

# Person-centred approaches and older families

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## Aim of this resource

Good practice in person-centred approaches and planning with people with learning disabilities naturally includes involving the people who know the individual best – usually their family. Whilst there is a great deal of good work happening around the country with people with learning disabilities, many facilitators have expressed concerns that they have less success positively engaging with older families.

Planning for the future is the number one priority of most older families. Family carers are desperate for reassurance that the person they care for will be safe, happy and well supported in the future to achieve the most from their lives. People living with older family carers are often worrying about what will happen to themselves and their ageing carers when their relative can no longer provide long-term care. No one wants to wait for a crisis solution, but often older families don't have the information or support to be able to explore alternatives safely. Person-centred approaches to planning offer a solid framework for supporting older families to explore and plan for the future. Success is often dependant on the skills of the person-centred planning facilitators and it is essential that people in this key role are enabled to have the skills, understanding, time and support to fulfil their role effectively.

This resource has been written as part of the Older Family Carers Initiative in direct response to the concerns raised by person-centred planning facilitators and coordinators. This is intended for people who are already informed about person-centred planning approaches and want to make sure they are planning with older families in the best possible way. This report is intended as a tool to be used primarily by people whose role it is to:

- plan directly with older families
- coordinate person-centred planning on behalf of their Learning Disability Partnership Board.

The booklet covers three distinct areas:

1. Understanding and reflecting on what is different about person-centred planning with older families.
2. Using different person-centred approaches and tools with older families.
3. Key strategic and practical implications for person-centred planning facilitators and coordinators that need to be addressed locally.

We hope you find this report a useful tool for helping ensure you are able to plan positively with older families. Above all else, please remember that many older family carers have been worrying about the future for many decades. There will be no quick solutions and to get plans right you will need to ensure families are fully

involved and that trust and good communication are built up between all parties. Plans will take longer to facilitate but you are unlikely to get a second chance if you don't take the time to get it right the first time with older families. There is a lot that person-centred approaches can offer to build up older families' confidence in how a person will be supported in the future. That is the peace of mind that most older families are craving.

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## Part I: Focusing on older families

*Valuing People* recognises the neglect of many older family carers of people with learning disabilities. Family carers in their 70's, 80's and 90's have often been caring for many decades with relatively little support. Often these families are only identified once there is a crisis and they become visible. Identifying and planning with older families will enable older family carers and their learning disabled relatives to be better supported and able to plan for the future with greater confidence. Identifying older families and their needs will also enable local authorities to plan their services and support more effectively.

In *Valuing People* the Government defines 'older' family carers as those aged 70 years or more. But there is no fixed age that defines an older family carer: some authorities may choose 65 years or over, as this is when people are eligible for services for older people. Even if someone is not over 70, it's important that services know which people will soon be in that age bracket so they can plan services to meet the needs of older families in the future.

When talking about 'family carers', we mean people who are usually parents and who are still looking after a son or daughter with learning disabilities at home. However, older family carers may also be brothers, sisters and other family or friends of the person with learning disabilities. It's important to remember that not many family carers recognise themselves by the term 'carer' as most think this means the same as a paid care worker.

*Valuing People* has set out a number of targets and performance indicators for local authorities and their Partnership Boards to meet to ensure older family carers and their relatives are better supported. These targets include:

- identifying family carers over the age of 70 years
- ensuring that people living with older family carers are prioritised for person-centred planning by 2004
- making sure that older family carers have an 'agreed plan for the future'
- prioritising supported living options for people living with older families.

### Why focus on older families?

While *Valuing People* emphasises supporting family carers, it prioritises older family carers, a previously overlooked group. Many of these older family carers will have witnessed significant changes in services and support since they started caring and they may have found themselves increasingly isolated from effective support and services. Many older family carers were told in the past by doctors either to simply

'take him/her home and keep them happy' or to leave their relative in institutional care. Either way, people who are now considered older family carers were often told that their relative was unlikely to live beyond their early 20s. People simply never expected to still be caring 40 or 50 years later.

*'From the day she was born I worried about what would happen to her in the future. 'The future's' too close now and I still have no idea what to do.'*  
Older family carer

Older family carers often have increasing health and practical needs in their own right. In many cases, the person with learning disabilities they care for is providing an increasing amount of care and support for their ageing carer and they may have become mutually dependant on each other to be able to stay living independently in the community.

*Valuing People* estimates that at least 25% of people with learning disabilities not currently in touch with services are living with older family carers. Many of these people have been living a very inclusive life within their local communities, but many of these 'hidden' families will only become visible in a crisis. Unfortunately, in times of crisis services have little choice but to respond in a very reactive way. For too many people a crisis, such as an elderly parent being taken into hospital or dying, means that the person with learning disabilities may face losing their parent, home and local community all in the space of a few hours. They may then be placed anywhere that has a vacancy and that can meet their immediately identified needs.

If you have the opportunity to gain the trust of any older family carers they will tell you that they have two things on their mind almost constantly:

What will happen to their relative in an emergency?

What should they do now to start planning for the future?

Some older family carers have been told by statutory services; 'don't worry – when you eventually die we'll take care of your son/daughter'. But that is not enough to give older families peace of mind. People with learning disabilities and their older family carers want and need support to plan for emergencies and the long-term future with confidence. Person-centred planning offers an ideal framework for taking this forward.



## Part 2: What is different about using person-centred approaches with older families?

At first glance, this topic seems redundant. Good person-centred approaches always have the person at the centre, so why do we need to consider specific issues for older families? Surely by working in a person-centred way, we will automatically address their needs? This may be true. However, we want to share some reflections from our work that may be helpful to consider when working with older families and that may help you to ensure you are able to overcome barriers and support all parties to get the most from the opportunity offered by person-centred planning.

### Previous experiences of professionals and services – building trust

*When I first started working with older family carers I didn't have a good appreciation of the lifetime experience of caring that so many people have been through. An early task of my job was to conduct a number of interviews. During one interview with a woman in her mid-80s, everything was going well until I used the term 'learning difficulty' when talking about her son. She stopped me mid-sentence and said: 'When he was first born they told me he was an imbecile. Then they said he was a mongol. A few years later he was mentally subnormal, then mentally retarded, then mentally handicapped and then learning disabled. Now you're here telling me he has a learning difficulty and in another few years another nice young lady will come and tell me he's something else. Well he's John.' That was eight years ago and I have never forgotten.*

Sharing Caring Project worker

Some older families may have had very little or no contact with professionals over the decades they have been caring. Other families may have seen a succession of professionals come and go in their lives, resulting in different degrees of change. We know that the relationship between a person-centred planning facilitator and family needs to be based on trust. Families' experiences with previous professionals may colour whether, or how quickly they feel able to trust a facilitator. In the same way that we challenge the use of labels and their attached stereotypes for people who are disadvantaged, in this situation the label of worker or professional may create a certain picture for the family!

*Bill's mum and dad attended a review at their son's day service. The meeting felt quite positive until a key worker remarked (from the best of intentions) what a shame it was that Bill's parents had not let him do more for himself at home so that he was more independent now. His parents were devastated. They felt that they were being judged as having brought Bill up badly and holding him back. Bill was in his late 40s and his parents were in their early 70s. When he was younger, a doctor had told Bill's mum never to let him near the cooker and kettle because things like that were far too dangerous for people like him. No one had ever told them anything different. Six years later, Bill's mum still cries when she talks about how she was made to feel in that meeting.*

It is very important to recognise the impact that having had 'bad' experiences with professionals can have. Don't take it personally if the family seems to lack trust in professionals. It may be worth asking the family directly what their experience of professionals has been, and work from there. There are obvious things that you can do to build trust, like ensuring that you always turn up when you say you will and following through on promised actions and so forth.

If the older family has had very little or no contact with professionals, and you are the only contact that they have with services they may see you as resource for everything to do with services. If the family decide to trust you enough to open up to you then you need to be open to listening to what their needs are at the time of your contact and what their agenda is.

*A Carers Link Worker from Shropshire went to see an older family carer about an assessment. When she arrived she was directed to the commode that needed emptying, as the homecare workers had not turned up that morning. Even though this was not her role, she emptied out the commode first as this was the only way she was able to get on with the real purpose of her visit.*

Your agenda may be to go in and complete a person-centred plan with someone living with an older family carer, but that family's immediate needs may be different and they may have had no opportunity to speak to someone about that they want. If issues are raised then you need to follow them up, refer on to other people if necessary or explain and negotiate what is and is not possible for you in your role. Most of us prefer straight talk about what is possible, and can spot when 'I will see what I can do' is used as a fob off.

In their lifetime experience of caring, people with learning disabilities and their families might easily meet dozens of professionals and have to constantly re-tell

their story and create new relationships. This has been described as a very draining experience by many older family carers. Whilst we cannot guarantee that professionals will stay around, think carefully about who to ask to work with older families. Try to minimise the chance of another person being in a family's life for a short while and then disappearing.

## Messages from the past

*When the Sharing Caring Project in Sheffield was carrying out its research with older family carers in 1997, it found a high number of family carers saying that they expected their relatives to eventually live in one of the four big hostels that Social Services opened in the early 1970s. When asked, people said that when the hostels first opened professionals told them that they should send their relatives to the hostels for respite, as this was where they would end up living in the future. Many had followed this advice and felt they had peace of mind that this was where their relative would live in the future. However, for some families there were no vacancies when the need arose, or they were told (after 30 years of using the service), that it would be unsuitable as a long-term option. Few older families (at that time) had much information or understanding of the range of alternative accommodation that was available for people with learning disabilities in the city.*

We have seen, and often been part of, the shift in thinking about support for people with learning disabilities and their families. Years ago it was believed that the best way to serve people with learning disabilities was for individuals to live in institutions away from their families. Professionals will have worked to convince families that this was the best that they could do for their relative. Now it is commonly agreed that communities are richer for including people with learning disabilities as full members, and we are sharing these ideas with families. Families may have only heard one part of this story. They may have been told, and still believe that institutions are best, or, as in the story from Sheffield, that there are places in larger hostels reserved for their relative. The media, and local grapevines carry negative stories about community care much more quickly and effectively than positive stories. Older families therefore may have low expectations, or lots of 'evidence' of services and supports not working for families.

*One family carer in her late 80s dissolved into tears whilst discussing possible future housing options for her son. When the worker gently probed into her fears. It emerged that the mother was under the impression that if her son moved anywhere then she would no longer be allowed to have any contact with him. This is what she had been told by a doctor the last time the future had been openly discussed – when her son was first diagnosed shortly after his birth over half a century earlier.*

When you begin to work with an older family using person-centred planning, ask them what they have been told about the future for their relative, and what their impressions of this are. If necessary unpick these messages with families, to separate what may have been true years ago, but is not now. It will be particularly important to recognise that many people with learning disabilities may also have picked up mixed impressions of what might happen to them in an emergency from seeing their peers go through different experiences. Unpicking the assumptions of older family carers and their relatives requires a great deal of sensitivity and should not be rushed. You must recognise that this may be a very difficult process for some families who may feel like certain safety nets have been pulled from under them as assumptions are challenged.

### Recognise and respect experience

Older families bring a rich history and experience of dealing with difficult issues like prejudice, and resourceful ways of including their relatives in their local communities. Many people with learning disabilities living with older family carers never had any right to an education or support when they were younger. Benefits were few and far between and where people did receive support there was usually very little choice on offer. Family carers usually did not have the same career, social and financial opportunities that so many of us now take for granted. Many older family carers have felt isolated within their communities as a result of caring for decades. Thirty or 40 years ago there was often less understanding and empathy for people with learning disabilities and their families than there is now. Anecdotal evidence from older family carers highlights the impact of both careless and kind words – and how neither are forgotten:

*A couple in their mid-80's live at home and support their son who is in his late 50s. Their son was not allowed to go to school as he was deemed 'uneducable'. At the age of 17, he went to a day service for a year and a half but did not enjoy it – it was too crowded and noisy for him. He left when his mother became ill and she was unable to take him there and back on the bus. No-one ever followed up on him and he has been nowhere since. Talking to his parents, they repeatedly share five experiences that have shaped the way they respond to professionals today.*

1. *The family have only ever been separated from each other for one night, when their son was a teenager. He went to a respite unit and they went on holiday. As soon as the parents reached their holiday destination they rang to see how their son was settling. The staff on duty said he had not settled and was ill and distressed. The parents drove straight home early the next morning. When they picked up their son, the doctor on duty told them “You’d better not leave him again as I think he would die without you” They have never left him anywhere since.*
2. *When their son was in his early 20s, someone came round to make sure they were all registered to vote. The man was incredulous when he found out their son could neither read nor write and implied that they had done something wrong. His parents were mortified by this experience and their son was also distressed. Mum and dad have been reluctant to let strangers talk to their son ever since.*
3. *Following an informal inquiry about a residential home nearby, a social worker came to visit the family. They were not expecting her but invited her in for a cup of tea and a chat. Their son, not liking strangers or disruptions to his routines, stayed in the next room watching TV. In the course of the conversation it emerged that the parents (at this time in their late 60s) were very worried about the future and had not been able to discuss their worries or hopes with their son. The social worker immediately offered to go and talk to him about the fact that he couldn’t rely on his parents being around forever. When she got up as if to see their son, his parents bundled her out of the door very firmly. No other professional (except the GP) was allowed in the home for over a decade after this incident. To this day, the parents are very wary of any new visitors and it may take many visits before people are even introduced to their son.*

*Although this family’s response to workers is governed by their experiences in the past, there have been a couple of positive experiences that have made an equal impact on their lives:*

4. *When their son was in his early 20s he was out for a walk with his dad. A policeman walked past and stopped to say hello and spoke directly to the son and wished him a ‘good day’. Father and son have never forgotten that kindness from someone in an authoritative position.*

5. *The family's GP has been incredible and if she introduces someone to the family then they tend to trust them and accept their help more. She has bent over backwards to be supportive and makes regular home visits and has made sure that the rest of the practice staff are geared up to respond sensitively to the family. E.g., they don't often ask them to come into the surgery for appointments if the family ring as this distresses their son. Instead they offer visits without making the family feel as if they are putting anyone out.*

Many people who live with older family carers, particularly 'hidden families', have lived the most inclusive lives and it is only when situations change, or the ageing family carer is less able to facilitate opportunities that their lifestyles becomes more restricted. Many people with learning disabilities have been supported by their families to have jobs in local shops or factories, and were/are regular fixtures helping out at their local pubs, clubs, church groups and so forth.

It is absolutely critical to capture as much of the history of caring as possible. Doing a 'history chart' (described later as a person-centred approach), or 'What is the story?' map are ways that this history and experience can be shared and recognised. Understanding and respecting the journey older families have made already is usually the key to being able to take forward plans effectively and inclusively.

### **Be aware of jargon**

Even though it is likely that many older families might now have heard the term 'person-centred planning' – this does not necessarily mean that everyone has a shared understanding of it. After all, the reality for most older family carers is that they have spent a lifetime with the needs and wishes of the person with learning disabilities at the very centre of all the daily decisions and directions taken by the family, from where holidays are taken to whether a family carer is able to go out to work or to build up a social network independent of their relative. It is very important to check out that everyone is clear on what the person-centred approach is trying to achieve and what everyone's role is within that process.

Plain speaking is key to all person-centred approaches. Whilst we all try and work without jargon, we need to be aware that certain phrases may have different interpretations. For example, the phrase 'independent living' raises particular concerns from many older family carers. Independent living sounds like people would not be getting any support and that the person will be left alone to get on with life in the community. Many older family carers and people with learning disabilities do not realise that you can be living independently and still be receiving lots of appropriate support needed to ensure a person is safe, well cared for and able to lead a full, meaningful life. Often the only time older family carers hear about things like community care is when

something has gone wrong very publicly. Then they are able to read, watch and listen to a succession of ‘horror stories’ about people who have been let down or services where workers are accused of being abusive or neglectful. There are not enough opportunities for people to hear the good stories of when things work out for positively for people with learning disabilities and their families, even though this is the majority of people’s experience. If you have worked with families who have positive stories to tell, why not encourage them to share their story – the good and the bad bits. For many older families, there is nothing more powerful than hearing and seeing things from the point of view of other families who have been through it themselves.

### Recognise the priorities of different members of older families

*‘All I want is to know that he will be safe, happy, well looked after and able to do the things he likes. If I felt sure that would happen I could die in peace.’*

Older family carer

All parents want their children to be happy, healthy and safe. The stereotype of an older family carer is often someone who is *only* concerned that their relative is safe and healthy and they are often perceived by workers as being over-protective and restricting people’s opportunities to move forward. Older family carers worry deeply about who will speak up for their relative in the future. Whether appreciated or not, most family carers have fulfilled a lifetime advocacy role with and for their relative. They have always spoken up and acted from a desire to make sure that appropriate services and support for their relative is/will be in place. Their advocacy role has not always earned family carers a positive reputation with professionals, and family carers frequently describe themselves as having been labelled as ‘obstructive or overbearing’.

The reality is that older families have usually lived through so much change and uncertainty within services that they don’t feel there are any long-term guarantees for their relative’s future happiness and well being if they are not there to oversee it. Similarly, many older families don’t have the information about what options are available and what it might mean in reality to the person they care for. This, coupled with the reality that most of the people who are older family carers now always assumed that they would outlive their relative, has meant that there is often a genuine lack of confidence that services will be able to support people well in the future. Most older family carers of people with learning disabilities are parents. Amongst no other group of parents other than with parents of people with learning disabilities will you hear people wishing they could outlive their children so they can be sure they have had the best possible love, care and support for the whole of their life.

*Mrs H, a 91 year old widow from Shropshire told a worker: 'I got my three wishes last year: my son Basil died at home in my arms and before me... now I am content. I do not regret one bit these wishes – Basil was my life.'*

We need to demonstrate that we hear and appreciate families natural concerns about their relative. We need to find ways of supporting families to speak up about their particular concerns and priorities and that it may be very difficult for them to speak openly about their fears. We have to recognise that it is likely to take us (and others) a long time to build up the level of trust that older families need to be able to plan for the future with confidence.

### Planning for a family emergency

In practical terms, the biggest priority for older family carers is likely to be planning for emergencies. Again, many older family carers will have heard 'horror stories' of what can happen in an emergency and worry deeply about whether anyone will notice fast enough to support an individual if something happens.

*One family carer told a worker of an incident with another family where staff at a day service noticed that the daughter had come into her day service without her usual packed lunch for two days in a row. The first day a staff member assumed she had forgotten it and got her a sandwich from elsewhere. When the same thing happened the next day, another staff member asked her why she hadn't bought her lunch and the woman told her it was because her mum hadn't got up to make it. When the home was checked, workers found that mum had been dead in her bed for a couple of days.*

Person-centred approaches enable families to start to explore what are the most important things for the person and the family. It enables people to work together to find out what is important to and for each family member. This approach is particularly useful when looking at planning for an emergency situation. It is no good just focusing on getting supports right for the family carer without making sure that this solution fits well with the person. There have been situations where a family member has had to agree to use support service in an emergency situation, which they know is not ideal for the person due to lack of forward planning with services or lack of resources. This can cause additional stress in difficult situations to both people. By taking a person-centred approach to the whole family, support can be designed sensitively and in advance.

Person-centred planning enable families to think about the range of different things that can be done to ensure that both the family carer, person with learning disabilities and other key people know what to do in any family crisis situation.



A useful way of looking at this is to imagine that you are designing and providing different ‘cushions’ to deal with the impact of an emergency situation. Cushions can be different shapes and sizes and can be for the whole family based on what you are learning through person-centred planning. This can range from small actions such as making sure that a trusted neighbour has a key, to supporting an individual to learn how to use a telephone to call for help and having a completed Life Book that the person knows where to find it and feels willing to show people in a crisis.

**(See also ‘Planning for a Family Emergency’ – a good practice guideline from the Older Family Carers Initiative that can be downloaded free from the Foundation for People with Learning Disabilities website on [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)).**

### Different priorities

Like members of any family, people with learning disabilities may well have different priorities from their older family carers. This does not necessarily mean that there is a conflict of interests between the family carer and an individual, although workers often perceive this wrongly. Workers often say they feel caught in the middle and that their remit is to support the person with the learning disability more than the family carer. As a result, family carers often feel that they are being isolated or judged as being deliberately obstructive. When ‘conflict’ is unpicked, many find that people are just coming at issues from different perspectives and things have been blown out of proportion and are relatively simple to resolve.

*Philip is a man with learning disabilities in his early 40s who attended an empowerment group through his day service, which he enjoyed very much. At one of the sessions, it emerged that Philip still went to bed when his parents told him to. Workers and other people in the group rightly told him that as an adult he was entitled to make decisions about when he went to bed for himself and that it was not up to his parents. Full of confidence, Philip went home determined to go to bed when he wanted to that night. The next day workers got a phone call from his parents. Both his parents (who were in their early 70s) and Philip hadn't got to bed until 2am that morning. Philip had gone home the previous day being very assertive about his bedtime – but for the past 40 years he had been in a certain routine around his bedtime and he insisted on keeping it the same. This meant that although he wanted to stay up very late watching TV, he refused to stay up alone as he was anxious in the house at night, and he also had certain routines at his actual bedtime which included having his parents say good night when he was in bed and turning out his light. His parents were not angry just very tired and frustrated. It turned out that they too wanted Philip to be more independent with a view to his future, but they were frustrated that people had built Philip up without giving any consideration to the fact that they he didn't live by himself – he was*

*part of the family and what he did impacted on them too. They were most distressed by the fact that Philip was now very confused about the mixed messages he was getting from home and his day service. From then on, communication between his day service and family carers improved enormously and Philip has been able to develop his independent living skills further in a supportive and well-planned way.*

Skilful facilitators proactively and sensitively address these issues with families by clearly enabling family members to share their own priorities, see where these are complementary and where they differ, and work out ways to address any difference. Essential lifestyle planning is a person-centred planning tool that enables people to be able to look at what is working or not working for a person, their family and others that are involved in supporting the person. It uses this process to ensure that all perspectives are addressed and embraces any differences as key points to look at collective action planning. In addition facilitating a whole family plan (family essential lifestyle plan) may be the most productive approach to supporting people who have learning disabilities and their older family carers. If a family essential lifestyle plan is not needed, facilitators need to use other person-centred tools to ensure that you are clear about what is important to the family and how best to provide support. This may mean that you develop a full plan with and for the person with the learning disability. Additionally you then agree a support plan with the family which looks at how you communicate with each other, and who is doing what by when and in what manner. (For more information on family essential lifestyle plans and other styles of planning see [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk))

### **Ensuring everyone is heard**

A common issue when working with older families is making sure that everyone feels supported enough to speak up openly and honestly about how they are feeling and their worries and concerns. There can be some reluctance to be open on all sides. Much consideration is usually given to ensuring that people with learning disabilities are supported to speak up safely, but how a family carer might feel in a formal meeting is often overlooked. For older family carers in particular, it can feel like a very intimidating experience and take a great deal of courage to feel able to speak out, particularly if they feel they may be judged harshly for what may be deemed 'politically incorrect' viewpoints.

Both older family carers and people with learning disabilities often worry about offending each other or being perceived as holding people back. Some older families don't want to discuss moving on in front of each other in case one party takes it as a rejection or because it is simply too painful to be discussing your own mortality so openly. Even between caring couples, broaching the topic of what might happen in the future can be an incredibly sensitive issue if people are at different stages in their

willingness to confront this and their own mortality. After decades of living together, ‘the future’ can be an incredibly difficult subject to discuss and yet it is inevitable that it will emerge during any person-centred planning involving older families.

*Vicky lived at home with her dad, John, who was in his early 70s and in very poor health. Her mum had died seven years earlier and since then Vicky had been anxious about anything happening to her dad. Vicky and her dad were being supported to think about planning for the future since John was very concerned about Vicky being left alone suddenly in an emergency and having to go wherever there was a vacancy rather than making a planned move whilst he was still around to support her through the transition. Discussions about different options appeared to be going well and in all the meetings Vicky agreed with what was being suggested. After the third meeting, John requested to see the main worker alone when Vicky was out. He told the worker he was worried that Vicky was just going along with everything and agreeing with whatever he said at meetings but was really not happy about things. She had become more clingy when it was the two of them and was not doing as much for herself as she had previously. It was agreed that the planning sessions would alter. Vicky spent lots of dedicated time getting to know an advocacy worker and they went out together regularly and gently explored some of the issues she had about moving. It turned out that Vicky was worrying a lot about how her dad would cope without her, and also about practical things like whether she would be able to take all her belongings with her somewhere else and who would do things like help with her clothes shopping. Vicky was supported to make a list of all her concerns and she brought them back to the main meeting. With support, dad had also prepared a similar list and the planning became much more constructive. Vicky moved out a year later when dad's health deteriorated and he was no longer able to care full-time. The first place Vicky lived was ok but it was not what she and John had hoped for and she was not happy. Thanks to all the pre-planning and support that had already gone on, it was easier to identify an alternative and a suitable vacancy arose 14 months later. Vicky moved to a flat in a supported living project where she now lives with one other woman. She has blossomed in confidence and in the skills she has developed since living there and is very happy and rightly proud of her achievements. John died 2 months after she moved into her flat.*

Just as it is important to ensure that older family carers and people with learning disabilities are supported to find their voice and feel confident to speak up, it is equally important to try to ensure that other key family members and friends are part of processes. For older families in particular, person-centred planning offers a number of great mechanisms for approaching the subject of what role other people expect and/or wish to take in the long-term future of an individual's life. Experience has shown that having a third party present who can ask and answer questions can make a real difference to moving plans along.

*Mr and Mrs B and their daughter Pauline were starting to firm up plans for the future due to Mrs B's deteriorating health. The long-term dream of all had always been that Pauline would live on in her home after her parents had died. She had lived in that house for over 30 years, knew most of the neighbours and was well known in her local community. Pauline had always been reluctant to try any other services, as she had never felt the need. She had also never spent more than about four hours at home by herself, and certainly never at night. Unfortunately, as her mum's health deteriorated, it became harder for Mr B to cope with looking after both his wife and daughter's needs. It was also very difficult for Pauline to see her mum so poorly. A worker the family had known for years persuaded them to allow a referral to be made for a social worker who visited the family to discuss the situation. By chance, their daughter-in-law, Sarah, popped in to visit during whilst the social worker was there. She had not been invited but was very glad to be there. The conversation that followed lifted a huge burden of worry from Mr and Mrs B and Pauline. Sarah's husband had been really worried about the family but had found it difficult to raise his concerns, as Mr and Mrs B were adamant that he shouldn't feel he had to become his sister's full-time carer, especially since he had a wife and young family. When Sarah came, she asked the social worker a lot of questions about the different options and said that if it was ok with Pauline then she would always like to be involved in her life. One of the options discussed was Pauline trying out some short-break care at one of the local hostels. Pauline offered to take her and support her to settle in and have her back to their home for tea regularly. Pauline ended up really liking living away from home and with other people of a similar age to her. With the support of her social worker and the family as a whole, Pauline has now moved to a supported living core project. She has a boyfriend and has learnt to travel by herself to some places and has an active social life. Sarah and her see each other regularly for pamper sessions and Pauline confides a lot in her. Mrs B made a good recovery although she is still not strong. Pauline visits her parents once a week and they are still very much a part of her life, but now have the peace of mind of knowing that Pauline's brother and his wife will always look out for her when they are no longer around.*

We may find it easier to be heard by, and to speak in front of different people. Think carefully with the family about who should be involved in person-centred planning, when it will be helpful to plan all together, and when it may be helpful to do work separately, to ensure that everyone is heard within the planning process.

### **People with learning disabilities as carers**

Facilitators need to learn to recognise situations where older family carers and the person with learning disabilities are co-dependent. Such situations need to be handled with extreme sensitivity. Many people with learning disabilities are justifiably

proud of the way they are helping out their ageing relatives. Some people are mainly involved in household tasks such as carrying the shopping, cleaning and helping with cooking. Other people's roles often involve hands-on support with personal care.

*When Sam (in his early 60s) was living at home with his father who was in his late 90s, they very much looked after each other with the help of another daughter/sister. They had great systems worked out; for example, dad would write a shopping list and Sam would take it to the local shop. Unfortunately, dad became increasingly confused and it was hard for Sam to understand why his father kept asking the same questions and was getting so frustrated. A worker and Sam's sister thought it would be a good idea for Sam to have some breaks away from his dad to relax and start to get used to the idea of living away from home. Sam started going for tea visits at a local short-breaks unit and the visits seemed to go well. Sam is a very quiet and gentle man who gets on easily with most people. When he had his first overnight stay at the unit Sam became very angry and disruptive and showed a side to character that had never been seen before. The same thing happened after a second try. In the end, his sister and social worker realised that the trigger for Sam's anger and distress lay in the fact that he was desperately worried about how his dad was coping without him. As a result, more support was put in to support dad and Sam at home together. Some months later, when the situation deteriorated further, Sam and his dad moved on together. As his dad settled into the new older persons home, Sam relaxed and has since been supported to move into a small group setting close to his home and within the heart of the community that knows him well. He is still supported to visit his dad regularly.*

Just like family carers of people with learning disabilities are not always recognised and valued for the support they are providing, the same is true when roles are reversed. Often the amount of care individuals provide is either over looked completely or assumed to be inappropriate because of their disability. Older families can be fearful of any change that 'interference' might bring and many people with learning disabilities worry terribly about how the other person will manage if they are not there. Likewise, older family carers worry about being judged as unable to continue to care and that people might be taken away from them. The reality is that in many older families' homes, if one person leaves the home then both people are more likely to need to access alternative care and may lose their independence. In most circumstances, organisations will work hard to make sure that both people receive the appropriate support at home whilst that is what both people want, as this is not only a more family-centred approach, it is also generally more cost effective financially too.

Good family-centred planning should be able to ensure that the needs of both the person with learning disabilities and the older family carer are taken into account and handled with great sensitivity throughout the process.

## Knowledge of older peoples and carers' services

This paper has repeatedly talked about the importance of recognising the needs of older family carers as older people and as carers, and the issues that may arise from this. People who are facilitating person-centred planning processes with older families need to spend some time familiarising themselves with what is available for older people and carers locally as well as the systems for getting information, help and practical support. It is particularly important to understand the importance and potential benefits that a carer's needs assessment might bring to older family carers as a way of addressing and supporting the needs of the individual.

*A worker was supporting one older family to plan for the future after it became clear that the time was right for the daughter to move away from home. However, she and her father were worried about how well her father would manage without her. With the agreement of dad, the worker contacted Social Services and made a referral for a social worker from the older persons team to visit. In turn she linked dad into some local lunch clubs so that he would have some activities, got him linked into an alarm service so that he could get help in an emergency. She also got the local Citizens Advice Bureau to do a benefits check which dad which led to him being able to claim Attendance Allowance –particularly important since with his daughter leaving home, the household income was more than halved and the father would only have had a basic pension coming into the home. With her dad's needs met, the daughter was able to focus more on helping to plan her own (successful) move away from home.*

## Address practical issues

Whilst working to ensure that older families are fully involved in planning using person-centred approaches, don't overlook some of the smaller barriers that might seriously impact on older family carers being involved in the process. For example, where meetings are held can make a real difference, as transport and mobility can be major issues for many older family carers.

*As part of looking at different options for their daughter, a worker suggested a family to look around a range of vacancies in local accommodation. Mum and dad seemed reluctant at first, which surprised the worker. After some gentle probing, it emerged that dad (who was in his early 80s) was finding it increasingly difficult to drive the family around and was very anxious about driving in areas he was unfamiliar with. Also he could no longer manage to walk far and certainly couldn't manage stairs. The family were very grateful when the worker offered to do the*

*driving instead. Also, when it came to looking around places that had an upstairs, the worker used a digital camera to take photos of rooms upstairs so that he could visualise what his daughter's future bedroom might look like.*

Similarly, if you are sending out information then make sure that it is in a large font size (never below point 14) and that clear fonts are used. Don't assume that a lack of response from an older family carer means that they are not interested in being part of a person-centred planning process.

*A worker had been supporting a mother and daughter over a number of years. They had no other family in the area and were quite isolated. Following some confusion over important paperwork that had not been returned to the worker, the mother showed the worker two cupboards full of letters. It turned out that the mail went back over 12 years. Everything had been opened and if it looked like a bill it was taken to the post office to be paid. The daughter was able to recognise her own name but nothing else. Mum's eyesight had deteriorated to the point where she could not read at all. It took weeks to go through the mail and some really important information had been lost. For example, it emerged that mum's solicitor had retired several years earlier and he'd wanted to know where her Will should be moved to, there were also countless invitations to different meetings and information about a range of support that had never been followed up on but that might have been very helpful to the family.*

Follow letters up with phone calls and maybe an initial visit to talk over what person-centred planning means and work out the best way to make sure the older family carer and other relevant parties are able to be involved as much as they and the person they care for wish to be.

Many older family carers are less able to get out and about easily and worry that the person they care for is 'getting old before their time' because they are no longer able to support them to get to and from activities and social gatherings. Some family carers worry about the fact that when the bus drops off a relative from their day service on a Friday afternoon, they don't go out again until the bus comes back on a Monday morning.

## Conclusions

This section has highlighted some of the key issues and barriers that may impact on how successful person-centred planning with older families may be. You will not be able to overcome these barriers quickly, but demonstrating sensitivity and

understanding of how some of these issues might impact on older families' willingness and ability to be part of person-centred planning goes a long way. Above all else, taking time over planning and moving at the pace of the family is crucial to making progress, along with a non-judgemental approach. Older families have often been let down in the past or had their hopes and expectations dashed – you have a golden opportunity to make a real difference in the way that plans for the future are developed and implemented.

The next section will offer you more concrete ideas about ways of making different person-centred approaches work best with older families.



## Part 3: Using person-centred approaches with older families

Person-centred approaches offer us a different way of gathering information about older families. They can help us learn together about what is important to the person and their family, what they want for their future and what support they need. They can be in-depth, like Life Story books used to learn about people and plan for emergencies, or less detailed, used to learn about one area of someone's life, like a history chart mentioned earlier.

The person-centred approaches shared here are from personal futures planning, essential lifestyle planning, and good practice generally. Information from these approaches can be creatively presented as a portfolio or a life storybook for the person, providing clues that help plan for the future. You will want to select the approach or approaches that are best for the family you are supporting.

It should be noted that for some families, the gathering of information and having a way to add to this will be enough to help them deal with issues like – ‘who will know my son or daughter when I am gone?’ One mother described an essential lifestyle plan as a ‘life policy’. The emphasis on moving to action planning may need to develop more slowly as the facilitator gains that trust of the family. Action planning needs to consider the family as a whole, as a change in one part of the family will affect all other members. This is much more sensitively tuned when adults who have learning disabilities are living with older family carers.

All of the approaches described below can be used with and for the person with a learning disability but as we have indicated earlier these approaches may have to also be used for the family as a whole as well. A good example of this would be to look at relationship maps for both the person who has a learning disability and the older family carers and ask where the commonly shared relationships are; who are the people that are different in each person's life and what does this tell us about what is important to and for both of these people?

## Life story books and personal portfolios

We all already record our own lives in different ways, for example:

- a memento box of objects that reflect important events, people or times in your life
- a photo album that documents your life from birth to present day
- researching and drawing your family tree
- scrap books of special times, such as holidays
- a video showing ordinary and special times in your life
- audio tapes of children learning to talk or other events
- a notice board or large clip frame with photos of important people or special times
- a diary.

Older family carers and their relatives have a great wealth of gifts but may not be used to sharing or celebrating these. Taking time to talk and listen to people's experience will draw these out. Life storybooks and personal portfolios naturally draw and organise this wealth of information. It is never too late to start this process. Many older family carers worry about the person they care for receiving the right support at the time of a crisis and in the long-term. The process of completing some sort of life story book or personal portfolio can be a particularly useful foundation stone for working with older families in a meaningful and practical way.

The books/portfolios provide a lasting opportunity for families to work together to put down all the key information about an individual's life – their past, present and hopes for the future. Not only can this tool be used in an emergency, the process also helps people to start discussing what support might be needed in the future and who might be involved in a safe and sensitive way. However, facilitators must recognise that older families may need particular support with compiling books/portfolios since the process also involves older family carers facing up to issues of their own mortality, which can be quite traumatic without the right support.

The word portfolio describes a collection of information about someone's life. One way of collecting information about your life is through a life story book. Life story books can be used to gather a lot of different information about people, such as their history, what they like to do, who they know, and where they go. This information can reflect and illustrate the person's experiences and achievements, as well as his/her dreams and hopes for the future. People can record and represent their information in a way that reflects their ideas and gifts. This could include photographs, audiotape, artwork, letters, certificates, videos, and objects – anything that expresses something about their life and who they are. The Sharing Caring Project in Sheffield has been involved in a lot of life story work with older families and a paper on supporting older families to complete Life Books can be obtained from the project (see resources).

The members of People First in Manchester have compiled descriptions of their lives using different media, called them personal portfolios and presented this way of working on a video. Multimedia profiles are another way of recording and sharing personal information.

Life story books and personal portfolios therefore can be used as a means to gather person-centred information that can stand alone and help others to understand the person, inform people about their preferences and need for example in an emergency situation. However this information can then be used to generate a full plan e.g. using the information you have gathered in the Life books to help inform what is important to and for the person as the basis for an essential lifestyle plan.

### Relationships Circles

Relationship circles can be particularly empowering for older family carers who often worry about who else will be involved in their relative's life in the future. They may not realise how many people are involved regularly through outside activities and services, and it is great as a visual prompt and reinforcement to the family about who does actually know and care about someone. Relationship circles also offer the opportunity for other people to be drawn in and asked more about the relationship they have with the person now, and hope to have in the future. It also helps everyone to see clearly where the gaps are in someone's life and thus the importance of making plans to draw more people into the individual's life. It's a great way of other workers being able to work with older families and demonstrate how they see themselves as entwined in the person's life.

This person-centred approach is useful for:

- finding out who could contribute to getting the person connected
- identifying relationships that could be developed or strengthened
- showing the balance of family, friends and paid workers in the person's life.

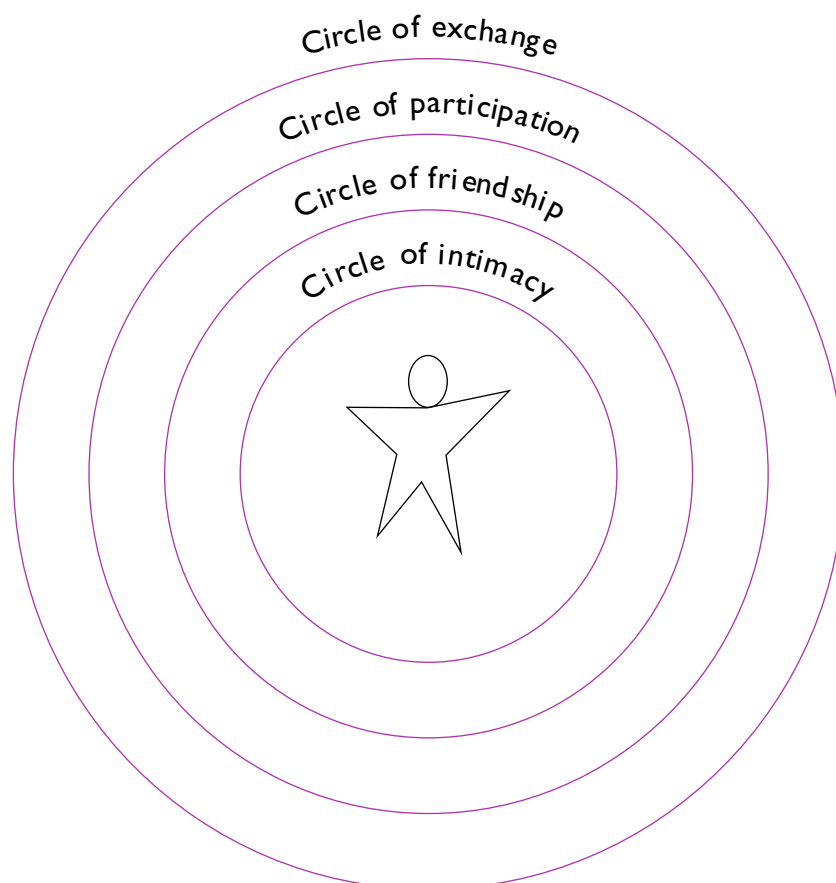
The deepening and expanding of relationships is fundamental to most of us. Judith Snow (1998) developed a simple way of illustrating the different relationships in a person's life:

*Circle of Exchange* – people who are paid to be in the person's life: e.g. paid care workers, other service providers, shopkeepers and the postman etc.

*Circle of Participation* – people who share experiences and interests with the person: e.g. work colleagues, members of the same club or church.

*Circle of Friendship* – people who simply choose to spend time with the person and share the enjoyment of each other's company.

*Circle of Intimacy* – those closest to the person: close family, partners and loved friends.



Completing the relationship circle:

The person's name or photo should go in the middle of the inner circle.

She/he might want to represent people in the other circles by writing their names, inserting photos, or drawing pictures or symbols. If people are included who are no longer involved in the person's life then it might be useful to note how long they have been absent. Often people will want to include people that have died and that they still feel close to. Sometimes the map can only be done as a 'best guess' on behalf of the person along with someone who knows the person well, but again older families will be absolutely essential in drawing out important links to people from the past as well as the future. It is important to remember that close relationships occur regardless of roles and responsibilities – people may have friendships with administrative, maintenance, and professional staff.

### Questions to ask

- Who is most important in your life?
- Who else do you see often? (Family, neighbours, people at work or at the day centre, people you see in the evenings or weekends)
- Who do you celebrate special occasions with, e.g. Christmas or your birthday?
- Is there anyone you feel close to that you have not seen for a while?
- How often do you see each of the people you have mentioned?
- Do you see them by themselves or as part of a group?
- Who makes the arrangements to meet up?
- How do you remember the people that have died?

Once the circles are complete, it is possible to look together at any themes or patterns in the relationships. Are, for example, most of the people paid staff or other people with disabilities? How close is the person's family? Where do members of the person's extended family feature or friends of the family? Does the person have any contact with neighbours or local people? Where are the gaps and what needs to happen next to address these questions?

Additionally the relationship circle starts to show the people in the person and family's life that can be developed as 'cushions' at times of need or emergency. If they are already involved in the person's life and contributing to the plan, it is more likely that dealing with any crisis would happen more smoothly. This is due to the fact that people are really getting to know what is important to and for the person and the family.

## Gifts

Identifying a person's gifts as a person-centred approach is extremely validating of the knowledge and expertise that older family carers have about their relative. It is empowering for older family carers who may not have heard other people appreciate their relative's gifts before. Usually meetings are held to review services or carry out assessments, rarely to talk about people's gifts and qualities. Again, this could bring a great deal of peace of mind to many older family carers that people like, respect and value the person they love.

This person-centred approach is particularly useful for:

- showing what the person enjoys, is good at, and can contribute to
- identifying things that the person may want to do more often
- starting to think about the kinds of people the person gets on well with.

Our gifts are what make us attractive to the other people we meet. Beyond being simply our interests or abilities, they are the parts of us that other people warm to – the parts of us that make people want to spend time with us: our personal velcro.

Gifts can be anything from a warm smile or cheeky sense of humour, to a concern for others, courage, or honesty.

To be successful in making our communities more inclusive we need to believe that every individual has gifts to offer other people, indeed that the community as a whole will benefit from including everyone. Sometimes people make it hard for us to see their gifts, but many people with learning disabilities have been let down all their lives and may find it difficult to trust and open themselves to new people as a result. They may think themselves unlovable and adopt behaviour that asks others to verify that. Getting to know people, and being trusted enough to see their gifts takes time.

We often need other people to help us to think about what our gifts might be. Here are some questions that Michael Smull uses to ask others about gifts and contributions:

- What do others like and admire about a person?
- Why do people choose to spend time with a person?
- What have the people who like and admire a person learned from them?
- How has the person made a difference in their lives? What have they contributed?
- Where else may these contributions be appreciated in the community?

### Skills and interests

Some older family carers may not know properly what a person does on a daily basis when they are at their outside activities. Similarly, people living with older family carers may no longer have the same opportunities to get out and about to different activities, or follow the hobbies that they once did, usually because of their family carers' health or because they can no longer provide the transport to or from activities. It is crucial to capture as much information about what a person used to do and enjoy as it is about their present activities. Older family carers will usually be a mine of information about this and have often never been asked in any detail. Again, involving the family carer will help them feel valued and involved and able to contribute.

This person-centred approach is useful:

- for showing what the person enjoys or has a passion for
- for showing what talents the person has and the things they are good at
- for showing what the person can contribute
- for identifying things that the person may want to do more often
- for identifying the places, people and activities that make the person happy.

There is an obvious crossover between this person-centred approach and the gifts approach. An interest or a passion for something is also a gift because it creates the possibility for a connection with other people, an opportunity for work or an interest

to explore at college. It is important to differentiate between the two, so that the less tangible gifts are not ignored, but it is not necessary to spend lots of time trying to decide precisely what is an interest and what is a gift. The most important thing is that everything is recorded. Many people have existing hobbies and interests, some of which may be hidden to the casual observer.

Questions to ask about interests include:

- What hobbies or activities make you excited and enthusiastic?
- What have you tried in the past?
- In what ways do you like to help other people?
- Do you have interests that you used to pursue and would like to try again?
- What makes a good day for you?

Supporting an individual and/or their family carers to describe a good day from morning to evening might reveal interests or hobbies that have never been formalised or even identified. For example, if I describe what makes a good day for me from the time I get up in the morning, one essential component is that I get to sing very loudly to chart music in the car on the way to work. This probably would never come up if you asked me what my hobbies are, but it is a very important part of who I am and helps me start the day in a positive frame of mind. If I was thinking about making connections for myself, I might start by trying to build on my love of singing in the car or my love of chart music.

## Hopes and dreams

There is a real need to separate out the hopes and dreams of older family carers from those of the person they care for. However, it is important that their hopes and dreams are acknowledged separately and unpicked to ensure they feel listened to and valued. This may be an area where there is a clear difference between what they want and what the person they care for might want. It will be critical to try to draw the links and priorities where possible and make sure that the common threads are identified and that even if people don't agree, they understand WHY the hopes and dreams might be different. Additionally it is also fair to expect that people who have shared such a close life journey together may have common dreams. This needs to be respected.

This person-centred approach is useful for:

- finding the direction that the person wants her life to go in
- inspiring
- bringing people together around a common purpose
- getting a sense of what makes the person tick – what motivates him/her.

People dream in different ways. Some people's dreams may be very small and simple – to have some peace and quiet, to be able to come and go.

Others access their dreams by thinking about what they would do if they won the Lottery or if they were told they only had six months to live. Their dreams might be about travelling or visiting people, studying, changing career or living in a particular place. Some people's dreams are more about a state of mind or about their spirit. For other people their 'dream' is to have what is important to them in day-to-day life. Focusing on what is important to them now may, therefore, be more significant than trying to identify dreams for the future. Sometimes you have to get a life before you can find your dream. This is particularly true for people who are ill or in crisis. Dreaming can be emotional both for the individual and for those supporting them. Sometimes it is hard to face up to what we haven't done and maybe never will be able to do.

Here are some questions to help people with learning disabilities and their older family carers think about their hopes and dreams for themselves and each other:

- In an ideal world, what would life look like for you? What would you be doing? Who is there? What does it sound, look, smell, and feel like?
- Take a moment and think about what gives direction to your life? What pulls you? What calls out to you? Describe the images, colours, smells, sounds, and feelings that give direction to your life.
- What kinds of relationships do you want in your life?
- What do you dream of for the lives of those most important to you?
- Where do you dream of living?
- Are there adventures or experiences that you seek, places that you would like to visit, new things that you have never tried?

Some people may need help to develop their ideas about what they want. One way is to get people together in a small discussion group, using pictures, magazines and photos. Exposure to new options and possibilities can also encourage people to desire a better situation. This can be particularly useful when working with older families. For example, often neither the family carer nor the person with learning disabilities has been given information about the range of housing and support options available, or how they might work in reality, so visiting some places or meeting other families where people have moved on successfully might help inspire their dreams.

### How to provide good support

It is absolutely crucial to get information from older family carers as well as the individual, as they will have a lifetime of experience to tell you about what support works or doesn't. This will also help make family carers feel valued for their years of caring and expertise. However, many older family carers will need help unpicking what they do as they have usually developed ways of supporting people that are just part of their everyday life and routines and they don't realise there is anything special or different about what they do. For example, routines around personal care, supporting people when out and about and so forth.



Information about providing good support from older families who are fairly isolated is particularly essential. There is a considerable risk to how well an individual is able to make a planned or emergency transition in the event of anything unfortunate happening to the family carer whereupon a wealth of information could potentially be lost forever. For example, one person's mum sent in a letter when her son first moved in to the new residential worker. When the worker started to support the man who had moved in, she was told to go and read the letter from the person's mum. Amongst other things it said that if her son was ever distressed, the best thing to do was to hold up your hands, sway gently and sing the 'Feed the Birds' song from Mary Poppins to him and then he would calm down. It worked brilliantly – but the chances of ever having found that out without the mum's help was incredibly slim!

This person-centred approach is useful for:

- identifying exactly what good support means for the person
- describing in detail what people who support the person must do
- seeing what support someone may need to participate in community opportunities, college or at work
- discovering what motivates the person
- examining ways in which the person might be supported to become more independent.

This person-centred approach describes in detail what support an individual wants or needs as well as what works for and motivates them. The 'how to provide good support' approach does not include things that the person can do for themselves. This approach should also address any important health issues that need to be considered. Where there are issues of health that are sensitive and/or very personal, a judgment needs to be made about who needs to know the information and in what detail.

One way of recording this is to put items under two headings: 'what works' and 'what does not work' for the person. The 'what works' section may include how the person likes to be treated, what kinds of people she gets on with best, or what motivates them, such as praise and encouragement, rewards, small steps and celebrations. The 'what does not work' section may include the situations that frustrate or frighten the person, when their energy levels are lowest, or when they get bored or miserable.

To be successful in supporting a person means helping them to have more of what works for them and less of what doesn't. Very often a key part of supporting someone to make choices for their future lies in understanding the way that that person communicates. A communication chart can be drawn up to enable new people to understand the individual better.

## Communication chart

Older family carers usually understand exactly what a person is trying to express, even without speech. The skill here is in getting the older family carers to realise that and support them to find a way of capturing that information for others to use. Similarly, this approach is useful for helping older family carers see that people may have different ways of communicating with different people and it can help them be reassured that others do understand and have good relationships with the person they care for. For example, in the course of completing a life book, one older family carer's son returned from the day service and started saying 'ten-pence' to his mum repeatedly. She immediately got up and fetched him a drink. When asked by the worker, she revealed that to her son 'ten-pence' meant he wanted a drink – 25 years earlier at his day service he used to have to take 10p with him for a drink so that's what he called drinks now. Her son's words were now part of her everyday life and language so she had not realised that it was anything special to be pointed out until an outsider (the worker) observed it. Following this, the carer and worker began to compile a comprehensive list of his vocabulary that became absolutely critical in supporting workers to communicate effectively with her son when he started at an overnight breaks service a few months later.

This person-centred approach is useful for:

- exploring people's different perceptions about how the person communicates
- explaining exactly how the person communicates with us.

Many people either do not use words to talk or use few words. This person-centred approach is vital to developing an understanding about the individual. It needs to be completed very early in the development of any plan. Start it with the people who know the person best like family carers, and then check it out with others involved in the person's life.

In getting to know a person who does not use words to communicate, it is vital to find out how they communicate and to be aware of subtleties that are easily missed. It is important to find out who knows the person well and who is able to read the slight changes that can tell so much about how a person is feeling.

Listening to someone who does not use words means finding out:

- What are the person's mood indicators – how do we know if she is happy, sad, bored or angry, frustrated or excited in different settings, at different times. How do we gauge likes and dislikes?
- How does the person indicate choice or preference?
- How does the person use eye contact?
- What do other facial expressions mean? Are they obvious, like smiling, or something easier to miss?
- Do they use different vocal tones?

- When does the person fidget and when does she pay attention?
- What does her posture mean?

Any changes in how the individual engages or presents are important for any transition and informing the planning process.

There are many ways of recording the information gathered at this stage and often support from a Speech and Language Therapist, who is creative and experienced, will help a group to think through how best to make this information individual friendly and accessible. These ways may involve photo-diaries, drawings, graphics and objects. Often it is necessary to try different ways of recording before the most accessible is found. One way is the communication chart used in essential lifestyle planning. The communication chart is designed to support people who do not use words or have difficulty in communicating with words, to talk. It is also useful for people who do use words but whose speech is more difficult for others to understand.

<b>At this time</b>	<b>When Kath does this</b>	<b>We think it means</b>	<b>And we should</b>
Any time of the day.	Kath looks to the left or right with a fixed expression for anything up to a couple of minutes.	Kath is having an absence.	Reassure her and talk calmly to her. Stay with Kath till she has recovered.
Any time of the day.	Kath makes a loud shouting noise.	Kath is unhappy with demans being made on her.	If you can stop the activitiy, do so. If it is something that Kath needs to continue with, eg. crossing the road, continue, but explain why in a calm, reassuring voice.
In the Jacuzzi.	Kath reaches out towards staff.	Kath is feeling unsafe.	Make Kath more safe, if she is sitting on the edge of the seat, help Kath to sit back and if Kath wishes carry on holding her hand.
Any time of the day.	Kath holds hand of staff.	Kath wants physical contact.	Tickle and or, stroke Kath's hand.

As shown in the diagram above, the communication chart has four headings.

- At this time – this describes the circumstances.
- When (person's name) does – this describes what the person does in terms that are clear to a reader who has not seen it (a picture or even a video recording may be preferred for e.g., a facial expression).
- We think it means – this describes the meaning that people think is behind the behaviour (it is not uncommon for there to be more than one meaning for a single behaviour – all meanings should be listed).
- And we should – this describes what those who provide support are to do in response to what the person is saying with their behaviour (the responses under this heading give a careful reviewer a great deal of insight into how the person is perceived and supported.)

It is easiest to complete the communication chart by starting from the two inside columns first (when ... does, we think it means) and then working out to the two outside columns (at this time, and we should). The most important thing to remember when compiling a communication chart is that the emphasis is on the appropriate response from those supporting the person, rather than on changing the behaviour.

The communication chart may never be finished. It should be an ongoing process of recording and review and it can be used as a logbook with the aim of understanding and supporting the person in the best way possible. Older family carers may need on-going support to help record and review information.

## History

It is essential to capture older family carers' perspective on a person's life history before it is completely lost. It may be that a history is developed with and for the person who has a learning disability and additionally a wider history about the whole of the family. This is particularly vital for people not using any/much services. Residential workers have talked about people coming into services in an emergency and having 'no identity' from before. This is because the parent has died suddenly and there has been no-one left to fill in the gaps of the past 40 years if the person is not able to do so themselves. Again, this may be really cathartic for the older family carer, to be able to tell his or her story and be listened to and know someone has recorded this for the individual.

A history or past experiences person-centred approach is useful to:

- keep in touch with the person's history
- identify the landmark or milestone events in the person's life
- trace themes through a person's life story
- identify experiences that must not be repeated
- celebrate achievements

- identify opportunities and positive experiences that can be built on
- identify people or activities from the past that have gone missing and which the person might want to reintroduce.

### Fears and nightmares

It is absolutely crucial to get family carers' perspective on what they think these are for the person they care for, but they must be supported to SEPARATE out and address their own fears and nightmares for the person and for themselves. The most critical bit for them is to be supported with what they say and this needs to be acknowledged and addressed. People need to be prepared to take action on issues that have been described in order that trust is not broken as it may be very hard for families to share these thoughts.

A fears and nightmares person-centred approach is useful to:

- identify experiences and situations to avoid at all cost
- identify places to avoid
- identify types of people to avoid
- enable people to name their fears, especially if there is conflict over what is the right way forward for a person.

### How I spend my time

It is important to acknowledge here that older family carers might feel some guilt about this. Many worry that the person is getting 'old before their time' because they are not able to support them to get out and about as much as they have previously, usually because of age-related issues and transport. Again, it is vital to get older family carers involved because there may be activities people are not doing that much now but they used to enjoy. Older family carers can help remind people about what they used to enjoy and help to get people started on things again. Also, it may be with some reluctance that people with learning disabilities get involved in pursuits, as they may be worried about their older family carer being left alone. It is important to bear this in mind and be particularly sensitive in situation where older family members may be mutually dependent on each other.

This approach is useful for:

- identifying the activities that the person is already involved in that may be a starting point for transition
- understanding more about the person's preferences so that they can be expanded upon.

This approach records the places that the individual goes during the day, week and year. Over a time span of this length it manages to cover both regular and occasional

activities. It also lists all of the activities and places a person is involved in. It might also be helpful to record to what extent the person participates in the activities and who else is involved.

Questions to ask

- Where do you go during the week?
- Where do you go in the evenings and at weekends?
- Who do you go with? (Alone? With family? With friends?)
- Who makes the arrangements for the activity (e.g. who books the bowling alley, looks out bus times etc.)?
- Do you meet and get to know other people at these places or activities?
- Which of the activities do you enjoy the most?

### Looking for patterns and themes

Once enough information has been gathered from the various person-centred approaches, it will be useful to spend some time reflecting on what has been collated. It might be possible to identify patterns or themes, which could help point to what is important now and what the person and their family want for the future.

Questions to ask include:

- What are the gifts and interests to appreciate and build on?
- What support and routines do we need to consider?
- What environments and places work best for her?
- Are there any particular timescales to work to in terms of short and long term plans?
- Are there any issues that particularly need to be addressed in terms of the person and their family?
- Are there times of the day that work best for her?
- What is the person already doing that she would like to do more of?
- What would take her closer to her hopes and dreams?
- How much time does she spend doing things in groups and how much time alone or with one other person?
- Could any of the activities be adapted to create opportunities for meeting and getting to know other people?

At this stage, it may also be important to cross reference information gleaned from using the person-centred tools with outcomes from any carers needs assessments that may have been carried out with older family carers.

## Conclusions

When you use any of these approaches with older families whatever the next stage is in making plans, make sure families aren't just left with a colourful piece of paper. It will have taken a lot of courage for many older families to go through the process and they can't just be left dangling. Make sure everyone is very clear on what happens next and what roles everyone takes. Don't leave everything to the family (unless it is clearly their choice) otherwise you may leave them feeling abandoned and that they are back at square one with no clearer idea about what will happen in the short and the long term and how to support their relative to bring about positive changes in their life. However now their situation will have worsened: their hopes and expectations may have been falsely raised and they will be unlikely to enter into the process again willingly.

Using person-centred approaches for planning with older families is one of the key objectives of *Valuing People* and Learning Disability Partnership Boards have usually invested a great deal of time and resources into ensuring that their strategies for implementing person-centred planning are successful. As this paper has shown, the particular barriers and issues facing older families may require more intense input from facilitators than with other groups of families. With this in mind, the next section will focus in more detail on some of the key strategic and practical implications that need to be addressed by person-centred planning facilitators and coordinators in order to ensure greater success in making realistic and plans that will bring about positive changes in the lives of people with learning disabilities and their older family carers.

Material in this section has been adapted from 'Friendship and Community' by Jo Kennedy, Helen Sanderson and Helen Wilson.

## Part 4: Key strategic and practical implications for person-centred planning Facilitators and Coordinators

This resource has already highlighted the key issues facing older families that may impact on the success of person-centred planning with older families. It has also highlighted the way that person-centred approaches can be particularly effective ways of working with individual families. This final section examines the strategic and practical implications of this for people who are coordinating person-centred strategies and those that are implementing planning on a daily basis with a variety of people, including people living at home with older family carers.

### Key issues for PCP Facilitators

Facilitators have a rich toolbox of person-centred approaches to draw on in supporting families and people who have disabilities. However this is not enough. These are some key considerations that need to run alongside any person-centred planning with and for people who have learning disabilities and their older family carers.

#### 1. Understanding the person in the context of their family

This paper has strongly recommended that person-centred planning facilitators are able to develop plans for and with the person who has a learning disability and for the family as a whole if needed. A family approach is important because of the mutual support, companionship, and the support that people with learning disabilities often provide to their older relatives due to their health needs and the shared history. **(For more information and examples of family essential lifestyle plans see [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk))**

#### 2. Developing person-centred cushions

Cushions are things that soften the impact of events, and person-centred approaches and planning can act as cushions for families. We need to remember that we cannot stop things happening but through careful planning we can really reduce the stress and uncertainty and ensure that people get support that makes sense to them and their families.

Facilitators will need to be able to answer the following questions:

- What cushions do the family already have in place?
- Who or what are they? The information may be given when people are developing a relationship map with the family.



- What support does the family need to ensure that their ‘cushions’ remain in place or to change their shape if they no longer are a good fit?
- How can facilitators gather this information as part of planning?
- Which of the ‘cushions’ are the top priorities for the family to develop?

You can use person-centred questions to gather information such as...

- If you had a magic wand that only did horrible things and you used it to give the person a really awful day – what would it be like?
- If you had only 2 minutes to give advice, suggestions, top tips to a supporter before you had to leave the person to be supported by them what would you say?

The answers to these questions can lead to a facilitator being able to describe a range of options and supports that can act as cushions. The skill is to ensure that there is a good balance between the needs of the family and the person who has a learning disability.

### 3. Maintaining community inclusion

Facilitators need to sensitively negotiate their role in someone’s life with regard to existing community networks, especially bearing in mind that many older families will not have had support from services. They may have well developed networks and friends. These need to be respected and maintained and not put under pressure through the planning process. Maintaining these relationships is vital.

### 4. Time and urgency

Facilitators will need to be clear about the time that they may need to plan successful with an older family. The importance of developing relationships, and encouraging story telling over a cup of tea needs to be stressed. This time will need to be negotiated with managers and be addressed strategically by person-centred planning Coordinators and Partnership Boards. A balance needs to be found between having to take time to get to know people and learn about their history where there may be urgency in addressing issues because of the particular needs of the family. Facilitators need however to resist the lure of the quick fix and make sure that solutions that are found are what people really want. There will be a greater need to explore with older families what is possible so that they can make decisions from an informed stance, as they may have had little up-to-date information about what is available for a very long time, if at all. Putting family members in contact with other families that have used person-centred planning approaches would be very useful as this makes it real and relevant.

## 5. Creatively in planning

Facilitators will need to be confident using the approaches described in Part 2 of this paper. There will be a strong need to use a 'pick'n'mix' approach depending on the family. For example, essential lifestyle planning will really help to look at balance between the person and their family but not give you a clear enough picture of a person's history. A Path can be used to create a compelling future but will not give the detailed day to day information about support issues. Being clear about why you are planning and what you need to learn at the outset will enable the facilitator to choose the approach much more productively without diluting the power of the specific approach.

## 6. Gathering information

Families will have all sorts of invaluable information at their fingertips. Ask people about things that they can share with you, like photo albums, projects that the person has done, and review reports. Use this information to form the basis of how you are going to start gathering information for the plan. This stops people having to go over things time and time again and recognises their contribution and knowledge.

## 7. Your own personal role and stance

Facilitators will need to be clear about their role and be prepared to and expect to be flexible. As a facilitator, it will also be important for you to stand back and think carefully about any prejudices you may have towards family carers or older people that may influence the way you may work with an older family. Think about the relationships you have had with older families in the past – whether they have been positive and why previous work may or may not have been successful. If there is any specialist work going on with older family carers in your area, it may be a good idea to get in touch with workers or carers groups and have a talk with them about the best ways to work positively with older families. Ensure you come to the process ready and willing to try to understand situations, issues and concerns from the perspective of both the person with learning disabilities and their older family carers.

As a facilitator, you will need to be someone that is able to work their way through the service system to get resources for the family, provide reliable information and be a point of contact for the family. This breadth of role has implications for the support that facilitators may need from others. Facilitators may need to gain new knowledge e.g. for example integrating the planning with regard to carers' needs assessments. Older families may need facilitators to be the point of contact for other people that are supporting their relatives. Facilitators must be clear with the family about what they are able to say or not say to other professionals to ensure that the person who has a learning disability and the family stay in control of the plan.

## Key issues for person-centred planning Coordinators and Partnership Boards

There are some key issues that person-centred planning Coordinators and Partnership Boards need to take account of strategically to ensure that more than lip service is being paid to planning with older families:

### 1. Time commitment, trust and consistency is needed from facilitators

Planning with older families will probably take more time than planning with younger families. Trusting relationships need to be built up and, since most plans with older families are likely to include the major issues of moving on, the process needs to happen sensitively and at a pace that makes sure that everyone is working together and feels a real part of the plan. It can take years before a family is able to actually go from the stage of identifying the dream to fulfilling it. People need to remain engaged during this time and if older families feel that they have been abandoned halfway through a process then not only will they feel badly let down, they are also less likely to engage with people over this issue in the future. The people who will then lose out will not only be the person with a learning disability who may have less choice about their future, but also services who don't have the information they need to be able to plan services and support most effectively.

### 2. Identify who will review plans and make sure people are doing what they should be.

When starting the planning process, facilitators also need to be really aware that someone needs to be identified to make sure that plans are regularly reviewed and that people are carrying out their assigned roles. Often family carers may take on this role, but it can be a very difficult for an older family carer to take on. Problems may arise where there are no other family members involved where an individual is not linked into any formal services. Then there will not be a key worker or equivalent to keep in touch with and get support from to move plans forward.

A study by Christine Bigby (2000) in Australia showed that what made the most difference to the experiences of people with learning disabilities who had moved on from living at home with older family carers was who, if anyone, assumed the role of overseeing and advocating for/with an individual as their family carer had previously. Bigby calls this 'key line succession planning'. The same principal can be applied to person-centred planning. If there are not systems built into the process for identifying who will support plans to be acted on, in the short and long term future, then they may fail to get off the ground at all. Person-centred planning coordinators need to take this on-board and build strategies for meeting it into their systems for supporting older families to plan for the future. Supporting the development of

strong circles of support around older families is an extremely effective way of ensuring that goals and dreams are not lost.

### 3. Link person-centred plans with Carers Needs Assessments

It is critical to ensure that person-centred planning facilitators understand how a Carers Needs Assessment can be used to provide real outcomes and support to family carers. *Valuing People* told local authorities that they would be measured on the percentage of older family carers ‘for whom a plan for the future has been agreed’. This is being measured by the number of older family carers of people with learning disabilities who have had a carers needs assessment. Furthermore, new guidance puts more emphasis on the carers needs assessment leading to real outcomes for the family carers. Coordinators need to ensure that facilitators are informed and understand how a carers needs assessment might be useful to moving things forwards for older families and how to go about getting one completed. Similarly, assessment and care management systems need to be able to respond to concerns and referrals from facilitators involved with older families so that any carers needs assessment can happen alongside the person-centred plan. Linking person-centred planning in with processes for carers needs assessment offers the opportunity for facilitators to make sure that the needs of both the family carer and the person with learning disabilities are being addressed.

### 4. Link outcomes into strategic plans

It is important that key outcomes from person-centred plans are linked into other strategic work that is going on in local areas. In particular, where housing and support needs are being identified then it is important to develop a system to link these needs into local housing strategies that are also being drawn up and implemented as a result of *Valuing People*.

Similarly, local authorities have been set a performance indicator through *Valuing People* that measure the percentage of family carers ‘for whom a plan for the future has been agreed’. This is currently being measured by monitoring the number of family carers over 65 years who have had a carer’s needs assessment. Since person-centred approaches with older families may well lead to a carers needs assessment being requested, it’s important to have good information systems set up so that older families needing support can be prioritised for person-centred plans and that facilitators can highlight any older family carers who might benefit from an assessment.

## Conclusions

Person-centred planning offers a strong framework for giving people the opportunity to open up on going relationships and processes that can continue to capture the learning about a person as they grow and make changes. This ongoing process, reinforced by a strong circle of support, will give older family members, if used sensitively and respectfully, a great sense of involvement, control, confidence and reassurance for the future.

Overall, if services are more joined up and seem to be linking together and offering older families some long-term commitment to support them with planning for the future then those same families are more likely to choose to take the risk of opening up and exploring their hopes, fears and dreams for the future and start to plan ahead.

Remember, planning is a promise and the start of a process and not the end.

## Part 5: References and Resources

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Free to download from [www.learningdisabilities.co.uk](http://www.learningdisabilities.co.uk)

## Resources

### **Good Practice Guidelines: Older Families**

The Older Family Carers Initiative has produced a number of good practice guidelines that can be downloaded freely from the website at [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk) Good practice guidelines cover topics including identifying older families, carers needs assessments with older families and planning for family emergencies with older families. The guidelines are intended as tools to help Learning Disability Partnership Boards, commissioners and older families to reflect on the way that services and support are offered to older families in their local area.

### **Carers Link Officer – Shropshire**

The Carers Link Officer supports family carers in rural Shropshire and is part of the Care Development Team hosted by the Community Council of Shropshire. Carers needs, dreams and plans for the future are recorded when family carers are regularly visited by the Carers Link Officer or the Older Family Carers Support Worker. Carers needs assessments for people with learning disabilities living with older family carers have also been developed. By building trusting relationships with families, the two workers are able to support families in thinking about their own needs and futures as well as the person they care for. For more information contact: Flick Pennal on 01939 211006 or email her on [flick.pennal@shropshire-rcc.org.uk](mailto:flick.pennal@shropshire-rcc.org.uk)

### **Lifetime of Caring**

A website that focuses on raising awareness of the needs of older family carers and their adult relatives with learning disabilities, provides open learning materials for frontline workers and offers practical suggestions for how services might become more responsive to older families. Website: [www.lifetimecaring.org.uk](http://www.lifetimecaring.org.uk)

### **Sharing Caring Project – Sheffield**

The Sharing Caring Project (SCP) is part of Sheffield Mencap and has been running since 1996. The project originally began working exclusively with older family carers but has recently expanded to offer information, advocacy and support to any family carer of an adult with learning disabilities in Sheffield. Reports and tools produced by the SCP include the reports 'Crisis Approaching!' and 'Preparing for the Future', 'My Life Book' and papers to support workers in completing Life Books with older families, and the training awareness video 'Elsie's Story'. For more information contact: Sharing Caring Project, Norfolk Lodge, Park Grange Road, Sheffield S2 3QF Tel: 0114 2758879 / 2767757 Email: [office.sharingcaringproject@btconnect.com](mailto:office.sharingcaringproject@btconnect.com) Website: [www.sheffieldmencap.org](http://www.sheffieldmencap.org)

**Older Family Carers Initiative** (OFCI) aims to support Learning Disability Partnership Boards to identify and meet the needs of older family carers of people with learning disabilities as prioritised in *Valuing People*, the Government's white paper on learning disability. The OFCI, led by the Foundation for People with Learning Disabilities, has produced these guidelines in partnership with Helen Sanderson and Alison Short to provide useful, good-practice reflections about ways of taking person-centred planning with older families forward. They are intended as a tool to help Learning Disability Partnership Boards, commissioners and frontline workers across England reflect on the way that older families are supported to plan in their area. OFCI is funded by the Department of Health through a Section 64 grant.

For more information about the Older Family Carers Initiative contact:  
Older Family Carers Initiative, Foundation for People with Learning Disabilities,  
Sea Containers House, 20 Upper Ground, London SE1 9QB Tel: 020 7802 1100  
Email: [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk) Website: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

**Helen Sanderson Associates** is a development agency exploring how person-centred planning and thinking can contribute to changing people's lives, organisations and communities. We provide training and consultancy in using person-centred approaches and planning with older family carers. We are working with families to develop family 'life story books' that include some of the person-centred approaches described in this booklet.

Website: [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)  
Email: [helen@helensandersonassociates.co.uk](mailto:helen@helensandersonassociates.co.uk)



## Notes

## Notes



## Our Mission

We promote the rights, quality of life and opportunities of people with learning disabilities and their families.

We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information.

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