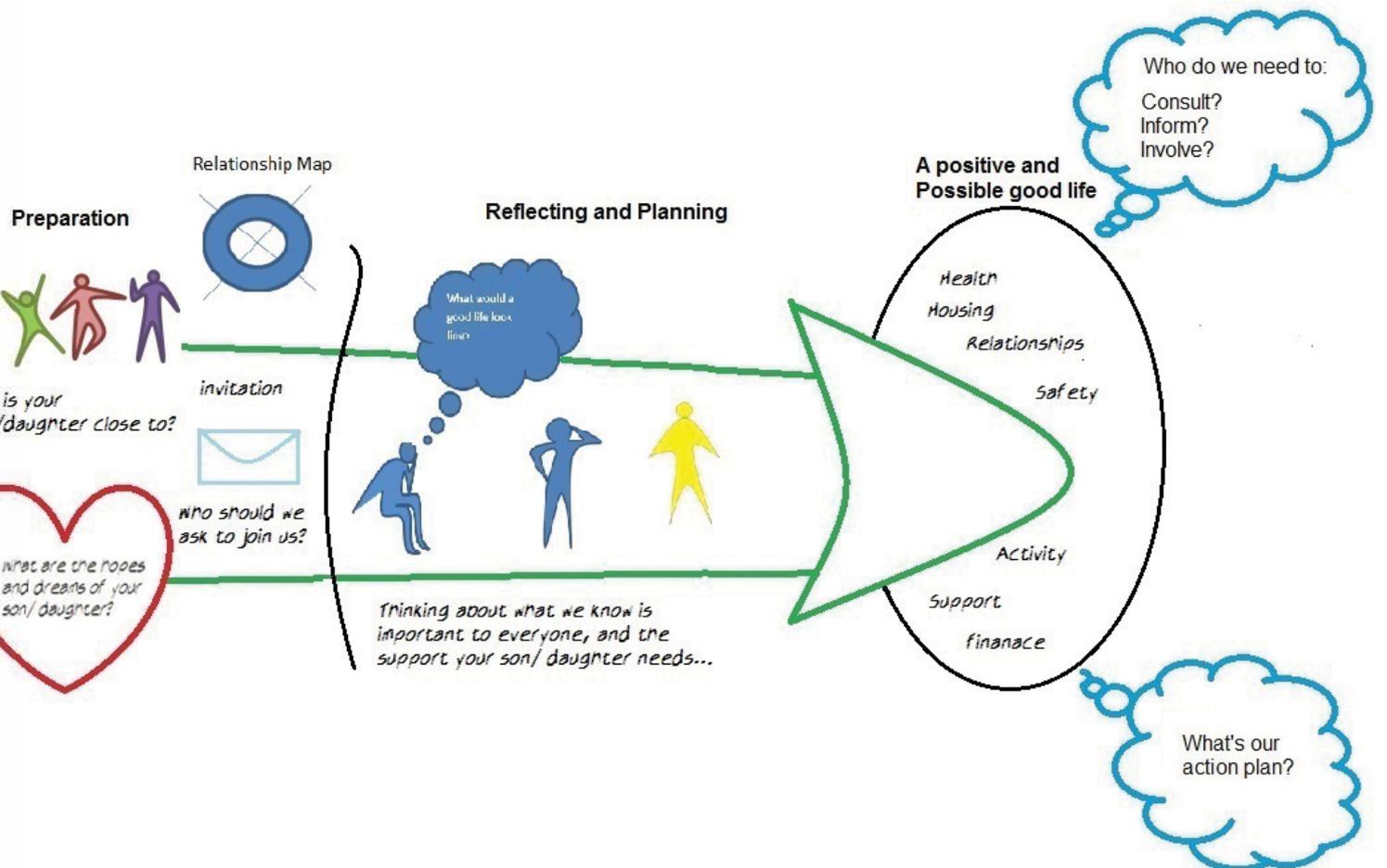


IMAGE:
Diagrammatical representation of the 'Better Futures Project' model of support
(illustrated by Tim Parr)

Background

Within the UK, Europe, USA, Australia and many other countries the majority of people with learning disabilities are continuing to live within their family home with their mother and/or father or siblings (Australian Institute of Health and Welfare, 2000, Braddock et al., 2001, Heller et al., 2007, WHO, 2011, Lunsky et al. 2014). The projected population growth in the 65 years plus age group, due to the ageing baby boomer generation, will significantly increase the number of older carers in the years ahead (Braddock et al., 2011). This is supported by an international review of published data undertaken by Coppus (2013) which also showed that increases in the life expectancy of people with learning disabilities have followed a similar trend in the world's developed nations to those found in the general population; hence older adults with learning disabilities represent an increasing proportion of older people in society. The WHO (2000) indicated that older people with learning disabilities and their ageing family carers were two vulnerable groups that were at particular risk as housing was often inadequate, health provision neglected, there was a lack of coordinated supports and such individuals were not productive members of their societies.

It is estimated that across the UK alone over 60,000 older parents (60 years plus) are caring for a son/daughter with learning disabilities (aged 40 years plus) (Foundation for People with Learning Disabilities, 2006). Studies report that many older family carers clearly articulate that they wish to continue caring for their son/daughter and likewise, adults with learning disabilities also indicate they want to continue living with their parent(s) (Prosser, 1997, McConkey, 2004, Taggart et al., 2012).

TABLE 1: Learning disability prevalence rates in Northern Ireland

Age Bands	Mild/moderate	Severe/Profound	Total
0-19	6,432	1,718	8,150
20-34	2,504	1,047	3,551
35-49	1,489	949	2,438
50+	1,473	753	2,226
Totals	11,898	4,468	16,366

McConkey et al. (2003) used information from the Health and Social Services Trusts to estimate the prevalence rates of learning disability in Northern Ireland (for those people known to statutory services). Table 1 details the study's findings of 16,366 people with a learning disability. Among the 16,366 people with learning disabilities known to services in Northern Ireland, most (almost 80%) live with family carers. With regards to older family carers (aged 60 years plus) caring for an adult with learning disabilities (aged over 40 years), McConkey et al. (2003) indicated that approx. 1,200 people with a learning disability are residing with a family carer. Around 640 (53%) were single parents, mostly mothers. Slevin et al. (2011) highlighted that over the next 30-50 years more people with learning disabilities in Northern Ireland will be living longer into their fifth, sixth, seventh and even eighth decades: placing greater strain on these older family carers. This places an onus on statutory services to forward plan for accommodating the growing numbers of older persons with a learning disability so they 'age-in-place' and remain in their family home if they wish (McConkey et al., 2003; Slevin et al., 2011).

In addition to a number of ageing family carers known to statutory services, there are also at least another estimated 30% of these older family carers not known to services: they only become recognised when

care breaks down and a crisis arises (Thompson, 2002). This is a 'double-generation' cohort of older family carers and adults with a learning disability that are likely to continue to grow as more people are living longer (Hewitt et al., 2010).

The reasons for why some older parent carers continue to care have not been well explored but they are likely to reflect the individual wishes of parents (Taggart et al., 2012). However, with their increasing age and infirmity, parents find themselves less able to cope with the demands of their caregiving role. This can impact negatively on their health and that of their relative with learning disabilities. Despite this, there is convincing evidence to suggest that older parents still feel obligated to continue in their caregiving role because they believe that 'they alone can provide high quality reliable, care' (Taggart et al., 2012; Bigby, 2004; Heller et al., 2005; Heller & Factor, 2004).

More recently, research is illustrating that a reciprocal role or co-dependency develops between the older parent and adult with a learning disability. The Foundation for People with Learning Disabilities (2010) noted that there was no fixed point where the balance of caring tipped so that both the older family member and the adult with a learning disability were caring for each other. Instead, this was usually a slow process where both parties gradually adapted to their changing role with the passage of time, unless in exceptional circumstances where the family member had an accident or suddenly became ill.

Where parent caregivers are unable to provide care, sometimes siblings may take on the caregiving role. Heller and Arnold (2010) undertook an international literature review to examine the health of siblings of adults with a learning disability. Of 23 studies reviewed, the authors presented a mix of results but overall there was a positive picture of psycho-social outcomes being reported. Siblings, mainly sisters, reported maintaining long-lasting close relationships with their sibling with a Learning Disability and also anticipated taking on greater supportive roles as they grew older.

Therefore, both parent and sibling carers of adults with a learning disability are a unique sub-group that face exceptional challenges and circumstances (Seltzer and Krauss, 1993, McConkey, 2005, Lunsky et al. 2014). As well as the associated effects of the ageing process, these parent and sibling carers too have to endure the effects of the extensive duration of the caregiving role (Haley & Perkins, 2004). This is accompanied by managing the effects of the ageing process in the person with a learning disability as well. Furthermore, these older family carers also have to bear the psychological stress that can be precipitated by anxiety for the long-term future care of their relative with a learning disability after their own death (Haley & Perkins, 2004, Taggart et al., 2012, Lunsky et al. 2014). Paradoxically, failing to plan for the future can be a major source of ongoing anxiety for both the older parent and sibling carers.

Inevitably, there comes a time when other arrangements are required. The health of the person with a learning disability, including their physical and mental health as well as chronic and enduring behaviours that challenge, may lead to these older family carers reluctantly exploring alternative care arrangements as they can no longer provide long-term care. More problematic are situations when family care ends through parental illness or death. The absence of adequate future plans and support systems can lead to crisis and emotional trauma for all concerned (Bigby, 2004; Heller et al., 2005), inappropriate 'placements' such as a nursing home (Thompson and Wright, 2001) and unexpected dilemmas for siblings or extended families (Ryan et al. 2014). Moreover, unplanned transitions are costly for service providers (Bigby and Ozanne, 2004). Despite the rational arguments for proactively supporting family carers to make future plans, available evidence suggests that family carers do not proactively develop a future plan and that in many cases future planning is more aspirational than definitive (Bowey & McLaughlin, 2007; Taggart et al., 2012).

Various explanations have been proposed for these older parents' reluctance to relinquish their caregiving roles. Future planning is an emotive topic. Carers may not make plans as a result of denial about the inevitability of their own mortality and the realization that they will not be able to provide care indefinitely. Moreover, they have difficulties in letting go of their loved ones as it may mean increased loneliness for them. Also carers may harbour deep concerns and anxieties about what will happen to their relative in alternative out-of-home placements. They may find the subject too painful to broach and do not make firm plans until it becomes unavoidable (Taggart et al., 2012; Chou et al., 2009; Bowey & McGlaughlin, 2007; McConkey et al., 2006). Older family carers may not receive the emotional support they need, lack the practical information about new forms of care options and may be unaware of the supports outside of the home; reporting that there is 'plenty of time' (Ryan et al., 2014). Nonetheless, older family carers vary in their engagement in future planning. For example, Seltzer et al. (1996) reported that carers in the United States were more likely to have made future plans compared with Irish carers, although the reasons for this are not clear.

Magrill (2005) reported that although older family carers wanted to continue caring for as long as possible, they also wanted to engage in future planning if the issues around such decisions were dealt with sensitively and carefully. Therefore, it is important that issues around future planning are considered in the context of the overall support needs of these older family carers and within the context of the family unit, with the dual aim of sustaining them in their present caregiving role whilst also assisting them to make plans for the future (Taggart et al., 2012).

Bickenbach et al. (2012) stated that policy makers and service providers around the world will face many significant challenges in the decades ahead as people with and without learning disabilities are living longer due to medical advancements/technology. These challenges and demands include:

'Strains on pension and social security systems; preparing health providers and societies to meet the needs of populations ageing with and ageing into disability; preventing and managing age and disability associated secondary conditions and chronic diseases; designing sustainable policies to support healthy ageing and community-living as well as long-term and palliative care; and developing disability and age-friendly services and settings.' (P2)

There is widespread agreement internationally as to the two core features underpinning a policy on ageing and people with learning disabilities in relation to accommodation options: '1) People should 'age in place' rather than leaving their home to live elsewhere, and 2) Shared responsibility for this client group across aged-care services and disability provision'. Bigby (2010) stated that:

"The disability service system will have to re-orient to incorporate knowledge and expertise around age-related support needs... and take responsibility for the development of specialist age-related services. It may also give the disability sector a much clearer mandate to lead and adequately resource partnerships with existing services or organisations.' (P11)

What is the ‘Better Futures Project’?

Global trends indicate that by 2050 there will be 2 billion people aged over 60 years (WHO, 2000); and there has been a greater focus on an inclusive approach to active ageing in the non-disabled population. This demographic trend is also evident in the learning disability population who are more likely to age earlier at 50 years (Bittles et al., 2001): and for people with Down’s syndrome 40 years. The inclusive approach to active ageing has not been targeted at the learning disability population because learning disability services have traditionally provided a cradle to the grave service, without proactively focusing on supporting older family carers to continue to care for their relative with a learning disability within their family home (Slevin et al., 2011; Taggart et al., 2012; Ryan et al., 2014). As people with learning disability age, they may also disengage from services and fail to develop new avenues for social-connectedness and community participation, so risking further isolation (Bigby, 2005). In keeping with the principles of the UN (2006), older adults with learning disability should be afforded the opportunity to ‘age-in-place’ with their older family carers, whilst being helped to maintain inclusive relationships within their communities.

Both older family carers and adults with learning disabilities are both at increased risk of isolation, loneliness and depression due in part to their reduced involvement in their local community (Beard & Petitot, 2011). A link between social disconnectedness and poorer health and well-being has been proven among older adults (WHO, 2002), although this may be worse for those with a learning disability. To date, both learning disability and mainstream older person services have not targeted how adults with a learning disability ‘age-in-place’ and engage in their local communities. This is despite the fact that the participation of people with a learning disability in their communities is widely encouraged in policy (‘Equal Lives’, DHSSPSNI, 2006); Northern Ireland Service Framework, DHSSPSNI, 2011). The ‘Better Futures Project’ offers a vehicle in which older family carers are supported to continue caring within their own family home, and both the carers and the person with a learning disability are socially connected within their communities.

Within N Ireland, there were no community-based services that specifically targeted the needs of these older family carers of people with a learning disability. In 2011 Positive Futures produced ‘The Careful Plans Report’ which focused on the needs of older family carers of people with a learning disability and identified a number of key recommendations as to how these needs could 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 3 year Project, which was extended by a further 1 year following receipt of additional funding from the Big Lottery.

There were two key aims of the ‘Better Futures Project’:

1. To develop and evaluate a range of support options designed to meet the needs of older carers of people with a learning disability and
2. To enable older carers to have the capacity to create emergency and future plans with their extended family and to share these with the South Eastern Health and Social Care Trust.

In order to achieve these two aims, there were 4 key objectives of the 'Better Futures Project':

1. To improve the physical and mental well-being of older family carers enabling them to plan for their future and those of their dependent sons and daughters with a learning disability
2. To decrease the social isolation experienced by older family carers of people with a learning disability leading to improved physical and mental well-being
3. To increase the knowledge and skills of older family carers so they are more able to deal with the physical, mental and social challenges of caring for a person with a learning disability and
4. To develop a new model of service delivery for older family carers, where other services will benefit from these and the resource materials.

This Report summarises the evaluation of the 'Better Futures Project' at the end of four years.



IMAGE: Positive Futures event in Stormont Long Gallery highlighting the issues faced by carers

How we carried out the study

Design

This study employed a mixed methods design. Stage 1 used three standardised questionnaires to collate information on the older family carers' health, stress, demands of caregiving and coping strategies across two time points (Time 1 or Baseline) and Time 2 (12-24 months into the Project). Stage 2 undertook three focus groups with twenty-five family carers to explore the benefits and challenges with the 'Better Futures Project'. In addition, one focus group with four Trust personnel, one focus group with six Positive Futures staff and face-to-face interviews with two senior managers from Positive Futures and one from the Trust were also conducted.

Sample

In total the 'Better Futures Project' provided direct support and interventions to 81 family units composed of 115 carers who cared for 88 dependent adults with disabilities (203 people in total). Of these 81 families, 64 family carers consented to complete the questionnaires prior to commencing the programme: a 71% response rate. However, only 42 family carers completed the questionnaires at time 2: a response rate of 65%. There were a number of individual demands and pressures ongoing with families such as ill-health and family crisis that were given as reasons as to why they no longer reported they could participate in the research element of the Project.

For Stage 2, purposeful sampling was employed to identify family carers who had been involved from each of the three-years in the 'Better Futures Project'. 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.

A total of 27 family carers participated in three focus groups that were held in November 2015. The focus groups lasted between 50-80 minutes and took place in a community hall. The focus groups were audio-taped and all were informed that the interviews were voluntary and they could withdraw at any stage.

Data collection

STAGE 1: Three standardised questionnaires were used to collect the data at the two time points as well as a demographic questionnaire completed by the main carer.

- **Perceived psychological distress:** The general health questionnaire (GHQ: 28) (Goldberg & Williams, 1991) is a 28-item questionnaire developed as a tool to detect those likely to have or to be at risk of developing psychological distress. Through factor analysis, the GHQ-28 has been divided into four sub-scales. These are: somatic symptoms (items 1-7); anxiety/insomnia (items 8-14); social dysfunction (items 15-21), and severe depression (items 22-28) (Goldberg, 1978). The traditional scoring method provided assigns a score of 0 for responses 1 and 2 ('not at all' and 'no more than usual') and a score of 1 for responses 3 and 4 ('rather more than usual' and 'much more than usual').

- **Difficulties/stress associated with caring:** 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) providing a 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 sub-scales to range from 0.72 to 0.9.
- **Carer's coping strategies:** The Carer's Assessment of Managing Index (CAMI) (Nolan et al., 1998) was used to measure family carer's coping strategies. The scale has 37 items based over three domains (managing events/problem solving, managing meanings, and managing/alleviating stress). Carers respond to the statements by choosing between "I do not use this" or "I use this and find it: not really helpful, quite helpful or very helpful". Cronbach alpha coefficients ranging from 0.64 to 0.80 are reported for CAMI sub-scales (McKee et al., 2009).

STAGE 2: An interview schedule was developed to explore what the older 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 between 50-80 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.



IMAGE:

Joan and Anne looking over information from the 'Carers' Right Awareness' session facilitated by the Law Centre

What we found

Demographics

In total 81 families, made up of 115 family carers caring for 88 adults with a learning disability were directly supported by the 'Better Futures Project' team over a 48-month time frame. There were 47 lone carers (mainly female) caring unaccompanied for a relative with a learning disability compared with 34 dual carers (normally a wife and husband). The majority of the older family carers were mothers caring alone; there were a few fathers caring alone; four siblings (three sisters and one brother) who were the main carer; one carer identified themselves as an aunt of the person with a learning disability and there was a set of grandparents providing care. All the family carers were aged 60 years plus (age range 60-92 years). Five families cared for two adults with a disability in the same household and one lone carer cared for three adults with a disability.

Activities the family carers were involved in

Positive Futures staff and volunteers worked directly with the older family carers offering them regular home visits to provide practical and emotional support to meet their needs. Specific individualised support was provided for each family. This, for example, allowed some families to stay connected to and access community-based activities that they had been involved with in the past. It provided the carers with innovative respite/short break opportunities to be freed from the burden of care, safe in the knowledge that their loved one was supported and contented. Other examples included, accompanying carers and people with a learning disability to attend medical and other appointments, practical support with everyday tasks at home, signposting carers in relation to finance, legal and housing issues.

The Project, in response to the assessed needs of the family carers, provided a large range of information, signposting and networking sessions that brought carers together. This also allowed for building relationships and the development of mutual support networks. The Project staff provided transport for the family carers to ensure they were able to attend and didn't miss out on the information and also, importantly, supported their dependant to free the carers up to attend. Project activities and sessions included:

- Personal Development programmes, support group sessions and events specifically for older family carers such as the COSY Group with 'Me Unltd' where they met a least once a month
- Bi-monthly information sessions that focussed on specific topics such as: entitlement to benefits for those over 60 years, changes in the benefits system such as personal independent payments as alternative to DLA, direct payments, Self-Directed Support, legal issues/carers rights, future support options (i.e. supported living and adult placements, general behaviour support/advice and one-to-one support for families home and fire safety)
- Specific practical and emotional information and short programmes on looking after the carers' own health: physical health (cancer: signs, symptoms and early detection, arthritis and other chronic condition management programmes) and mental health and well-being issues to enhance the carers' resilience and coping skills

- Being part of a carers' representative group, 'Project Partnership Group', to advise on the 'Better Futures Project'. The carers also have established themselves as a constituted Community Group, 'Carers over 60 years South Eastern Trust' (COSYSET) to continue to look for funds to provide support for activities
- The carers have also contributed to a number of key consultations relating to their issues with a wide range of organisations (Patient Client Council, RQIA, Self-Directed Support, Capacity legislation, Local Commissioning groups, SEHSCT, SET Carers Consultations and events, Local Councils)
- A number of luncheons, dinners, parties and social events over the life of the Project at key times of the year which proved highly popular. Friendships have blossomed and mutual support has been developed. Those hard to reach family carers who couldn't attend also had small group or individual activities to maintain social connections in their local areas.

A major component of the 'Better Futures Project' was to equip the family carers with the knowledge and skills to enable them to make informed choices around emergency and future planning. The Positive Futures staff supported all of the family carers to develop an emergency plan including a 'Message in a Bottle' in their fridge (a community initiative which captures key information for emergency personnel). The majority of older family carers have now developed a Future Plan, with the remainder in the process of completing their plan.

There were 6402 direct support hours provided from the 'Better Futures Project' staff to the families to undertake these activities. In addition, there were 1163 hours invested in the training of the 'Better Futures Project' staff and the sessional support staff to ensure the staff were equipped with the knowledge and were competent in the skills required to competently work with these families.

Activities the adults with a learning disability were involved in

The adults with a learning disability also received support from Positive Futures staff and volunteers to engage in a range of social activities in their local communities. In response to the substantial assessed unmet need, 'Better Futures Project' established the 'Get Up and Go Group' (GUAGG) a social group for people with a learning disability that runs bi-monthly events. Several times a year the group, which has flourished in membership, gets together and creates a programme of activities and trips for the following months. There has been a diverse range, such as bowling, the monthly Black Moon Night Club in the MAC, trips to the Ulster Museum and Titanic Belfast, days out to Newcastle and Portrush, frequent musical theatre outings, snooker, shopping, arts and craft evenings and Pizza and Wii or Movie nights. All of these were facilitated by Project staff and volunteers.

Those who did not enjoy being part of a group or require one-to-one support have had their needs met by being supported to attend and participate in individual activities. These have included Travel Training, using a mobile phone, attending their local gym, cross stitch, walks, bird watching, visiting local libraries, Elvis Tribute and WWF wrestling in the Odyssey, and using IT devices through loan of devices such as iPads. Some have been signposted to other suitable one-to-one training such as 'Be Safe: Stay Safe', an individually tailored programme facilitated by Leonard Cheshire Charity. The Project has also provided independence training for a group of the dependents who completed the 'Cook It Course'. A spin off has been the establishment of friendships that the families have nurtured outside of the Project. This also provided respite time to the carers while knowing their loved one is participating in doing things they enjoy with people they choose to spend time with having fun and a laugh. There were 646 direct hours from the 'Better Futures Project' staff and volunteers to support the adults with learning disabilities to undertake activities.

Stage 1: Results

Carers' Psychological Distress (GHQ):

Table 2 below shows the older family carers' self-reports on their perceived psychological distress using the four sub-scales and total score of the GHQ 28. The mean score for this group of carers at Time 1 was 5.3 (range 0 to 24: maximum possible 28) and the mean score for the carers at Time 2 was 5.2 (range 0 to 17): there were no significant differences between Time 1 and Time 2. Table 2 further shows the carers' self-reports on the GHQ for the four sub-scales of Somatic, Anxiety, Depression and Social Dysfunction of the GHQ 28. There were no significant differences for the family carers between Time 1 and Time 2 on these four sub-scales.

TABLE 2: Psychological distress scores for the family carers at Time 1 and Time 2 (GHQ)

	Time 1 (N=64)	Time 2 (N=42)
Somatic	1.9	2.3
Anxiety	1.6	1.4
Depression	0.4	0.4
Social Dysfunction	1.4	1.1
Total Score	5.3	5.2

However, over half of the family carers (51.6%) scored above 4 on the Total Sub-scale of the GHQ which is taken as the cut-off point as indicative of psychological distress. This figure decreased at Time 2 to 40.5%, indicating that one fifth of these family carers had reduced their psychological distress: although this was not statistically significant but is clinically important.

Difficulties associated with caring (CADI):

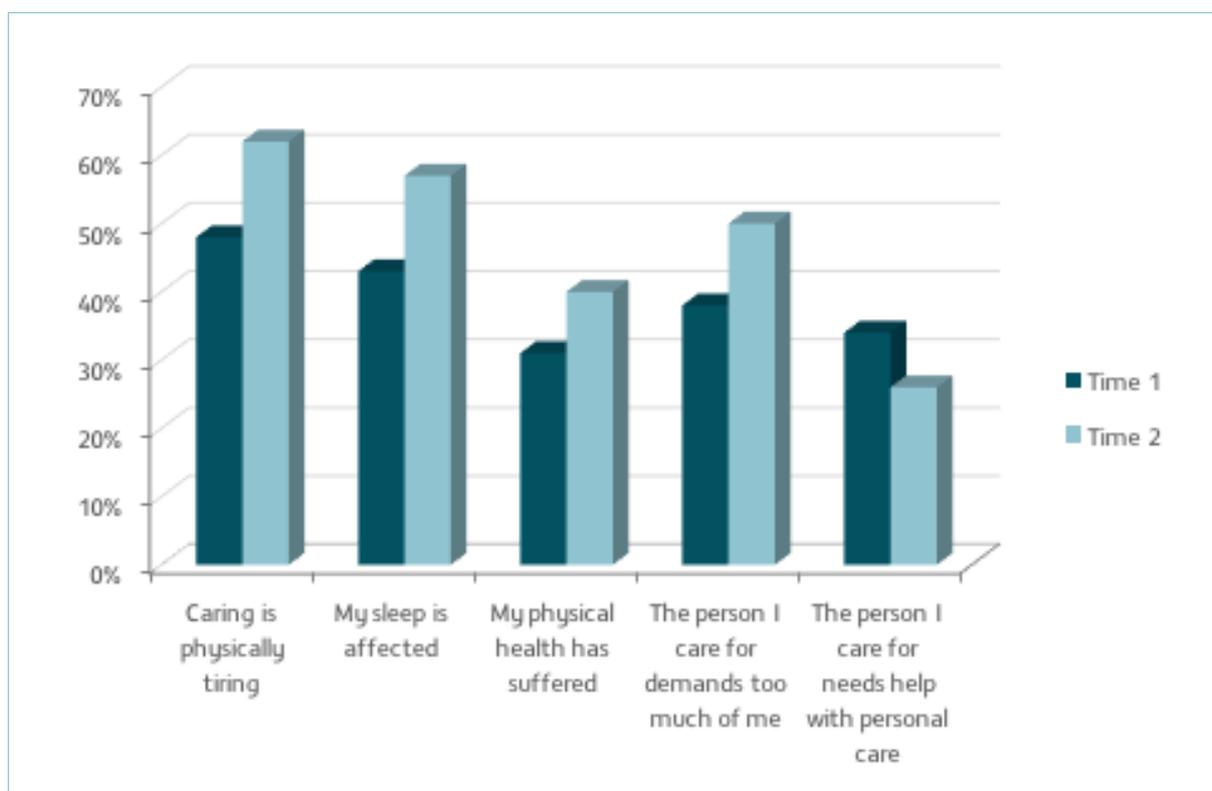
Table 3 below shows the carers' self-reports on their perceived difficulties in caring for their relative with learning disabilities on the CADI. The total stress score for the family carers at Time 1 was 54.9 (range 32 to 141: maximum possible 144). The mean score for the carers at Time 2 was 55.9 (range 30-103). There were no significant differences between Time 1 and Time 2 for total stress score on CADI. Table 2 further shows the carers' self-reports on the CADI for the sub-scales of care-dependent relationship, physical demands of caregiving, family problems, restricted social life, financial consequence and poor professional support. There were no significant differences for the family carers between Time 1 and Time 2 across these seven sub-scales.

TABLE 3: Carer’s difficulties scores (CARDI) for the family carers at Time 1 and Time 2

	Time 1 (N=64)	Time 2 (N=42)
Care-Dependent Relationships	12	11.6
Family problems	15	15.3
Physical demands of caregiving	11.7	12.2
Restricts social life	5.7	5.8
Poor family support	3	2.7
Money worries	2.5	3.1
Poor professional support	4.2	4.1
Total Stress Score	54.9	55.9

Figure 1 below illustrates that for the majority of these older family carers they reported caring to be both very physically and emotionally demanding, and also stressful. Just less than half of the family carers (48%) reported caring to be very ‘physically tiring’ and this increased to 62% at Time 2. Just less than a half of family carers (43%) also reported that their ‘sleep was affected’ as a result of their caregiving and this increased to 57% at Time 2. Just less than a third of the family carers (31%) reported that their physical health had suffered and this increased to 40% at Time 2.

FIGURE 1: Carers report on the physical demands of caring (CADI)



The older family carers further reported that over a third of the adults with a learning disability ‘demanded a lot of their time’ (38%) and a third of family carers also reported that the person needed ‘a lot of help with personal care’ (34%). 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 2 below illustrates that just less than half of the family carers reported their 'emotional well-being had suffered' (47%) as a result of caregiving, this figure had slightly increased to 54% at Time 2. Just less than half of the family carers reported being 'helpless and not in control of the caregiving situation' (43%), this slightly increased at Time 2 (47%). Just over a third of family carers reported that they could not 'relax because of worrying about caring' (39%) at Time 1, this again had slightly increased to 43% at Time 2. 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 age.

FIGURE 2: Carers report on the emotional demands of caring (CADI)

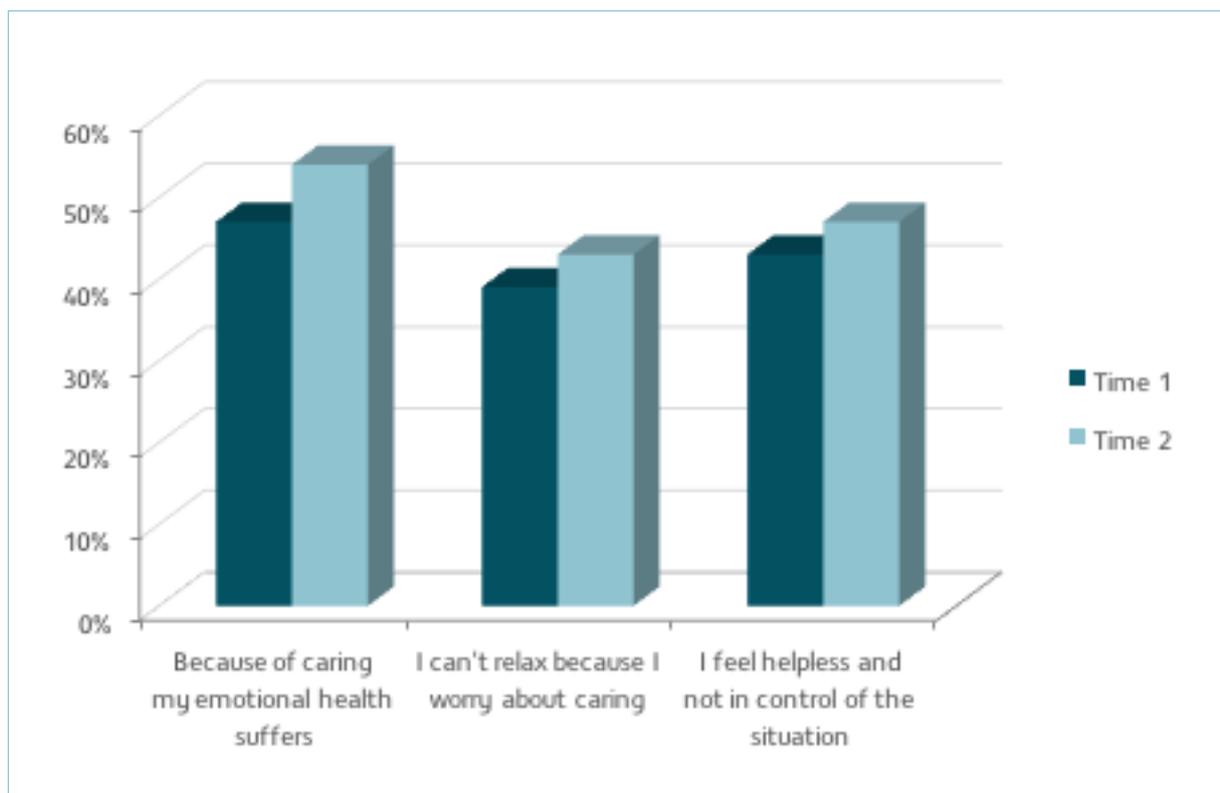
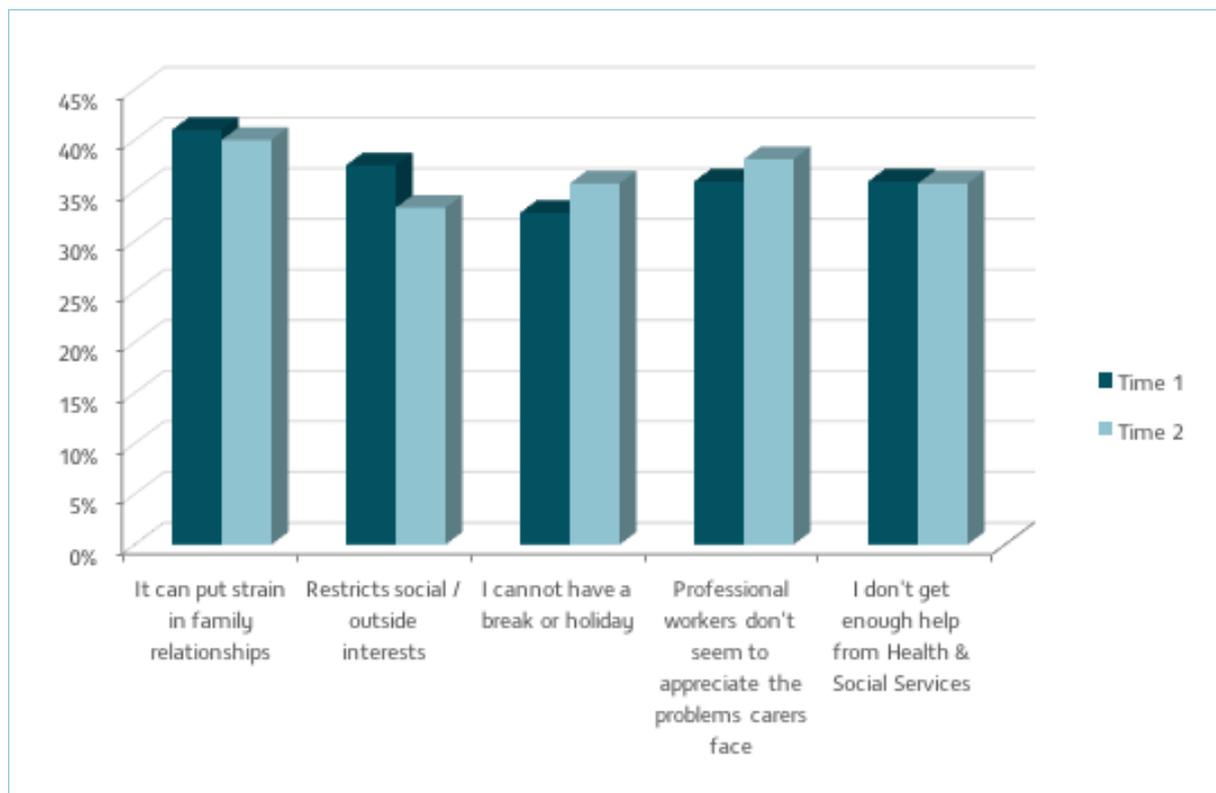


Figure 3 below illustrates how just over a third of the family carers found caring to 'restrict their social/ outside interests' (38%), this figure had slightly decreased to 33% at Time 2. Just less than half of the family carers reported that caring 'put strain on family relationships' (41%), this figure remained the same at Time 2. A third of family carers (32%) reported that they 'could not have a break/holiday' as result of caring, this figure slightly increased to 36% at Time 2. Over a third of family carers reported that 'professional workers don't seem to appreciate the problems carers face' (36%) and the carers reported they didn't 'get enough help from health and social services' (36%). As can be observed from Figure 3 these figures don't change at Time 2.

FIGURE 3: Carers report on informal and formal supports of the CADI at Time 1 and Time 1



Family carers' coping (CAMI):

Table 4 shows the family carers' self-reports on their coping strategies they use when caring for a relative with a learning disability on the CAMI. The total score for the family carers on the sub-scale of 'managing events/problem solving' at Time 1 was 41.3 and at Time 2 was 46.3: this was found to be statistically significant ($p < 0.001$) meaning the family carers increased their skills in managing carer stress.

TABLE 4: Carer's coping scores (CAMI) of the family carers at Time 1 and Time 2

	Time 1 (N=64)	Time 2 (N=42)
Managing events/problem solving	41.3	46.2*
Managing meanings	20.3	21.5
Managing/alleviating stress	43.2	42.3

*Wilcoxon Test ($z = -2.74, p < 0.001$)

However, the total score for the older family carers on the sub-scale of 'managing meanings' at Time 1 was 20.3 and at Time 2 was 21.5. Likewise, the total score for the family carers on the sub-scale of 'managing/alleviating stress' at Time 1 was 43.2 and at Time 2 was 42.3. These results were found not to be statistically significant between Time 1 and Time 2.

Shortcomings within Stage 1:

Of the 81 families who took part in the Project, 64 older family carers consented to complete the questionnaires prior to commencing the programme (a 79% response rate) and 42 family carers completed the questionnaires at time 2 (a response rate of 65%). There were a number of individual demands and pressures ongoing with families such as ill-health and family crisis that were given as reasons as to why they did not wish to participate in the research element of the Project and also having the questionnaires re-administered at Time 2. As the sample size of this study was reduced from 64 family carers at Time 1 to 42 at Time 2, this will have limited the effect size required to identify a statistically significant effect.

The lack of statistical significant results across the three standardised scales (GHQ, CADI and CAMI) and many of the sub-scales, may reflect how the effects of the ageing process for the family carers (i.e. slowing down, mobility issues, additional health problems, etc.) and caring for others, places further stresses and challenges upon these carers: thereby needing additional support as they age. Similarly, the lack of differences may also be expected given that these carers are ageing into their sixth, seventh, eighth or ninth decades: compounded with the associated age related health conditions, limited support networks and the ongoing demands of caring for a person with a learning disability who is also ageing. There are also issues around the sensitivity and specificity of the three standardised questionnaires to identify the changes in health with this population.

Furthermore, this evaluation was not an in-depth research study that included a control group of similar older family carers caring for a relative with a learning disability, and not involved in the 'Better Futures Project' (i.e. receiving routine Trust services/supports). Therefore, we cannot compare whether the family carers who engaged in the 'Better Futures Project' and whose scores stayed the same or slightly increased, did better than those family carers in a control group who it could be argued scores may have deteriorated. A future in-depth research study is required to clearly identify the effect of the 'Better Futures Project' compared to a control group.



IMAGE:

Dependents supported by the 'Better Futures Project' attending an awareness raising event in Stormont

Stage 2: Findings

Six themes emerged from the focus groups with the older family carers and Positive Futures and Trust staff, as well as the face-to-face interviews with the senior managers. These transcripts were compared and contrasted and the following themes were identified from the participants' narratives:

- Changing needs of older family carers and people with a learning disability
- Responding to the needs of older family carers and people with a learning disability
- Supporting families to develop future plans
- Involving siblings and adults with a learning disability in the decision making process
- The benefits for the family carers and adults with a learning disability being involved in the 'Better Futures Project' and
- Addressing the challenges and moving forward: working together.

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, Positive Futures and Trust staff.

Theme 1: Changing needs of older family carers and people with a learning disability

Within this theme there were four sub-themes: *'long-term caring impacting on the health of family carers'*, *'complex health needs of the adults with learning disabilities'*, *'not wanting to think about the future'* and *'the impact of not planning for the future'*.

Long-term caring impacting on the health of family carers

Many of the older family carers reported the physical and mental health costs associated with the long-term caring for a relative with a learning disability and as they also aged, such as 'feeling more physically tired' and 'less energetic than before'. Carers also reported on their current health status and that of their spouses with associated age-related health conditions, further presenting difficulties in providing long-term care into the future.

'I am not getting any younger and I don't have the same energy and I cannot do anything spontaneous, and it is very, very difficult. I am not feeling so good and my husband is not feeling so good either.' (P7, FG3, FC)

'It wears you emotionally down; your physical well-being suffers too.' (P4, FG3, FC aged 91 years)

For many parent carers they had become lone carers as the result of the death of a spouse. This posed more challenging for fathers caring for a daughter with a learning disability particularly related to personal care tasks, as they had not only lost their wife and life partner, but they had now to take on additional demanding and sensitive caring tasks. Caring for an ‘elderly parent’ or ‘ill spouse’ or ‘grandchildren’ was sometimes reported further complicating the caring duties of already strained older family carers. Other family carers spoke of feeling ‘isolated’ particularly when caring alone; this restricted their opportunities in engaging in local community activities.

‘I mean if you wanted to go for a day somewhere, you cannot go.’ (P5, FG3, Family Carer)

‘For the likes of us older carers who live on their own caring, you cannot get to classes, I have given up my art class and other classes but have kept up my book club once a month... it’s good to do something outside of the house, it boosts your mental health.’ (P7, FG3, Family Carer)

Complex health needs of the adults with learning disabilities

All of the family carers, Positive Futures and Trust staff interviewed identified the complex health needs of the person with a learning disability. For many older parent carers it was an adult son or daughter with a learning disability, for other older carers it was a grandchild, sibling, or nephew with a learning disability for whom they provided constant care for, caring that lasted decades and impacted upon the whole family structure.

‘Your life is just so surrounded with them, their changing needs...you think of their needs all of the time before you think of your own needs.’ (P2, FG1, Family Carer)

‘Having a disabled son/daughter means a disabled family.’ (P5, FG1, Family Carer)

All the participants noted that as the adults with learning disabilities themselves were also ageing with age related health conditions, this added further burden to the older family carers. The level of disability and support varied from person to person, from someone with a mild learning disability to someone with a severe/profound disability with no mobility. Other carers highlighted the complex issues with a relative with ‘autism’ that provided additional challenges. Many of the adults with a learning disability had a range of health problems such as mobility issues, sensory problems, being peg-tube feed, epilepsy, sleep problems, mental health problems and challenging behaviours. A few adults with learning disabilities had a diagnosis of ‘dementia’: which presented with and will further present with many difficulties in the forthcoming months and years. This complex issue of dual ageing with the family carer and the person with a learning disability is well summarised by one of the Positive Futures staff:

‘I would say the majority of the carers that we’re working with, there are some quite complex issues, ranging from bereavement, mental health issues, physical illness, the whole range really and obviously family carers are getting older and older, and trying to cope with these challenges and care for their son or daughter with a learning disability and we would probably all want more time to be able to work so it is a challenge, it is a challenge in terms of the time.’ (Senior Manager 1, Positive Futures)

Not wanting to think about the future

All of the family carers reported the constant worry and anxiety they held about 'what would happen to their relative with a learning disability when they were no longer able to provide care', either through illness or death. Where would the person 'live', who would provide their 'care', would the person be 'safe and secure' and would the person with a learning disability be 'happy and contented'. Many of the family carers were emotional when the topic of planning for the future was raised, indicating that this topic was very 'scary' and when openly discussed brought 'FEAR in capitals'.

'I always wish my son would die before me.' (P2, FG2, Family Carer)

'I cannot sleep at night thinking about it.' (P5, FG3, Family Carer)

'The most important thing is what is going to happen to my son's when I am no longer around, where are they going to be?' (P7, FG2, Family Carer)

For some carers this was still a significant and emotionally raw issue to be addressed, not only their own mortality but the consequences of not being the sole care provider. These poignant quotes highlight the future realities they are faced with:

'I just feel that there is nobody will ever look after her the way I would look after her.'
(P3, FG2, Family Carer)

'Unfortunately I haven't got my head around that yet.' (P3, FG1, Family Carer)

'I have to say I try hard to ignore the fact that one day I am not going to be here.'
(P5, FG3, Family Carer)

IMAGE:
Brian with his son Robin



Both Positive Futures and the Trust staff were also 'sensitive' to the emotions and fears this topic raised with family carers, other family members and the person with a learning disability.

'The daddy in particular couldn't even talk about it for crying, he was so upset about the idea of it and felt a failure as a parent and it was difficult for him.' (P4, FG5, Trust Staff)

Impact of NOT planning for the future

Family carers, Positive Futures and Trust staff all recognised that not planning for the future would present 'greater crisis' than making a plan early with the family having an input to the future plan. One set of carers, were an aunt and uncle who became carers for their nephew with a learning disability when both his parents were tragically killed. There was no future plan in place as to where would he live and who would provide his care; this also included financial security:

'My fear was that if anything happened to us, he would have the same trauma again that he had when his parents died and not knowing where he would end up and whether he would be happy and all that sort of thing. From that point of view it was really important, we had to do something... only for Positive Futures we wouldn't have created a future plan.' (P1, FG2, Family Carer)

'I think you are carrying an underlying level of anxiety that you don't recognise... it's like being in fog... then Positive Futures comes along and helps you... when the sun comes out it is good.' (P1, FG3, Family Carer)

'My husband has been ill for a very long time, on and off. I would not pressure him to make a plan for our daughter's future but eventually we did it together, it was a great relief for both of us. I would not have liked to have been left to do all that myself.' (P6, FG3, Family Carer)

'Those carers are now getting older and we recently had one carer who passed away and it highlighted that actually the planning hadn't been done beforehand and it was back to the crisis and "what are we going to do?'" (Senior Manager 1, Positive Futures)

Theme 2: Responding to the needs of older family carers and people with a learning disability

Within this theme there were three sub-themes: '*challenges for statutory services responding to the needs of older family carers*', '*shortage of suitable housing options*' and '*Positive Futures' values and ethos*'.

Challenges for statutory services responding to the needs of older family carers

A number of the family carers and also Positive Futures and Trust staff highlighted that the needs of older family carers, and their ageing relative with a learning disability, were '*not a priority within statutory*

service providers'. Positive Futures and Trust staff were not able to identify '**specific policies**' or targets that related to older family carers of adults with learning disabilities and there was '**no strategic direction**'.

'I'm not aware of a specific policy for future planning...we undertake a person-centred approach to all our clients.' (P2, FG5, Trust Staff)

'There is no strategic planning really... but generally where people with learning disabilities are placed at home we don't have anywhere to place the person...we frantically try to find them somewhere suitable.' (P3, FG5, Trust Staff)

'There is no forward planning, there is no future planning by our politicians.'
(P2, FG4, Positive Futures Staff)

Several family carers strongly indicated they were not acknowledged by statutory services until a 'crisis' occurred. Trust staff highlighted the lack of recognition of the needs of older family carers within their services, not proactively planning. Family carers, Positive Futures and Trust staff reported that statutory services were a crisis service:

'I always find that learning disabilities...were bottom of the pile, forgotten, and I mean at the bottom of the pile.' (P4, FG2, Family Carer)

'There is no strategic planning really... but generally where people with learning disabilities are placed at home we don't have anywhere to place the person...we frantically try to find them somewhere suitable.' (P3, FG5, Trust Staff)

'The statutory system is crisis led, crisis managed.' (P1, FG4, Positive Futures Staff)

'Many family carers are saying we don't necessarily want our son/daughter with learning disabilities to move out of the family home now, they are saying I'm alright at the minute, if I had a bit of support I will keep caring... carers will happily continue caring. If you put in no support they are going to reach a crisis point much sooner. I think if carers knew what would happen in five years, what housing options would be available for their son/daughter with learning disabilities, that would be OK, but they don't know.' (P3, FG4, Positive Futures Staff)

'Essentially, the model (Trust) is a crisis approach, you know, so when it all goes horribly wrong everybody runs around going "what are we going to do?' (Senior Manager 1, Positive Futures)

Another issue that was raised by all the participants was statutory services staffs' busy workloads and at times staff shortages, and how this then impact's upon the relationships they have with family carers.

'Our social workers are very, very overloaded.' (P4, FG3, Family Carer)

'We are at full stretch here managing the actual core services.' (P4, FG5, Trust Staff)

'There seems to be issues about staff shortages.' (Senior Manager 1, Positive Futures)

'We don't have the time to be able to go into someone's home and spend an hour, two hours with families.' (P2, FG5, Trust Staff)

'We don't get into any of what we would like to be doing with families at any great level because of the workloads.' (P4, FG5, Trust Staff)

Shortage of suitable housing options

Family carers, Positive Futures and Trust staff all highlighted the lack of housing options available in their local community. One parent carer highlighted that as it takes considerable time to develop a future plan and to ensure the person with a learning disability is included, then:

'It is a bit pointless... you wonder why bother, why promise you this and not produce it... it adds more stress and frustration.' (P2, FG2, Family Carer)

'Housing isn't available, funding isn't available, there is nothing prepared, we cannot really offer anything to people, we haven't got the resources.' (P1, FG5, Trust Staff)

'What is the point of getting families to develop a future plan exploring supported living options, when the system doesn't allow the person with learning disabilities to move on...but the family has to wait until someone dies to get a place.'

(P5, FG4, Positive Futures Staff)

Family carers also highlighted that some of the facilities offered were a great distance from the family home and the person's local community. One family carer stated that:

'My main concern would be that he is kept within the local family area... I know of some parents who have died and they have been send to other parts of N Ireland... they are just put wherever there is a space, there is no thought into it.' (P4, FG2, Family Carer)

Positive Futures' values and ethos

In contrast to the pressures reported on the statutory services above (i.e. lack of policies/strategy, a crisis response service, busy staff workloads and shortages, etc.), all the participants highlighted the holistic ethos and values that underpin Positive Futures as an organisation and their staff.

'Positive Futures has a more in-depth involvement, a more strategic approach to older families.' (P3, FG5, Trust Staff)

'We do have our corporate plan and our strategic aims. They are very high level, so the future planning would come under growth/diversification of services.'

(Senior Manager 1, Positive Futures)

'We're working with families in a much more preventative, proactive way and whether that is families of a young child or whether that is families, elderly, older carers, actually it's the same principles because you are trying to avoid that costly crisis because that crisis is so expensive in terms of the practical resources and the finances to manage that, but just the emotional distress and trauma that families have to go through to get to that point before they get the help.' (Senior Manager 1, Positive Futures)

In addition, Positive Futures were successful in obtaining the Big Lottery funding to develop the 'Better Futures Project' that developed a specific programme targeted at older family carers supporting people with a learning disability. This also included a formal evaluation.

'The fact there was a whole Project around older people with learning disabilities and their ageing family carers, an awful lot of planning went into the funding for the Project.'

(P1, FG2, Positive Futures Staff)

'This specific Project is about influencing practice and changing the way people with a learning disability and their family carers are supported.' (P4, FG2, Positive Futures Staff)

'We've had a stability of the Project coordinator throughout the whole Project... the stability means that the knowledge and the connections and the networking that's been set up has really just grown and grown and grown, it's making those links between other local groups.' (Senior Manager 1, Positive Futures)

Many of the family carers reported that the Positive Futures support workers and volunteers were **'very friendly, open, approachable and you didn't feel you had to hide anything from them'**. These staff were able to offer the family carers the **'time'** they needed to explore their feelings and reassure them relating to planning for the future and addressing those concerns that they had hidden for so long.

'One of the Positive Futures staff sat me down and spent 2hrs with me.'

(P3, FG3, Family Carer)

'But they coax out of you what you really feel and no matter what you say to them you don't feel as though they are judging you at all.' (P4, FG2, Family Carer)

'The staff in Positive Futures are brilliant.' (P5, FG3, Family Carer)

The support workers and volunteers within the 'Better Futures Project' were well trained about the needs of older family carers and the needs of adults with learning disabilities. This also included the personal attributes staff needed to support the family carers to explore and develop future plans.

'Remembering the birthdays, anniversaries... tiny key details make all the difference; these help build the very strong attachments with the family carers.'

(P2, FG4, Positive Futures Staff)

'Talking about planning for the future can cause emotional distress, I found it very important to have a conversation to get to the family carers first and then reassure them... building trust and the carers had to get to know us.' **(P5, FG2, Positive Futures Staff)**

'Family carers had to realise that we would follow-up what we talked about, the emergency plans and the future plans, and filled these forms out with the carers even though it was emotional and difficult... it may have taken 3 or 4 visits. Still it was done, which was a big thing for them.' **(P4, FG2, Positive Futures Staff)**

'You had to allow time about 2hrs on the first visit and have extra time if needed... you must leave plenty of time. The family carers were so thankful and grateful that we didn't rush them, we took our time and allowed the trust to develop.'

(P3, FG4, Positive Futures Staff)

Senior managers within Positive Futures highlighted how the support workers and volunteers were closely supported through supervision and training, ensuring each member of staff worked within the ethos and values of Positive Futures.

'So all of our staff have regular person-centred supervision. So that is done on an eight weekly process where essentially, the staff member is meeting with their line manager and the focus for person-centred supervision is "Are you clear about your responsibilities?" Looking at performance, "Are you meeting your responsibilities?"'

IMAGE:

Supporting Donna at home to let Mum and Dad (Maureen and John) go out



Supports, in terms of what you need to be able to do it, and then also as part of that, all staff have performance management objectives. So those are set on an annual basis and we would be reviewing them ongoing through the year via PCS but also there'd be a mid-point review and an end of year review. Staff within the Project, you'd need to speak to them, but my view is they are very clear about their responsibilities and what they need to be doing and perform very well against those objectives.'

(Senior Manager 1, Positive Futures)

Theme 3: Supporting families to develop future plans

Within this theme there were 3 sub-themes: **Training, Supporting families to develop a future plan earlier and Early Transitions.**

Training

This theme focused on how the training supported the 'Better Futures Project' support staff to work with families to develop a future plan. This involved the staff, as well as Trust staff, undertaking a two-day workshop on Future Planning delivered by Ulster University staff. The workshop offered staff a structured framework to approach families, this included resources and tools to work with the family carers, siblings and adults with learning disabilities. Family carers, Positive Futures and Trust staff reported that the training and resources were very helpful in helping them to work with families to develop a future plan.

'So it's about trying to work out who in the family we need to be working with and sometimes you will get some family members who are really engaged with you and others that do have that resistance, or longer to build up that relationship and that's where the skills of the family worker and the Project worker are absolutely essential because it's sort of feeling your way with a family and going at the family pace as well.'

(Senior Manager 1, Positive Futures)

'The future planning training provided you with very good structures that we can go through and working with families, helping to build that rapport that is so needed.'

(P2, FG4, Positive Futures Staff)

'The future planning resources were very well received in terms of the quality of them and the usefulness of them... overall very positive.'

(Senior Manager 1, Positive Futures)

'There was a lot of good stuff in the future planning training... the training gave me confidence to go and talk to family carers about future planning.'

(P2, FG5, Trust Staff)

Part of the training got family carers to explore the person with learning disabilities circle of support. After identifying the person's support network, then an 'emergency plan' could be developed. This then naturally flowed into the development of a future plan exploring other areas.

'Message in a bottle helps family carers to think about what will happen if something was to happen to me, so that is the springboard the family needs to talk about planning for the future.' (P1, FG2, Positive Futures Staff)

'I had only completed the emergency plan a month ago when I needed to use it. I was away overnight, the emergency plan worked: my daughter was well cared for. I could have cried... I was so happy the fact that it worked. That was Positive Futures that did that for me.' (P2, FG3, Family Carer)

Positive Futures have started the role of preparing, doing that emergency plan... they have also put me in contact with the Law Centre and been able to get the Trust to stand up and listen.' (P6, FG2, Family Carer)

A solicitor who specialized in **'wills and discretionary trusts'** delivered a very informative session and this was reported to be excellent. Staff then could inform family carers of some of the issues pertaining to wills and trusts, signposting the carers to these specialized solicitors across Northern Ireland. Some of the family carers have now contacted a solicitor, and a will and/or discretionary trust have been developed or in the process. For other family carers this has yet to be completed: this may be related to which year they started the 'Better Futures Project'.

'We have been to the solicitor in Belfast a few times, and she is very good.'
(P1, FG2, Family Carer)

'We met with the solicitor and have taken some action on that to set up a lifetime trust for our grandson.' (P5, FG3, Family Carer)

'The solicitor's talk on wills was brilliant, very helpful for us as staff but also for families... empowering families to plan for the future.' (P4, FG5, Trust Staff)

'We went to the solicitor and set up a trust fund.' (P6, FG2, Family Carer)

Supporting families to develop a future plan earlier

There were mixed responses from the family carers that the topic of future planning was not identified earlier by statutory staff. A few family carers reported being sensitively approached by a social worker to think about different housing options for their relative with a learning disability. These carers reported being fully supported to explore the different housing and care options over a period of time. The transition from family home to alternative accommodation in the person's local community was reported to be very successful both by the carers but also by the person with a learning disability. Hearing these success stories and how this planning was managed were very much appreciated by the other family carers.

'I do have a good social worker and it was through her when my daughter left school that she did quite a lot for me in arranging care for her.' (P5, FG2, Family Carer)



IMAGE:
Jacqueline with
her dad John,
her sole carer

'I had already begun some work with the learning disability team... yearly reviews... respite... but Positive Futures helped to complete the paperwork work... emergency plans and a clear future plan... I found this absolutely wonderful.' (P2, FG3, Family Carer)

However, for many of these older family carers no one from the statutory sector had proactively approached them about exploring the development of a future plan. It was only through the referral to Positive Futures 'Better Futures Project', and subsequently the exploration and support to develop a future plan.

'I see a light now where I am not just as set in thinking my son should go before me.'
(P2, FG2, Family Carer)

'Until I got involved with Positive Futures, no one had discussed future planning with me. I really didn't have much contact with social workers a remark to say you should think about a future plan... but no direction or no structure.' (P2, FG2, Family Carer)

'I have a very very good social worker who would help me with anything (day-care, respite), very good... but I did not hear of future planning until I got involved with Positive Futures.' (P1, FG2, Family Carer)

'We had no input from the Trust at all. It was promoted by Better Futures staff, message in a bottle and that kind of thing.' (P5, FG2, Family Carer)

One member of Positive Futures staff highlighted that the current Project worked with older family carers who had provided long-term care, however, younger family carers may not expect to become long-term carers as they age:

'There is also a generational issue with younger family carers expecting something very different from older family carers, the younger family carers are not going to do this for the rest of their lives.' (P2, FG4, Positive Futures Staff)

'Until I got involved with Positive Futures, no one had discussed future planning with me. I really didn't have much contact with social workers a remark to say you should think about a future plan... but no direction or no structure.' (P2, FG2, Family Carer)

Early transitions

Family carers, Positive Futures and Trust staff all agreed that carers should be approached at an earlier age to consider developing a future plan and not waiting until a crisis has occurred.

'Future planning should start much earlier; it needs to start as part of transition.'
(P2, FG4, Positive Futures Staff)

'I would suggest future planning at transition times, when the young person with learning disabilities is leaving school and going into adult services... we need to plan ahead.' (P3, FG5, Trust Staff)

'So if there was a shift and the resources actually go into the proactive, of which future planning is absolutely fundamental and essential, that then becomes a much better model of support for families.' (Senior Manager 1, Positive Futures)

Theme 4: Involving siblings and adults with learning disabilities in the future planning decision-making process

This theme identified two sub-themes: *'sibling's involvement'* and *'the involvement of the adults with learning disabilities'* in developing the future plan.

Siblings' involvement

For a number of parent carers, involvement of siblings as a potential future carer was not an option, as they had no other sons/daughters. Likewise, for some sibling carers, they may have been the only non-disabled sibling thereby limiting future carer options. However, for those parent carers where there were non-disabled siblings there was a mixed response in considering them as a future carer. Some parent carers did not want to *'burden'* their son or daughter and their families, with the full-time responsibility and care of the sibling with learning disabilities.

'My mother would like her daughter with a learning disability to live with me, but I don't want her to live with me permanently... my sister would like to live with me full-time... so my idea of living is different from what my mother and sister would want.'

(P3, FG1, Sibling)

'I have a younger daughter who said she will take on this caring role in the event of anything happening to me... but my thoughts on that are that it is not fair on her, although I would want that as I know my daughter with a learning disability would be well looked after in her own home.' **(P3, FG2, Family Carer)**

'My daughter lives abroad... my son has a very busy job... so my thoughts would be that my son with a learning disability would go into statutory care... but I haven't planned it directly.' **(P2, FG2, Family Carer)**

Other parent carers have had aspirations that a sibling, normally an adult sister, would take on this role: but this had not been formally explored and agreed upon. A few parent carers had reported that they have had already discussions with these non-disabled siblings and some siblings have agreed to take on this future caring role.

'I have a daughter and she has always said she will look after her sister with a learning disability... my daughter will move into the family home and continue to look after her.'

(P5, FG2, Family Carer)

'One of the staff from Positive Futures was out with me discussing my daughter's future plan when my other son phoned, although we had never discussed her care after I was gone, I was encouraged to speak to my son. I did, and he has agreed to manage her finance and her overall care... that's a great relief of my mind.' **(P3, FG3, Family Carer)**

Adults with learning disabilities' involvement

There was a mixed response from family carers, Positive Futures and Trust staff about whether they had involved the person with a learning disability in the decision-making process about the development of the future plan. Where they were not involved, one of the main reasons cited was that the person with learning disabilities would have a very limited understanding of what was being explored and planned, due to their cognitive ability.

'A lot of future planning is done in the absence of the person with a learning disability as they cannot cope.' **(P1, FG5, Trust Staff)**

Another reason for not involving the person with a learning disability in this process was the fear of **'upsetting them'**, creating undue anxiety, because it would have introduced the idea that there would come a day when their carer would not be available to care for them.

'I said to my son would you like to go into that supported living scheme... he said yes... but he thinks when we have popped our clogs... but I said what about in a few months' time... he said you are doing my head in, do you want rid of me no!' (P3, FG3, Family Carer)

'We put the person with a learning disability we support first, we would try and actively involve him/her as much as we can... we need to be thinking about their communication, how best to involve them.' (Senior Manager 1, Positive Futures)

Although when some family carers, Positive Futures and Trust staff had explored the topic directly with adults with a learning disability this worked well:

'He was very much in all the discussions, both with us and on his own, with the people in the residential facility and with his social worker.' (P4, FG2, Family Carer)

'I undertook took some initial future planning discussions with a group of adults with learning disabilities in a day centre, you weren't just talking to one person but to a group, it worked well.' (P3, FG5, Trust Staff)

Theme 5: Success of the 'Better Futures Project'

There were two sub-themes identified within this theme: **'benefits for the adults with a learning disability'** and **'benefits for the family carers'**.

Benefits for the adults with a learning disability

All of the family carers described the activities the adults with learning disabilities were involved in with the support workers and volunteers during the week and more so in the evenings and weekends. These included:

'We started a group called Get Up and Go Group. It's about promoting inclusion and participation... they go swimming, bowling, shopping, attending a health programme.' (P4, FG2, Positive Futures Staff)

Some of the family carers reported that some of the people with learning disabilities were able to learn and develop new skills. These included **'sewing', 'bowling', 'learning to use the buses and this has increased the individuals independence'**. 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 a learning disability you feel very assured that your son/daughter is **'safe'**.

'My daughter does a sewing class which is amazing every fortnight, she really looks forward to it.' (P5, FG2, Family Carer)

Benefits for the family carers

All of the family carers reported the benefits of the respite they availed of when the person with a learning disability was involved in various activities. They also stressed that it was important for them to know that their dependent was being offered opportunities to engage in various support groups offering **'practical and emotional support'**. The contact with the support workers and volunteers, as well as the engagement in the specific groups with other family carers, had supported them in many ways, diminishing the **'isolation'** and promoting their emotional well-being.

'The respite they provide is just marvelous, it allows me to get out of the house and attend those meetings.' (P1, FG3, Family Carer)

'I was part of the Cosy Group...it is really good and you could discuss things with other carers... it made me feel less isolated.' (P7, FG3, Family Carer)

'Being able to be among people of like mind... being able to share similar experiences even small things I found very beneficial... so the social side and sharing are very rewarding.' (P4, FG2, Family Carer)

'We put in a support worker if a family carer is very isolated who can take the person with a learning disability to an activity... sometimes the support worker can take the carer out as well shopping, etc.' (P2, FG5, Positive Futures Staff)

'I think actually getting the family carers involved in their own groups... it offers them mutual support and see they are not the only people in this situation. One carer found it easier to discuss things she could not talk to her own family about and was then in a position to go and talk to her own family... its sort of empowerment.' (P5, FG4, Positive Futures Staff)

'Positive Futures has helped my mental health as they helped my daughter... all the wee groups I went to was wonderful.' (P6, FG3, Family Carer)



IMAGE:

Maureen and John at the Positive Futures Event

'I think the families and the carers we get to meet have often been through extraordinarily difficult times and I suppose there are resilience and a resistance sometimes in terms of "look, this is difficult but I have to keep going here because if I don't nobody else is going to". If you are keeping going, why would you want to rock the boat in terms of letting somebody else come in, especially if you feel you have been let down previously. So, absolutely, there is resistance and people just thinking it's just somebody coming in, whereas actually once they get working with us and get working with our staff they're just like "wow".' (Senior Manager 1, Positive Futures)

Overall, the family carers, Positive Futures and Trust staff all reported that the 'Better Futures Project' was very successful for both the older family carers and the adults with a learning disability.

'The 'Better Futures Project' has definitely been a positive experience for me and my two sons; I have greatly benefited from it.' (P4, FG2, Family Carer)

'Only for Positive Futures I would be actually lost.' (P5, FG3, Family Carer)

'Positive Futures has actually empowered me to open my mouth, stand up for myself.' (P4, FG3, Family Carer)

'One family carer said that Positive Futures has given her, her life back, she could see elements of what she used to be... coming back to herself.' (P5, FG4, Positive Futures Staff)

'I have one older family carer who said I had nobody even to listen to me before Positive Futures came along... so getting support is a massive thing to me and my daughter with a learning disability.' (P3, FG4, Positive Futures Staff)

To summarise 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 summarises 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.'
(P6, taken from the Interim Report)

Theme 6: Addressing the challenges and moving forward: working together

There was a belief expressed by Positive Futures and Trust staff that both organisations should work more closely together to support these older family carers. A more proactive approach, providing a more age appropriate family-centred support to the carer and the person with a learning disability, thereby putting in the correct supports that prevent crisis from happening.

'I think the Trust should refer families to organisations like Positive Futures, we would have more time to build relationships and trust...and we can be more creative and flexible in how we address family's needs. But Trusts would have to refer on to voluntary organisations, there needs to be more collaboration with the Trusts.'

(P3, FG4, Positive Futures Staff)

'There needs to be better collaboration with the Trust social workers regarding referrals and working more closely together... it's a very cheap option.'

(P2, FG4, Positive Futures Staff)

'We need to be singing from the same hymn book.' **(P3, FG5, Trust Staff)**

A number of family carers and Positive Futures staff highlighted that, despite the success of the 'Better Futures Project', it was a Project based on fixed funding from the Big Lottery: the Project will terminate when the funding finishes in Summer 2016.

'I think the big one is that this is a fixed term Project... it is life limited and it's really difficult because this Project really works, you know you're making a difference, you know you're making an impact but you know you can only do it for another few months.' **(Senior Manager 1, Positive Futures)**

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

'I certainly think that the 'Better 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.' **(P7, taken from the Interim Report)**

'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.'

(P6, taken from the Interim Report)

'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.'

(P9, taken from the Interim Report)

Comments on estimated cost of the Project

There is a considerable if complex evidence base on the improved quality of life outcomes and cost efficiencies of models of community accommodation for adults with a learning disability. Strydom et al. (2010) undertook an evaluation of the cost of services of 212 older adults with a learning disability (aged 60 years plus) in England. The majority of this sample resided in some form of residential/supported accommodation (83%), whereas only 17% of these adults with a learning disability lived with a family carer. The average weekly cost was £790 (£41,080) per older person with a learning disability in England. Overall costs were highest for those living in residential accommodation and lowest for those adults living with their family carers. Strydom and colleagues reported that despite these older adults with learning disabilities accounting for only 0.15%-0.25% of the population, they however consume up to 5% of the total care budget. The authors highlight that any interventions that meet the needs of adults with learning disabilities and their family carers, and is cost-effective, should be sought. The 'Better Futures Project' is the first be-spoke family service model that clearly addresses the needs of adults with learning disabilities and their older family carers.



IMAGE:
Barbara and her son Mark at an awareness raising event with Lisburn City Council

Detailed examinations of the cost of the 'Better Futures Project' were not explicitly part of the agreed University's evaluation. However, some observations can be made in broad terms if only to provoke consideration as to how the costs of a Project such as the 'Better Futures Project' can be estimated. In basic terms, the total cost of the Project can be divided by the number of beneficiaries per annum. The number of beneficiaries during any given year is not easy to compute. Over the 4 years of the Project, 115 older carers were supported. Based on the running costs of the Project being £539,000 over 4 years, the cost break down as follows:

- **Year 1:** 30 older carers supported = £4,491 per older carer
- **Year 2:** 60 older carers = £2,245 per older carer
- **Year 3:** 100 older carers = £1,347 per older carer
- **Year 4:** 115 older carers = £1,171 per older carer

This does not include the 88 persons with a learning disability who were also direct beneficiaries of the Project.

Comparative costs with other similar services are not easy to find. One approach is to examine comparable services using the unit costs for 2015 produced by the Personal Social Services Research Unit (PSSRU) for the UK. For example, one hour of social worker, client-related work in adult disability services ranges from £55 to £79 (average £67). The cost of a family support worker with direct client contact is £50 per hour and social work assistant costs are £29 per hour. More pertinently, if the older family carer was no longer able to support his/her relative with a learning disability within the family home, based on current figures, the HSC Trusts would have to pay approx. £30,000 - £41,080 per year for a residential/nursing home placement (Strydom et al., 2010; PSSRU, 2014). Individuals requiring specialist care can cost in excess of £150,000 per annum (PSSRU, 2014).

It therefore can be argued that the 'Better Futures Project' offers a low-cost support package to each family that can provide opportunities to support these families without large increases in overall spend. This then could result in a cost reduction in the longer term, by proactively identifying the older family carers' needs and developing a bespoke family support solution, which could avoid family breakdown and the person with a learning disability being placed in a residential facility. This is in keeping with the principles of the 'Equal Lives' Report (DHSSPSNI, 2005) that identified ageing as an area that required specific planning within learning disability services and the Northern Ireland Learning Disability Service Framework (2015) that recommended that all people with a learning disability aged 50 years and over should have:

- The impact of ageing taken into consideration when assessing and managing their needs; and
- The option to remain in their own home with their family carer for as long as possible with appropriate care and support to do so.

The 'Better Futures Project' is the first bespoke family service model that clearly addresses the needs of these adults with learning disabilities and their older family carers, and is a low cost Project compared to the high cost services provided by the HSC Trusts.

Conclusion

This report shows that the aims and objectives of the ‘Better Futures Project’ were not only achieved but clearly exceeded expected outcomes. Over 130 older family carers and nearly 100 people with learning disabilities were supported by the **‘lifetime’** that this Project offered. The ‘Better Futures Project’ with their dedicated and committed team of staff and volunteers have not only been able to **‘listen to and respond to families and build trust’** but to develop and put in place a bespoke array of family services (i.e. respite/ short breaks, support groups, practical information, emotional support, knowledge, information sharing, signposting, emergency and future plans).

This family-centred model has clearly met the specific needs of each of these families caring for a relative with a learning disability. Narratives from the family carers, Positive Futures and Trust staff all highlight the achievements and **‘lifeline’** the ‘Better Futures Project’ has offered these older family carers to continue to support and care for their relative with a learning disability within their family home.

Although the original Big Lottery target was to identify and work with 30 carers per year for 3 years (90 carers in total), this Project has continued to support many of these families into a second, third and fourth year, particularly as many of these carers reported that **‘when the funding runs out, not having this service could be detrimental to everybody’s health.’** Another carer strongly voiced that the **“Better Futures Project’ is what we should have had many years ago from statutory services.’**

At the heart of the ‘Better Futures Project’ is the holistic ethos and values espoused by the entire Positive Futures organisation and staff that **‘they are there for all of us... finally, our isolation has been broken and we have contact again with the outside world’.** Positive Futures have successfully developed a family centred model for future service delivery in one part of Northern Ireland to support older family carers to continue to care for their relatives with learning disabilities within their own homes. This evaluation report evidently shows the substantial benefits that the ‘Better Futures Project’ has made to this vulnerable group of older carers and their families as well as the person with a learning disability.



IMAGE:

Eilish chats over an issue with Better Futures support team member Joanne at a bespoke carers Information Fair

Recommendations:

This report concludes with a number of recommendations:

Recommendation 1

Service commissioners and the HSC Trusts must recognise the value in identifying and supporting older family carers of people with a learning disability. The 'Better Future Project' is a holistic innovative programme that proactively addresses many of the needs of these older family carers and the person with a learning disability together. In order to proactively meet the needs of these families and avoid crisis scenarios occurring, the Trust should contract with a suitable non-statutory provider to deliver a bespoke family carer support service similar to that developed by the SE Trust and Positive Futures. This support should have the following features:

- A trusted relationship is built between support staff and the main family carer(s).
- Consistent efforts are made to engage with the wider family circle so that continuity of family care is facilitated.
- Opportunities are created for carers to meet socially with other carers to share information and receive informal support for their personal wellbeing.
- An emergency and future care plan is developed for the person with a learning disability that is shared with family members and support services.
- Carers are provided with the telephone contact of the main link person whom they can contact in an emergency.
- Accessible information is provided about the practical supports that are locally available to families caring for a person with a learning disability.

Recommendation 2

Increased resources should be made available to increase the proportion of older family carers who can avail of short breaks/respite during the day, evenings, weekends and overnight. These supports need to be locally available and offer the person with a learning disability enjoyable leisure, educational or work activities of their choosing. They should involve the local community and voluntary organisations in developing and extending existing host family/shared lives schemes which are available to a lesser or greater extent across a number of the Trusts in Northern Ireland.

Recommendation 3

Further assistance should be provided to carers and/or the person with a learning disability to enable them to successfully manage Direct Payments or Self Directed Support in order for them to purchase a scheme like the 'Better Futures Project'. The hourly rate for these payments must be in line with those paid by Trusts to their staff and common across Northern Ireland.



Recommendation 4

The PHA (through the Research and Develop Office) should commission a value for money evaluation of the 'Better Futures Project', compared to the costs involved with older family carers who do not receive this innovative bespoke family support service. This cost evaluation would assess the outcomes for the carer, the family unit and the person with a learning disability, as well as the direct and indirect costs involved in providing the support services. In addition, it would also be beneficial to collate evidence on a range of demographics and services including usual place of residence, accommodation charges, income and sources of income, and receipt of all healthcare, social care and other services (day care, domiciliary care, short breaks/respite care and nursing care, in-patient stays, primary and community care contact). Time spent caring by family, other unpaid carers and external providers and aids and adaptations used by the adults with a learning disability.

Recommendation 5

The potential of extending this bespoke family model to all family carers of adult persons with a learning disability should be explored with the aim of fostering the resilience of families and their capacity to provide effective informal support for their relatives throughout adulthood. Similarly, this be-spoke family model could be expanded to other vulnerable and hard-to-reach populations such as those with severe and enduring mental illness, dementia, brain injury, etc.

Final Comment

This report clearly outlines the evidence which demonstrates that the 'Better Futures Project' was an effective, community-based intervention which delivered its key aims and enabled family carers to continue in their caring role.

References

- Bickenbach, J., Bigby, C., Salvador-Carulla, L., Heller, T., Leonardi, M., LeRoy, B., Mendez, J., Putnam, M. & Spindel, A. (2012) The Toronto Declaration on: Bridging Knowledge, Policy and Practice in Aging and Disability.
- Bigby C (2004) Ageing With a Lifelong Disability a Guide to Practice, Program and Policy Issues for Human Services Professionals. London: Jessica Kingsley Publishers.
- Bigby C. (2005) Growing old. Adapting to change and realizing a sense of belonging, continuity and purpose. In Learning Disability. A Life Cycle Approach to Valuing People (Grant G., Goward P., Richardson M. & Ramcharan P. eds). Open University Press, Maidenhead, 663–684.
- Bigby, C. (2010) A Five-Country Comparative Review of Accommodation Support Policies for Older People With Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1) 3–1.
- Bigby C and Ozanne E (2004) Comparison of specialist and mainstream programs for older carers of adults with intellectual disability: considerations for service development. *Australian Social Work*, 57: 273–287.
- Bittles AH, Petterson BA, Sullivan SG, et al. (2001) The influence of intellectual disability on life expectancy. *Journal of Gerontology* 57(7): 470–472.
- Bowey L and McGlaughlin A (2007) Older carers of adults with a learning disability confront the future: issues and preferences in planning. *British Journal of Social Work* 37(1): 39–54.
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001) Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 115–121.
- Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, L., Tanis, E. S., & Wu, J. (2011) The state of the states in developmental disabilities, 2011. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Chou Y, Lee Y, Lin L, Kroger L and Chang A (2009) Older and younger family caregivers of adults with intellectual disability: factors associated with future plans. *Intellectual and Developmental Disabilities*, 47(4): 282–29.
- Foundation for People with Learning Disabilities (2006) 'Planning for Tomorrow'. Foundation for People with Learning Disabilities.
- Foundation for People with Learning Disabilities (2010) Circles Of Support And Mutual Caring. Foundation for People with Learning Disabilities.
- Haley, W. E. & Perkins, E. A. (2004) Current Status and Future Directions in Family Caregiving and Aging People with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, (1), pp 24–30.
- Heller, T. & Arnold, K.A. (2010) Siblings of Adults With Developmental Disabilities: Psychosocial Outcomes, Relationships, and Future Planning. *Journal of Policy and Practice in Intellectual Disabilities*, 2 (1), 16-25.
- Heller, T., Caldwell, J., & Factor, A. (2007) Aging family caregivers: Policies and practices. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 136–142.
- Heller T and Factor A (2004) Older Adults With Developmental Disabilities and Their Ageing Family Care Givers. Rehabilitation Research and Training Centre on Ageing With a Developmental Disability. Chicago, IL: University of Illinois.
- Heller T, Caldwell J and Factor A (2005) Supporting Ageing Caregivers and Adults With Developmental Disabilities in Future Planning. Rehabilitation Research and Training Centre on Ageing with a Developmental Disability. Chicago, IL: University of Illinois.
- Hewitt, A. L. et al. (2010) 'Parental Caregivers' Desires for Lifetime Assistance Planning for Future Supports for Their Children with Intellectual and Developmental Disabilities' *Journal of Family Social Work*, 13(5), 420-434.
- Llewellyn G, McConnell D, Gething L, Cant R, and Kendig H. (2010) 'Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample.' *Res Dev Disability*. 31(6), 1176-86.

- Lunsky, Y., Tint, A., Robinson, S., Gordeyko, M. & Ouellette-Kuntz, H. (2014) System-Wide Information About Family Carers of Adults With Intellectual/Developmental Disabilities: A Scoping Review of the Literature. *Journal of Policy & Practice in Intellectual Disability*, 11(1), 8-18.
- McKee, K., Spazzafumo, L., Nolan, M., Wojszel, B., Lamura, G. & Bien, B. (1999): Components of the difficulties, satisfactions and management strategies of carers of older people: A principal component analysis of CADI-CASI-CAMI. *Ageing & Mental Health*, 13(2), 255–264.
- McConkey R (2005) Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research* 49: 600–612.
- McConkey R, McConaghie J, Barr O and Roberts P (2006) Views of family carers to the future accommodation and support needs of their relatives with intellectual disabilities. *Irish Journal of Psychological Medicine* 23(4): 140–144.
- McConkey R, Spollen M and Jamison J (2003) *Administrative Prevalence of Learning Disability in Northern Ireland*. Belfast: DHSS&PS.
- Magrill D (2005) *Supporting Older Families: Making a Real Difference*. London: Mental Health Foundation.
- Newell, R., and Burnard, P. (2006) *Introduction to Nursing Research: Incorporating Evidence Based Practice*, Blackwell Publishing, London.
- Nolan M, Grant G and Keady J (1998) *Assessing the Needs of Family Carers: A Guide for Family Practitioners*. Brighton, UK: Pavilion Publishing.
- Prosser, H. (1997) 'The future care plans of older adults with intellectual disabilities living at home with family carers?' *Journal of Applied Research in Intellectual Disabilities*, 10(1), 15-32.
- Ryan, A., Taggart, L. and Truesdale-Kennedy, M. (2014)' Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary.' *The International Journal of Older People Nursing*, 9(3), 217-226.
- Seltzer, M.M., Greenberg, J.S. and Krauss, M.W. (1996) 'A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation.' *Psychol Aging*, 10(1), 64-75.
- Seltzer, M. M & Krauss, M.W. (1993): 'Current well-being and future plans of older caregiving mothers.' *Irish Journal of Psychology*, 14, 47-64.
- Slevin E, Taggart L, McConkey R, Cousins W, Truesdale-Kennedy M and Dowling S (2011) *Rapid Review of Learning Disabilities, Challenging Behaviour and Ageing* commissioned by the Research and Development Office. Ulster University.
- Strydom, A, Romeo, R., Perez-Achiaga, N., Livingston, G. & King, M (2010) Service use and cost of mental disorder in older adults with intellectual disability. *The British Journal of Psychiatry*, 196, 133-138.
- The Australian Institute of Health and Welfare (2000) *Australia's health 2000: the seventh biennial health report of the Australian Institute of Health and Welfare*. Canberra: AIHW.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A. and McConkey, R. (2012) 'Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability.' *Journal of Intellectual Disabilities*, 16(3), 217-234.
- Thompson, D. (2002) 'Growing Older with Learning Disabilities'. *Journal of Learning Disabilities* 6(2): 115–22.
- Thompson D and Wright S (2001) *Misplaced and Forgotten: People With Learning Disabilities in Residential Services for Older People*. London: The Foundation for People with Learning Disabilities.
- World Health Organisation (2001) *Healthy Ageing – Adults with Intellectual Disabilities: Summative Report*. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 256–275.
- World Health Organisation (2011) *Mental health Definition: intellectual disability*. Available at: <http://www.euro.who.int>
- World Health Organisation (2000) *Ageing and Intellectual Disabilities – Improving Longevity and Promoting Healthy Ageing: Summative Report*. World Health Organisation, Geneva.



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