

Growing older together: supporting people through transitions

“... A key question is how to constructively improve the lifestyle and minimise the restrictions imposed by growing old...”

There are points of transition in the lives of older people with learning disabilities, and their families which offer services the challenge of providing support that either enhances or diminishes the qualitative nature of their experience.”

Matt Janicki

The aim of this section is to:

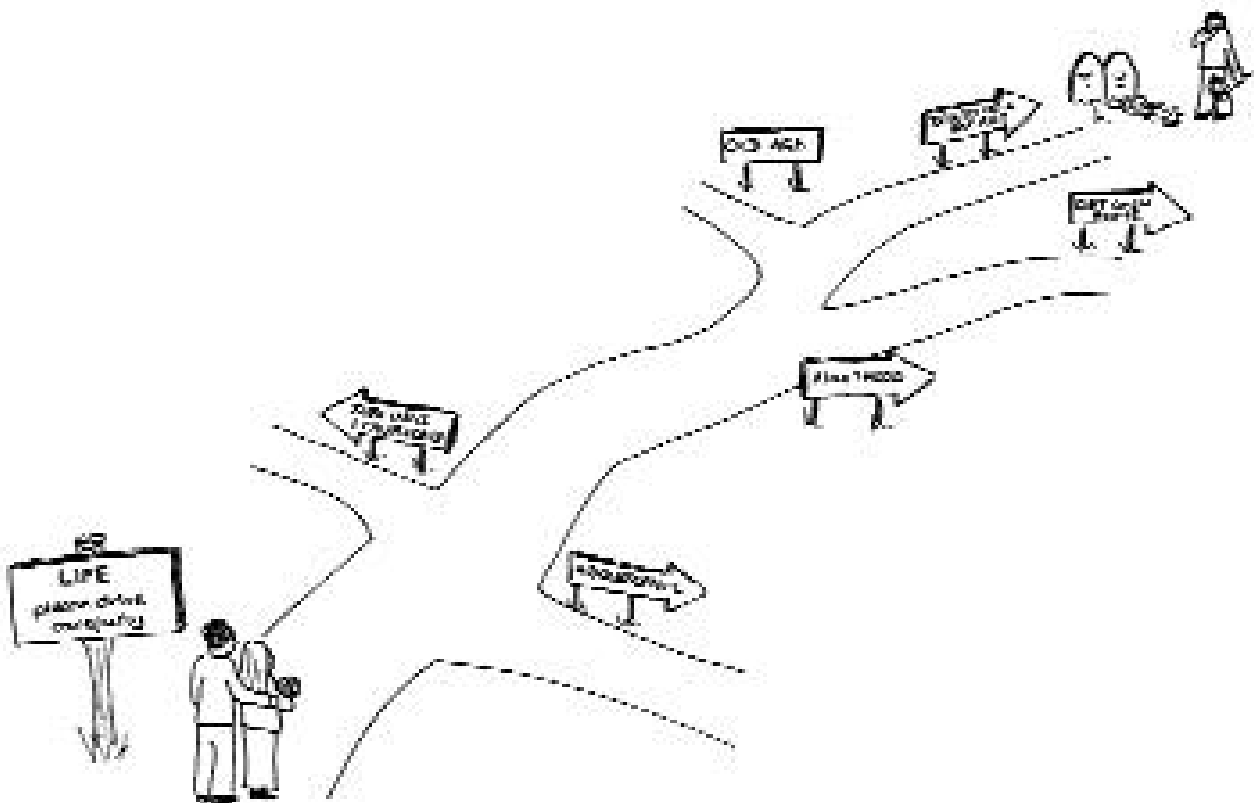
- Identify the major transitions facing older family carer's and their adult children with learning disabilities.
- Identify ways to support families in transition.

Some writers talk about the experience of having a disabled child as akin to the experience of having a bereavement. The idea is that the parents have to go through a grieving process before they can adjust to their new circumstances and accept their child's disability. Other writers suggest that their experience is more complex than a simple 'adjustment' at the time when the child is born. It has been suggested that there are a number of milestones in a child's life that will emotionally challenge their parents.

As we have mentioned before, paid carers and staff come and go but families are in for the duration! Family carers have to cope and adjust to a number of different challenges or transitions in their 'caring career'.

These include:

- Being told their child has a learning disability.
- When their child reaches school age – making choices and decisions about what sort of educational opportunities would be right for their child.
- Adolescence and the move from children's to adult services.
- If their son or daughter has the opportunity to leave home – in adulthood.
- Growing older together.
- When health and illness (or bereavement) makes it difficult and then impossible to care any longer.



As older family carers and their adult children move through life, there are some important things to remember.

These families:

- Have been together for a long time.
- People's identity is often caught up in being the "mother of..." "daughter of...", and there is a great deal of mutual dependence.
- Parents have been 'caring' for a very long time.
- Parents become vulnerable – both in terms of their own health, and the shrinking of their support networks. This can be both frustrating and frightening.
- Relationships change and develop as the years progress.
- Their middle-aged son or daughter with learning disabilities can often express concern about their ageing parents and many naturally begin to take on a more caring role.
- Parents have been worrying for years about what will happen when they can no longer care, that time is getting closer.
- Middle aged people with learning disabilities face transitions from parental care and might have seen friends and peers go through sudden changes - the future is uncertain and a bit frightening.

Coping with transitions and change

It is a truism, but nothing does remain the same. Change is an integral part of life even though change can be disconcerting and unsettling. A dictionary definition describes transition as the **"passage of time, from one place, state, act or set of circumstances to another."**

On a personal note:

This is a picture of my son Michael when he was about 8 months old.



This is Michael aged 29 with one of his support workers.

Michael is still my son and I am still his mother, but the nature of our relationship has changed. Out of respect I now have to ask Michael's permission to use these photographs. It will continue to change and evolve as we both get older. It has gone through, and will go through again, a number of transitions!

Think about your own relationships with your parents. How have these changed over the years? Has it always been easy to negotiate this change?

Are you a parent yourself? In what ways do you think your relationship with your children change, as they get older? Were there any points when it became particularly difficult?

As a family we had always planned that Michael would leave home when he became an adult. As a family we actively encouraged Michael to do so when he was 23 years old. But despite all our planning, it was still a huge wrench and took quite a long time to adjust to. You might know something is right in your head, but not necessarily feel it in your heart! The most important thing about going through any transition – **it takes time!**

Transitional situations have an emotional dimension and can incur feelings of loss, even if the transition from one situation to another is a positive one, actively pursued by an individual. Take the example of having a first baby. This might have been a long held ambition and brings great joy, but the loss of sleep and freedom can be felt keenly.

A family can have been planning for their son or daughter with learning disabilities to leave home for many years and see it as a very positive move. But it can still feel very strange and bring up powerful and even painful emotions.

Going through a transition in your life can cause people to feel a sense of discontinuity, uncertainty, and even anxiety and loss. Adapting to transitional changes is a process that can take time and is often fraught with different emotions. Some writers have likened it to the grieving process with distinct stages, including anger, depression and disbelief, before adaptation and acceptance.

Exercise 6

A transition in your own life!

Think about a transition in your own life, maybe changing school or moving house, getting married or having children, leaving your country of origin and coming to live in a different culture.

What can you remember about this transition? Was it you who decided to make the change in your life or was it imposed on you as the result of someone else's action or decision?

Can you describe:

- **How you felt?**
- **How you coped with the changes?**
- **Where you turned to get support?**
- **Did it take you a long time to adjust?**

Transitional changes can, and often do, generate very emotional responses.

Transitions facing families growing older together

There are three major transitions facing older family carers and their adult children with learning disabilities.

These include;

- **Growing older together –** Recognising mutual interdependence.
- **Planning for the future –** For a time when parents are too old to continue to care.
- **The post parental care phase –** When the person with learning disabilities no longer lives with their parents.

What are the practical implications of these transitions?

Services have to acknowledge that as people grow older together the importance of taking a dual or family focus is vital. Support has to be targeted to both the carer and the person with learning disabilities.

This has implications for the way that different services work together, particularly older people's services and learning disability services. The clarity about who is the cared for and who is the carer becomes less clear, as potentially both are eligible for community care services in their own right. Both also potentially become eligible for support services as a carer.

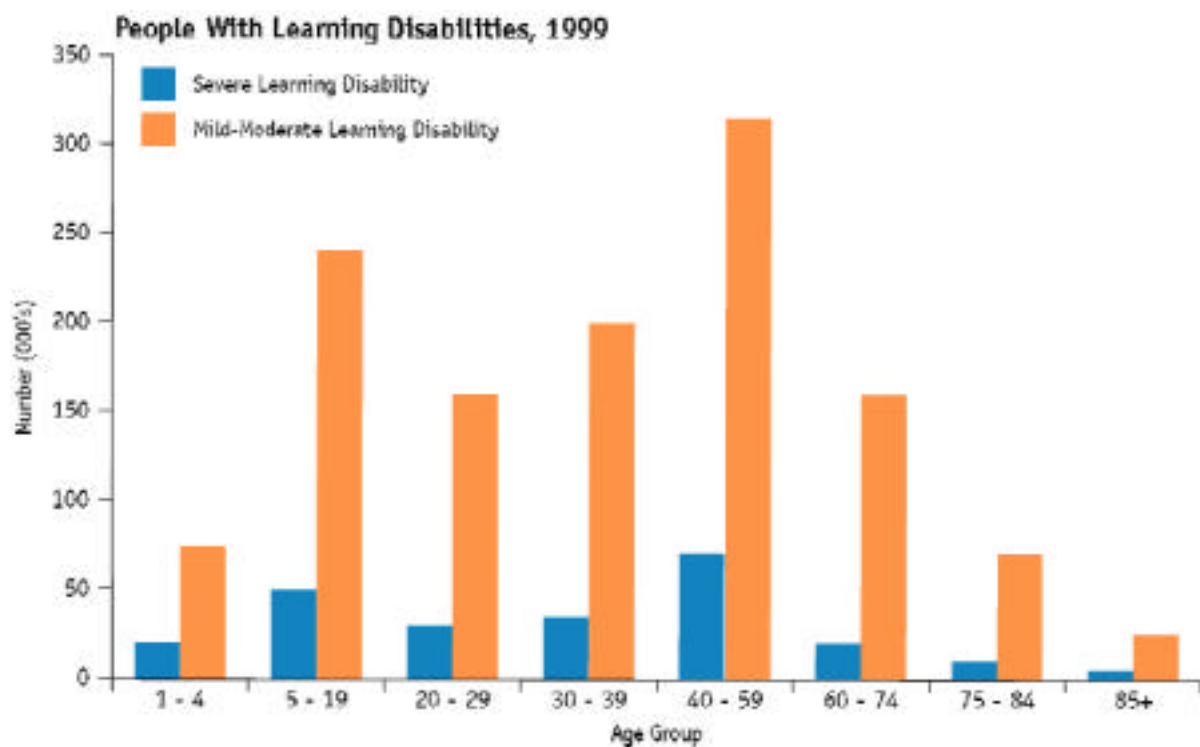
Both might need support from independent advocacy or carer's services to ensure that all perspectives or points of view are taken into account.

1 Growing older together



“My son and I are a team. I just need a little help to keep us a team.”

If we look at the demographic profile of the population of people with learning disabilities across all ages, there is a bulge of people in the middle age ranges sometimes referred to as the ‘baby boom’ generation. The majority of these men and women with learning disabilities live in the community supported by family carers who are in their 70’s, 80’s and even 90’s. (*Family Matters*, DoH. 2000)



Source: *Valuing People: A New Strategy for Learning Disability for the 21st Century*, DoH (2001)

In general, the UK is an ageing society. People are living longer and life expectancy is increasing for us all. If we look at the population of people with learning disabilities there is a marked increase in people's longevity and many more people are living into old age.

There are two implications of these trends.

- One is the significant numbers of people with learning disabilities who are currently being supported by older family carers.
- The second is that more and more people with learning disabilities are likely to outlive their parents and spend upwards of 20 years in what one writer has called, 'the post parental care phase'. (*Moving On Without Parents*, Bigby C. 2000)

Developing an understanding of the ageing process is therefore an important part of supporting older family carers and their middle-aged sons and daughters. There are three dimensions to the ageing process;

- Physical,
- Emotional,
- Social.

Remember, that for each person the ageing process will be different.

But some physical changes associated with ageing will be common and include some of the following:

- Muscle loss.
- Increase in body fat.
- Changes in vision.
- Changes in hearing.
- Hormonal changes.
- Reduced immunity.
- Slowing down of the gastrointestinal system.
- Changes in the body's sensitivity to temperature.
- Shrinking gums.
- Bladder changes.
- Reduced heart muscle strength.
- Changing sleep patterns.
- Changes to the feet.

All things people will need to adjust to.

As people age their vulnerability to certain illnesses like cancer, dementia, heart disease, arthritis and strokes increases. (For a fuller discussion of the health related risks of ageing, see the National Service Framework for Older People 2001 – DoH.) It is recommended that all people over 75 have an annual health check with their GP. Older carers might need to be supported to do this.

Alongside these physical changes, many older people become more socially isolated as their networks of friends and family gets smaller. What Alec Guinness, the actor, referred to in his autobiography, as his 'ever diminishing circle of friends', as a result of so many people dying. For many people, retirement from work can be a difficult time and can reinforce isolation if alternative activities and networks do not take its place.

A combination of these social changes and the increased vulnerability to ill health mean that old age can be a very challenging and difficult time for some people. Just at a time when their support networks are likely to be getting smaller. No wonder Janicki highlighted the important role services should play in constructively improving lifestyles and minimising the restrictions imposed by growing old.

Implications of growing older together

It needs to be recognised that for some people with learning disabilities, (in particular people with Downs Syndrome in middle age) there is a vulnerability to specific health problems. This means that at the same time that their parents become vulnerable to certain health problems, potentially so do they. For example, it is estimated that people over the age of 85 have a 1 in 4 chance of developing dementia. Research shows that for people with Downs Syndrome, that age related risk is bought forward by 40 years.

Another implication of growing older together, as we have already discussed, is the fact that as carers become frailer, their son or daughter with learning disabilities can play an increasing role in the support of their parents. *"He will finish up caring for me"*, one mother told researchers from Bristol. (*'He Will Finish Up Caring For Me'*, Robinson v. & Williams C. 2001.)

Another implication is that the lifestyle of the person with a learning disability can become unduly restricted by the fact that they are living with a person older than themselves, and are forced into a prematurely more restricted lifestyle. Some carers have said to the social services that they worry about people "getting old before their time".

Transport & 'Getting Old'

Steven's Story

Steven (42) has learning disabilities and lives with his parents who are both in their eighties. Until 4 years ago, Steven's dad had regularly transported his son to different activities and services but as his health deteriorated all these activities had ceased. Steven now had no contact with other people and places outside his immediate family home. It was not until a routine visit by a worker some years later that it emerged that both Steven and his parents were frustrated by his lack of activity – his parents in particular were worried that Steven had no opportunity to socialise with people his own age and was getting 'old before his time'. It emerged that Steven's carers had no idea that alternative transport could be provided or where to find that information. A programme of new activities was arranged with transport provided. Steven is enjoying his services and his parents are enjoying the break from caring.

There are therefore a range of issues that need to be addressed in terms of developing practical support to families as they grow older together.

Practical support for families growing older together includes:

1. Contact with services.
2. Emergency provision.
3. Support to keep on caring.
4. Health – access services and support.
5. Information.

Contact with services

There are two dimensions to this:

Firstly,

- The big challenge for services is to try and make contact with those families who are currently not in contact with learning disability services.
- This serves the dual purpose of supporting the carers as they get older, but also ensures the person with learning disabilities gets the support they need to make successful transition from parental care when the time is right.

Secondly,

- Even those families where the person with learning disabilities is currently using and known to services, the key word remains proactive outreach.
- For all the reasons we have outlined below, many older families are reluctant to seek help. Services need to make the running.
- This has not traditionally happened, because we have a care management system where the triggers for assessment are usually sparked off by a crisis. To avert a crisis families need contact with services *before* small problems and difficulties become too great.
- Services need to invest in these families. In areas where there is a dedicated worker for family carers of people with learning disabilities, much has been achieved. These carers workers can both champion the cause of older carers locally, and advocate on behalf of individual families. They become the link between families and services.

The Carers Worker employed by the Shropshire Rural Council gained the trust of older family carers in the county and was able, not only to develop a supportive network of families, but also make contact with families previously not in touch with services. The Carers Worker from the Sheffield Mencap, Sharing Caring project, has also gained the trust of individual families and developed a range of support services that represent a beacon of good practice in the UK.

Practical ideas that these workers developed include:

- **Dissemination of information for family carers via - newsletters, videos, audio cassettes.**
- **Support groups.**
- **Establishing lunch clubs.**
- **Developing training videos – to develop staff’s and carers’ awareness.**
- **Lifebooks and video projects to capture people with learning disabilities’ stories, and give carers choice to share experience and knowledge.**
- **Preparing family carers to get the best from their carer’s assessment.**

Day services and respite facilities can play a key role in keeping contact with families.

One of the targets of the White Paper is that every person with learning disabilities receiving services will have a **named person as a key point of contact by 2002**. This person could play a vital role keeping in touch with family carers.

It has also been suggested that keeping in touch with family carers could be an integral part of the annual review process.

The family carer could be invited in, visited or telephoned, for an informal chat to ensure they are getting all the support that they might need to keep on caring.

This should not detract from the planning and reviewing process for the person with learning disabilities, but rather act as an essential part of a comprehensive person centred plan. The family carer's health will impact on the person with the learning disability.

Yearly reviews will not be enough on their own to 'keep in touch' with family carers and to maintain an awareness of any difficulties bubbling away under the surface of family life. Staff need to be able to pick up on changes and respond quickly.

Other ways for day services to keep in touch with families are;

- To run support or information groups.
- Provide newsletters.
- Introduce 'drop in surgeries' so older family carers come for a chat.
- Telephone calls.
- Communication books – so home and day services can keep one another in touch with important things that are happening.
- Arrange meetings that are at times convenient to families.

The more contact there is, the less likelihood of a crisis taking everyone by surprise. This is;

- Better for the person with learning disabilities.
- Better for family carers.
- Better for services.

2 Coping with emergency situations

Older family carers are usually particularly worried about what will happen to their son or daughter if they suddenly need to go into hospital or have an accident or die. This is the ultimate worry. So practical ideas for coping with emergency situations and crises are important and valued by families and staff alike. Plans need to be in place for any person with a learning disability living with an older carer.

We have to plan for the worst and hope for the best. Making sure that every one knows what to do and who to turn to in an emergency is a very important way of reassuring older families.

Exercise 7 **Ask your self this question**

What would happen to the people with learning disabilities that you support if they or their carer was suddenly taken ill or had an accident?

What plans are in place to help support them in such an emergency situation?

Would you know who to contact?

How regularly do you review and update this information?

Examples of things that have been found to help.

- Life storybooks have been developed by the Sharing Caring project in Sheffield to ensure that vital information about the person with the learning disability is not lost. The books include a detachable contact page which is kept at a local authority hostel that is accessible 24 hours a day. This gives basic information about the person, including whether they have a lifebook and where it is kept. On several occasions social workers have been able to ascertain vital information about the person, which ensures appropriate support in a time of crisis where a parent has had to go into hospital. This is particularly important when the person with learning disabilities has limited verbal communication.

John's Story

When John's mum had an accident and was taken into hospital, the social worker checked whether John had a lifebook before she visited, because she had no up-to-date information about him. When she visited, John was distressed about mum, scared he would be moved away from his home and reluctant to talk to a stranger about what would happen next. The social worker was able to ask him whether she could look at his lifebook and remind him where it was kept. She used it to prompt him to answer questions and complete her assessment. As a result of the information in the lifebook, the social worker arranged home support daily, which enabled John to stay at home until his mum left hospital 2 weeks later.

- In Bradford a special emergency card has been developed and distributed by www.bradford.com Care Alliance. Family carers are encouraged to carry the card in their handbags and wallets, so if they are in an accident or suddenly taken ill – the card can be found. This then alerts people to:
 - a) To the fact that a person with learning disabilities is at home or day services.
 - b) Any important contact and who to link up with over the care of the person.

In Bradford they have also produced a card for family carers, which spells out who to contact in an emergency – with key telephone numbers.

- In Shropshire a **grab sheet** has been developed which is a double sided A4 sheet of paper and provides key information about the person with learning disabilities, including not only health details, but how they communicate, key

contacts for emergency use in residential and day services. Older carers feel reassured after a couple of incidents in day services where accidents happened and people ended up in hospital being supported by staff who didn't really know them.

- City Wide Alarms – In Sheffield, the City Wide Alarms service has worked with the Sharing Caring project to alter the way it collects information for emergencies. City Wide Alarms respond 24 hours a day, 365 days a year to emergencies once the alarm has been raised by the subscriber pressing the pendant or pull a cord. If someone signing up for the alarm is caring for someone with learning disabilities at home, then this triggers an additional questionnaire about the individual. Then, if there is an emergency at the home, it is instantly seen on screen that a person with learning disabilities is living at that address, also enabling the right services and support to be contracted. In Sheffield City Wide Alarms now offers free initial connection to older carers of people with learning disabilities, referred to by the Sharing Caring project.

3 Support to keep on caring

- Good assessment.
- Practical help.
- Emotional support.
- Breaks.
- Changing health needs.
- When the carer becomes the cared for – supporting people with learning disabilities who provide care for their parents.
- Keeping in contact.

“Just because we are coping doesn't mean we don't need help!”

‘It's hard because when you get to a certain age, it hits you that when you were younger and you caught something or got ill then you could shake it off. I get worried because I'm not as physically well as I was and I can't do as much looking after as I used to. This makes it hard on my husband.’

Services need to develop their 'older carer' awareness and provide **flexible** support, which can accommodate changing needs, in a **proactive** way and allow people to stay together for as long as they want and are able.

Services need to:

- Provide good accessible information about available support services.
- Assess people's needs (as carers, as older people, and as a person with learning disabilities in a caring role within the family).
- Develop flexible support plans.
- Review their effectiveness.
- Respond to changing needs.

Good assessment is vital

People need to be assessed as both family carers and as older people and as people with learning disabilities and as carers.

Carers Assessment & Relationships

It is a huge step forward for people to ask for help. It is some people's first contact with services, so it needs to be got right.

- **Asking the right questions is key.** It is important to be clear about what sort of support people provide for one another. Don't expect the carer to know what's out there in terms of help and support.
- It is important to understand how the carer and cared for interlink. In their routines and daily rhythms. You need to ascertain which parts of the days are particularly stressful for them and target support.
- It is easy to misunderstand the amount of caring the person with learning disabilities is providing their parents. The questionnaire devised by the Older Carers Support Scheme in Sheffield (see resource section), visiting scheme revealed much greater levels of dependence on the person with learning disabilities by their parent than had previously been recognised or appreciated.
- **If the right assessment isn't made the support package could be inappropriate.**

Mrs B's Story

Mrs B (71) cared for her husband who had been disabled through an accident and her son (32) who is autistic. Mrs B was finding it increasingly difficult to cope, particularly with her son whose behaviour was often verbally and physically abusive towards her. A social worker had been assigned to support the family to find alternative accommodation for her son, but the application for funding was turned down. The social worker contacted an independent carers' organisation for support and advice. The carers' worker made several visits to Mrs B who disclosed details of the abuse, saying she was finding it difficult to manage. In discussions with the social worker, the carers' worker discovered that no carer's assessment had been completed and submitted alongside the application so there was no indication of the level of stress the carer was under. The carer's worker supported the social worker to complete a carers' assessment and the funding was immediately awarded. Now that he has moved into alternative accommodation, mother and son have re-established a more positive relationship and see each other at least once a week.

Practical help

Sometimes small things can really make a difference.

- Help to keep up the garden of a bereaved wife.
- Help with heavy tasks such as shopping, hoovering or ironing.
- Many of the services available to older people locally could make a difference – like house maintenance schemes.
- Befriending schemes that give the person with learning disabilities an opportunity to get out and about, it also gives the carer a break.
- Transport features prominently as an area that inhibits people maintaining their leisure activities and reinforces social isolation.

Help with transport can really help maintain people's sense of independence and quality of life. For these reason it is a vital area in which services should invest.

Emotional support

Having someone who is in regular contact (like the visitors from the Sheffield scheme or the carer support worker) can be hugely reassuring for families.

Support to overcome the potential social isolation that many older people face can be countered by providing support groups, lunch clubs, coffee mornings and day trips. Often the person with learning disabilities may come too. It's important to remember

as lots of people with learning disabilities living with older carers don't often get the chance for a break and enjoy being out together. Don't assume they will always want a break from each other.

For information on setting up a support group, see Andrew Holden's GOLD project in the resource section. Remember, group work won't suit everyone and many older family carers might not want group activities. The opportunity for one to one support must be provided.

Breaks for parents, breaks for their adult son and daughters with learning disabilities

The importance of providing breaks has long been recognised for all family carers. This can be an extremely important element in a support package for older family carers and the adult sons and daughters. The approach to breaks for this group must be flexible. Breaks can mean:

- A change of scene – day trips or a little holiday – perhaps together if that is what they prefer.
- A couple of hours "off" for the older carer and a new leisure opportunity for the person with learning disabilities.

"It makes me so happy to know she's having fun".

"We just wanted someone to take him for a walk since my legs have packed in! He always loved our afternoon walks".

- Providing an opportunity to develop a model of "shared care" between family and services can help make the transition of the person with learning disabilities to new living arrangements easier.

Finally, it is vital that any support plans that are put in place are regularly monitored and reviewed. You need to develop relationships based on trust. Keep asking the questions, is everything okay? **Keep demonstrating your concern.**

4 Changing health needs

- The health care needs of the older carer are often a neglected area.
- The research *'In Their Own Right'* (Robinson V. & Williams C. 1999.) found that family carers of people with learning disabilities had not been well served by the Carers Recognition and Services Act (see section on Carers) and many of them were not accessing statutory assessments. The carer's assessments that were actually undertaken often missed out the health of the carer, even though many of them were suffering from chronic and disabling conditions.
- Make sure family carers have access to health information and the annual 75+ health check with their GP. Be alert to a sudden deterioration in health. Supporting people to get to the doctors is a priority, as is supporting them to comply with recommended treatment. *A single older carer was told by her GP that she needed an operation and would then need three months to fully recuperate afterwards. She put off all further GP appointments for 6 months until she finally told a carer's worker the situation. A social worker became involved who gradually helped her son to access respite so that once the operation happened, the time in respite was easier for him and has helped his carer to cope.*
- Supporting people to remain healthy is one of the most important ways of ensuring families can continue to care for one another.

Also, many older carers may need more help supporting people with learning disabilities to health appointments, eg one older carer whose health was failing was unable to support her son to go to their GP for blood sugar tests for his diabetes. This only came to light following concerns about her son's weight loss from day service staff. After liaising with the GP practice and explaining the situation, the practice nurse visited the son at home for his checks.

The Bradford Mencap project recommends that a model/proforma letter is given to carers and they are encouraged to approach their GP so it can be marked on their records that they are a carer. GP's also have a crucial role in identifying carers and making sure they know about their right to a carer's assessment.

Growing older together – people with learning disabilities taking on a caring role

Although parents of people with learning disabilities usually see themselves as 'perpetual parents' in relation to their adult children, the reality is that these same 'children' often offer vital supports to their parents in later life. The relationship between 'carer' and 'cared for' can begin to blur as parents find themselves becoming older and developing mobility, sensory impairments or other chronic disabling health conditions. Their adult children can become their legs and eyes, literally, in some cases.

This can often go unnoticed by staff in support services, or even fail to be fully appreciated by the parents. The support does not necessarily always develop in relation to physical needs either. Parents can become very emotionally dependent on their offspring for company and providing a sense of purpose in their lives. People who have been living together and sharing a life for over half a century are clearly going to be close and in many ways mutually dependent.

This questionnaire developed by the OCSS has helped identify much higher incidences of mutual interdependency and carers' responsibility than previously recognised.

Do you have any problems/help with activities such as:-

	<u>problems</u>	<u>help</u>	<u>from whom</u>
shopping	<input type="checkbox"/>	<input type="checkbox"/>
cleaning	<input type="checkbox"/>	<input type="checkbox"/>
gardening	<input type="checkbox"/>	<input type="checkbox"/>
getting out of the house	<input type="checkbox"/>	<input type="checkbox"/>
meeting people	<input type="checkbox"/>	<input type="checkbox"/>
hospital appointments	<input type="checkbox"/>	<input type="checkbox"/>
cleaning windows	<input type="checkbox"/>	<input type="checkbox"/>
bathing dependents	<input type="checkbox"/>	<input type="checkbox"/>
bathing oneself	<input type="checkbox"/>	<input type="checkbox"/>
getting up/down stairs	<input type="checkbox"/>	<input type="checkbox"/>
washing clothes	<input type="checkbox"/>	<input type="checkbox"/>
filling forms	<input type="checkbox"/>	<input type="checkbox"/>
other problems coping with your caring situation	<input type="checkbox"/>	<input type="checkbox"/>

Does the person you care for regularly help you?

shopping	<input type="checkbox"/>	cooking	<input type="checkbox"/>	gardening	<input type="checkbox"/>	other, specify
housework	<input type="checkbox"/>	medication	<input type="checkbox"/>	paying rent	<input type="checkbox"/>	
getting around	<input type="checkbox"/>	companionship	<input type="checkbox"/>	personal care	<input type="checkbox"/>	
collecting benefits	<input type="checkbox"/>						

Do you provide regular care/support for anyone else who does not have a learning disability?

yes no

if yes please specify

.....

On average how often do you manage to go out each week?

	<u>comments</u>
Most days	<input type="checkbox"/>
2/3 times a week	<input type="checkbox"/>
once a week	<input type="checkbox"/>
less than once a week	<input type="checkbox"/>

Where do you usually go?

shopping	<input type="checkbox"/>	post office/bank	<input type="checkbox"/>	cinema	<input type="checkbox"/>	other, specify
paying bills	<input type="checkbox"/>	visiting family	<input type="checkbox"/>	social club	<input type="checkbox"/>	
social outing (with dependent(s))	<input type="checkbox"/>	social outing (by self or with friends)	<input type="checkbox"/>	bingo	<input type="checkbox"/>	

Ref: Sheffield Visitors Scheme – Questionnaire

To date not many services have developed ways of supporting people with learning disabilities who have grown into a caring relationship with their parents, targeting support for the person with learning disabilities as 'carer'. In the North East, the North Tyneside Carers Centre (see resource section) has begun to run courses for people with learning disabilities who are in a caring role. They have included practical sessions to deal with stress, how to relax and what to do in emergency situations.



Supporting people with learning disabilities in their caring roles needs to be developed by services as one of the consequences of growing older together, including a recognition that whilst, not every person will be caring for their parents, many more will be caring about them. Obvious concerns are worrying about ill health, frailty and even death.

The importance of Lifebooks in the lives of people with learning disabilities

The process of planning is like constructing a bridge between now and the future, a useful tool in this process can be the development of Lifebooks of the son or daughter with a learning disability.

These books fulfil many roles.

- They can be great fun to do for the person with the learning disability. The focus of attention is on them and building a picture of their story and them as a person. Their special relationships, likes and dislikes, modes of communication, aspirations for the future.
- Putting together a Lifebook is a great way of involving family and friends in thinking about the person with the learning disability. By thinking about their past and present it is possible to engage people in thinking about the future and how it might be different.
- They ensure that vital information about the person with learning disabilities is not lost and can provide the staff who are supporting them, both now and in the future, with valuable insights into the person themselves.

In terms of developing person centred planning, lifestory work is the foundation on which you have to build. Every person with a learning disability should have his or her story recorded – as a book or a video – the format is less important than the fact of doing it.

5 Support to plan for the future

Things that need to be in place to support families with the planning process

Getting the right support now

“It is very difficult to support families to plan for the future when they are not being supported to cope in the present.”

**Older Asian Family Carers worker,
SCP, Sheffield**

Families cannot plan for the for the future if they have no experience of receiving support.

For example, the work with Older Asian Family Carers at the Sharing Caring (see resource section) project found that of all the families they had contact with only one family had any regular and ongoing support from services. Before the project worker could start to address the issues of planning for the future, she had to concentrate on getting basic support into the families before they could have any confidence in discussing the future.

Shameen’s Story

I found myself caring at the young age of nine. I had a brother aged eleven, and a sister aged six years old, both my brother and sister had learning disabilities and cerebral palsy. We had to feed them, bathe them, dress them, toilet them and they were unable to walk. Both had mental and physical disabilities. I also had a sister aged 4, but we did not realise that she had special needs until she was at the age of eight. I was taking time off school to take my mum to the Baby Clinic, Hospitals, Dentists and Opticians as my mum could not speak English and my dad was at work, so I had to go with my mum. My younger sister had to go to special clinics to see different doctors and I always went with my mum. When someone in the family was ill, I had to take them to the doctors. I had to go to the parent evenings at schools, dentist appointments, collect milk from the clinic, go shopping with my mum, as she could not read the prices. My brother and younger sister had to have

lots of operations to help them walk and I had to translate all the information from the doctors. When they were in hospital I had to stay with them because my mum was at home looking after the family.

My family had no help from the social services, they did not know what respite care was or home help. They did not know what the social services were or how to contact them. My mum, dad and me just carried on helping and supporting each other all alone.

In 1985 my mum was taken ill, she had to stay in hospital for four months. Both her kidney's had failed and she had to use a kidney dialysis machine. I had to look after the family, my dad, my five brothers and sisters and visit my mum in hospital. My mum decided to do her dialysis at home, she hated being in hospital and was worried about the children. My mum came home and had to do her dialysis four times a day and had to take lots of different tablets. I had to check her blood pressure, temperature and give her tablets every day four time a day because my mum couldn't read English. Every week I was taking my mum to the hospital for check ups. Our family was going through a very difficult time and help from social services would have made a great difference.

A social worker came to visit us and I asked for help. She saw my mum walk very slowly to the toilet and just because she could walk a few yards she said we could not have any help. The social worker who visited us did not have a clue what we were going through. My mum could not cook, clean or do any household work, in fact she needed help for herself in bathing and dressing. She always felt tired, cold and weak and we had to do everything for her and yet we got NO help from the social services.

After a few years my mum had a kidney transplant which was successful. She did not have to do the dialysis which she had hated. The family helped and supported my mum. In 1997 my father made a complaint to the social services and the manager came to visit the family, he saw that we were having a lot of problems and gave us two social workers. They helped us to get home help, someone to come in the morning to get the children ready to go to the day centre, and a carer in the evenings to give them a wash and get them ready for bed. The social worker kept in touch. My dad found a leaflet from the Sharing Caring project at a clinic offering support and help. He got in touch with the project and thanks to them we get some respite care at the weekends to give my parents a break.

I am sure that there are other families in Sheffield and other parts of England who have experienced and have gone through very difficult times without any support and help from the social services. We needed help years ago but we never got it. My brother is now 36 years old, and my sister is 25 years old and live at home. My other sister is now 31 years of age. As the years went by she got worse and is now in a nursing home. She needs 24 hour care, 7 days a

week, 365 days a year. I believe if we had help she could have got better and we could have supported her at home instead of her being in a nursing home. My mum passed away 11 months ago, we struggled for so long and we got help at the very end, but we needed help at the beginning. There was a big strain on the family because we had no one to turn to for help. But when we did ask for help we never got it. Since 1997 we have been receiving help from social services but before 1997 we had been looking after 3 children with learning disabilities and my mum who had kidney failure/transplant and needed someone to look after her, all by ourselves.

I worry a lot about the future. There are lots of services available out there but most of the Asian families are unaware of these services and how to get them. There are families who do not have anyone who can read, write or speak English, which makes it really difficult for them to apply for these services never mind getting them.

Exercise 8

The burden of care fell heavily on Shameen's shoulders from a young age. Can you list the sort of help and support services could have provided. How would services in your area reach out to families with such high levels of need?

Would you be able to help the families you know access support?

While this is particularly pertinent for families from minority ethnic and cultural groups, who tend to have a higher level of unmet needs than the majority community, the general principle holds true for all families.

Research has shown that the majority of older family carers are happy to continue caring, and many express higher levels of satisfaction than carers from younger age groups. But the worry about 'what will happen in the future' is never very far away from peoples minds.

What will happen when I'm gone?

"I worry about the future every day. What will happen to Jill when I'm gone?"

Many older family carers are anxious to start thinking about the planning process now, in preparation for the time they can no longer care, but are simply unsure where to start with services. Some families are further down the planning process than others.

Families need information about what could or might be possible and an understanding of how the system works. Most of all they need time to process the information and reflect on a range of options and consider what suits both them and their son or daughter best.

Staff should never forget that parents are having to deal with painful issues like their own mortality and the potential vulnerability of their son or daughter with learning disabilities after they have died. Too often they feel pressured into making a decision.

The planning process is not helped by the fact that staff and parents often have contradictory views of each other's attitude to planning for the future.

Staff often say:

- Families don't want to know.
- We cannot get them to plan.
- We make plans and then they go back on them.
- Parents are overprotective and smothering the son or daughter – holding them back.

Families often say:

- They are terrified about what will happen to their son and daughter in the future.
- They are worried by stories of abuse.
- It's impossible to get social services to sit down and plan.
- It's impossible to get a straight answer out of the housing department.
- They have expectations – or not – that siblings will care.
- To do anything different (i.e. leave people in their own home) takes a lot of energy.

6 How can we build a bridge across this divide?

Planning for the future

The myth in services that the majority of older family carers do not plan for the future is simply incorrect. It is clear from the work of Christine Bigby and others, that

families *do* make plans for the future, but they often don't find a way of linking these plans to the formal planning systems of services. They often remain as a set of informal arrangements. But they tend not to be comprehensive, as is discussed below.

Research by Gordon Grant (*'Views And Experiences Of Users And Carers'*, University of Sheffield, 1999.) has shown that whilst families do make plans they are quite fluid, and change over time. This reflects changing circumstances and alerts us to the fact that plans need to have some sort of built in flexibility as people's needs do change, along with their circumstances. We have already discussed how middle aged people with learning disabilities potentially face upwards of twenty years in the post parental care phase as older people in their own right. Needs change as you get older, but we cannot necessarily predict in which way!

It is therefore less important to have a prescriptive plan for the future, than developing a comprehensive plan that builds in the capacity to be flexible as people's needs change. The role of services is to assist families to develop a comprehensive approach to the planning process and find ways of linking the informal planning process to the more formal planning arrangements of services.

Planning for the future is one of the keys to supporting older family carers and their adult children with learning disabilities. This is perhaps the most important transition these families will make.

It has been recognised that there are two functions to planning for the future:

- Planning the smooth transition from parental care.
- Ensuring the long term well being of the person with learning disabilities and optimising their quality of life.

Developing a comprehensive approach to planning:

Different dimensions of the planning process include:

- Financial – wills and trusts.
- Housing – where people will live and how they will be supported.
- Key person succession planning – ensuring there is someone to speak up and advocate for the person with a learning disability.

Financial

If families want to make financial provision for their learning disabled son or daughter they are advised to make a Will and consider establishing a Discretionary Trust. Mencap offer a very good information service and have published a number of booklets. They also have a list of solicitors who have experience in this area (contact through Mencap). Families are always advised to seek a lawyer's advice, particularly in relation to setting up a Trust. There are different sorts of Trusts and careful consideration has to be given to which one best suits their family circumstances.

Families need to be aware of the potential impact on the entitlement of the person with learning disabilities to benefits if they inherit a substantial sum of money. Consideration also needs to be given as to who will support the person with a learning disability to manage their money. One avenue for protecting people with learning disabilities money has been the Court of Protection, though it has been described as being a costly and bureaucratic service. The Lord Chancellor's office is currently reviewing the whole question of capacity, protection and the Court of Protection.

It is also recommended that people with learning disabilities themselves be supported to make a Will.

Housing and residential care

Where people live and how they are supported is often the major focus for attention when it comes to thinking about planning for the future. *'Valuing People'* (DoH 2001) has emphasised the importance of thinking about future residential accommodation for people living with older carers and is making some funding available through the Learning Disability Development Fund (DoH 2001).

This is often the area that families find most worrying and confusing, because people do not know what range of options are available. Neither are families aware of how services process things and make priorities about placements. Families need information. Families need to be aware that there may be choices! This can be provided in a number of ways:

- Written information is available about all the different options – including how you enable a person to stay in their own home if they want to.
- Local services 'showcase' a range of provision.

- Housing providers make a video of what is on offer and how to access it.
- Planning workshops are organised for families to discuss the future – for both carers and people with learning disabilities, not forgetting siblings.
- Families are offered the chance to discuss options available.
- Staff are informed and knowledgeable – so they can offer constructive advice and guidance to individual families.

Parents need to be informed about the difference between residential homes and supported living. How placements are funded, monitored and reviewed. They need to be made aware that it is possible to make a range of different arrangements where the person with a learning disability remains within their own home. The organisation *Housing Options* has done lots of work in this area. They suggest that there are a number of different options that families can pursue which allow the person with a learning disability to live in the family home in the post parental care phase. These include where the family homes has been:

- inherited directly or put in trust,
- gifted to a social landlord, charity or similar body,
- sold or leased to a social landlord, (i.e. A housing association, charity or similar body),
- passed on by a relative through the tenancy with the intention of allowing continued occupation.

For more information see the resource section.

7 Families need to know there are choices

Jane's experience

Getting Jane sorted for the future was one of the most pressing concerns for her parents as they reached their 70's. They looked at a number of local services and did not really feel very comfortable with any of them. Jane was very well established in the local community and as a family they felt that it might be better for her to stay in the family home and for mum and dad to move out into smaller accommodation.

A Discretionary Trust was set up by their solicitor with Jane as the chief beneficiary. Her two brothers and an ex-teacher became the trustees. A

local Housing Association with a good reputation for supporting tenants with special needs became involved. The Trustees then leased the house to the Housing Association for 21 years. The Housing Association was then able to get a grant to do essential alterations to the house. Social services agreed to pay for the support Jane needed.

Now two other young women with learning disabilities share the house with Jane. They are supported by a dedicated project worker. Getting the right level of support and getting agreement on funding has not always been easy but a good working relationship between the families, trustee's, Housing Association and social services has meant that Jane has successfully made the transition from parental care and remained in her own home.

"We left Riley Crescent... this departure was the hardest step we had taken to help Ruth to be independent".

"The fact that we could not achieve absolute security for Ruth caused enormous worry."

"When Mum and Dad moved out I was excited and I wanted to get my freedom... I felt nervous without Mum and Dad, but I am okay."

Key person succession planning – ensuring that there is someone to speak up and advocate for the person with a learning disability

Housing and residential plans need to be as flexible as possible to accommodate the people's changing needs as they get older. Planning for the future can never be a one-off process with the 'the plan' written down and then filed away until it is needed. This plan might help ensure a smooth transition from parental care to another environment, but it cannot accommodate the changing needs of the person with learning disabilities as they grow older. Research indicates that older people with learning disabilities are extremely vulnerable to unplanned moves and inappropriate placements.

Key Person Succession Planning

The implications for the planning process is a need for families to identify not only future residential and support options, but to identify a person or persons who will be there in the future for the person with learning disabilities, as an advocate and a friend, a person who will ensure that as the person's needs change, services respond appropriately. Most often they are siblings, or other relatives, (usually women).

This is what Christine Bigby, in her book *'Moving On Without Parents,'* calls for **"key person succession planning."** For many parents this is the thing that concerns them most is who will care when they die.

Who'll look out for her when I'm gone? Who'll keep an eye on what is happening in her life and sort things out when things go wrong?

Bigby's recognition of what families were doing in terms of key person succession planning links with the movement in this country establishing networks of caring and supportive relationships for people with a learning disability. The key is the fact that a person, or persons need to have a long-term commitment to the person with learning disabilities to be a friend and advocate. It is about recognising the importance of ensuring that people with a learning disability are linked in to their families and communities and not isolated and ghettoised in services.

In terms of services being involved in the planning process it means extending discussion wider than just the parents and ensuring siblings, in particular, are an integral part of the planning process. Services should be supporting families to plan and not attempting to take over the process.

Some older parents find it difficult to discuss their concerns for the future with other family members. They either 'don't want to burden them' or make assumptions that they either will 'take over' or 'won't be involved at all' . The need to involve other family members in the discussions between parents and families is therefore crucial.

When planning for the future, families may need help to recognise that the current parental role can be split. It might be that siblings feel ill-equipped or not motivated to 'care' for their brother or sister on a daily basis – but are more than happy to take on the role of 'caring about' the person in the sense of being the key person in succession planning.

Mr and Mrs S's Story

Mr and Mrs S (79 & 77) lived at home with their daughter Barbara (38). Mrs S's health had deteriorated considerably and Mr S was effectively caring for his wife and daughter, despite not being in robust health himself. A worker from a carers organisation visited on a regular basis and the topic on the family's mind was 'what will happen in the future for Barbara?' Having explored a range of accommodation with the worker, the family decided that Barbara would stay on in the house when they died in accordance with Barbara's wishes. Mr & Mrs S did not discuss this with their other adult children as they did not want them to feel 'burdened' with caring. When Mrs S's health took a turn for the worse, Mr S was finding it difficult to cope but insisted he could carry on. At this stage, their daughter-in-law became involved. With support from the carers' worker and social worker, the daughter-in-law found out about respite options for Barbara and insisted that she would help oversee her care in the future – wherever she was. Until then, her husband had not wanted his wife to feel she had to take on any caring responsibilities. Over the next few months, Barbara tried a number of different respite settings and began spending more time with her brother and her family. Once Mr and Mrs S could see that their son's family would be involved in the future, they became much more open to Barbara being supported to move elsewhere on a long-term basis. In time, a place in supported accommodation was found close to her parents. With the particular support of their daughter-in-law, Barbara made a smooth transition and is now very happy and settled. Barbara's confidence and skills have blossomed and she is supported to visit her parents on a regular basis. Mr and Mrs S are extremely happy with the way things have turned out and recognise that the turning point was when their daughter-in-law and son became involved and demonstrated their commitment to support and speak up for Barbara in the long-term. This has given them the peace of mind they longed for – that someone will 'care' when they are no longer around.

So, if services are to support a comprehensive planning process they need to:

- **Provide information in a range of formats including family workshops to highlight a range of different options.**
- **Encourage families to make financial and legal arrangements.**
- **Explore a range of residential options – including staying in own home.**
- **Facilitate family network discussions.**
- **Allow families time and support to work through decisions.**

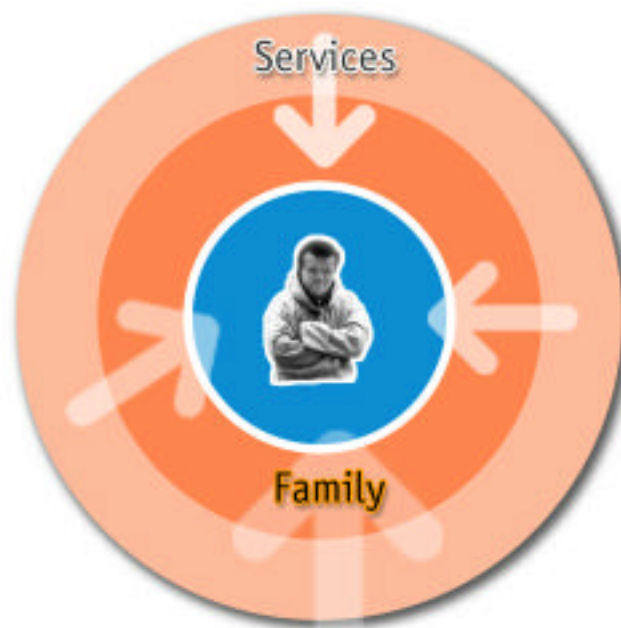
Services can play an invaluable role in helping families decide what is best for their individual circumstances. Services are not only in a position to provide information about what is available, but also support people to make decisions.

At a recent day on Direct Payments, people with learning disabilities and some family members came together to hear more about the scheme and what it could mean for them. The workshop ran small group sessions for people to explore what they wanted in the future. At one workshop a man with learning disabilities in his early forties talked about how much he wanted to leave home and get a place of his own. Simultaneously his parents, both in their late 70's were discussing how much they would like their son to leave home because they were 'quite tired nowadays', but they said he had absolutely refused. Workers running the day picked this up in their debriefing session and were able to facilitate a family meeting where the issue was discussed and an agreement reached that the son could and would move into his own accommodation.

8 Moving on – the post-parental care stage

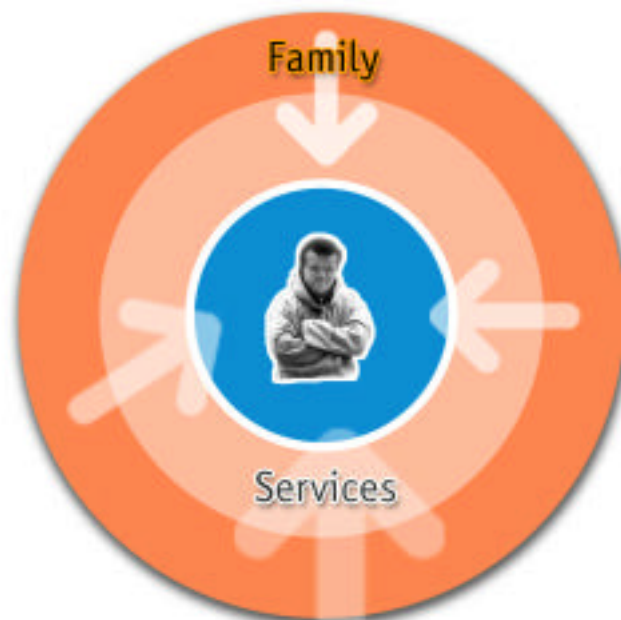
"It's the hardest thing I've ever done. I felt so guilty when she went to live in the home. But what could I do? I was getting on myself."

Sheffield carer



We have to constantly remind ourselves: when people with learning disabilities live at home with their parents, then services have to work through the family. If you can't engage the family you might not get to the person with the learning disability.

On the other hand, when the person with a learning disability leaves home and is supported by services, then the family, if they want to stay involved, often have to work hard to build relationships with staff in services.



This can be very hard for older family carers who have been caring for their son or daughter for decades – sometimes longer than the support workers they come into contact with have been alive! Staff need to be sensitive to some of the feelings this can incur for the older carer, and work hard to minimise the trauma involved in this significant transition in the caring relationship.

Older family carers might be experiencing a range of emotions:

- Difficulties in ‘making transitions’ – and seem overly controlling to staff.
- Finding it really difficult to relinquish the control they have had over aspects of their son’s and daughter’s lives.
- Feeling guilty for ‘putting the person in care’.
- ‘Worrying they can’t cope anymore’.
- Worrying about whether they have held their son or daughter back.
- Relief.
- Critical of staff because they are doing things differently.
- Surprised the person is doing more than they used to at home - or less!!
- Experiencing a loss of their identity – *“I’ve been his mother for 55 years. He is my whole life!”*
- Feel like they’ve lost their purpose in life, (and might succumb to illness or a chronic disabling condition once that purpose is removed).

Staff in services need to be aware of the possibility of older family carers feeling some or even all of these emotions. Staff in services cannot stop people having the feelings, but you might be able to do things that make them easier to manage by developing a sensitive approach.

Things that might make a difference:

- **Preparation:** the planned transition allows time to prepare the carer and the person with learning disabilities. Change can be introduced on an incremental basis, slowly, if necessary, starting with visits, perhaps an overnight stay, a week’s trial, before a full-scale transfer of care.
- **Share information:** staff in services need to explain how they work, what they do (and, perhaps, don’t do) and some of the ideas that underpin their approach to working with people. Services need to listen to what families have to say and take any concerns seriously. There has to be a sharing of perspectives. A **Lifebook** can be a very useful way of doing this, bringing people together by focussing on the person with the learning disability.

- **Families need to be encouraged to visit and remain involved.** When people leave home, they are not leaving the family. Placing someone in a service miles away from their family home and community networks should be avoided. If it really cannot be avoided, ensure practical measures are in place to make visits for older family carers happen, eg, arrange transport.

Remember to involve all the family. Services need to acknowledge the role of eg Circles of Support and/or key people and find ways of working in partnership with them. This can be quite challenging to staff as people outside the service may be scrutinising or even critical of the support they provide.

Finally:

- Staff need to recognise the emotional dimension of the transition for both the person with the learning disability and their older family carer, and exhibit understanding as people adjust to the different set of circumstances they find themselves in.

Exercise 9

List the different transitions older family carers and their adult sons and daughters with learning disabilities face, as they grow older together.

Describe how you think services could support them through one of the transitions you have identified.

Exercise 10

Supporting families to plan for the future.

One of the performance indicators proposed by Valuing People is :
The percentage of carers aged 70 and over, for whom a plan has been agreed.

In what ways could your organisation contribute to:

1. Finding older family carers in the area.
2. Developing plans with families.

How could your organisation support families, carers and the person with learning disabilities to begin to prepare for the future?

How could you begin to develop this work now?

In this section you have had the opportunity to reflect upon:

- the experience of families growing older together,
- the transitions they face as they grow older together,
- what ways services can respond to and support people as they go through these transitions in their lives.

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