

Preparing for the future:

A training manual for staff
working with family carers of
adults with learning disabilities

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Introduction

This training manual is produced in collaboration with staff from the University of Ulster and Equal Futures (a Scottish based charity). The manual and two-day training workshop are designed to equip staff with the knowledge, skills and resources required to approach family carers of adults with learning disabilities to develop a 'future plan'. This manual is a facilitator's resource, which will enable you to work with a family carer either on a one to one basis or in a small group setting.

The programme provides interactive resources and skills that put the knowledge into practice through education, support and exercises. The six session plans have been drawn together from work undertaken in Scotland with Equal Futures based upon a family carer education programme on future planning called 'Safe and Secure'. This programme is based upon directly working with family carers, whereas the Northern Ireland programme is based upon a train-the-trainers model: training staff to deliver future planning education directly to family carers. Knowledge recently gained from research staff at the University of Ulster across Northern Ireland has also been embedded into this new programme (McConkey et al., 2005, Slevin et al., 2011, Taggart et al., 2012, Ryan et al., 2013).

The programme is made up of six sessions. They can be used as a whole or in parts to suit the family carers needs: the sessions are flexible so feel free to adapt or add anything to the programme. The six sessions are:

- › **Session 1**
Exploring your own Future Plan
- › **Session 2**
Circles of Support, Person Centred Planning and Emergency Planning
- › **Session 3**
Signposting housing and support options
- › **Session 4**
Making sound financial and legal decisions
- › **Session 5**
Direct Payments
- › **Session 6**
Supporting a Family Carer to make a Future Plan

How to use this training manual

This training manual has been designed for staff who provide support to family carers of adults with learning disabilities.

Training manual and two-day training workshop

The training manual is based upon providing the staff with more detailed information on each of the six sessions, the worksheets that staff can complete with the family carer and other resources that may be helpful. Some exercises can be used in team settings to help colleagues in their learning, so that families receive consistent support. The training manual will support the staff in completing the two-day training workshop. Each of the six sessions should also be read again prior to meeting the family carer and using the exercises/resources provided. The PowerPoint presentations from the workshop are at the end of each session.

We would encourage you to work through the six sessions in the set order; although the programme is flexible and depends on the stage where the carer is at. Each session has aims and learning outcomes that we hope you achieve while working through the training manual and the two-day training course. At the end of each session there are worksheets which can be used with the family carer. These will guide your discussion for that session. These can be printed out for the families and you are very welcome to adapt them to make your own versions for each family. You will also find useful exercises at the back of each session. Some can be used with the family carer. Others can be used to promote understanding and awareness for staff. This will enable staff to understand the family's problems and help them explore their thoughts and feelings for the future. At the end of each session there is a list of resources, websites and references for further reading that you and/or the family carer can use.

An A4, four ring binder has been used for this training manual. This will allow you to lift out what you need and also add your own information in this folder, using plastic pockets at the back of the workbook.

Who is this training manual for?

The training manual has been designed to help develop a future plan for any group or organisation interested in working with family carers of adults with learning disabilities. 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 learning 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 learning disabilities to develop a future plan.

Benefits of the training workshop

It is anticipated that through attending the two-day training workshop and using the training manual, staff will gain the appropriate knowledge, skills and resources to enable them to work successfully with family carers to develop a future plan.

The benefits of this programme for staff and family carers are:

- › To increase the knowledge and skills base of staff through the provision of information and resources that will enable them to educate and support family carers and persons with a learning disability on planning for the future
- › To provide a resource where staff can work with family carers and persons with a learning disability on either a one to one or group basis with the aim of increasing specific future planning activities
- › To improve communication between staff persons with a learning disability and family carers around the sensitivities involved in future planning
- › To create a more informed workforce regarding the issues facing family carers and the skills required in supporting them to make a future plan
- › To facilitate more informed decision making processes and a more realistic understanding of available options
- › To decrease carers' feelings of fear and burden and to increase feelings of satisfaction and self-efficacy for the family carers
- › To promote a more active role and information for the person with a learning disability

About the authors

Dr Laurence Taggart is a Reader at the Institute of Nursing and Health Research, University of Ulster. He has worked there for over eleven years and has been involved in a range of research projects involving people with learning disabilities. Over the last four years Dr Taggart has been exploring the needs of family carers of adults with learning disabilities.

Angela Thompson is a Research Associate at the Institute of Nursing and Health Research, University of Ulster and has been involved in developing the Future Planning programme along with Dr Taggart. She is the Chairperson of Foyle Down Syndrome Trust in Londonderry and is a carer to a young man with Down Syndrome.

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Alison Roy has spent several years working in settings as part of Care in the Community initiatives in Scotland. She has worked with teams to implement strategies and to develop innovative approaches to develop future plans with family carers. At Equal Futures Alison builds Circle of support with people with learning disabilities who would otherwise be more isolated.

Putting Future Planning into Context

Just as the general population are living longer lives as a result of advances in medicine, nursing and technologies, people with learning disabilities are also living longer, with many of them living into their '70s and '80s.

For the general population, ageing is generally determined by chronological age (i.e. 60-65 years); retirement from work; and also in the way that person's physical or mental health status impacts upon their capacity to function. However, such milestones have recently become blurred as the pension age in the UK and other westernised countries has recently increased (it is now 66 years and expected to increase further). Many people are retiring early or later from their jobs, and the person's adjustment to growing older can also be viewed as subjective.

Such universal agreed milestones for the general population have limited application to most people with learning disabilities as they grow older. Firstly, it has been strongly argued within the empirical literature, that the ageing process commences younger in people with learning disabilities at approximately 40-50 years. Adults with Down Syndrome are more likely to develop dementia from their late '30s and early '40s, and consequently are more likely to die younger. Likewise, adults with severe and profound learning disabilities are also more likely to die from respiratory, epilepsy and cardiovascular related health issues, and or cancer, at a younger age (Slevin et al., 2011, Ryan et al., 2013).

Nevertheless, many more people with learning disabilities are living longer than their parent(s) today. Secondly, the majority of people with learning disabilities will not be in employment, they will have limited day care options, fewer respite breaks, less educational, social and recreational activities, as well as fewer social networks. Furthermore, many adults with learning disabilities will not be married, therefore, will have no spouse or dependents to care for them later in life; parents (and even siblings) will have to continue caring for their son/daughter as they also grow older. And thirdly, little is known about the mental health of older people with learning disabilities in terms of how they cope and adapt to the process of ageing.

From the evidence, people with learning disabilities are outliving their family carers in Northern Ireland compared to Ireland, Great Britain and other countries. It is clear from the growing literature that family carers want to continue caring for their son/daughter with learning disabilities. (Foundation for People with Learning Disabilities, 2003, McConkey et al., 2005, Taggart et al., 2012). Likewise, people with learning disabilities would also like to continue living with their parent(s) within their family homes.

Dillenburger and McKerr (2009) in a study of 29 ageing family carers in Ireland using a structured interview format, reported the complex relationships of networks that family carers utilised including siblings, extended family members, neighbours and church contacts. However, 36% of carers did not report use of informal support. The authors also reported the ageing family carers were twice as likely to experience psychological ill-health and were also more likely to be socially and economically disadvantaged. Black and McKendrick (2010) also undertook a study of 36 older

carers (50 years plus) in Northern Ireland and found that the majority of parents wanted their relative to remain with them in their family home.

Statutory services therefore need to ensure that this growing older population with learning disabilities can continue to be cared for by their ageing families within their own family homes: within a proactive model rather than the crisis approach that exists today. Likewise, where older people with learning disabilities and their ageing family carers cannot be supported within their family homes, then alternative appropriate living models or options have to be developed to meet the complex needs of this population. This places an onus on statutory services to be forward thinking in planning for and accommodating the growing numbers of older persons with learning disabilities and other complex needs when planning out-of-home placements.

Future planning

The main concern for the majority of family carers is what would happen to their son/daughter with learning disabilities in the future when they can no longer care, or die. Weeks et al. (2009) in Canada examined the current and future concerns of 33 family carers of adults with learning disabilities. The authors found that the main concern expressed by the family carers was worry about the future, followed by concerns about funding of services in the future, appropriate housing and care options.

‘Succession Planning’ or ‘Future Planning’ is based upon family carers proactively planning in the event that they become unable for whatever reason, (normally deterioration in their own health or their death), to continue to care for their son/daughter with learning disabilities within their own home. The health of the person with learning disabilities, including their physical and mental health as well as chronic and enduring behaviours that challenge, may also lead to family carers exploring alternative care arrangements as they can no longer provide long-term care. Furthermore, family caregivers need also to develop ‘emergency plans’ in the event that due to illness they are unable to care for their son/daughter for a short-period of time. Magrill (2005) reported that family carers wanted to continue caring for as long as possible, and also wanted to engage in emergency plans and future planning, if the issues around such decisions were dealt with sensitively and carefully. Without adequate plans and supports in place, individuals with learning disabilities may be placed in inappropriate settings.

Taggart et al. (2012) examined ageing family carers’ preferences for future care and the support systems required to make such future plans across Northern Ireland. A mixed methods 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

learning 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 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
- › Solutions for future planning

Avoidance, lack of guidance and a lack of appropriate residential provision were also cited as obstacles to making future plans. This was compounded by the emotional upset experienced by carers in thinking about the future. Taggart et al. (2012) clearly identified the emotional, informational and practical supports required by these ageing family carers. It is clear that future planning should start before the problems associated with age and ageing become apparent in the both the person with learning disabilities and the family carer.

Policy

The UK endorsed the Convention on Rights of People with Disabilities in 2010. Article 19, which relates to living independently and community inclusion, is particularly relevant to ageing. The most comprehensive review of policy in relation to ageing in people with learning disabilities was undertaken by the WHO (2001) in association with an 'expert' group of researchers drawn from the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). There is widespread agreement internationally as to the two core features underpinning policy on ageing and intellectual disabilities in relation to accommodation options:

- › People should 'age in place' rather than leaving their home to live elsewhere
- › There should be shared responsibility for older people with learning disabilities across aged-care services and disability provision.

On reviewing the implementation of these twin policies across five countries Australia, Canada, Ireland, UK and USA, Bigby (2010) concluded that service practices fell short of aspirations.

"Data from all countries suggest that broad policy intentions have not reached as far as program development or funding policies. Supporting residents to remain in their own homes, appears to be feasible but is hampered by the absence of firm policy

commitment and defined programmatic strategies such as provision of flexible funding” (Bigby, 2010, p. 10).

One reason cited for these policy failures was that a much clearer conceptualisation is required of ‘ageing in place’. Given the increased life expectancy of this population, many older persons with learning disabilities are now living with ageing family carers and indeed may outlive their parents. Mencap (2002) among other organizations has highlighted the extra future demand that will fall on services in the next twenty to thirty years.

The Northern Ireland Context

The ‘Equal Lives Report’ (2005) identified ageing as an area that required specific planning within learning disabilities services in Northern Ireland. Likewise, ‘Caring for Carers’ (2006) advises the Health and Social Care Trusts that they should pay particular attention to the needs of older people who are themselves providing substantial care to others.

‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’ (DHSSPS, 2011) highlighted that ‘a one size fits all service will be less attractive in the future’ (p. 95). The implementation of the ‘Transforming your Care’ recommended the five Health and Social Care Trusts to develop Population Plan’s. Part of these plans embodies the joint commitment to improve the health and wellbeing of these ageing family carers and older people with learning disabilities to reduce the health inequalities and ensure quality, safety and continuous improvement across all the services commissioned and provided.

The Northern Ireland Learning Disability Service Framework (2012) recommended that all people with learning disabilities aged 50 years and over should have the impact of ageing taken into consideration when assessing and managing their needs. This Framework further stated that all people with learning disabilities should remain in their own home with their family carer for as long as possible with appropriate care and support to do so. Furthermore, the top priority area proposed for action by the Commissioner for Older People for Northern Ireland Report (2013) was ‘a better place to grow older’.

The Scottish Model

The origins of Future Planning and personal network building began as far back as 1986 in Canada with a group of older parents who wanted to ensure a secure future for their sons and daughters with a learning disability after they became ill or died. Their experience was that the available models of service delivery were inadequate to ensure a safe and secure future for their relatives. They decided to investigate what groups elsewhere were doing to address this concern and through their research discovered innovative approaches in other parts of the world: in the USA, Australia and New Zealand where groups had begun to use grant funding to provide continuous advocacy and to develop support networks for their adults with disability. It became clear to them that the issue of a safe and secure future affected all families with relatives with disabilities, regardless of the age of the parent. Younger parents too were interested in securing the future of their children.

They founded PLAN and in due course developed Safe and Secure, a guidebook to help families with a disabled relative to build a personal support network and a plan for the future (Etmanski et al 1997). This model has been adapted and used within Scotland today, by Equal Futures (Etmanski et al with Rowley D 2011). There was at the time no robust precedent from which to draw evidence for the effectiveness of the approach so PLAN committed to undertaking an externally verified social audit to measure both the soft and hard impact of their work. Reports were produced in 2002 and 2005 and by that time families reported significant improvements in their feelings of security about the future:

- › 84% of families reported feeling less isolated
- › 92% of families reported they felt supported
- › 88% of families reported they felt more hopeful about the future and
- › 74% reported having greater peace of mind.

Conclusion

Future planning is a painful and sensitive topic that many parents, siblings and persons with a learning disability, do not want to face. However, with an increasing ageing population of people with learning 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 a learning 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 burdens and increased spending on inappropriate crisis placements.

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Putting Future Planning into context



Dr Laurence Taggart, Angela Thompson

Background

- People with learning disabilities are now living longer into their sixth, seventh and eight decades and predicted to continue to do so in the future
- Many are living with their ageing family carers who will be in their 70's, 80's and 90's, mainly lone mothers
- Both the adults with learning disabilities and their family carers want to continue living in the same household
- Parents fear what will happen to their son/daughter with learning disabilities when they are unable to care for them due to poor health or when they die (Slevin et al., 2011, Ryan et al., 2013)

Policy

- The 'Equal Lives Report' (2005) identified ageing as an area that required specific planning within learning disability services
- 'Transforming Your Care' (DHSSPS, 2011) highlighted that 'a one size fits all service will be less attractive in the future' (p. 95)
- The Northern Ireland Learning Disability Service Framework (2012) 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



Policy

- This Framework (2012) further stated that all people with a learning disability should remain in their own home with their family carer for as long as possible with appropriate care and support to do so
- Northern Ireland has a higher proportion of older people with learning disabilities living within their family home and cared for by an ageing family member than elsewhere in the UK and Ireland

Taggart et al. (2012):

- The study was conducted across all 5 H and SCTs in Northern Ireland with family carers aged between 60-94yrs caring for a relative with learning disabilities aged 40-69yrs in the same household
- There were two stages of this study
- Stage 1, questionnaires were distributed to 112 family carers to collate information on their health, caregiving demands and future planning preferences
- Stage 2, 19 in-depth interviews were undertaken with family carers to explore their health and a range of issues around future planning

Demographics

- Most family carers were mothers caring alone although some siblings (mainly sisters) had also taken on this role: many were caring for over 50 years
- Ageing fathers were more likely to take on this caring role later in life when their spouse died bringing many new challenges

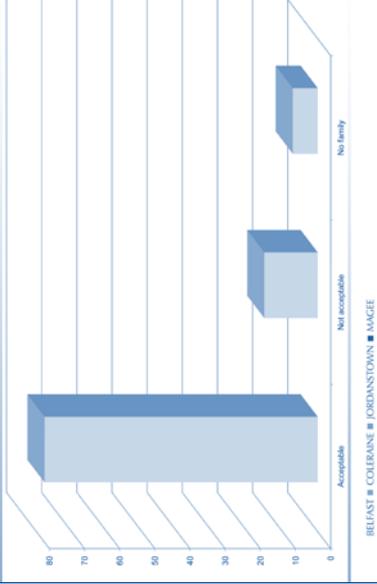


Planning for the future

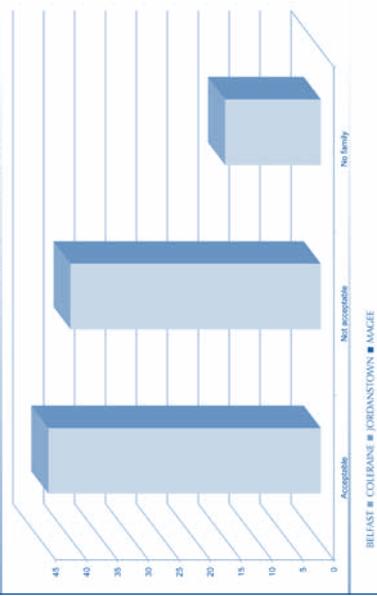
- All the carers expressed concern about the future care of their relative but found future planning a very sensitive topic
- Most of the family carers had not made plans for the future care of their relative with learning disability when they could no longer provide care due to ill-health or death
- Few carers had received information about future planning options and little if any emotional and practical support from service providers



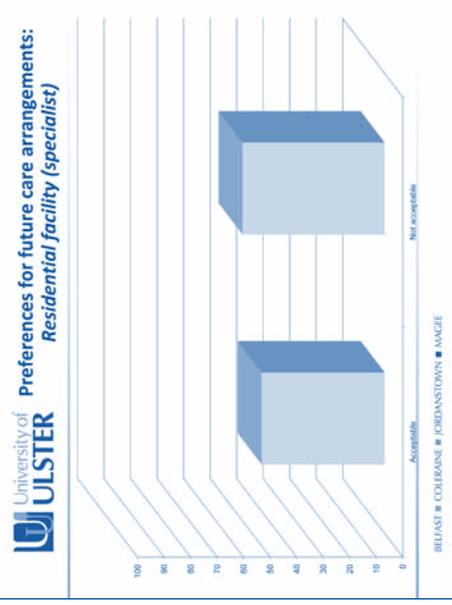
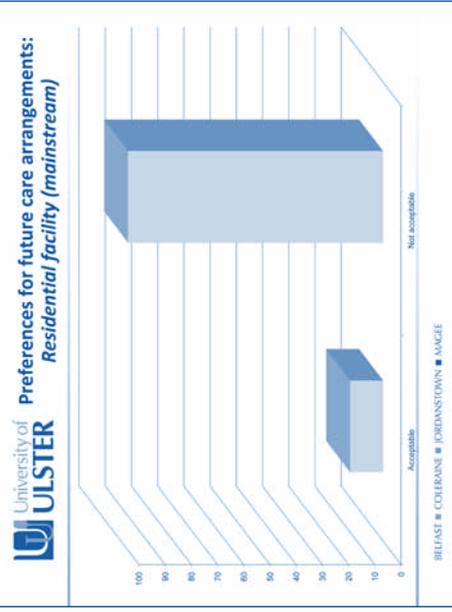
**Preferences for future care arrangements:
*Staying in the family home with support***



**Preferences for future care arrangements:
*Moving into siblings home***







Planning for the future

- Barriers to future planning included: denial, not wanting to let go, lack of appropriate service provision, and a lack of guidance and support from formal services
- Solutions offered by the carers included: person-centred future plans, one-to-one support/guidance from professional staff, one-to-one or group education, early preparation, guidance/support from services, and appropriate and accessible information.

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Implications for service providers

• This is more urgent than ever given the limited resources in existing long-term residential care for people with learning disabilities, the increasing life expectancy of both parties and the changing family demographics of families that makes substitute family care less likely

• This lack of information, support and appropriate services, calls into question, whose responsibility it is to develop future planning training and resources aimed at family carers and whose duty it is to approach them to make such plans?



Conclusion

• Family carers are the cornerstone of providing inexpensive care for a person with a learning disability: a trend that is set to continue

• The consequences of not supporting these family carers will continue to lead to crisis management, increase in anxiety and caregiving burdens and increased spending on inappropriate crisis placements



Session 1:

Exploring your own Future Plan

Aims:

- › To identify what a future plan is
- › To recognise why families do not make future plans
- › To understand how much it takes for a carer to ask for help

Learning Outcomes:

By the end of this session staff will:

- › Have a clear understanding of what a future plan is
- › Have the skills and knowledge on how to raise this sensitive subject with family carers and overcome the barriers.

What it means to plan for the future

Many of us make assumptions about the future; mainly that it will take care of itself. Some of us will indeed get by, and deal with crises if and when they happen. However, for families who have a relative with a disability, the future will not necessarily turn out as anticipated. Families may find themselves in situations which rapidly deteriorate, and in which they might feel they have little control or influence. This can be alleviated when families are able to plan, and to put measures in place which pre-empt potential predicaments.

It is not so long ago, that parents tended to outlive a son or daughter with learning disabilities; so there was often no impending need to consider what should be in place as parents aged. People with learning disabilities are now living longer, often into their sixth, seventh and eighth decade (Slevin et al., 2011). Parents are understandably fearful of what will happen when they are unable to care for their son or daughter. There are many sensitive issues to contemplate, which take time and patience to resolve.

The process of planning for the future can easily become confusing and overwhelming. However, by addressing each aspect separately it is possible to reach decisions which are right for each family.

What is a personal plan?

A personal plan is a written summary of family carer's plans for the social, housing and financial well-being of a family member with a learning disability. Families will

tell you that a good life for their relative should include the following elements:

- › Caring and loving relationships
- › Living in a place which is right for them
- › Having real choices about who they live with how they live their life
- › Making a positive contribution to their own community
- › Having financial security in place

What is a future plan?

A future plan is a description of a desired future for a carer's relative. It is about the person with the learning disability being able to live the best life possible which covers all aspects of well-being of that relative. This is why staff must address dreams as well as fears, worries and hopes.

A clear written statement of the family carer's future plan will help you as a staff member to focus on their values, traditions and history; and help the family to plan with these elements in mind. Clarifying and sharing the desired future plan for the relative of the person with a learning disability, is very important because:

- › It enables key people to understand the relative's perspective
- › It invites the involvement of other members of the family, i.e. siblings
- › It encourages others to understand what is involved and gets them thinking as to how they can help
- › It suggests new opportunities for the family
- › It helps to move the family forward
- › It can change the present

What is a carer afraid of?

What keeps many carers from even thinking about the future, let alone trying to formalise the future wishes of their relative with a learning disability?

Reasons include:

- › Avoidance/Denial
- › Fear of opening up
- › Fear of death
- › Fear of getting it wrong
- › Lack of support and guidance
- › Asking for help

Avoidance and denial

Carers can feel that this is a very personal journey for them and therefore they do not want to discuss it. Many are in denial of their caring role changing as they get older and many cannot think of death. They do not want to think of the crisis situation which will arise when they are no longer able to look after their family member with learning disabilities (Taggart et al., 2012).

Fear of opening up

Sharing your hopes, dreams and worries can mean a carer discussing intensely personal matters with a partner, family members, friends and staff. For a carer this can be awkward. Some are afraid that people will not listen, or will laugh at them and not take them seriously. Carers have grown up believing in self-sufficiency and resilience (Taggart et al., 2012). They take their responsibilities seriously and many have tried all their life to ensure that no one else would have to shoulder their responsibilities. They do the best that they can do. Carers have difficulty in letting go of their family members.

They need to ask family, friends and professional workers to:

- › Help them with their future plan
- › Help to carry out their wishes after they can no longer care or are gone
- › Believe in their relative with learning disability and the possibilities for their future.

This is a big step for many carers and a difficult one to make.

The reasons family carers give for not making a Future Plan

- › ‘We are not in crisis yet, we still have loads of time.’
- › ‘The process is too costly, both financially and emotionally.’
- › ‘I don’t know who to turn to. My community support is too small.’
- › ‘I am worn out from too many previous battles. I just need a break.’
- › ‘We are still young.’
- › ‘The future is too hard to contemplate.’

Fear of death

Someone said “When people are born we rejoice, and when they marry we celebrate, but when they die we try to pretend nothing has happened”. The fear of death is there for everyone. It will always lurk just beneath the surface never quite deep enough to be ignored. It can present itself as anxiety, a sense of impermanence or as loneliness.

What separates a carer of a person with a learning disability from any other family is that they need to address the future of their relative beyond their own life time. The carer must think of how life will be for their relative with a learning disability without them; without their compassion and commitment. Sometimes confronting and accepting their own mortality can spur a carer into action to realise that it is better for everyone if they think about and begin to organise their affairs.

Fear of getting it wrong

Carers feel they will have to make the perfect plan. They will be afraid that they have not covered all the bases, e.g. housing, financial. This is why it makes sense to plan one step at a time, so that each aspect can be considered carefully. This will make it more likely that the plan is the best it can be. Remember to explain to the carer that a future plan will have enough scope to adapt as circumstances change.

Lack of support and guidance

Many carers do not know who to turn to for advice and practical support (Taggart et al., 2012). They are not aware of local organisations and professionals who can help them plan for the future. Two of the complex areas carers must consider are housing options and financial matters. Carers will benefit from receiving a range of good information. This will help them to reach decisions which are right for their relative.

“I think that part of the problem is that we don’t know what to do. We would need advice directed by a professional who can deal with future planning.”
(Mother, 84yrs)

What do family carers want for their relative with learning disabilities?

Family carers want their relative with learning disabilities to be safe, secure and happy in their lives when they are no longer able to provide care as a result of poor health or death. They wish for them to live as independently as they can in the surroundings and life style that they have chosen. A family carer wants to be assured that when they die the person with the learning disability will be cared for and that their future plan will be put in place.

Taggart et al. (2012) in Northern Ireland found that the most acceptable option was for the person with learning disabilities to continue to remain living within their family home with family support (82.6%) or with paid staff support (77.1%). Just over half of the family carers (52.6%) reported it to be acceptable for the person to move into the home of a sibling. By contrast, moving into non- disability residential (85.3%) or nursing home (75.5%) accommodation was not acceptable

for the majority of these carers. Similarly, a learning disability nursing home accommodation was also unacceptable for many parents and siblings (75.5%). However, just less than half of the carers (46.3%) reported it acceptable for the person with learning disabilities to move into a learning disability facility.

What do people with a learning disability want when their family carer is unable to look after them?

We've thought about what carers want for their relative with a learning disability. In doing so, we've also considered our own aspirations and the challenges we face in living the life which is right for us. Of course, there are some differences, we are all unique individuals. And yet, there are also similar themes for all of us. No research has been undertaken that has asked adults with learning disabilities where they would like to live when their family carers are unable to care for them.

Asking for help

Carers play a very important role in caring for their family member with a learning disability. This is an unpaid role with little support. Every carer has a life time experience of caring. They have a great knowledge and can be seen as an expert who should be valued. Some people with a learning disability are not known to the health service until a crisis occurs and this is because the carers have not asked for help. Many carers do not ask for help, except in a crisis situation.

Why is this?

- › A very deep sense of personal responsibility
- › Concern that it indicates a sign of failure on their part
- › A history of mistrusting health services
- › Previous bad experiences/ rejection of assistance in the past
- › Dissatisfaction with current or past provision
- › Worries that if they show they have difficulties their son or daughter will be taken away.
- › Not knowing who to ask
- › Feeling that their opinions are not listened to or valued by services, especially when it comes to planning services for their family member.
- › Experiencing negative staff attitudes to families and their lack of knowledge or experience
- › Lacking the confidence that any support given by paid health and care workers is of a high quality and also that it meets the needs of the person with the learning disability
- › Uncertainty about the future and a fear as a result of cut backs, services may be stopped or changed
- › Lack of flexibility in services, as a result of which families are told what is available, which is often not what the person requires.

How to overcome the barriers

Building a relationship with the family is a very important part of overcoming the barriers. Trust has to be built up slowly. To build up trust you should:

- › Ask how things are going - show you care and are truly concerned
- › Listen to what the carer has to say
- › Do not dismiss what they say because it is not what you would do
- › Do not assume that you know best
- › Engage families in discussions, allow them to listen to each other and share their views
- › If families do express their anger, do not take it personally, allow them to vent their anger and listen to them
- › Do not promise something if you are unable to provide it, but explain that you will carry out research to find the solution
- › Reassure the families that you are there to listen and not judge
- › Do not lose touch with the family but follow up regularly

Listening is very important

We need to listen to people and build support around their individual needs not our assumptions:

- › Make time to listen
- › Do not interrupt when the carer is speaking
- › Avoid using the attitude, 'this is what is on offer' instead use 'what is it that you need?'
- › Record the families discussions/views
- › Provide practical support to enable them to attend meetings or case conferences with solicitors or the Housing Executive
- › Have respect and appreciation for all the things the families have contributed to the support of their family member, build a bond with them

What are the advantages of having a future plan?

- › The family carer and person with a learning disability is at the centre of the future plan
- › It details what is important in the person's life and allows them to continue these activities
- › It helps a person to become involved in their community so that they do not spend time being isolated or spend all their time with services, which they may not like or need
- › It can lead to action, making sure that the person's wishes are listened to and respected
- › It is a good way of getting family and friends involved in the person's care
- › It can lead to lasting friendships and circles of friends
- › It gives the family carers confidence that the person with a learning disability will be well looked after the way that they have planned

Guideline 1:

The first future planning visit

Name of carer:

Date:

Topic	Date	Comments	Signed
Read relevant information and resources available.			
Arrange to visit the carer and suggest arranging to meet for approx. 6 sessions. Explain that each visit might be 1-2 hours.			
Greet the carer. Ask how everything is (observe if the carer is relaxed or stressed and if this looks a suitable time to introduce the subject).			
Introduce the topic of future planning to the carer. Give some examples of why it is important, such as ageing parents or a change in family circumstances.			
Ask the carer if they have made any plans for the future, when they are no longer able to continue in this role. Be aware that they may become tearful or upset.			
If the carer has not made plans, what prevents them from doing this? Listen to the carer's voice their concerns/fears. This can be a very emotional time for them and they may need time to compose themselves and gather their thoughts together.			

Ask the carer if they have discussed this with the other members of their family. What was their reaction?			
Introduce leaflets and examples of a future plan.			
Encourage the carer to ask questions/express their views. Give them time to think about what you have told them.			
Explain and complete the worksheets with the carer and leave with the carer in a folder for future reading. Encourage the carer to share with other members of the family.			
Aim to build trust with the carer, by being honest with them. Do not promise something that you cannot do.			
Introduce the letter of intention, encourage them to write this before your next visit and keep in a sealed envelope. During the last session, review this, and write a new letter if appropriate.			
Record in the care plan the subject you were discussing and dates for a follow up.			
Additional comments			

Worksheet 1:

Identifying your starting point

On a first visit to the family carer, a sensitive approach will go further to building a trusting relationship. It's possible that this discussion will be emotional for the carer. These questions can be asked conversationally, which is less intimidating for the family carer.

If you are going to take notes in the presence of the carer, explain this to the carer before you begin. This prevents the carer from feeling anxious about what you are writing. Do ensure you show that you are listening, and not distracted by your note taking.

The 'Identifying your starting point' worksheet, encourages the family carer to think about their hopes and dreams for the future but also their fears and concerns.

They may complete it themselves or if they request you can scribe for them. This should be kept in their personal file for future reference.



Identifying your starting point

What are your thoughts on planning for the future of ...?

Do you have anything in place?

What are your goals and dreams for...future?

What are your worries and concerns about...future?



Worksheet 2:

A letter of intention

A letter to the future is a family carer's opportunity to tell their future carer how they would like their relative with a disability to be cared for. It will address who they will live with, where they will live, arrangements for their financial security and so on. This is not an easy letter to write. It is a very emotional letter, written from the heart. Encourage the family carer to write what they currently would like to happen for their son/daughter and what is in place.

This letter should be written before the Future Planning sessions begin and kept in a sealed envelope. Throughout the following weeks you will work with the family carer to develop a more realistic future plan as they will explore their options available to them. A future plan will change as circumstances change. There are a couple of sample letters included and a template which can be used in this exercise.



Blank letter of intention

Dear,



With love,

Identifying your starting point:

Worked example 1

What are your thoughts on planning for the future of...Sarah...?

I know that we need to plan for the future and I have started one with my daughter. My husband and I both work, I work part time so that I am here each afternoon when she comes home from the day centre. We don't want to think of the future but we are both getting older and we won't be here for ever. It is making a start that is the hardest thing to do.

Do you have anything in place?

We have looked into housing options and have even gone along to look at a few places, taking Sarah our daughter with me. She didn't like the residential home. She found it too noisy and too regimental. Sarah doesn't have a routine in the house, which is maybe because I am not good at keeping to routine. Sarah liked the idea of living in a house with other women her age. I have asked my social worker to find out more details. We have thought of the options of arranging for Sarah to stay in our house. At present I am not sure how this will work but my husband is looking into it. In some ways that could be a good option as my son lives close by with his family.

What are your goals and dreams for...Sarah's...future?

My dreams are that Sarah will be safe and happy. I hope she will have some friends to mix with and go out shopping or go out for tea with. She helps out two mornings a week at the hairdressers and she really enjoys it. I hope that this could continue. At the day centre she is learning life skills and how to keep the house tidy and look after herself.

My goal would be that she lives as independently as she can. I would love her to meet someone, a man to share her life with, but I am not sure if that will happen.

What are your worries and concerns about...Sarah's...future?

I do worry about the future. What will happen when my husband and I are no longer here? However we are both fit, active people so I intend to be around for a good few years yet.

I worry that Sarah will find it difficult to adjust to living without us. Also that she will be lonely with few friends and won't get out much. I worry that she would not like the living solution we found for her and that she won't settle.

What if her job finishes or her day centre placement ends, what will she do then? Sarah could not cope with nothing to do all day. It is a constant worry and that is why we as a family need to make sound plans for the future, ones that Sarah wants but also ones that I know she will be.

Identifying your starting point:

Worked example 2

What are your thoughts on planning for the future of...John...?

I am scared about the future. I have always thought that John will live with me and my husband. He died 2 years ago and I do find it difficult at times. John is 45 years old and a strapping big man. He doesn't always listen to me. I know I should be doing more with John but I am now 68 years old and I don't really enjoy bowling or going to the cinema, so I guess he is missing out in things.

Do you have anything in place?

I have always thought that my daughter would take John to live with her when I am gone but now she has 4 small young children. She said that she still will take John but I am not sure that she could cope.

My husband left a will when he died and left everything to me. I haven't made a will as I am not sure who to ask or what to do. My daughter and son can sort it out when I am gone.

What are your goals and dreams for...John's...future?

My hopes and dreams are that John enjoys life and doing things that he enjoys, like going swimming, bowling and going to the pub for the odd pint. I want him to have friends who will take him out. I want him to have choices of what to do with his life. I want him to be happy where he lives and maybe have a pet.

What are your worries and concerns about...John's...future?

I am worried that John will be sad and lonely and that he won't have any friends. He doesn't like being lonely as it makes him frightened and sad. I am worried that my son or daughter will move and therefore he will have no one he knows near him. I know he will have to live somewhere else but John doesn't like a lot of noise and likes living at home. I am worried what he will do whenever I am not here.

Letter of intention: Worked example

Dear Peter,

You are the joy of my life.

I have looked after you for over 45 years and have enjoyed each minute of it.

This is not an easy letter to write as I don't want to think of a time when you will be on your own, without me, but I do need to think about what will happen to you.

I would like you to go and live with your sister Sally and her family. I know you will enjoy living on the farm and I am sure Sally would love to have you living with her and her six children. I don't think you would want to live in one of those residential homes as you like quietness and time on your own.

You could still go to the day centre and see your friends at the weekly bowling club.

As you know I don't have much money but what I have I will leave to you. I will open a bank account just for you and Sally can help you get money when you need it.

I have also left you lots of photos and scrap books for you to look at and remember me.

Be safe and happy

Love Mum.xx

Resources

www.nhs.uk/carersdirect

www.caringwithconfidence.net

www.carersuk.org-ni

www.crossroads.org.uk

www.mencap.org.uk/older-carers

www.yourlifeyourchoice.org.uk

www.valuingpeople.gov.uk

www.dotheduty.gov.uk

www.learningdisabilities.org.uk “What kind of future”

info@carerni.org

www.equalfutures.org.uk

Thinking Ahead: Produced by the Foundation for People with Learning Disabilities - <http://learningdisabilities.org.uk/publications>

A-Z Guide for Carers: This guide is for informal carers, to provide help and support, without payment, to a family member who may not be able to manage without this help because of frailty, illness or disability - <http://indirect.gov.uk/a-z-guide-for-carers-pdf>

NI Direct: Information on support services available for people who have a learning disability, their families and carers - <http://indirect.gov.uk/support-for-people-with-learning-disabilities>

Supporting you as an older family carer: A booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term. <http://www.learningdisabilities.org.uk/content/assets/pdf/publications/supporting-you-older-family-carer.pdf>

Carers Northern Ireland

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Future Planning

Session One Exploring your own Future Plan





Aims of session

- To identify what a future plan is
- To recognise why families do not make future plans
- To understand how much it takes for a carer to ask for help

Learning outcomes

- By the end of this session you will have,
 - A clear understanding of what a future plan is
- Have the skills and knowledge on how to raise this sensitive subject with family carers and overcome barriers





Research tells us,

- People with learning disabilities are living longer and some are caring for their parents in the family home
- There is a 'new' population of people with a learning disability who are not known to health and social care
- Future planning needs to start before parents get too elderly or reach a crisis point.

What is your understanding of a future plan?



Future plan

- This is a **desired** future for the family carers son or daughter so that they can live the best life possible
- To live in a place that is right for them, having choices of who they live with and where
- Having financial security in place
- Making a positive contribution to their own community

What is your experience?

- Have you spoken to family carers on the subject?





What is your experience?

- Haven't really spoke to carers on the subject
- Not sure how to approach the subject
- Have tried but the carer cut me off and said she wasn't interested
- Have approached a family carer and things are moving slowly.



What are carers afraid of?





Carers

- Denial
- Avoid the topic
- Fear of opening up to express their worries and hopes for their young person
- Afraid people will not listen to them
- Afraid that staff will think they cannot cope (could take their young person away)

Carers

- Afraid of dying
- Fear of getting things wrong
- Unsure who to turn to
- Feel there is a lack of support for them



How do carers feel when they are asked?

How do carers feel when they ask?

- A very deep sense of personal responsibility
- It indicates a sign of failure on their part
- Anxious about previous bad experiences
- They do not know who to ask
- A lack confidence in the quality of health services



What are the advantages of a future plan?



Advantages of a future plan

- The family carer and the person with a learning disability is at the centre of the plan
- It makes sure that the persons wishes are listened to and respected
- It is a good way of getting family and friends involved in the persons care
- It can lead to lasting friendships and circles of friends
- It gives the family carer confidence that the person with a learning disability will be looked after in the way that they planned



What are the disadvantages of a future plan?

Disadvantages of not having a future plan

- Continual worry/ stress about the future
- Family and siblings are not involved in the future care
- The person with learning disabilities hopes and dreams are not listened to
- The person with learning disability is not at the centre of their future plan
- Crisis care can result in the person with learning disabilities live away from where they are at present

What can you achieve in your first session with the family carer?

- Introduce the topic
- Give information leaflets to family carer and person with learning disability
- Watch for a reaction
- Ask have they made or thoughts of making plans
- Introduce the letter of intention (show examples) encourage them to write one
- Explain that you will help to signpost the family to people who can help and advise them (NIHE, solicitors)
- Aim to build their trust

Session 1 Worksheet 1

Identifying your starting point

- What are your thoughts on planning for the future of?
- Do you have anything in place?
- What are your goals and dreams for future?
- What are your worries and concerns about future?

'Letter of intention'

Dear

Love

Any questions





Session 2:

Person Centred Planning, Circles of Support and Emergency Planning

Aims:

- › To identify how family, friends and professionals can be useful allies in developing person centred planning, circles of support and emergency planning

Learning outcomes:

By the end of this session staff will:

- › Support carers to bring family, friends and professionals into their person centred planning, circles of support, and emergency planning
- › Develop the skills required to use family, friends and professionals as part of their person centred plan, circles of support and emergency planning

Person Centred Planning

Person Centred Planning is a type of life planning. It's helping the person with learning disabilities to lead their life the way they want.

The aim of Person Centred Planning is to improve life experiences for people with learning disabilities. It is a way of gathering information about the person with learning disabilities and then using this information to help solve problems and create opportunities

It is different from assessment and individual programme planning (which help the person with learning disabilities to get the most out of the services which are available).

Person-centred planning has several key features:

- › The person with learning disabilities is at the centre of the planning process
- › Family and friends are partners in planning (it brings people together to get everyone involved to help plan)

- 
- › The plan belongs to the person with learning disabilities and shows:
 - › What is important to them now
 - › What is a good life
 - › What makes a good day
 - › What makes a bad day
 - › What are their hopes and dreams for the future
 - › Who are the important people in their future

Person Centred Planning is helpful because:

The person with learning disabilities is at the centre of the plan and in this approach there is a central commitment to really listening to the person with learning disabilities. By embracing this approach the family and friends are discouraged from assuming they know what the person with learning disabilities want and it is easier to identify what is important for the person with learning disabilities now. The plan helps the person to be part of a community of their choosing and helps the community (e.g., churches, clubs) to welcome them. This reduces isolation or spending time in services (e.g. day centres) which they may not enjoy.

Person Centred Planning can:

- › Help health care worker see what support the person with learning disabilities would like and what they need
- › Be useful to the support worker to help improve services offered and plan future services
- › Be useful in making both small and big changes in the person with learning disabilities' life e.g. Future living /housing arrangements

The plan puts into action what a person wants for their life and ensures that supporters keep on listening. In this way the plan remains 'live' and can be changed and updated as required. The plan can lead to form a support/emergency plan for the person with learning disabilities and can also lead on to planning for the future.

How can you make sure that the person with learning disabilities is at the centre of their plan?

It is important that the person with learning disabilities knows that it is their plan and that everything they say is important. Ensure that all discussions are directed to them and not around them. Encourage them to lead the plan as much as possible with encouragement and support. Support them to choose who will help them with their plan, and to decide where and when the planning takes place. Give the

person with learning disabilities space and time to think about what they want. Do not assume that you know what they want or need. Support their ideas and choices even if you do not agree with them.

Person Centred Planning Tools

MAPS	Making Action Plans
PATH	Planning Alternative Tomorrows with Hope
ELP	Essential Lifestyle Planning

These are all tools to help someone create and plan their own life. They begin with a history of the person's life important milestones and identifying future hopes, which serve as a foundation for the person future planning.

Social support networks and why they are important

When we consider our own lives we might think of ourselves as independent or self-sufficient. Maybe we feel in charge of our day to day life. But how long could we actually get by without the involvement of others? In fact, each of us is interdependent; our relationships are fundamental in enabling us to live our life.

The impact of this recognition is far greater than our contemporary society appreciates or acknowledges. Understanding this interdependence is essential to our health, our quality of life and our sense of belonging.

Many of us have a rich diversity of friendships in our lives, ranging from acquaintances to more meaningful relationships such as family, friends and professionals. Those we value most are often sustained over years; adapting and growing as we move through different life stages: education, work, family. We form friendships with our work colleagues and people in our neighbourhood. The common link is that each relationship is through choice. We tend to think of friendships as something which just happens naturally. We forget the initial spark which initiated it and what it took develop into friendship.

When people think about their friendships, there are often common themes about what they feel makes the relationship important:

- › Being there for me - in the good times and the bad
- › Being open and honest, without judging me
- › Making me feel worthy
- › Accepting of who I am

How we build social support networks

Most of us learn the art of friendship in our early years. The first attempts of pre-school children to join a group are often rejected. They must keep trying before being accepted by their peers. There are three main skills which children learn while playing with each other:

- › How to initiate contact with peers
- › How to maintain play: skills of interaction
- › Conflict resolution: how to negotiate, share and compromise

As adults we learn to hone these skills and to appreciate the finer points of sustaining friendships:

- › Communication: staying in touch by phoning, texting, emailing and meeting up
- › Reliability: being on time, doing what we agreed to do
- › Asking about their life: how they're feeling, what's happening
- › Being able to say sorry and to forgive
- › Reciprocity: being able to give and take - being there for each other

The health benefits of social support networks

There is a mass of evidence to indicate that social support networks may be one of the critical factors distinguishing those who remain healthy from those who fall ill. Social supports affect the sense of control we have over our wellbeing and improve our ability to stick with healthy behaviour patterns. Our confidence increases as does our self-esteem, which in turn gives us a better quality of life.

Is it the same for everyone?

In families with a relative with learning disabilities there can be a heavy reliance on parents to provide most of the support and social opportunities. Parents often feel it is their responsibility to do so and that they don't want to be encroaching on other people. However, there will come a time when this can no longer be sustained. This means having a supportive network of family, friends and neighbours to help support them as the carer and the person with learning disabilities. Likewise, many families will also need the support of professionals/paid staff and also voluntary organisations. Research has shown that for many people with learning disabilities they identify paid staff to be part of their Circles of Support..

Individuals who lack supportive ties are vulnerable to a wide variety of negative consequences. If they are not surrounded by people who have a vested interest in their well-being, the person may be at increased risk of abuse, neglect and exploitation. Added to this, the needs of someone with learning disabilities can be overlooked by a busy, overworked service system; unless there are friends/advocates who will speak up for them to ensure that all needs are met. This includes sustaining existing family ties and friendships, and creating opportunities for new ones to develop.

What are the barriers to friendship?

The ability and opportunity to make friends may not come so easily to some people. This can be for a number of reasons:

- › Going to different places from peers in their community

- › Having limited opportunities to socialise
- › Key people in their lives not recognising the importance of friendship, or how to help make it happen
- › Feeling anxious because previous attempts to make friends were rebuffed
- › Lacking in confidence and self-esteem
- › Those close to the person having fears and feeling anxieties

Families will often think that they know who their relative with learning disabilities friends are. Assumptions might be made about potential new friends: that they are unsuitable, that they would not be interested or that they would not have time. Good friendships can be discovered by paying attention to who their relative gets on well with; who they sit beside, laugh with, reach out to.

Friendships between people with learning disabilities are often undervalued; others don't recognise the strength of the bond between people. These are important relationships which provide mutual support, both practical and emotional. As with any friendship, self-esteem and confidence are enhanced, so people feel more open to new opportunities. People feel safer too, sometimes feeling more accepted.

Unfortunately, these friendships often do not extend beyond the place where people with learning disabilities meet up such as day-centres. While we can make our own arrangements to meet colleagues out of work, people with learning disabilities often need the support of others to make this happen. It's important that these friendships are recognised, and that key people and families make the effort to encourage relationships outside the usual setting. The focus should be on doing the ordinary things together: meeting up in a café, going to a group together, going for a walk.

Another element of friendship is being able to adapt when there are changes. If a friend changes job or moves away, we generally try to stay in touch. People with learning disabilities often have little control or choice when circumstances change within their friendships and connections can be easily lost. It's important that families and others make the effort to maintain these friendships.

Developing new friendships usually happens when we go to new places: a different café or perhaps join a club. The more outgoing among us might make new connections on our first visit. Most people will take longer to identify who they would like to be friends with and to make the first tentative steps. The key to making friendship more likely is for the encounter to become a regular event. It's important that trying new things is set at a pace and a level which is right for the person with learning disabilities.

Understanding the fears and anxieties of families

Many families do recognise the importance of friendship in their relative's life and do what they can to sustain existing relationships. However there can be ambivalence when it comes to actively seeking opportunities to develop these friendships, and new friendships can be particularly daunting to contemplate. There are three main challenges that families face:

- › Asking
- › Opening
- › Believing

What it takes to ask

It can make us feel vulnerable to ask something of others. There is anxiety around exposing ourselves to scrutiny that we aren't coping as well as we'd like others to believe. There is fear of our request being refused. There is uncertainty about how to ask. Yet reaching out and asking is integral to developing and deepening our social support networks. Friendships often form because we ask others to participate in a shared activity. We invite acquaintances over for tea to get to know them better. We ask neighbours to water the plants when we are on holiday. Each of these casual invitations and asking for some help presents an opportunity for the relationship to grow.

This process is not so easy for families when it comes to reaching out on behalf of their relative. Families can have high expectations of what they must do: that they must be self-sufficient in looking after their relative with learning disabilities, and there is a fierce pride in doing this. It can feel risky to a family to ask for help. They worry that others will feel obliged to help; or worse, do so out of pity. This anxiety often comes from the prejudices and discrimination they have faced from society's perception of disability. But if families do not reach out to others, there is a greater risk involved; that their relative will lead a life less enriched, and more unfulfilled.

Letting people in

In order for others to come into a family's life, there needs to be a place for them. It is impossible to meet people or deepen a friendship if there is no time to spend with them. This is an issue for many people with disabilities, who may have inflexible routines. An outsider might perceive that there is no apparent need for a friend. If opportunities for friendship are to be created, it might involve re-organising a schedule to allow space for others to engage with the individual.

On a more subtle level, some actions of families might unintentionally inhibit the involvement of others. Families have probably got into the habit of doing many things for their relative with learning disabilities. The presence of others might mean changes to family routines as well. Sometimes it can feel intimidating to have new people involved, there is a pressure to get everything right. There can be feelings of guilt on the part of the family that they missed something, or should have tried

harder. When other people become involved, the family will have to loosen some control; which can cause anxiety. This might show itself in the actions of the family which could include resisting changes or undermining the contribution of others. It is a big step to accept that changes are inevitable, and it requires patience and understanding to allow families to reach this conclusion.

The process of letting go is a lifetime task. Friendships provide a catalyst to accomplish this task. The person with learning disabilities will grow richer from having experiences from outside their immediate family. Their friends can inspire and encourage them to participate and contribute to society.

Believing in possibilities

Out of the three challenges, this might be the most difficult for families to come to terms with. Families worry that the distinctive traits or history of their relative might make them unappealing to other people. Parents have sharp memories of the absence of invitations to birthday parties, the strangers who stared at their child, the look of pity from a passer-by. The hurt and feelings of rejection become embedded. Families struggle to truly believe that there is a caring community of people available to offer friendship to their relative. It is this lack of belief which affects the ability to open up to others and to trust in their integrity. It will take perseverance and resilience to demonstrate to families that the pursuit of friendship is not just worth it, but essential to the wellbeing of their family member.

Involving family, friends and professionals in developing the future plan

Circles of Support

The process of planning for the future of someone with learning disabilities can be complex. Sharing this load with family, friends and professionals can be the key to more successful outcomes for the individual, and give reassurance to their family. A Circle of Support is simply a team of people who come together out of commitment to the person. Their purpose is to ensure the health, safety and wellbeing of the person. This is the essence of what families provide for their relative, but this cannot be sustained as parents/siblings grow older.

It makes sense to involve other family members, friends and professionals at an early stage, so that the work of sharing knowledge and ideas can be done while parents/siblings are able to share and discuss their views. The really important factor is that it is the person with the disability who is at the heart of the Circle; and all decisions must involve the person as fully as possible, and be in their best interest.

Who is in the Circle of Support?

It is important to find the right people to be in the circle. The key to this is paying attention to who has a good relationship with the person with learning disabilities, and the family carers: and clearly cares about their welfare. This will range from family members, neighbours, friends, professionals and other key staff in the family carers local community. Look for people who are team players, whom you can imagine getting on well together. The Circle members also have to bond with each other. They have to share ideas and tasks, and develop their roles together.

It's usually best if most of the people in the Circle know the person informally, and do not have a direct paid role. This is because there may be times when Circle members have different opinions, and it could put a paid person in an awkward position, where they have a conflict of interest. However, a paid worker who is no longer directly involved with the person can be ideal; they bring a wealth of knowledge, and can now be impartial. There will also be occasions when it makes sense to invite a professional person to be part of the Circle because they have specific knowledge; perhaps relating to finance or health.



Every Circle is unique

- › The focus is what makes sense for the person and their family
- › The aim is to; ensure the person lives their life well
- › Give families reassurance

Microboards

This is a small group of people, made up of close family members and friends who get together to develop a support network for a person with a learning disability. It is founded on acknowledging and respecting the person's wishes and takes into account the person's safety and comfort. It is based on person centred planning and provides a flexible way to meet the person's needs. It can result in an improvement of life for the person with the learning disability as responsibility is shared with a small number of people. Microboards are on-going and not crisis orientated and not reliant on professionals. They are a great way of meeting the persons, needs, hopes and dreams.

Emergency Planning

What is an emergency plan?

An emergency plan aims to lay out the best way to support a person with learning disabilities when an emergency occurs. The contents of the emergency plan will help stop the emergency turning into a crisis. It is usually made in advance when family carers have had time to arrange it and discuss plans and ideas with family members and friends.

Family emergencies can include:

- › Someone may take ill suddenly
- › Planned or unplanned hospital admissions
- › Friend or other relative may become ill
- › Motor car 'trouble'

A family emergency can result in temporary or permanent changes in the life of a person with learning disabilities. It can result in the person not understanding what is going on, may cause them to be disorientated, out of their normal routine, and upset.

Why is an emergency plan useful?

- › It reduces family carer's anxiety as they know that during the emergency their son or daughter will be safe and looked after with people who they know
- › Without a plan, in the event of an emergency, decisions will be made by someone who may not know the person with learning disabilities. This may result in the person with learning disabilities becoming 'labelled' as having a behaviour or mental health problem when they do not
- › The person with learning disabilities will know the people looking after them, (other family, and friends) and will be able to continue their daily activities
- › The process of compiling an emergency plan can help family carers start to think about long time planning for the future and understand that it is essential for their loved one

Guidelines on how to make a plan

It can be difficult for the family carer to start the process of making an emergency plan. It can be started at the Annual Review Meeting or when the Carers Assessment is being completed.

You should encourage the family carer to make a list of:

- › People who could help them draw up the emergency plan, (partner, siblings, close friends health care workers.)
- › Think about the type of emergencies which may arise, (e.g., grandparents taken ill, close family member needed hospital treatment.)
- › Make a list who could help out in the event of an emergency (family, friends, neighbours, paid workers) have they got the contact details
- › Put ‘cushions’ of support in place before an emergency happens:
- › Explain to the person with the learning disabilities what you are planning and ask for their input. Ask them who would they like to stay with in the event of an emergency
- › Teach the person with the learning disabilities how to call for help, for example using a mobile phone with photographs of the people to contact
- › Write down all names and contacts of all people in the emergency ‘team’
- › Make sure people in the team know where the spare keys for the house are located
- › Write down the code of the house alarm
- › Put a ‘Message in a Bottle’ - important details can placed in a bottle and in the fridge
- › Share this information with the key worker
- › Compile an information sheet so that friends/family looking after the person with the learning disabilities will be able to continue their care. Give this to them or place in the house somewhere that it is easy to find

Emergency planning gives a family carer ‘peace of mind’ as they know that in the event of an emergency their son or daughter will be looked after until the emergency has resolved. Failure to make an emergency plan can result in crisis care, which is not what the family carer or the person with learning disabilities wants.

Siblings

Having a brother or sister with learning disabilities can have a massive impact on the whole family. Brothers, sisters and other family members may struggle to come to terms with the lifelong diagnosis, as they don't understand why their brother or sister has a learning disability or if it will in the future 'go away'.

Siblings can also face specific challenges when their brother or sister has learning disabilities. Many siblings can feel angry and upset when they realize their brother or sister has a learning disability and therefore can't do some of the same things they can do, e.g., run, talk, or play.

Some siblings face bullying at school as a result of their sibling's disability, and feel too embarrassed to bring their friends home after school. They feel that family life is not normal or the same as their friends.

Also a child with a learning disability can have a drastic impact on the amount and quality of time parents have available to spend with the other siblings. They can experience their brother or sister attending hospital appointment or clinics with their parents when they need help with their homework and so on.

Positive thoughts

Siblings are a very important link in the life of a person with learning disabilities. They can make several positive contributions:

- › They usually have grown up with their brother or sister and therefore they share a family history and understanding of them.
- › They don't 'see' the disability as others would.
- › They can help to broaden their brother or sister's social network, by introducing them to their friends.
- › They are a link to helping them developing new interests, join new activities/clubs etc., go out for an evening for a meal or clubbing.
- › They are a similar generation to their brother or sister so are able and more willing to take them out to events/social gatherings which the family carer may not want to attend



Negative thoughts

Family carers often do not engage siblings in helping to create a future plan for their brother or sister for several reasons,

- › They do not want to burden them with the responsibility of caring for their brother or sister
- › They feel they should be allowed to get on with their own lives
- › They are reluctant to discuss the future with all of their children; this can result in the siblings finding it difficult to broach this subject

However some family carers can feel it is the responsibility/duty of the siblings to look after their brother or sister with learning disabilities. This may never have been discussed with the siblings or the person with learning disabilities - who may not want to live with their siblings.

Family discussions are very important both to the siblings and to the person with learning disabilities. Each should have a voice on the way they would like to live their lives. Discussions need to take place early and if possible be recorded so that siblings can plan their lives around their brother or sister.



Resources

www.inclusion.com

www.sclد.org.uk

www.helensandersonassociates.co.uk/

www.in-control.org.uk

www.learningdisabilities.org.uk

www.handsoffmyplan.co.uk

www.trans-active.org.uk/teenz

www.velamicroboardsni.com

www.paradigm-uk.org

www.learninAcommunity.us

www.personcentredteams.co.uk

[www.learningdisabilities.org.uk/our-work/changing service-delivery/an-ordinary-life](http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life) (a video clip about person centred planning)

Department of Health (2001) Valuing People: A new strategy for learning disability for the 21st Century. The Stationary Office, London

Department of Health (2008) Valuing People Now: From Progress to Transformation. The Stationary Office, London

Worksheet 3

Circles of Support:

Where do people fit in your life?

Aim:

The aim of this exercise is to identify where we place the people in our relationships: those we feel most close to, and who we only need sometimes.

Why:

To understand the diversity of relationships, and the different roles they match in our life. To have awareness of the differences for someone who has disabilities and the detrimental effect this can have on the person's well-being.

How:

Each family carer to be given the "Relationship Circles" hand out and asked to fill in each section. Participants should be very specific and should be asked to write names. They will not be asked to share the detail, only the general themes.

Where to place the people in your life:-

Circle of intimacy

Close family, close friends, people you can't live without.

Circle of friendship

The good friends; people you can rely on, people you call with good news, people you can moan to. This might also include family you don't see so regularly.

Circle of participation

People you know from the places you go: work, clubs, groups, church, community

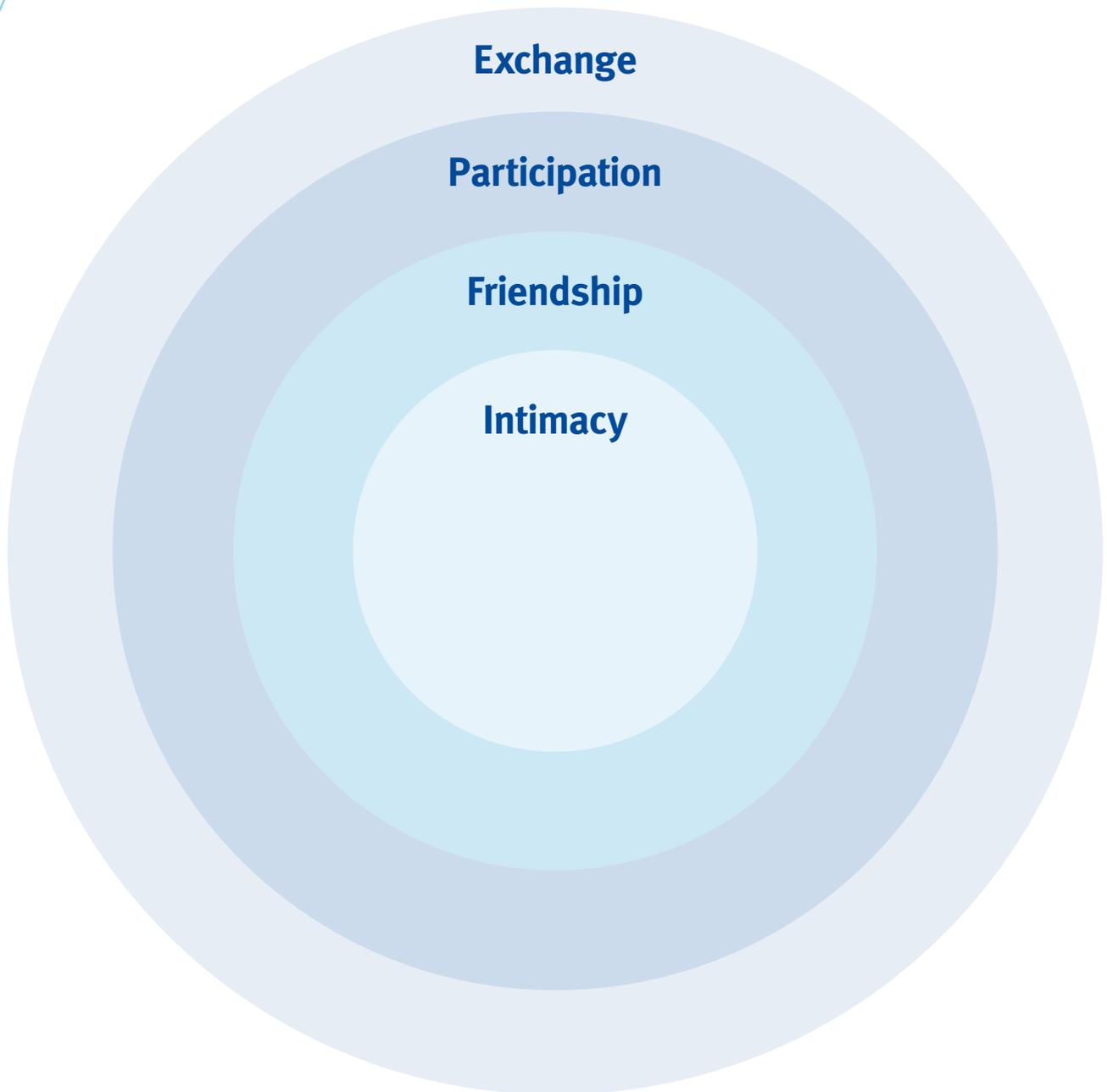
Circle of exchange

People you pay because they do work or provide a service for you: dentist, doctor, hairdresser, childcare, tradesmen.

Everyone might have the same number of people within the Circle of Intimacy. Those without disabilities will usually have a lot of people within the Circles of Friendship and Participation, and very few in the Circle of Exchange. However, those with disabilities, particularly someone who has complex support, will often have very different Circles. They are more likely to have most of their connections in the Exchange Circle, and very few in the Participation Circle. It is this imbalance which can be detrimental to a person's opportunities to develop friendships. Relationships are formed in the places we go. It is these which are most likely to grow, and for those people to move from our Circle of Participation into our Circle of Friendship.

Worksheet 3

The people in my life



Session 2

- Person Centred Planning
- Circles of Support
- Emergency Planning
- Siblings.



Aim of session

- To identify how family, friends and professionals can be useful allies in, person centred planning developing, circles of support and emergency planning.



Learning outcomes

- By the end of this session you will be able to,
- Support family carers to bring family, friends and professionals into circles of support, person centred planning and emergency planning
- Develop the skills required to use family, friends and professionals as part of a future plan



Person Centred Planning

- Life planning
- Helps the person with learning disabilities to live the way they want
- Person is at the centre of the plan
- Family carers and health care workers need to listen and not assume.

The plan will explain

- What is important to them now
- What is a good life
- What is a good day
- What makes a bad day
- What are their hopes and dreams for the future
- Who are the important people in their future.



Worksheet 2:1



Insert your photos

What is important to you now?

What is a good day?

What makes a bad day?

Who are the important people in your future?

What is a circle of support?



What is a circle of support?

- A group of people who have a commitment to a person to help them have a good life
- Some circles are informal and come together once or twice a year
- Others may meet regularly and contribute to developing a person centred plan/future plan.



Circle of support can

- Help to make things happen now
- Play an important role in the future when the family carer is no longer around
- Helps with planning of small or large changes
- Help with making new connections to people and places
- Provide friendship and a sense of belonging.





A Circle of Support

- Can provide continuity in persons life after the death of a family carer
- Can keep an eye on things and speak up for person with a learning disability.



Be aware that

- Circle members can come and go
- It will develop its own life and shape
- Some families use a paid facilitator to organise circle meetings eg through direct payments.



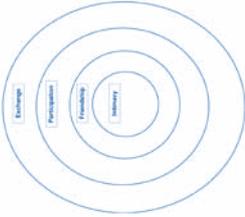
Who will be in a Circle?

- People who have a good relationship with the person:
- Family members/ siblings
 - Friends
 - Neighbours
 - Local community
 - People from places the person attends
 - People from the past
 - Relevant professionals.



Worksheet 3

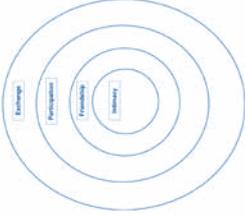
The people in my life

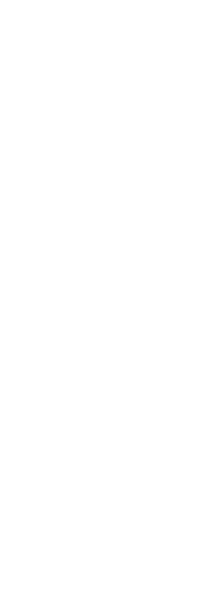




Worksheet 3

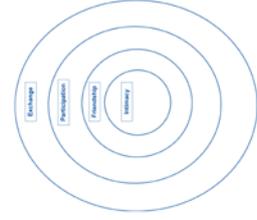
The people in my life





Where do people fit in your life?

The people in my life



Do a relationship map for yourself

Think about:-

- Who is most important in your life?
- Who are you close to and see often?
- Who do you know from places you go?
- What else do you do?
- Who do you have to pay?



Every Circle is unique

- The focus is what makes sense for the person and their family
- The aim is to ensure the person lives their life well
- It gives families reassurance.



Person Centred Planning Tools

- MAPS Making Action Plans
- PATH Planning Alternative Tomorrows with Hope
- ELP Essential Lifestyle Planning
- All tools will help to create and plan a person's life.



Emergency Planning

- To help support a person with learning disabilities when an emergency occurs
- To stop the emergency developing into a crisis situation.



Why is it useful?

- Reduces anxiety for family carer
- The person with learning disabilities will know who is looking after them, therefore reducing stress
- Without a plan decisions will be made by people who may not know the person well
- Compiling an emergency plan can help family carers start to think about a future plan.



Making a plan: A carer's guide

- Talk it over with your son/daughter, explain all
- Teach your son/daughter to use mobile,
- Contact all people on the team: store their mobile numbers etc.
- Know who has the spare keys
- Make sure someone knows about any house alarm(including the code number)
- Message in a bottle
- Information sheet.

Siblings

- Massive impact having a brother/sister with a learning disability
- Positive and negative thoughts
- Some family carers feel it is the duty of the siblings to look after their brother /sister with a learning disability.



Any questions?





Do you or
someone
you know
need **sup-**
port in
order to
achieve a
better **qual-**
ity of life?

If so **Vela Microboards** N.I. Ltd
may be able to help.

Vela Microboards N.I. Ltd is a regional voluntary organisation which assists in the establishment and support of small, individual, associations of close family members and friends, who come together to develop a support network with an individual person. (This association becomes the Vela Microboard). The Vela Microboard focuses on enhancing quality of life through the use of a person centred approach.

Introduction

In 1997 a group of dedicated people established a Management Committee and formed Vela Microboards Northern Ireland. In 2002 funding was obtained for a 2 year project from the Community Foundation for Northern Ireland. Vela Microboards N.I. Ltd is a regional voluntary organisation which assists in the establishment and support of small, individual, associations of close family members and friends, who

come together to develop a support network with an individual person. The first Microboards were developed in Canada in the early 1980's. They were set up in an effort to provide supports directly to an individual, supported by their family and friends. The Microboard enables the individual to avail of supports that can adapt rapidly to changes in a person's needs, interests, relationships and environments.

In addition to Canada and Northern Ireland, Microboards now exist in Australia and the United States of America.

Vela Microboards N.I Ltd

What is a Vela Microboard?

- A Vela Microboard is small group (micro) of committed family and friends who come together with a person to establish an association (board) that will address the person's needs in an empowering and individualised fashion.
- Person Centred Planning is central to the Microboard Concept
- It is the responsibility of the Microboard members to ensure that there is a clear focus on the identity, needs and express wishes of the person the Microboard is set up for.

Vela Microboards NI is committed to addressing the following:

- Social exclusion of marginalised people
- Uptake of Direct Payments
- Promotion of the Microboard concept

- Innovate and creative models of empowerment
- A community development approach to meeting individual need
- Capacity building for families, carers, and community

Our services include:

- Complete explanation of the Microboard concept and process
- Advice on membership and formation of Microboard
- Maximisation of Social Services Support
- Minimisation of red tape
- Transforming lives
- Exposure to best practice and increasing choices
- On going networking
- Continuing support to Microboard as required



CONTACT THE PROJECT WORKER

Susan Taylor, Project Worker, Vela Microboards N.I. Ltd, P.O. Box 250, Bangor, Co Down, BT20 9WW
t: 07834 352 180 e: info@velamicroboardsni.com w: www.velamicroboardsni.com

MISSION STATEMENT

Vela Microboards NI Ltd, will strive to effect change at policy, organisational and practice levels and, using person centred approaches, to enhance the lives of individuals by encouraging the promotion and creation of microboards throughout Northern Ireland.

This is an example of how a circle can work for a person with a learning disability

Jane's Circle of Support

Jane was 45 years old and living with her mother who is age 76. Her father died 12 years ago. It was only through the family carers meeting with her social worker that she heard about circles of support. With the help of her key worker and friends she arranged a circle meeting for Jane. Jane's brother, his wife, a neighbour and friend from the church attended the meeting. With the help of her mum Jane explained what she wanted the circle to do for her as she wanted to be more independent and be able to get out more without her mum. She knew that her mum did not enjoy going shopping or going to the cinema. She also wanted to be able to attend church and some of the midweek services.

The circle discussed what they could organise. The friend from church suggested that whenever she wanted to attend church the friend would take her. Also there was a young woman's group who had monthly meetings but also met up for lunch, bowling and keep fit once a week. Her sister in law suggested that she, with her friends would take her shopping weekly, therefore giving mum a rest and time to herself. To promote independence they proposed using direct payments money for Jane to attend simple cookery classes along with a circle member and then for mum to supervise her in the kitchen. Jane was very glad that she was getting help to lead her life the way that she wanted.

Future circle meetings included discussing future planning for Jane. She wanted to remain at home with mum but would look at sheltered accommodation for a placement in the future. This was all discussed with the key worker and details of mum and Jane's wishes were recorded.

All circle members exchanged mobile numbers.

Jane was happy; her mum was contented that friends would be looking out for Jane. The network of support was working.

Add your name here...

One-page profile

Insert your
photo here

What people like and admire about me

Add what people like and admire about you...

What's important to me

Describe what is important
to you...

How to support me

Describe the support you need...

Important things you should know about me:



How I communicate:

Hi I'm

Things you can do to help me:



Things I like:



Things I don't like:

Important things you should know about me:

- I have autism
- It takes me longer to understand things



How I communicate:

- Makaton
- Simple speech
- I listen to everything

Things I like:



Books DVDs films
Music Eating Chinese food
Cats Football

Hi I'm

Jack

(could add
photo)

Things you can do to help me:

- Help me to get dressed.
(I can't do buttons up)
- Help me to cook dinner,
(I can't cut my food up)
- Help me to use the bathroom for
shower and toilet (I don't like
baths)

Things I don't like:



Loud music
People shouting
Big dogs

In emergencies:

- There is a spare key at, Mrs Browns, she lives
- 2 doors down
- Tele; 123456789

Daily activities:

- I go to the Tower Day Centre every other day, a bus picks me up at 9am and returns at 4pm
- On Tuesday I work in the local hairdressers ('Hair to Go' tele, 585746321)
- I go to church at St Peters every Sunday at 11.30am

Who to contact:

- Brother David, mobile 78968852413 address, 5 Fast lane
- Sister Sarah, mobile 9685231247
- Key Worker, Mary Wallace mobile, 795135745
- Social Worker, Flo Green, mobile 753951789
- GP, Dr Wright, 04574123687

What I need:

- Tablets in kitchen cupboard above kettle
- Special drinks in fridge
- Pads for bed at night in drawer beside the bed

Things you can do to help me:

- Explain everything slowly to me
- Allow me to get my DVD player and CD player
- I need my mobile phone and charger
- I need my iPad

Hi I'm

Jack
(add a photo)

Jack does not like to be left alone; he will get very upset and does not like silence (that's why the TV is always on)
Keep reminding him what has happened but he needs constant reassurance that everything is ok
He likes to be kept busy

Session 3: Signposting Housing and Support Options

Aims:

- › To understand the housing and support options available for people with learning disabilities
- › To recognise how different housing and support options are funded and the legal dimensions involved with each
- › To identify if the person with learning disabilities has the capacity to rent/own their own home.

Learning Outcomes

By the end of this session staff will:

- › Know the different housing and support options available for people with learning disabilities
- › Be able to sign post family carers in the appropriate direction to the different housing/support providers in their local area
- › Understand the legal and financial implications behind the different housing options
- › Be able to support family carers to explore the different housing and support options have a knowledge of resources available

Introduction

Everyone wants a home of their own, their own space to decorate how they like and live how they want. It should reflect their own personality. Their house becomes a haven and sanctuary, somewhere to relax and 'chill out' and somewhere to invite friends and family, have laughter and fun. A home is a place that should provide continuity and security and ensure privacy and happiness. For most people that is what a home is like, so why should a home of a person with a learning disability be any different?

When a family carer is exploring housing and support (or personal care) options for their relative with learning disabilities they will feel very emotional. For their son or daughter this is a big step on the road to independence but it signals big changes for the family carer. Exploring the housing and support options will produce doubts

and fears of the ability of the family carer and wider family to let go. Research in Northern Ireland has clearly shown that older parents/siblings carers want their relative with learning disabilities to stay within their own home either with family support or professional support, or move into a home of a sibling. Residential care is a lesser preferred option (Taggart et al., 2012).

Family carers are afraid of change they will always worry about their loved one. Will they like it? Will they get good support/care? Will they blame me if they don't like it? Will they cope? What happens if the staff change or there are financial cutbacks? Change can be good when the family carers are aware of the housing and support options available to them. Having the appropriate knowledge and having the emotional and practical support from a well-informed professional will help family carers with this transition period.

The relationship between housing and support

Housing and support can be either provided separately by different organisations or offered together by the same organisation. Traditionally housing and support was provided by Health and Social Care Trusts in Northern Ireland. More recently a number of alternative providers such as Positive Futures, PRAXIS, APEX and Trinity Housing) have been offering people with learning disabilities different living and support arrangements.

Housing options

The majority of people with learning disabilities in Northern Ireland live with their family. Many family carers may have limited knowledge about the different housing options that are available, it is important therefore to explore these housing options as well as their advantages/disadvantages with the carers and the person with learning disabilities. The following is a list of potential housing options for a person with a learning disability, The right choice will depend upon the person's dreams/aspirations, level of need and what is available for them locally:

- › Supported living
- › Residential care
- › Nursing home accommodation
- › Adult placements (or shared lives)
- › Intentional community

The second list below outlines other alternative housing options. Some of these are suitable for people with learning disabilities who want to share, others for those who want to live alone. These work with various support/personal care arrangements. The support can be flexible depending on the persons needs and

can include anything from low level visiting support to intensive 24 hour care and support. These other housing options include:

- › Renting a flat/house on your own
- › Shared or outright ownership
- › Family investment
- › New Build
- › Specialist buy to let
- › Private sector leasing

Barriers to getting your choice of housing and support

Though research has shown that many older adults with learning disabilities may prefer to live with their family carers within their own home (McConkey, 2005), many younger people with learning disabilities who live with their family carers would like greater independence with the option of living independently or with friends in small houses. There are a number of barriers which can hinder family carers and people with learning disabilities getting their desired housing options:

- › **Resources:** Due to people with learning disabilities living longer there is a greater demand for housing and different support options. Health and Social Care Trusts do not have enough appropriate housing and support options. This can be due to reductions in housing budgets and can lead to difficulty in finding housing suitable for the person.
- › **Planning by local authorities:** A lack of planning by the local housing authorities can mean that there are not enough housing options available and that houses are not available in suitable locations. As a result immediately available options may not meet the needs of family carers and the person with learning disabilities.
- › **Planning by families:** A lack of planning by family carers can be due to denial: not wanting to let go: little information about future planning and staff not having the skills to sensitively approach these carers (Taggart et al., 2012). This can lead to a crisis situation which can result in an emergency placement/housing solution which may not be beneficial to the person with learning disabilities: such as a nursing home for the elderly or a hospital. It is a lack of practical information, advice and advocacy which results in family carers not planning for the future as they are not aware of their housing/support options available to them. Even if families do have plans in place there can be a lack of a joint approach between the families and local authorities. This means that families may have a plan in place but have not shared their plan with relevant authorities (key worker).

- 
- › **Complex Needs:** Some people with learning disabilities face greater barriers to accessing appropriate housing and support options. This can be due to the lack of available local services, staffing levels and resources. This can result in people with learning disabilities remaining on waiting lists for a long time or getting housed miles away from their home and family. This includes people with profound and multiple learning disabilities, those with severe challenging behaviour and/or mental health problems and people with complex physical health needs. The lack of suitable housing and intensive support packages results in the local Health and Social Care Trust placing people in inappropriate residential/nursing homes or hospitals.

Points to consider when starting off exploring the housing and support process

The family carer needs to explore the following:

- 
- › What type of preferred housing/supports would the family want for their relative with learning disabilities (i.e. stay within family home, what type of support is needed, move into the home of a sibling, move into supported living/residential care, etc)?
 - › What type of preferred housing/supports would the person with learning disabilities want?
 - › Does the person with learning disabilities have the capacity to understand these choices?
 - › What type of supports does the person with learning disability need?
 - › What accommodation would suit the person best (shared housing, own house, residential home)?
 - › The location of the accommodation; is it near their circle of support, current services they use (i.e. day centre, employment, education, recreational activities) and their local community

You can help family carers understand the nature of different options by arranging visits, showing them examples of housing options through leaflets/literature and DVDs (see the Resources section).

Remember selecting a housing option will take time to organise so it is beneficial to start early and visit different types of housing supports. Family carers can find it helpful to talk to other families who have experience of a relative with learning disabilities who has gone through this process of deciding future accommodation.

Arrange for the family carer to visit the housing options and if they request, go with them for support. Remember this is a big step for a family carer and they may not

hear all that is being said to them. Hence you may need to go over these options again exploring the benefits and disadvantages.

Points to note when looking at housing and support options

- › The atmosphere of the housing option may be shaped not by those who live there but by those who work there. In group settings an individual's needs and aspirations can become secondary to others
- › People living in individual housing options can become isolated and lonely
- › Not all housing options welcome the active involvement of family and friends
- › If the housing option has a high turnover of staff then this can lead to a loss of caring. This can have an immediate impact of the people living there
- › Sometimes authorities may ultimately decide where the family member lives and with whom

Guidelines 3: Exploring housing and support options

Name of carer:

Date of visit:

	Date/Comments
Read the information and resources available.	
Arrange to visit the carer and suggest the visit may be 1-2 hours long.	
Greet the carer and ask how everything is (observe if the carer is relaxed or stressed and if this looks a suitable time to introduce the subject).	
Discuss the ideas and wishes of the person with the disability. Where do they want to live, what sort of house/accommodation do they want and who would they like to live with. How do they think they will cope? What help do they think they will need? This will give you a picture of their wishes and dreams.	
Discuss the ideas and wishes of the family carer. What level of care do they think their family member will need? What type of accommodation would most suit their family member and where would they like the accommodation to be?	
Ask if the family carers would find it helpful to meet with other carers who have already planned their relative's accommodation successfully and are happy to share their ideas. (Your Team Leader may know of such families who they can put you in touch with).	
If you are future planning with a number of families then it may be beneficial to encourage them to meet and share their ideas and experiences.	
Leave resources (leaflets and phone numbers) of the Northern Ireland Housing Executive with the carer.	
Allow the carer time to think about the subject and discuss with other family members.	
Confirm a date and time for the next meeting.	
Record in the care plans your discussion, plan and date for your next visit.	

Resources

[www.nihe.gov.uk/disability tenant manual.pdf](http://www.nihe.gov.uk/disability%20tenant%20manual.pdf)

www.nihe.gov.uk/housing

www.mysafehome.info

www.housingandsupport.org.uk

www.housingandsupport.org

www.in-control.org.uk/site/INCO

www.ilf.org.uk/about

www.hoptions.demon.co.uk

www.arcuk.org.uk

www.doh.gov.uk

www.disabilityrightsuk.org

www.nidirect.gov.uk

NIHE Head Office
The Housing Centre
2 Adelaide Street
Belfast
BT2 6PB
www.nihe.gov.uk
03448920900

Sheltered Housing
Northern Ireland Federation of Housing Associations
38 Hill Street
Belfast
BT1 2LB
02890230446
www.nifha.org

References

'Living Alone or with others: Housing and Support for people with learning disabilities', by Nigel King. (Contact Mental Health Foundation Publications Department on 020 7535 7441

Bigby.C.(2000) Moving on without parents. London: Paul H. Brooks

Harker. M and King. N (2000) Leaving Home, Moving On: Housing Options for People with Learning Disabilities. London. The Mental Health Foundation.

Session 3: Creating a Home

Aims:

- › To identify what home means to each of us
- › To recognise the common themes and acknowledging the diversity of ideas of home

Why

Most of us aspire to what we think of as our “dream home”. To achieve this will depend on a number of factors, including financial resources, employment and responsibilities. We draw our inspiration from being in our friends’ houses, watching TV programmes, reading magazines and exploring the internet. This experience is not always the same for people with learning disabilities, who often have more limited exposure to the possibilities of what home could mean for them.

How

Use the template “My home is...” to identify your aspirations and the important elements which make a house a home for you. You can use this template with someone with learning disabilities and their family to promote discussion and to explore ideas of “home”. These questions will help to guide the conversation:

Where I will live

- › What kind of home would you like to live in? (house, flat, with a garden)
- › Where do you want to live? (town, country, near family and friends)
- › Why do you want to live there? (what’s important, thoughts, feelings)
- › What do you want to live close to? (a park, shops, cafes, bus route)

Who I will live with

- › Would you like to live by yourself or with other people?
- › Who would you like to help you live in your own home?(informal support, paid)
- › Would you like to have a pet?



What I do at home

- › How do you relax? (watch TV, listen to music, hobbies)
- › What household tasks are you comfortable doing? (cooking, dishes, laundry)
- › Do you like to have friends and family to visit?

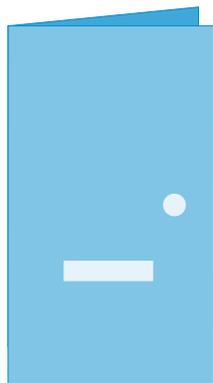
My favourite room

- › Where do you most enjoy spending your time?
- › What do you like best about this room?
- › How is the room decorated? (colours, furnishings, objects, pictures)

My home is...

Where I will live

Who I will live with



My home is....

What I do at home

My favourite room

Planning for the Future

Exploring housing and housing related support options for people with a learning disability

Northern Ireland Housing Executive



Applying for Social Housing

Presentation by:
Donna McStravick
Complex Needs Officer



Housing Executive

Applying for social housing

- How to apply – 2 pathways



Housing Executive





Housing Selection Scheme

- Created to be open & fair
- Give applicants a choice as to where they want to live – choose 1 or 2 areas of choice + participating landlords within those areas
- Anyone using the scheme will be
 - Assessed
 - Registered on Common Waiting List
 - Allocated a property according to the rules of the scheme



Housing Executive

How we Assess a Housing Application

- An applicant is assessed & awarded points according to their housing needs
- Points are awarded under 4 categories
 - Intimidation
 - Insecurity of tenure
 - House condition
 - Health/social well-being assessment



Housing Executive

Position on the waiting list is determined by the level of points awarded

Complex Needs Applicants

Some applicants' circumstances will be such that general needs accommodation alone will not be adequate for their needs i.e. applicants with *intense* care and / or support needs or "Complex Needs"



Housing Executive

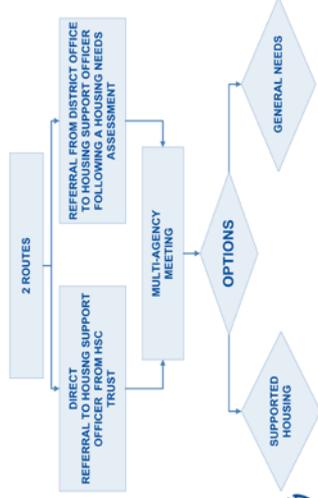
Complex Needs Triggers

- > Where the applicant is for e.g. frail elderly/learning disability/physical disability & requires intensive support
- > Where the applicant is involved with 2 or more Primary Care Teams within HSC Trusts e.g. Disability Team, Mental Health Team etc
- > The range & intensity of points scored on support/care/functional matrix
- > Where the applicant or household member has been admitted for respite care
- > Other details of the case – warranting further investigation into potential complex needs



Housing Executive

COMPLEX NEEDS - REFERRALS



Housing Executive

KEY NIHE PERSONNEL

- Housing officer
- Senior housing officer
- Housing support officer



Housing Executive

Next steps

- Timescales
- Allocation of suitable accommodation
 - General needs
 - Supported accommodation



Housing Executive

Session 4:

Making sound, financial and legal decisions

Aims:

- › To understand why it is important that family carers make a will
- › To provide an overview on how to plan for and protect the financial well-being of a family member with a learning disability
- › To provide information and resources on how to draft a will and plan an estate

Learning Outcomes:

By the end of this session staff will:

- › Understand why family carers put off making a will
- › Understand that it is very important for each family carer to have discussed with other family members that they have made a will
- › Have knowledge of the importance of different types of trusts (especially Discretionary Trusts)
- › Be able to signpost the family carer on how to find a suitable solicitor

Why make a will?

Without a Will you cannot be sure that your money and property (your estate) will be passed on according to your wishes. Not making a Will can cause family disputes, financial worry and unnecessary uncertainty for those closest to you when they least need it.

Good reasons to make a Will:

- › You can give clear instructions to provide for your spouse, partner and or other family and friends
- › You can choose who has legal authority to deal with your property after your death - your Executor

- › You can make special provisions for family or friends who may have particular health or other problems, and protect their financial wellbeing
- › You may be able to minimise Tax due on your death (Inheritance Tax)
- › You can prevent disputes amongst those who survive you.

What problems might arise if a will is not made?

- › Family disputes and unnecessary hurt at a difficult time
- › Some or all of your estate may go to someone you do not want to benefit. [according to the laws of Intestacy]
- › A partner with no automatic rights to inherit as your next of kin may be left without financial support or a home
- › Vulnerable children or adults may not benefit from the financial protection which you could otherwise plan for them. Inadvertently you may not provide for someone important to you
- › Some of your assets may be used to pay Tax unnecessarily
- › If you have remarried, children of an earlier marriage may not receive an inheritance.

NB. Marriage or entering into a civil partnership revokes a will. It is therefore it is important that as circumstances change the will is also changed

How do I prepare to make a will?

- › Find a solicitor with the necessary experience to prepare a Will. If you have special circumstances to consider such as planning for the future of a child with a disability or a vulnerable adult, check if the solicitor has experience in this area and can advise and draft Wills to take account such special circumstances. Not all solicitors will be suitably experienced. Ask the solicitor to provide a quote.
- › Draw up a list of your assets which are the things you own, and estimate their value. Often we are worth more on death than when we are alive, due to life policies, and debts being paid off by insurance on death. Assets include property, bank accounts, investments, insurances, shares, cars, boats and other valuable items.
- › List liabilities that may need to be paid on death such as Mortgages, loans and credit card accounts.

- › Decide to whom you wish to leave a gift or an inheritance, whether friends, family or charities, and list their names and addresses to be able to give the solicitor
- › Decide what you want to leave and to whom. You may choose to leave:
 - › A specific item such as jewellery
 - › A sum of money
 - › Property
 - › A share of your estate
 - › Part or the entire residue of the estate, once other gifts have been made
- › If you want special provisions to take account of a vulnerable relative or friend, it would be helpful to provide the solicitor with specific information about the following:
 - › Nature and degree of any disability
 - › Prognosis and likely life expectancy
 - › Present living arrangements for care and training
 - › Changes that might arise in the foreseeable future
 - › Present capital and income of the vulnerable person
 - › Any other likely source of financial provision

Can a will be challenged?

A Will may be challenged after a death if:

- › It did not comply with certain formalities
- › The person who made the will (the Testator) did not have the necessary mental capacity to understand the implications of the Will
- › The person who made the will was acting under the influence of another
- › Reasonable financial provision was not made for certain family members or dependents. A child with a learning disability for whom no provision is made under a parent's Will could make a claim against the parent's estate under the Inheritance (Provision for Family and Dependents) Northern Ireland Order 1979

What is a Trust?

A Trust can be created during one's lifetime or in a Will. If created in the Will it would be termed a "Will Trust".

A Trust is a legal arrangement which allows nominated people called "Trustees" to hold assets (the Trust Fund/Trust Property) on behalf of other parties (known as beneficiaries). The beneficiaries have the benefit of the Trust but do not own the assets of the Trust outright.

The Trustees do not own the assets but they have the power to manage and control the assets subject to the terms of the Trust. They must always act in the best interests of the beneficiaries. It is normal to have two or more Trustees.

Trusts have many uses and can be very helpful in financial planning. Children or incapacitated adults can be beneficiaries of Trusts when they would otherwise be unable to hold assets in their own name for any number of reasons which might include age, mental incapacity or financial vulnerability.

Types of Trust

There are different types of Trust to suit particular circumstances:

- › Life Interest Trusts are set up to benefit named persons during their lifetime
- › Disabled Person's Trust is a particular type of Trust which can be used for a person who falls under the definition of "disabled" as set out in legislation. This type of Trust can bring Tax benefits but be less flexible than a broad Discretionary Trust
- › Discretionary Trusts give Trustees discretion as to who should benefit from the Trust, and the extent to which they should benefit

A Discretionary Trust is generally acknowledged as being the most flexible form of Trust and particularly useful where a potential beneficiary of the Trust would lose State funding if he or she had a defined right to receive a specified sum or income.

When a Discretionary Trust is set up it is often helpful for the person setting up the Trust (the Donor) to write a **Letter of Wishes** to the Trustees expressing wishes as to how the Trust Fund might be applied, although this cannot bind the Trustees.

Who should be chosen as trustees

The importance is in the word "Trust". Trustees do not need particular qualifications. They can be personal or professional. A personal Trustee might be a trusted family member or friend and would not charge for services. A professional Trustee may be a solicitor an accountant or other institutional Trustee and would charge for their time.

As a Trust may last many years it is important to think of age when choosing Trustees. Trustees can retire, and normally a Trust will allow the appointment of new Trustees during the term of the Trust.

If the aim of a Trust is to protect the interests of a vulnerable person, it is helpful that at least one Trustee knows that person well. Trustees can be beneficiaries of a Trust but it is preferable that they are independent and at least one is not a beneficiary of the Trust.

Trustees must be active in managing the Trust assets for the best interest of the beneficiaries. They can engage financial advisors and other professionals to guide them, and pay for such services from the Trust assets. Beneficiaries can take legal action against Trustees who do not look after their best interests, and neglect their responsibilities as Trustees.

When does a Trust end?

A Trust should be drafted to be wound up once the purpose of the Trust has been served, for example on the death of the vulnerable person it was intended to assist, or when children reach an age at which they can manage finances independently.

Mental Capacity

Mental capacity (Capacity) is a key concept in considering financial planning and ownership. To make legally binding decisions one must be capable of understanding the implications of such decisions.

Children are generally not considered to be legally capable until they reach adulthood. Adults are presumed to be legally capable until it is shown that they are not. “Capacity” does not have a universal definition and the assessment of capacity is something society struggles with. The capacity needed to:

- › Choose what to wear each day
- › To marry
- › To make a Will

differs in each case. In the context of finances and property, whether a person is capable is ultimately a legal decision often informed by medical opinion.

An adult may lose capacity due to a catastrophic accident or illness. Some reach adulthood without ever acquiring capacity, for example individuals with significant learning disabilities.

Under the Mental Health (Northern Ireland) Order 1986, if the High Court is satisfied that a person is incapable by reason of mental disorder of managing and administering his property and affairs, the person is deemed a Patient, and the court can intervene. The court has power to appoint a Controller (often a family member) to manage the patient’s property and finances. This would be arranged

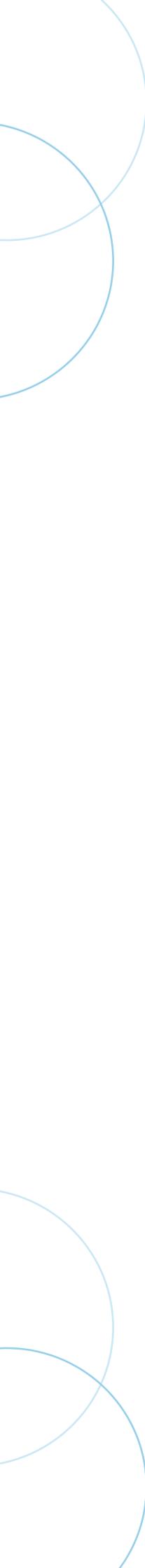


through the Office of Care and Protection. Mental disorder means mental illness, mental handicap and any other disorder or disability of the mind. Often (but not always) a Patient would not have adequate capacity to make a Will. In such circumstances it is possible for a Statutory Will to be made on the Patient's behalf through the Court if the Court so authorises.

The law in Northern Ireland dealing with mental capacity is currently under review and new legislation is expected within the next couple of years which will dramatically change the law in this area. It is expected that in the future a person's capacity will be assessed relevant to each important decision they wish to take (i.e it will be defined on a decision specific basis) rather than the current broad categorisation.

Definitions

Administrator	The name given to a Personal Representative not appointed by a Will.
Affidavit	A declaration in writing made on Oath before someone who is authorised to take and administer Oaths.
Assets	Property, investments and belongings of the person who has died with together comprise their “estate”.
Beneficiary	A person (or persons) who benefit from a Will.
Bequest	A gift of a specific object or sum of money.
Chattels	Personal belongings for example: household goods, jewellery, cars, pictures. Not business assets, property or investments.
Controller	A person appointed through the Office of Care & Protection in the High Court of Justice with authority to manage the property and affairs of a Patient under the terms of the Mental Health Order (NI) Order 1986
Devise	A gift of a house or land.
Discretionary Trust	A Trust which identifies potential beneficiaries but gives the Trustees discretion to decide the amount of income to be paid to which beneficiary (ies) capital.
Enduring Power of Attorney	A legal document which authorises someone to act on behalf of another in respect of their financial and property affairs.
Estate	All the assets and property of a deceased person including property, investments, money, personal belongings, cars and jewellery
Executor	The name given to a Personal Representative if appointed by a Will.
Guardian	A person who would become responsible for children in the event of a parent’s death before the child reaches 18 years of age.



Inheritance Tax	A Tax which may be payable if a deceased person's estate exceeds a specified amount set by the Treasury. It takes into account gifts made within 7 years of death
Intestate	A person who dies without making a Will.
Issue	Your children and generations arising from them such as grandchildren.
Legacy	A gift of a specific object or a sum of money.
Letters of Administration	The document issued by the Probate Office of the High Court to an Administrator.
Life Interest	A gift that gives someone the right to use an asset, receive income or the right to occupy property, for the duration of their life.
Office of Care and Protection	The Office of the High Court dealing with the affairs of children or vulnerable adults.
Patient	A person deemed to be mentally incapable of managing his/her property and financial affairs as defined under the Mental Health(NI) Order 1986.
Personal Representative	A general term which covers both Administrators and Executors.
Probate	A document issued by a Court to the Executors named in a Will authorising the Executors to administer the estate
Residue	The part of an estate left after debts, specific bequests and legacies have been paid
Residuary Beneficiary	A person who shares in the residue of an estate.
Statutory Will	A Will executed with the authority of the High Court for someone lacking mental capacity.
Testator	A person who makes a Will.
Trustee	A person responsible for administering a Trust.
Will	A document which states what is to happen to a person's possessions after death.

Guideline 4: For the visit on financial guidance

Name of carer:

Date of visit:

	Date	Comments
Read all information and resources available.		
Arrange to visit the carer and suggest the visit may be 1-2 hours long.		
Introduce the topic of making a will, ask if the family carer has made a will or what has prevented them from doing so.		
Explain that you recommend that they get advice from a legal professional who specialises in this area of work in relation to people with learning disabilities.		
Introduce the following topics: <ul style="list-style-type: none"> • What do you want to achieve in your will • Choose a solicitor • Choose your executors • Choose your trustees • Choose guardians • Letter of wishes/intention 		
Allow the carer time to ask questions - this may be an emotional time for them.		
Allow the carer time to think about the subject and discuss with other family members.		
Leave resources (leaflets and phone numbers) of how to contact a solicitor.		
Confirm a date and time for the next meeting.		
Record in the care plan your discussion, plan and date for your next visit.		

References

Some websites which might assist in tracing suitably experienced solicitors are:-

- i) Mencap (<http://www.mencap.org.uk/northern-ireland>)
- ii) STEP (<http://www.step.org>)
- iii) Solicitors for the Elderly (<http://www.solicitorsfortheelderly.com>) Many members are specialists in relation to issues of mental capacity, and the preparation of Wills and financial planning for more challenging situations.

Session 5:

Direct Payments

Aims:

- › To understand how direct payments can help you in developing a future plan

Learning Outcomes:

By the end of this session staff will be able to:

- › Explain the benefits of direct payments to a family carer
- › Signpost or help a family carer towards accessing direct payments

The Direct Payment Scheme was introduced to allow family carers to define, choose and direct their own supports giving them increased control over the services most suitable for their son/daughter with a learning disability and also the family's requirement.

The money allocated can be utilised to pay for personal/support assistants, domiciliary care, day-care, transport, supported employment, home modification, respite care and therapies.

There is growing evidence to illustrate the success of the direct payment scheme for older family carers in the UK and USA (Stainton, 2002, Stainton and Boyce, 2004, Heller and Caldwell, 2005, Caldwell and Heller, 2007, Caldwell, 2008).

Ageing family carers reported the scheme to be very positive, giving them increased choice and empowerment, increased flexibility in scheduling services and a greater sense of trust of the personal assistants. In addition, these ageing family carers also indicated greater feelings of confidence and optimism, and decreased their anxieties about going out for social activities and out to work.

Older people with learning disabilities also experienced greater community integration and leisure satisfaction.

References

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Heller, T. and Caldwell, J. (2005) Impact of a consumer-directed family support programme on reduced out-of-home institutional placement. *Journal of Policy and Practice in Intellectual Disabilities*, 2 (1), 63-65.

Caldwell, J. and Heller, T. (2007) Longitudinal outcomes of a consumer directed programme supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities*, 45 (3) 161 – 173.

Caldwell, J. (2008) Health and Access to Health Care of Female Family Caregivers of Adults With Developmental Disabilities *Journal of Disability Policy Studies* 19(2), 68-7

CILNI

Centre for Independent Living NI

Helen Anderson & Martha McWilliams
Independent Living Adviser

CILNI

is run by and for disabled people and provides the following services:

- Information
- Advice
- Training
- Advocacy
- Peer Support
- Payroll Service

Philosophy of Independent Living

That all human life is of **value**

That anyone, whatever their impairment, is capable of exerting **choices**

That disabled people have the right to exert **control** over their lives

That disabled people have the right to **participate** fully in society



What are Direct Payments?

Cash payments instead of Trust services

Arrange your own support

How can Direct Payments be used?

Employing own staff

Contracting with a service provider

Engaging self-employed workers

Mix of Direct Payments and Trust Services

Direct Payments

Not treated as taxable income

Will not affect Social Security benefits

Direct Payments

Choice, control, flexibility

Dignity, self-esteem, confidence

Family, friends, relationships

Work, study, getting out and about

Value for money

Improved quality of life due to personalized services



Direct Payments

Non-institutional

Support rather than care

Person-centred

Current move towards "Self Directed Support "
and "Personalisation"

Gov policy (Transforming Your Care & Who Cares?)



Responsibilities around Direct Payments and Self Directed Support

Looking after the money

Finding staff & being a good employer

Finding the right service & agreeing terms

Legal responsibilities (insurance, Ts&Cs, HMRC, etc)

Back-up arrangements (Trusts still have a legal duty to provide care if arrangements break down



Looking after the Money - support from CILNI

How much money? (DP rate x no of hours)

How much needs to be kept back (HMRC, holiday cover, etc)?

How much can be paid to worker or service provider?

Sending in returns to Trust every 3 months (Bank statements, record of how money was spent and receipts in using service provider)

CILNI Payroll Service

Net wages are calculated

Payslips are sent to client's home

Payments for HMRC calculated

HMRC Paying-In slips sent to client's home

Monthly tax returns sent to HMRC on-line

Cost - £25 per pay run

Finding Staff & Services

People you know

Asking around

Advertising

Advice & support CILNI

Important to find the right staff/service provider

Support from CILNI for PA Employers

- CILNI can help with all aspects –
- Advising on safe recruitment procedures
 - Finding staff
 - Compliance with employment law
 - How to manage staff
 - Advice on how to be a good employer

Recruitment of staff

- Job Description
- Person Specification
- Advertising
- Interviewing
- Terms & Conditions

Job Description for workers

- Main duties of the post
- Who the employee is responsible to
- Hours of work
- Rate per hour



Person Specification

Personal qualities of employee

Skills necessary to do the job

Additional skills

Capacity to be flexible

Advertising

Word of mouth

Job Centre (including job centre on-line)

Gumtree and other free classified ads sites

Schools/Day Centres

Community Groups

Local college

Interviewing

Ask appropriate questions

Ask applicants the same questions

Request and take up references

Access NI check (if needed)

Support from CILNI in contracting with a service provider

- Identifying a suitable service
- What to clarify and agree on before engaging a service provider



How do people access Direct Payments?

Service users or their representatives should speak to their Social Worker, Care Manager, CPN or Learning Disability Nurse.

Those who lack capacity to consent to Direct Payments being all or part of their social care will receive support from their Trust to have an Authorized Person appointed through the OCP. This currently has financial implications for families, but can be appealed.



A few quotes.....

"It's the best thing that has ever happened to me"

"It really has been a life changing experience"

"Since starting Direct Payments, I feel in control"

"Direct Payments is much easier than I thought"





Q & A



Direct Payments Help Deliver Independence by offering:

- Flexibility
- Choice
- Control
- Empowerment
- Support
- Reduced Stress
- Respite



If you think you would benefit from having more control over the assistance you get, then Direct Payments may be worth considering. Simply contact your local CILNI, your Social Worker, Care Manager or Learning Disability Nurse by phone, email or visit the CILNI website.

Company No: NI 058552 Charity No: XR 62285

CILNI received funding from the Health and Social Care Board and the Northern, Southern, and Western Health and Social Care Trusts.

Contact Us

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T: 028 8224 8926

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www.cilni.org

Self-Directed Support



centre for
independent
living
n.i.

Direct Payments for People with a Learning Disability



CILNI promoting Choice, Control & Independence for disabled people

www.cilni.org

Self-Directed Support and Direct Payments

If you or someone you support has a learning disability and requires support from Social Services, you may wish to consider transferring all or part of the services you receive over to Direct Payments. This is where you receive money from Social Services to pay directly for the support you require. Self directing your support using Direct Payments can offer you greater choice, control and flexibility. For many people this has offered opportunities to develop greater independence, confidence and has reduced stress.

Mary, who is a young woman and has a learning disability, lives alone and gets support from her Personal Assistant to enable her to go shopping, socialise and encourage her to keep her home tidy and clean.

Many people use Direct Payments to directly employ one or more Personal Assistants (PA). A PA can provide support with personal care and assistance with activities both inside and outside of the home.

Direct Payments enable people with a learning disability to live active, independent lives in the community. Once set up, they allow the person who needs the support or their representative the opportunity to manage the money to employ PA or to purchase a service from an agency.

What can the Personal Assistant assist with?

One of the main benefits around using Direct Payments is the opportunity to employ someone as a Personal Assistant (PA) to provide assistance to meet your needs in a way and at a time that suits best. As every person who needs support is unique, the support provided by the PA is tailored to meet their individual needs. The role of the PA is to fit in with the chosen personal / family lifestyle and provide appropriate support as and when required.

Joe and Sarah, parents to four very young children, one of whom has a learning disability, are now able to take all of their children out at the same time with the help of a PA they pay using Direct Payments.

This tailored assistance can create opportunities for those family members and friends who normally provide support to have a rest while knowing that their family member or friend is also enjoying their break.



How do I get Direct Payments?

If you do not currently receive support from Social Services but feel that you need some help, contact your local CILNI (Centre for Independent Living NI) office. An Independent Living Adviser will be able to help you assess what support you might need and refer you on to Social Services.

If the assessment highlights needs that Social Services have a duty to meet, CILNI can then provide you with help in recruiting a PA if you don't already have someone in mind. CILNI also provides support with setting up the paperwork and guidance on how to be a good employer.

You can even choose to have a combination of Direct Payments and services provided directly by Social Services.

Direct Payments WILL NOT affect your household income or benefits. Also, if you are not happy, you can stop them at any time and return to getting a service provided directly by Social Services.

Adam, who has a learning disability has reduced the number of days he attends his local Day Centre and instead, his mum employs a PA to help him enjoy his favourite activities.

