Development and testing of a manual and training programme on future planning for front-line staff across N. Ireland

Dr Laurence Taggart & Angela Thompson
Ulster University
March 2015
# Contents

Acknowledgements ................................................. 4

Executive Summary ............................................. 5

Background ......................................................... 7

**Phases 1 & 2:**
Development of the training manual and two-day training programme 11

**Phases 3 & 4:**
Delivery and evaluation of the training manual and two-day training programme 15

Discussion ......................................................... 29

References ......................................................... 32

Appendices ......................................................... 35
Acknowledgements

This grant was funded by a Research & Development Office Knowledge Transfer Scheme awarded to the first author. We would like to thank the members of the Steering Group, and our external speakers and family carers who attended each workshop. We would also like to thank the five Health & Social Care Trusts, and the voluntary and charitable sector organisations for releasing their staff to attend the two-day training workshop.
Executive Summary

Background

The life expectancies of people with intellectual disabilities are significantly increasing with many more people now living with their older family carers. There are more adults with intellectual disabilities living today with family carers in Northern Ireland (NI) compared to the rest of the UK, a pattern that will continue: not planning for the future is not an option anymore. Many of these older family carers are female and are lone carers. This brings additional burdens as both the person with intellectual disabilities and their carer(s) have to manage the effects of the ageing process together. However, there comes a time when family carers cannot continue to provide care for their relative with intellectual disabilities as a result of illness or death, therefore other arrangements are required. The absence of adequate future plans and support systems can lead to crises, social isolation and emotional trauma for all concerned, inappropriate placement and unexpected dilemmas for siblings or extended families.

Future Planning training programmes

There are two international training programmes that work directly with family carers to support them to develop a future plan (‘The Future is Now’ & ‘Safe & Secure’). Both these programmes focus on similar areas (i.e. exploring the barriers and enablers to developing a future plan, circles of support, housing options, financial security, making a future plan, etc.). However, these programmes are solely dependent on the family carer’s attendance at the training programme and his/her proactive development of the different aspects of the future plan with minimal or no support from front-line staff who do not receive any information on the barriers and enablers to future planning. Therefore, those family carers not at the contemplation stage will not start to begin to plan for the future, and many carers may not complete a future plan given the number of individual, family and organisational barriers they may face in their journey.

Aim of study

A recent study in N. Ireland reported that many family carers would like to make future plans if front-line staff can support them sensitively and are able to provide them with the correct information, emotional support and signposts to the appropriate personnel (Taggart et al., 2012). This Knowledge Transfer grant allowed the research team to develop 1) a training manual with resources (including a CD) and 2) a two-day training programme both the training manual and the workshop together trained staff to act as facilitators thereby supporting family carers to explore the barriers and enablers and develop a future plan. The training manual was developed as a stand-alone resource and the two-day training programme was an additional support for staff to develop their knowledge, skills and confidence to approach family carers to support them to develop a future plan. The training manual and two-day training programme enabled staff to support a wider number of family carers to develop a future plan: thereby creating greater sustainability than the two earlier programmes.
Methodology

The training manual and the two-day training programme were developed, and were piloted twice and amendments made. The two-day training programme was then delivered on fifteen occasions across N. Ireland from March–Sept 2014: all participants who attended the workshops received the training manual. The titles of the six sessions of the training programme were: Exploring your own Future Plan; Circles of Support, Person Centred Planning and Emergency Planning; Signposting Housing and Support Options; Making Sound financial and Legal Decisions; Direct Payments and Supporting a Family Carer to Make a Future Plan.

The two-day training programme was delivered by a member of the University and supported by input from members of the NI Housing Executive (NIHE), staff from the Centre of Independent Living NI (CILNI) and two solicitors who specialise in working with people assessed as lacking capacity to make decisions. At least one family carer who had completed or was in the process of completing a future plan was present to speak with staff highlighting the barriers and enablers to developing a future plan over the course of the two-days. All staff were asked to complete a written evaluation sheet at the end of the workshop. Two focus groups were held with seventeen staff several months after they had received the training.

Results

In total 215 staff attended the two-day training programme delivered fifteen times across N. Ireland. The majority of participants reported that the training manual (incl. resources and CD) was very useful, had the appropriate information with references and websites for further information, and contained localised information regarding housing, care providers, finding a solicitor, direct payments and writing a future plan. The resources, exercises and information leaflets were also reported to be helpful in explaining what a future plan was with the family carers and adults with intellectual disabilities. The majority of staff also reported that the two-day training programme increased their knowledge, confidence and skills in approaching families to explore the option of developing a future plan. The additional input from the three external speakers and the family carers were again highly evaluated by the staff.

Some staff reported that raising the topic of future planning with family carers may raise ‘unrealistic expectations’ in terms of housing and may also increase family carers anxieties further. Staff reported a number of organisational barriers in terms of putting the training into practice; these related to ‘workload’, ‘prioritisation’ and ‘whose responsibility it is to approach family carers to support them to develop a future plan’.

Conclusion

Exploring housing options, financial security and future care have the potential to reassure family carers that an agreed plan, in other words security, has been developed and will be put into place when family carers can no longer provide care. Both the training manual and two-day training programme have the potential to alleviate the on-going anxiety and stress that many family carers experience in the decades they provide caring to their relative with intellectual disabilities. The majority of the staff reported that the training manual and the two-day training programme were very helpful in improving their knowledge and skills, and increasing their confidence to approach family carers about developing a future plan. However, organisational difficulties were reported by these staff to implement the training from the two-day programme. Despite the benefits reported of the manual and the training, of over 200 staff from the statutory and voluntary/charitable sector organisations across N. Ireland, it appears that there are significant challenges for front-line staff to implement the training in terms of developing future plans with family carers.
Background

Changing demographics

Over the past century, life expectancies for the general population have dramatically increased. Similarly, life expectancies for people with intellectual disabilities have also significantly increased. People with intellectual disabilities are now more likely to be living with an ageing family carer who themselves will have additional support needs. These carers constitute a non-normative group as their caregiving role begins at birth and continues through childhood long into adulthood (Ryan et al., 2013). In some cases, the caregiving role of parents can span up to eight and nine decades ending only with their death.

Adults with intellectual disabilities living with ageing parents

The proportion of people with intellectual disabilities living with family carers differs across countries (Braddock et al., 2001). Within the United Kingdom, 60% of people with intellectual disability live with their families (King and Harker, 2000), of which one third live with family carers over 60 years of age (Foundation for People with Intellectual Disabilities, 2006). In the United States, estimates of nearer three-quarters living with ageing family caregivers have been reported (Heller et al., 2005), of which 25% are aged 60 years or older (Braddock, 2002). The majority of these ageing family carers are female, mainly mothers (Seltzer et al., 2005).

Regional differences have also been reported across the island of Ireland. Barron et al. (2006) undertook a detailed analysis of NI and the Republic of Ireland’s (RoI) databases. Using both the databases, data were obtained on over 12,500 people with intellectual disabilities living with family carers; half lived with two parents, 30% with a lone parent and just under 20% with another relative. More people in NI were identified as living with family carers, which was attributed mainly too less available residential accommodation. Almost twice as many people lived with family carers in NI (4.35 per 1000) compared with RoI (2.67 per 1000). The demand for out-of-home placement was much greater in NI, especially for lone carers.

The reasons for such variation in family caregiving in intellectual disabilities have not been well explored but they are likely to reflect the individual wishes of parents (Taggart et al., 2012). 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 intellectual disabilities. Despite this, there is convincing evidence to suggest that parents still feel a duty to continue in their caregiving role because they believe that ‘they alone can provide high quality reliable, care’ (Bigby, 2004; Heller and Factor, 2004; Heller et al., 2005). Paradoxically, failing to plan for the future can be a major source of ongoing anxiety for both parent and sibling carers (Smith et al., 1995; Walker and Walker, 1998, Taggart et al., 2012).

Planning for the future

Inevitably, there comes a time when other arrangements are required. The health of the person with intellectual disabilities, including their physical and mental health as well as chronic and enduring behaviours that challenge, may lead to 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 crises, social isolation and emotional trauma for all concerned (Bigby, 2004; Heller et al., 2005), inappropriate placement (Thompson and Wright, 2001) and unexpected dilemmas for siblings or extended families (Ryan et al., 2013). Moreover, unplanned transitions are costly for service providers (Bigby and Ozanne, 2004). Additionally, some family carers may be unknown to services (Janicki et al., 1998) and may come forward only in times of desperate need.

Despite the rational arguments for proactively supporting family carers to make future plans, available evidence suggests that this is not the case and that in many cases future planning is more aspirational than definitive (Bowey and McGlaughlin, 2007, Taggart et al., 2012). Various explanations have been proposed for these ageing 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 realisation 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 and an end to their role in life. Also carers may harbour deep concerns and anxieties about what will happen to their relative in alternative out-of-home placements. They find the subject too painful to broach and do not make firm plans until it becomes unavoidable (Bowey and McGlaughlin, 2007; Chou et al., 2009; Taggart et al., 2012).

Siblings or other extended family members who may be willing with support through regular respite to provide a home for their relative with intellectual disabilities find there is no likelihood of regular weekly on-going support for them, and domiciliary care for the personal care needs of the dependant may be the only support that they can expect. This is causing tension in the next generation of ageing family carers and misses out on a much happier cheaper solution for the future needs of the person.

Ageing carers may lack information about new forms of housing and care options and may be unaware of the long-time frames required to secure housing options and support outside of the home; reporting that there is ‘plenty of time’ (Taggart et al., 2012, Ryan et al., 2013). When families do choose an option such as supported living within an organisation, they are informed there is no money and you need to wait for a ‘vacancy’ or ‘void’ to come up within existing provision. There is also a serious lack of provision of new monies to provide planned transition and the current situation is respond to a crisis not planning for the future.

Nonetheless, 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 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 sensitively and carefully. Therefore, it is important that issues around future planning are considered in the context of the overall support needs of family carers 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) in NI examined ageing family carers' preferences for future care of adults with intellectual disabilities and the support systems required to enable carers to make such future plans. A mixed methods two-stage design was employed. In Stage 1, a structured questionnaire was used to collate information on the health, caregiving demands and future planning preferences of 112 parent and sibling carers; aged 60–94 years. Over half of the carers were lone carers, mainly female, with many reporting a wide range of health problems. A third of these carers reported that their caregiving resulted in high levels of anxiety. The main preference of the carers was for the person to remain in the family home,
with either the family and/or paid staff to support them. A minority of parent carers preferred the person to move into the home of a sibling, although some favoured the person moving to a residential facility with other people with intellectual disabilities. The majority of carers did not want their relative to move into an older people’s residential/nursing facility.

In Stage 2, 19 in-depth semi-structured interviews were undertaken with a sample of ageing parent carers to explore a range of issues around future planning. Four main themes were identified around future planning: unremitting apprehension, the extent of planning, obstacles encountered and solutions for future planning. Avoidance, lack of guidance and a lack of appropriate residential provision were cited as obstacles to making future plans compounded by the emotional upset experienced by carers in thinking about the future. Taggart et al.’s study clearly identified the emotional, informational and practical supports required by these ageing family carers which is also echoed in the international literature (Heller and Factor, 1994; Kaufman et al., 1991; Prosser, 1997).

**Rationale of this knowledge transfer project**

To date there are few future planning initiatives that have been developed and tested with older family carers of persons with intellectual disabilities but there are two that can inform knowledge transfer in NI. The ‘Future is Now Programme’, Chicago, USA involves training both the family carers and the person with intellectual disabilities; it is based around Person-Centred-Planning and a peer support model that includes the family carers and people with intellectual disabilities as co-leaders of groups. Heller & Caldwell (2006) followed-up 49 older family carers who received the programme and found that these family carers were more likely to complete letters of intent, take action on residential planning and develop special needs trust. The family carers also reported decreased carer burden and increased opportunities for daily choice making for the person with ID. ‘Safe and Secure’ is another programme that was developed in Canada (PLAN, 2008), and then adapted for use in Scotland by Equal Futures a carer-led voluntary organisation (Etmanski et al., 2011). This programme is based around a six-step guide to planning the family carer’s future, using 1-1 discussion and group workshops with family carers directly.

However both these small-scale programmes were developed outside of the wider service structures and supports that are available to families and no attempt has been made to share the approaches with personnel who are already in contact with families: such as social workers and community nurses. Both of these requirements are necessary in order to ensure the programme can be accessed equitably irrespective of where carers live. This proposal is built upon a body of research and including the first author’s experience that highlighted the need for a different approach to future planning that offered a more sustainable model. It is against this background that the following knowledge transfer proposal was conceived and successfully funded by the Public Health Agency Research & Development Office in 2012.

**Aims of the project**

- To develop a training manual (incl. resources and CD) that can increase the knowledge of statutory and voluntary staff on the barriers and enablers of future planning across N. Ireland.
- To develop a two-day training programme to support statutory and voluntary staff to develop their knowledge, skills and confidence to approach family carers to support them to develop a future plan.
- To deliver the two-day training programme across N. Ireland.
- To explore the usefulness of the training manual and the training programme.
The objectives of the training manual

- To increase the knowledge base of staff through the provision of a training manual that includes resources (i.e. user friendly information leaflets on future planning, practical information on housing, direct payments, making a will, etc.): these resources were also made available on a CD.
- To act as a stand-alone resource for staff working with family carers to develop a future plan on either a one-to-one or group basis.
- To make the training manual freely available to all staff after the completion of this project.

The objectives of the two-day training programme

- To improve communication between staff, persons with an intellectual disability and family carers around the sensitivities involved in future planning.
- To create a more informed workforce regarding the individual, family and organisational issues facing family carers and the skills required from staff in supporting them to make a future plan.
- To facilitate more informed decision making processes and a more realistic understanding of available options.
- To promote a more active role and information for the person with an intellectual disability.
- To decrease carers’ feelings of fear and burden and to increase feelings of satisfaction and self-efficacy for the family carers.

Methodology

The process for the knowledge transfer involved four stages.

| Stage 1: Development of a training manual and the two-day training programme: | Development of a training manual and the two-day training programme: Using the literature and through using a series of consultation workshops, the training manual and programme were developed. |
| Stage 2: Piloting the training manual and training programme: | Piloting the training manual and training programme: This was achieved using four train-the-trainers workshops (2x2 days) between Sept 2013 and Jan 2014 and obtaining feedback from staff on the training manual and programme. |
| Stage 3: Delivery of the two-day training programme: | Delivery of the two-day training programme: The programme was delivered to a range of statutory and voluntary staff across NI using 15 two-day workshops. All participants were provided with the training manual. In total, 150 staff were offered the free two-day training course: although 215 staff attended the training workshops. |
| Stage 4: Evaluation of the manual and training programme: | Evaluation of the manual and training programme: This was achieved using written feedback sheets form the participants and two focus groups. |
Phases 1 & 2

Development and testing of the training manual and two-day training programme

Pilot Workshops

Two pilot workshops were undertaken in September 2013 in the Southern Health & Social Care Trust (SEHSCT) and in January 2014 in the Western Health & Social Care Trust (WHSCT). Table 1 illustrates that a total of 19 staff attended the two-day training programme. All the participants received the training manual.

**TABLE 1: Staff attendance at the pilot two-day training programme**

<table>
<thead>
<tr>
<th></th>
<th>Trust staff</th>
<th>Voluntary sector</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workshop 1 (SHSCT)</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Workshop 2 (WHSCT)</td>
<td>7</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>8</td>
<td>19</td>
</tr>
</tbody>
</table>

The majority of the staff who attended both training programmes were Trust staff (i.e. social workers, intellectual disability nurses, day care workers) and one Intellectual Disability lead attended from the WHSCT: the other participants were from the voluntary/charitable sector and all were involved in the provision of intellectual disability services (i.e. Positive Futures, Destined, Mencap, Praxis). Several staff also attended from the Patient & Client Council.

Most of the participants attended the full two-days of the training programme and they were also given the training manual that included user-friendly information, exercises, and leaflets for the family carers and people with intellectual disabilities. Feedback was obtained on the training manual and two-day training programme.

Format of the two-day workshop

Ulster University and ‘Equal Futures’ (a Scottish based charity) staff jointly undertook to deliver the first workshop. They were supported by input from the N. Ireland Housing Executive (NIHE), a solicitor who specialises in working with people with incapacity and staff from the Centre for Independent Living NI (CILNI) who focused upon Direct Payments. Throughout the two-days, there was also input from two family carers who had completed a future plan for their daughter/son with intellectual disabilities. These parent carers were able to summarise the sensitive nature of future planning and the individual, family and organisational barriers, and also the enabling factors that supported them to complete a future plan. Six sessions were covered throughout the two-days (three sessions per day):
Session 1: Exploring your own future plan.

Session 2: Identifying family, friends and professionals as your own support network.

Session 3: Exploring housing and support options (delivered by the NIHE).

Session 4: Making sound financial and legal decisions (delivered by a solicitor specialising in situations where there are concerns about capacity of a person with an intellectual disability to make decisions).

Session 5: Direct payments (delivered by staff from the CILNI).

Session 6: Supporting a family carer to make a future plan: questions and answers.

Content of the training manual

The training manual was designed to educate staff on the individual, family and organisational barriers and enablers to future planning. The manual and resources can be used by any professionals (i.e. social workers, nurses, day-care workers, residential care workers, physiotherapists, occupational therapists, speech and language therapists etc.) and in any setting. This could be in an intellectual disability or mainstream older people services, statutory or voluntary and day-care or residential as long as the staff are genuinely interested in working with the family carer and person with intellectual disabilities to develop a future plan.

Each session in the manual contained background reading to what is Future Planning, policy context, the power points from the six sessions, exercises which could be used by the participants with the family carers, the family carer and person with intellectual disability leaflets on Future Planning and a list of local resources including websites for further reading.

Evaluation of the workshops

After each of the six-sessions, the participants completed a written evaluation of the sessions. At the end of the two-days the participants completed an overall written evaluation of the workshop and training manual; and also verbal feedback was obtained. One focus group was conducted two-months after the delivery of each workshop to explore the enablers and barriers to the implementation of the Future Planning programme within practice. The research team reviewed the feedback and changes were subsequently made to the workshop, training manual and resources.
Results

All the participants completed the evaluation sheets on the six-sessions and training manual. Overall the feedback from both pilot workshops was very positive. These can be observed from the following quotes:

“The workshop and training manual have been really useful... there is loads of practical information to share with families”. (SEHSCT)

“Insight was given into all aspects of supporting a family carer to make a future plan, my confidence has increased”. (Positive Futures staff)

Training manual and programme content and structure

The majority of the participants reported that the two-days were needed to deliver such an extensive curriculum. This allowed for enough time for discussion after each session and also during Session 6: questions could be asked and answered among the group and also with the family carer representatives. There was universal agreement among all the staff participants, as well as the carers, that the input from the external speakers was invaluable. Evaluations from the participants confirmed that it was beneficial to have the family carer’s representation at these workshops explaining why they made a future plan and the personal/family, housing and financial difficulties as well as the organisational issues they encountered in working through this process.

There were mixed results regarding the content of some of the sessions within the first workshop. Most participants reported that sessions 1 and 2 were informative and helpful. However, some participants reported that these sessions were not always focussed and needed to be geared more towards the family carer in order to avoid staff giving the person unachievable or unrealistic goals. These were amended both in the delivery of the second two-day pilot workshop and within the training manual. Session 2 was amended to focus more on person-centred-plans and also emergency planning. Staff reports from the focus groups stated that having these person-centred-plans and also emergency plans in place first, naturally permitted future planning to be discussed and more importantly to develop. Furthermore, given the potential significant role siblings can play as potential future carers, information pertaining to this group was added in the delivery/discussion to Session 2 and also in the training manual. Exemplar templates of emergency plans were added within the resource section. Feedback from the majority of the participants from this second pilot workshop on Sessions 1 and 2 were very positive.

A member of the NI Housing Executive (NIHE) delivered session 3. Many of the participants reported that despite this information being interesting it was not always clear and specific to adults with intellectual disabilities living with a parent carer. This has been addressed and local Housing Support Officers from the NIHE, who deal specifically in Complex Needs, were approached and asked to deliver Session 3 in each workshop. In addition, they worked with University staff and developed a specific power point that focused upon how to apply for supported housing and their specific housing details in their trust area that could be given to family carers. This amended Session 3 was reported to be clearer and more helpful by both the participants and also family carers in the second pilot workshop.
There was very strong agreement among the majority of the participants that Session 4 focusing on financial security, wills and trusts, and sound decision making was extremely informative and helpful: for many staff this was the first time they had been given this information. It was important to have a solicitor who was a member of the Society of Trust and Estate Practitioners (STEP) and a member of Solicitors for the Elderly deliver this session as they are specialists in relation to issues of mental capacity and the preparation of wills and trusts for more challenging situations. A list of solicitors who deal with wills and trusts was compiled for each trust and placed within the training manual.

Session 5 was delivered by staff from the Centre of Independent Living N. Ireland. Over three-quarters of the staff and family carers reported that session 5 on direct payments was very informative: many stated they were more confident when introducing the topic of direct payments to family carers now. The accompanying resources within the training manual were reported to be self-explanatory and staff also indicated that it was good to have appropriate web links within the training manual.

Session 6 focused upon pulling the information from the previous 5 sessions together and exploring how staff could start to approach a family carer to develop a future plan. This session used a group discussion format to identify individual/family problems as well as organisational issues that may prevent a future plan not being developed, as well as identifying solutions to such barriers. This was again strongly evaluated as very helpful to share practical concerns regarding approaching family carers and working through the six sessions given their current workload.

There was universal consensus that the ring-folder manual was the most suitable option as pages could be easily lifted out to photocopy or leaflets could be added. The exercises were all reported to be useful but some were identified to be too wordy which could result in family carers not being able to understand or lose interest: these have been amended. Also examples of completed exercises (i.e. the letter of intent) would be useful: this has been added. The power points, web sites, additional reading material and local contacts/addresses were also reported to be very useful.
Phases 3 & 4

Delivery and evaluation of the manual and two-day training programme across all Trusts in NI

Design

It was agreed that the two-day training programme would be delivered free, three times in each Trust between March–Sept 2014. In total, fifteen workshops were delivered. Each Trust agreed to provide premises and also advertise the workshops. Flyers with the addresses and dates for these workshops were distributed across each Trust.

Participants

Figure 1 shows the staff from the various occupational backgrounds (i.e. social work, nursing, day-care opportunities, OT’s, etc.) who attended the two-day training programme. Over 80% of staff who attended the two-day training programme were from the Trust compared to 18.8% from voluntary or charity organisations (Positive Futures, Cedar Foundation, ARC, APEX, PRAXIS, MENCAP, DESTINED, AUTISM NI, INSPIRE, Patient Client Council).

FIGURE 1: Occupation of participants on the two-day training programme
It was identified that staff who were in direct contact with family carers would be best placed to attend the two-day training programme. Through the NI Social Care Council, social workers could obtain accreditation for attending this course and were provided with details of how to do so.

Training manual and two-day training programme

The training manual and two-day training programme were amended and updated in light of the feedback from the two pilot studies as identified above. The titles of the six sessions of the workshops were amended to:

Session 1: Exploring your own Future Plan
This session discussed what a future plan is and why do family carers avoid this topic. This session explored the advantages and disadvantages of having a future plan. Staff were provided with the resources to introduce the topic of future planning to family carers and the person with intellectual disabilities.

Session 2: Circles of Support, Person Centred Planning and Emergency Planning
This session helped staff by providing them with the resources they will need to get family carers to explore who their own support networks are (i.e. siblings, other family members, friends, neighbours, professionals, etc.). Such support networks could become part of their emergency and future plans.

Session 3: Signposting housing and support options
This session explored what housing and support options were available and how staff could signpost family carers in the appropriate direction to the different providers in their specific Trust area: this session was delivered by a member of the NIHE.

Session 4: Making sound financial and legal decisions
This session explored financial security (i.e. wills, discretionary trusts, leaving a house to the person with an intellectual disability, etc.). Staff were provided with information where they could signpost a family carer to an appropriate solicitor in their specific Trust area. A solicitor who specialised in legal considerations when there were concerns about capacity delivered this session.

Session 5: Direct Payment
This session explained how family carers could apply for direct payments, and how direct payments could be used to support the family carer and the person with intellectual disabilities. Staff were provided with the appropriate resources about direct payments and how to signpost family carers to the local organisations in their specific Trust area: staff delivered this session from the Centre for Independent Living in NI.

Session 6: Supporting a Family Carer to Make a Future Plan
The session consolidated the knowledge, skills and resources learnt from the previous five sessions. This session explored potential barriers for staff approaching family carers but also organisational barriers they may encounter. Solutions were explored in a group format with the staff in overcoming these barriers.
Training Manual

The training manual was designed to provide staff with more detailed background information on the importance of future planning, local policy context and literature on each session including a copy of the power points. The aim of the training manual and resources was to give participants the knowledge and resources they would require when visiting a family carer and person with intellectual disabilities to work through the sessions together to develop the future plan. Additional resources including a CD were included such as copies of letters of a future plan the family carers leaflet and the person with an intellectual disability leaflet introducing the topic of future planning, and other resources/worksheets: these were developed with the aid of a local charity. In order to support staff to have access to the supporting resources/worksheets, a CD was also included in each training manual so they could print off the resources when required. Copies of the manual and CD can be obtained from Dr Taggart at Ulster University.

Format of the two-day training programme

Angela Thompson from the Ulster University acted as the Research Associate for this project. Angela along with Dr Taggart and two staff from ‘Equal Futures’, developed the material for the two-day training course and the supporting training manual and resources. The training manual provides the structure for the two-day programme. Angela liaised with the five Trusts, voluntary organisations and other stakeholders to co-ordinate the planning and delivery of the fifteen workshops across N. Ireland.

Angela was joined by a solicitor who specialises in wills and trusts, several Complex Needs Officers from the local NIHE and several staff from the Centre for Independent Living NI (CILNI) to deliver the two-day workshop. They were supported by input from two family carers from each Trust who had completed or were completing a future plan for their daughter/son with intellectual disabilities.

Evaluation of the workshops

After the end of the two-day workshop the participants were asked to complete a written evaluation sheet on the benefits of the training workshop. In addition, verbal feedback was also obtained in a group format after Session 6, exploring the individual, family and organisational barriers and enablers to future planning.

Focus Groups

Participants: One focus group was conducted in the WHSCT and another in the SEHSCT several months after the delivery of the workshops to explore the enablers and barriers to the implementation of the Future Planning programme within the Trusts. In total, seventeen staff took part in the two focus groups. A participant information letter, via an e-mail, was forwarded by the Trust lead to all the participants in the respective Trust of those staff who had received the training.

Interview format: An interview format was developed that explored the two-day training workshop (i.e. course content, structure, external speakers, etc.), the training manual and resources, and the enablers and barriers to putting into practice the training with the family carers. The two focus groups were facilitated by the Research Associate and were audio-recorded and transcribed verbatim. The focus groups lasted approximately 30 minutes.
Analysis: In order to ensure the validity and consistency of the qualitative data reported within the study, a range of a priori methods were employed (Slevin & Sines 2000; Parahoo 2014). First, recording the two focus groups and transcribing the tapes verbatim assured consistent and accurate accounts of the participants’ accounts. Second, the data were subjected to a thematic content analysis using Newell & Burnard’s (2006) framework. Third, to authenticate these key themes and sub-themes, as identified by the second author, another member of the research team (first author) was asked to examine a random selection of the transcripts: disagreements were discussed and consensus sought.

Results

The results of the evaluation sheets will be presented alongside the themes identified in the focus groups and are supported with evidence in the form of narrative accounts expressed by the staff.

Demographics

A total of 215 staff attended the fifteen workshops across the five Trusts. The research team developed a flyer to advertise the Future Planning two-day training programme that was e-mailed widely across both statutory and voluntary organisations within each Trust. The training was targeted at social workers, intellectual disability nurses, day-care workers, OT’s, managers, etc. Figure 2 shows the numbers of staff who attended from each Trust.

FIGURE 2: Numbers of staff who attended the workshops
Table 2 shows the numbers who attended from each Trust and the characteristics of the participants.

**Table 2: Demographics of staff who participated in the workshops**

<table>
<thead>
<tr>
<th>Trust</th>
<th>No. attended</th>
<th>Trust staff</th>
<th>Voluntary/Charitable organisations*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belfast</td>
<td>46</td>
<td>43</td>
<td>4</td>
</tr>
<tr>
<td>Northern</td>
<td>48</td>
<td>48</td>
<td>0</td>
</tr>
<tr>
<td>Southern</td>
<td>28</td>
<td>28</td>
<td>4</td>
</tr>
<tr>
<td>South-Eastern</td>
<td>39</td>
<td>28</td>
<td>12</td>
</tr>
<tr>
<td>Western</td>
<td>54</td>
<td>40</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>215</strong></td>
<td><strong>183</strong></td>
<td><strong>32</strong></td>
</tr>
</tbody>
</table>

From the 215 participants who took part in the training, 204 people completed a written evaluation of the workshops (95% response rate) (see Appendix 1).

**Expectations of the training**

Overall the majority of the participants were seeking information about ‘what was a future plan’, ‘what were the barriers for family carers not planning for the future’, ‘how to overcome these barriers and how support a family carer to develop a plan’ and they wanted ‘user friendly resources’. Most participants stated they wanted to develop their ‘confidence to approach a parent about making a future plan’. Some of the participants highlighted they wanted more specific information on ‘different housing options’ and ‘support/care packages’, others were requesting information on ‘wills and trusts’ and also on ‘direct payments’. A small number of participants reported that they attended the workshops to ‘update their current knowledge’. However, for a few participants they ‘were not clear what the training was about and they were told to attend’.

The majority of the participants (91.2%) reported that their reasons for attending the training were fully met as they ‘increased their knowledge on the need for future planning’, ‘developed practical skills to talk with family carers’ and ‘got resources that they could use with parent carers and also the person with intellectual disabilities’.

“A very enjoyable course, well done to all”. (WHSCT)

“An excellent and informative course, let’s not lose the momentum”. (NHSCT)

**Knowledge and Confidence of Future Planning**

Just less than two-thirds of the staff reported that they had little knowledge of future planning (59%) prior to commencing the two-day training workshop (see Table 3). After attending the two-day workshop, 99% of the staff reported that they now had increased their understanding of the barriers and enablers around future planning. Table 3 illustrates the pre and post percentages of knowledge of future planning.
**TABLE 3: Staffs’ Pre Post Knowledge Scores**

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Pre Training</th>
<th>Post Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little</td>
<td>59%</td>
<td>0%</td>
</tr>
<tr>
<td>Some</td>
<td>29%</td>
<td>1%</td>
</tr>
<tr>
<td>A lot</td>
<td>12%</td>
<td>99%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The majority of staff reported that as a result of attending the training workshop and having the ‘appropriate resources’ they reported ‘being more empowered and confident in approaching a family carer’ to introduce the subject of future planning.

“I feel much better prepared now to formulate a future plan with a family carer”. (SEHSCT)

“I have more knowledge and confidence now to work alongside service users and their family carers to help them to make a future plan”. (NHSCT)

Participants from the focus group stated that their increase in knowledge allowed them to ‘introduce the topic of future planning to a family carer’ as they had the knowledge to answer questions and ‘signpost them in the right direction.’ All participants in the two focus groups stated that they enjoyed the workshops and had approached family carers and left the information leaflets.

However, staff from both focus groups agreed that the most difficult part of future planning was ‘getting the family to think about a future plan’ and they explained that the first step was often the hardest but once the ‘ice was broken’, ‘the family carer did talk about their fears and worries’. This introduction took time for the staff, sometimes months for the family to realise that ‘this was a subject that they needed to think about.’ There were mixed responses from some family carers and as some were reluctant to engage in conversations around this topic.

**Format of the workshops**

The participants reported that the workshop was ‘structured’ as there was a balanced blend of short talks followed by group discussions; ‘the group work provided good interaction between Trust staff and those from the voluntary sector.’

“Great relaxed training allowing people to share their experiences and solutions to other staff problems”. (NHSCT)

“I have learnt a lot from just listening to other staff talking about their experiences”. (WHSCT)
“It was very valuable to listen to the voluntary organisations and to realise that they are also encouraging future planning with their family carers”. (SEHCT)

All the staff reported that the workshops were not rushed and was delivered in a relaxed atmosphere that aided learning. Over 94% of the participants reported that they would recommend the two-day training workshop to their work colleagues. The staff within the focus groups commented that they would encourage all new staff to attend the workshop and that it should be rolled out yearly to all staff.

“I would highly recommend this course”. (WHSCT)

**Training manual and resource materials**

The majority of the staff (95.9%) stated that the training manual and the resources/exercises were extremely ‘helpful’. Many of the staff reported that the structure of the six sessions was ‘clear’, ‘precise’ and ‘build upon each other and aided them to approach family carers’ and to systematically work through a future plan. Likewise, the majority of staff (97.5%) reported that the training manual was well laid out, easy to understand and an excellent resource providing more detailed information such as further reading/references, web links, exercises and local contacts/addresses specific to each Trust. Staff stated that it was beneficial to have the power points in the manuals as well as background reading. Participants in the focus groups stated that they had shared their manual with other staff that had not attended the training that found this very informative.

Some of the participants in the focus group reported that they had printed out and shown the resources to some family carers. The focus group also stated that having the manual on a CD was also a great source of information and was easy to print out.

**User-friendly future planning leaflets**

The majority of the participants reported that the family carers leaflet was an excellent way of getting ‘through the door’ with many older parents. It was something they could leave with the family carer to read over and then call back to answer questions and introduce the topic in more detail. However, some of the staff in the focus group explained that they ‘had given family carer leaflets out and got a mixed response in return’. A small number of family carers had declined the leaflets as they reported that they had ‘no problems at present’ and a few commented that ‘they did not have time to think about future planning’. ‘this is not a priority at present.’

The staff within the two focus groups highlighted that there were a small number of family carers who, when they received the leaflet were ‘happy to listen to what they had to say’. Some family carers admitted they had a plan in their own head of what they wanted for their son/daughter (including who the person with intellectual disability could live with) but they had not discussed this with anyone, husband or siblings. Some family carers were ‘anxious’ of how to bring up the subject with the family and a few stated that they were afraid what their family might suggest for their son/daughter as it might not be what they wanted. The key worker was therefore able to give the leaflets with the family carer so other family members could read.
Some staff in the focus groups stated that when completing or reviewing a carer’s assessment, they had taken the opportunity to ‘explain emergency planning in more detail and introduce future planning’. The leaflet for the person with an intellectual disability was also well received by the family carer and the person with the intellectual disability. One member of the focus group stated that she sat with the person with the intellectual disability and talked them through the activities. ‘They liked the easy format and colourful pictures’ and she reported that they learnt a lot about the person’s views and feelings.

Facilitator

The majority of the staff highlighted the ‘friendliness’ and ‘relaxed manner’ of the University member of staff as she encouraged group discussion.

“The trainer put the information across in a fantastic and interesting way... she was very friendly, very interactive and approachable... she created a relaxed atmosphere”. (BHSCT)

“Great to see that the facilitator was also a carer, she made things real”. (NHSCT)

Again the staff in the two focus groups highlighted that the facilitator was very approachable and she had forwarded additional information to the participants through emails, keeping them up to date.

Invited speakers

Many of the staff reported that they liked the input from the invited speakers (the solicitor, the NIHE and the CILNI) and the opportunities build into the two-day workshop to talk to these speakers after their session. The speakers encouraged questions and they were always clearly answered.

NIHE

In the written evaluations and during the focus groups, the majority of staff noted that it was very beneficial to meet the Complex Needs Officer that was working in their Trust area and also obtain their contact details. They all stated that the issues of housing, supported living and lack of housing was explained in great detail and they stated that they now could pass this information onto family carers with more confidence.

The focus group explained that raising the subject of housing was difficult for the key workers in both Trusts. Many families were aware that there was a lack of supported living accommodation available in their local area, ‘so why should they bother to look into it’. Key workers were reluctant to raise the expectations of the family carers but agreed that through the training they now were able to encourage the family carer to get their son/daughters name on the NIHE waiting list; and if required they were able to help them fill in the form. They were able to dispel myths of ‘having to take the first place that was offered to them’ and explain how the NIHE worked.

Each of the Complex Needs Officer who attended the workshops said that they were delighted to have been invited to speak at the workshops as this gave them ‘an opportunity to ensure that staff understood
how to get a person with intellectual disability onto the correct housing list and to encourage staff to contact them verbally with questions. They all stated that from the workshops they were now receiving more communication from Trust staff and more referrals. This was ‘very productive’ for them as they ‘could forecast the amount of supported living which would be required in the future’.

“I can now put a face to the name!” (NHSCT)

“The housing speaker was very honest”. (SHSCT)

“It was good to get the NIHE contact details, which I can pass on to my families”. (WHSCT)

Solicitor

All participants agreed that the solicitor gave an excellent presentation on a very difficult subject. It was delivered in a very sensitive manner with no power points and there was plenty of time for discussion during the session and afterwards. The evaluation showed that this was a subject which all participants had little knowledge about although a small number discussed how they had to deal with problems concerning wills in the past. They now reported they were ‘more equipped to deal with the legal situation when it came up again’.

“The solicitor was excellent; she was able to answer all the questions asked and spoke in a manner that everyone understood”. (SEHSCT)

“This session was exceptionally informative and very useful”. (BHSCT)

The majority of the staff in the two focus groups agreed that they had found one way to introduce future planning was through the topic of ‘wills and trusts’. They found that the family carers were open to discussion on this subject, if even just to ‘tell stories about family wills’. Staff stated that they were now very equipped ‘to signpost, offer advice, give leaflets and information (including names of solicitors in their area) on this subject’.

Centre for Independent Living NI

Some participants stated that they were aware of direct payments as it gave the family carer more choice and allowed the person with the intellectual disability to enjoy activities that they wanted to do, but ‘it can be difficult to organise’. Some staff stated that they knew about direct payments from previous presentations but found this session ‘a good refresher’.

“The speaker from Direct Payments demonstrated that getting a direct payment can make changes to a family carer’s life”. (WHSCT)
The subject of direct payments however produced mixed results with some staff in one of the focus groups stating that ‘some families had never heard of it’ and some reported ‘it was too much trouble to try and organise, even though it sounded like a good idea’.

Staff reported now they had a greater knowledge of how direct payments was organised and reported they could explain it confidently to the family carer and what was required in order to set it up. They did agree that some family carers would find it difficult and due to this would not bother to explore this option and some said that ‘the Trust has no money so why am I bothering to fill in forms’. All participants said that they were able to give out the leaflets about direct payments for family reading and contacts for the CILNI who would visit the family carer in their home.

Family carers
Many of the staff reiterated that one of the strengths of this two-day course was having the two family carers present who either had completed a future plan or were in the process of developing a future plan. Hearing the personal and honest stories of these carers at the different stages of the development of their journey and being able to talk to them during the breaks, made future planning more significant for all the staff. The focus group again reiterated the importance of hearing the views of the family carers.

“The family carer gave a very emotional insight into her life as a family carer, it was honest and from the heart”. (WHSCT)

“Listening to these older family carer gave me a new understanding of how much continuous caring they do with little help and the need to help them develop a future plan”. (BHSCT)

Benefits of developing a Future Plan

There was consensus from all the staff that every family carer, young and old, should be informed about the benefits of developing a future plan for their son/daughter or relative with intellectual disabilities early before a crisis occurs (i.e. illness of a main carer, death of a main carer). However, participants stated that ‘many family carers are in denial’ and ‘do not want to think about preparing for the future’, so every family will need the appropriate help and encouragement to talk about their feelings and the practicalities of develop a future plan within their families.

Individual and family barriers to future planning

Throughout the fifteen workshops both the staff and the family carers in Session 6 through open discussions and group work highlighted a number of individual and family barriers that may prevent a future plan from being developed. This was further supported by information raised in the two focus groups.

Raising expectations of family carers
Some participants stated that if they encouraged family carers to put their son or daughters name down for accommodation through the NIHE or local Trust, ‘will a room will become available to them, when they
want it’. When this is unachievable due to lack of vacant accommodation or if the person’s complex needs cannot be catered for in the chosen home then the family carer can feel let down by the key worker.

Housing options
The availability of appropriate housing options in the family’s local area can be a problematic and many participants reported that they ‘could be giving family carers false hope when suggesting to them to apply for housing’. Family carers may expect that their son/daughter or relative with intellectual disabilities would be automatically offered accommodation when requested. This could cause additional problems due to the desired housing option not being suitable for the person with the intellectual disability when they need it and waiting lists.

“Families think that there will be a house ready for their son when they want it, but they don’t realise that there is a lack of housing”. (BHSCT)

Also the lack of new builds and closure of homes is a major problem. Whilst housing accommodation is a problem family carers need to be aware of the correct way to put a name on the correct waiting list and that this does not mean they will get the accommodation of their choice but it is letting the NIHE be aware that they are looking for accommodation. Key workers need to be able to encourage family carers to think about supported living for their son or daughter. They need to be able to signpost them in how to apply for it, meet other families who have a son or daughter there and also to visit the accommodation with their son or daughter to let them see it.

Increasing family carer anxiety
Some of the participants reported that ‘introducing the topic of future planning to a family carer may increase their anxiety as they would think that their son/daughter with intellectual disability may be moved out to supported accommodation whilst both parties wish to remain at home’. Some family carers may feel that the choice has been taken out of their hand.
Rejection
‘Rejection’ by a family carer was described as ‘a big challenge for the key worker’. Some staff reported that in ‘hounding’ them about future planning they would ‘lose the respect of the carer’. All the participants believed that it would be very difficult to help an ageing family carer and stated that the emotional conversation of future planning needed to begin at an ‘earlier stage’ and recommended that the topic should be raised whilst the person with the intellectual disability was moving through transition both in education and in the Trust services, usually at the age of 19 years.

“At the age of 19 children move into the adult intellectual disability services, it is here that we need to give them information about future planning and encourage them to start planning”. (SHSCT)

“During the transition phase the families are given a lot of information about the future: future planning should be included here”. (WHSCT)

Organisational barriers to future planning
There were a number of organisational barriers reported that could prevent staff from working with family carers to develop a future plan.

Workload
Many of the participants agreed that there would be problems/challenges with the implementation of the future planning process. One major challenge is that ‘future planning would add to their already heavy workload’. Some staff reported that ‘they did not have the 1-2 hours to spend weekly/monthly supporting the family carers to work through this emotive topic’ and also ‘to work through the six sessions’.

“I have too much work to do already so I am going to find this difficult to implement”. (BHSCT)

“Our work has risen three fold and there is an increasing amount of paperwork to complete”. (NHSCT)

Prioritisation
Some participants reported that while workload was a concern, it needs to be ‘prioritised’ and ‘future planning should be placed as a high priority as if it is put in place it will help to avoid a crisis’. One participant stated that her workload was ‘a crisis response only’, as she had no time for anything else. A number of the participants reported that ‘at present in NI future planning is not a government target so therefore there is no emphasis on the subject to be offered to family carers’.

“This should be a priority, but so is everything else we do for family carers”. (BHSCT)
“We are finding it difficult to cope with everything we do at present, so we are firefighting and the crisis situation is our priority”. (SEHSCT)

“As busy as we are, this topic needs to be given top priority for our family carers”. (WHSCT)

Who’s responsibility is it to approach family carers?
After a lot of discussion it was agreed that ‘the key worker who worked closely with the family carer should be the person to introduce future planning’. All statutory and voluntary staff who have input into the life of the person with the intellectual disability, and also the family unit, should also be encouraged to signpost the family carer through group meetings, talks, etc.

Solutions
Despite such individual/family and organisational barriers, many staff offered a number of innovative solutions to ensure future planning was offered to family carers and also support to work through the process.

Early Future Planning
A number of the staff suggested that in order to ease their job to support family carers and to diminish the carers’ anxieties, future planning should start at an early age and not just with older family carers. Staff could distribute the family carer and person with intellectual disability leaflets to plant the seeds of future planning to all families.

Management attendance
When staff were exploring how to overcome these organisational barriers (i.e. workload, priority, whose responsibility it is to approach family carers) to future planning, many of the participants suggested ‘that managers and senior managers should attend the two-day training workshop’. Having managers attend the training will highlight the ‘importance of having a future plan and thereby avoid crisis management’. Furthermore, managers also needed to be aware of the significant amount of time required by staff to work with the parent carers, the person with intellectual disabilities and also siblings or others to develop a future plan.

“This needs to be mandatory; managers need to attend the training workshop”. (BHSCT)

“Excellent course which needs to be recommended to leads and managers”. (SHSCT)

Prioritising Future Plans
Staff suggested that the senior managers across the five Trusts and voluntary organisations need to highlight the importance of future planning to all staff. One suggestion was ‘to add a question on future planning into the carers’ assessment tool’ (i.e. have you developed a future plan). This would be
an opportunity to gain as much information as possible from a family carer on whether the carers have developed a plan, the stage they are at or whether this topic was still too sensitive to approach. Several staff highlighted that ‘not all family carers have had a carers assessment completed’ so therefore you would not be involving all families. Another suggestion was to ‘allocate time at the person with intellectual disability’s annual review to introduce the topic of future planning’ and be able to ‘distribute the family carer and persons’ leaflets’.

**Carer’s assessment and/or person with intellectual disability review**

Another suggestion was that complex or difficult issues could be managed with the introduction of a family group conference, which would involve the social worker, the person with the intellectual disability, family members which would include siblings and even close family friends. This would be an opportunity of all involved with the person with an intellectual disability to discuss options available and how they can become involved and help out. It is similar to circles of support but with the advice and encouragement of their social worker.

Members of the focus group recommended that the training should be given to family carers along with their siblings and key worker. It was here that the family could discuss the topics with the key worker and discuss the way forward. Also they felt that family carers would open up more and discuss their fears and hopes for their son/daughter.

**Promotion of future planning by all organisations**

All participants agreed that the topic of future planning needed to be reinforced by groups in the voluntary/charitable sector, example through Positive Futures, Mencap and Autism Initiative, and also through carers’ forums within the five Trusts. These groups could provide information days and educate all the family members, but maybe more importantly it would give the family carers to discuss the subject together.
Discussion

This study has successfully developed and piloted a stand-alone training manual that focused upon improving staffs’ knowledge about the barriers and enablers to future planning and the additional information staff need regarding housing, direct payments and financial security to support them to signpost family carers onto the appropriate professionals. As part of the training manual a number of user friendly resources were developed for staff to work through the journey of future planning with carers and also with the person with intellectual disabilities. Alongside this training manual, a two-day training programme was developed, piloted and delivered across NI to 215 staff from both the statutory and voluntary sectors. Staffs’ written evaluations and findings from the two focus groups have highlighted the benefits that both the training manual and two-day training programme offered.

The training manual was developed as a stand-alone resource and the two-day training programme was an additional support for staff to develop their knowledge, skills and confidence to approach family carers to support them to develop a future plan. The training manual and the two-day training programme would allow staff to support a wider number of family carers to develop a future plan: thereby creating greater sustainability. However, despite the positive feedback from staff about the manual and the training programme, issues were raised by staff regarding the how this knowledge is transferred into practice. Many staff highlighted the organisational barriers to future planning such as ‘workload’, ‘prioritization’ and ‘whose responsibility it is to approach family carers’ to support them to develop a future plan. Having a training manual and attending a two-day training programme does not automatically lead to family carers being supported to develop a future plan.

Further research is required to explore if and how this training has been applied within practice. How many of the 200 plus staff who have been trained have approached family carers either via 1-1 support or via small group education as intended with the training manual. What additional individual, family and organisational barriers have been identified by the staff who are applying this training into practice? This includes issues with housing and care packages, identifying and approaching solicitors who can address concerns around capacity and also direct payments. How have senior management valued the future planning training by prioritizing time for staff to work with families, has key personnel been appointed to focus solely on working with families to develop a future plan, is there greater communication between the statutory and voluntary sector, etc.? How is the person with intellectual disabilities being involved in the decision-making process of their future? And of equal importance does the development of a future plan decrease family carers’ feelings of fear and burden and increase feelings of satisfaction and self-efficacy?

Over 200 staff attended the two-day training programme and all received the training manual with accompanying resources in a CD format. As highlighted in earlier research in NI, Taggart et al’s (2012) study calls into question whose responsibility it is to develop a future plan with family carers and whose duty it is to approach them to make such plans? Future planning is a sensitive topic that staff appear reluctant to raise with family carers even within existing policies and practices (Dept. of Health, 2003; Heller et al., 2007). Hence, a vital first step is to determine which members of the statutory services or voluntary sector should accept responsibility to initiate such early discussions with family carers and support them and their relative through this emotive journey. This is more urgent than ever given the limited resources in existing long-term alternative housing and support options, the increasing life expectancy of both parties and the changing family demographics of families that makes substitute family care less likely (Slevin et al., 2011; Ryan et al., 2013).
Some senior management have voiced their opinion that future planning is the responsibility of social workers per se (Parish & Lutwick, 2005). However, there is a wider network of Health and Social Care personnel across NI who could also potentially fulfil this role, such as those working in other professional areas in the statutory sector (i.e. nurses, PAM, etc.) but also the growing number of staff in the voluntary sector who have built strong relationship with the person with intellectual disabilities and their family carers. This project has offered training to all members of staff from both the statutory and voluntary sectors providing them with the knowledge, skills and confidence to support families to develop a future plan. Clearer communication will be required between the statutory and voluntary sectors in identifying which front-line member of staff will act as the lead person to work with the family carer to develop the future plan to avoid duplication. Furthermore, the training manual and two-day training programme could be offered to other personnel who work with adults with intellectual disabilities and their family carers but who are not known to the intellectual disability services such as staff working in older adult services.

Limitations

A shortcoming of this study is that only two focus groups were conducted mainly with self-selected staff from the statutory to explore the training manual and resources, the two-day training programme, and the enablers and barriers to applying the training into practice. A criticism may be that this is a small number of staff and not representative of the wider population of both statutory and voluntary staff (Parahoo, 2014). Many of these staff had not approached a family carer to work through the process of developing a future plan. No formal evaluation of this training was undertaken to examine if the development of a future plan decreased the family carers’ feelings of fear and burden, and increased feelings of satisfaction and self-efficacy for the family carers.

Recommendations

This study concludes with a number of recommendations:

Front-line staff:
- All staff working with people with intellectual disabilities should receive training and regular updates that promote good practice in recognising the changing needs of ageing parents and sibling carers, and the effects of ageing on the person with intellectual disabilities, as they grow old together.
- Key staff to be identified who are responsible and accountable to approach family carers and to support them to develop a future plan, and update the plan as circumstances change.

Training of professionals:
- All professional courses (i.e. social work, nursing, psychology, occupational therapy, etc.) should include future planning within their course curriculum.

Implementation:
- The training manual and resources (incl. CD) to be available to all statutory and voluntary/charitable sector organisations so staff can utilise this resource, this could also include making the resources available online.
- A facilitator needs to be available to deliver the two-day training programme across each Trust annually and provide regular updates as statutory and voluntary/charitable staff change, and as further evidence and resources become available.
• Within the carer’s assessment form, the H&SCT social workers should ask has a future plan been raised with the family carer and then for this practitioner to work in partnership with the person with intellectual disabilities, the family and the other agencies involved to identify rules, responsibilities and timeframes for completing the future plan.
• When a future plan has been developed, this will need to be reviewed annually given the changing circumstances of families, hence the significance of the identification of a key member of staff to undertake future planning.

Management:
• Senior management from both statutory and voluntary/charitable sector organisations to attend a shortened future planning training programme: this will help them to understand the barriers/challenges to the implementation of future planning that their organisations will face and identifying ways to ensure that the training can be translated into practice.
• Senior management to ensure facilitators are appointed within each Trust to continue future training events and regular updates.

Future research:
• What is the effect of the training manual and the two-day training programme for family carers in terms of carer burden, satisfaction, self-efficacy, stress, anxiety and depression at baseline, six and 12 months post intervention? This needs to be formally assessed.
• To explore how people with intellectual disabilities are involved in the decision-making process about the development of their future plan.
• To develop a bespoke training manual and training programme where the family carer, person with intellectual disabilities, sibling (if appropriate) and front-line staff member come together to develop a future plan: three to four families/units could come together to participate in this type of new model.

Conclusion
In conclusion, future planning is a painful and sensitive topic that many older parents and siblings do not want to face. However, with an increasing ageing population of people with intellectual disabilities, governments and service providers cannot ignore the changing needs of this population and their parent and sibling carers. Internationally, family carers are the cornerstone of providing inexpensive care for a person with an intellectual disability and other disabilities: a trend that is set to continue (Emerson et al., 2012). Therefore, such changes in demographics and health needs of these two populations must be set against the current government fiscal constraints and limited in-home and out-of-home options. The consequences of not supporting these family carers will continue to lead to crisis management, increase in anxiety and caregiving burden and increased spending on inappropriate crisis placements.
References


## Two-day evaluation form:

### Your contribution

What did you hope to achieve from this two-day training course?

<table>
<thead>
<tr>
<th>Event Materials</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Was the training manual useful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b) Was the training manual easy to understand?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c) Were the references/resources/web addresses helpful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) Did the hand-outs complement the sessions?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>e) Did the hand-outs aid understanding?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>f) Was the group work helpful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Comments (please give further comments on any of the above)

### Over reflections

<table>
<thead>
<tr>
<th>Over reflections</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Overall was the two-day training course valuable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b) I would recommend this event to others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c) Please rate your level of knowledge/skill/ability on future planning:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>i) Prior to the event</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>ii) After the event</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Overall comments about the event