

# Perspectives on ageing with a learning disability

Cally Ward

January 2012  
[www.jrf.org.uk](http://www.jrf.org.uk)



Pat

*Everyone gets older. We celebrate getting older every year with our birthday. Some things are good about getting older. Some things are difficult about getting older. It is different for everybody.*

*(Pat, Growing Older with a Learning Disability group member)*

This paper explores what people with learning disabilities and their families have to say about getting older, their experiences and feelings, and what is most important to them in later life.

Older people with learning disabilities are a diverse group. Each individual comes to later life with his or her own unique life experiences and hopes and fears for the future. Their needs for community support and services vary greatly.

Chronological age is often used as a trigger to access services and support for older people. However, this is not a useful indicator of a person's age-related needs. Some people in their 50s with chronic health conditions can feel prematurely old and have restricted lifestyles, whilst other people in their 80s and 90s can still be robust, active and very healthy. It is well evidenced that people with learning disabilities have high levels of unmet health needs as a result of the inequalities they have experienced in the health system (Bigby, 2004; Bigby, 2010). This puts them at risk of increased health problems in later life.

Some groups of people with learning disabilities carry particular age-related health risks. People with Down's syndrome make up between 15–20 per cent of the population of people with learning disabilities who have a known cause for their disability. They are at high risk of developing a number of age-related health problems prematurely, including Alzheimer's disease. Therefore, for the purposes of this paper, we are including people of 50 and over as falling into the older age group.

## About the author

My interest in the issues of ageing and people with learning disabilities goes back a long way and is both professional and personal. On a personal level, as the mother of a 40-year-old son with Down's syndrome, I am only too aware of the future challenges he faces in terms of his health. As a family we are growing older together and need to plan for a time when our circumstances inevitably change. Like so many other families, we face the future with a degree of trepidation.

My working life has been devoted to championing the rights of people with learning disabilities and their family carers. I believe passionately that they have the same right as anyone else to enjoy life opportunities and get the support they need to do so. Sadly, many of the present generation of older people with learning disabilities have been denied this and now face double discrimination. Devalued as disabled people they have had limited choice and control throughout their lives – now as older people, they are exposed to the inherent ageism of a society which makes assumptions about what they can and cannot do, and are all too frequently institutionalised by the way services are delivered.

Because of the work I have done on ageing, I worry that the needs of older people with learning disabilities fail to get the same attention as those of younger people with learning disabilities. We all face transitions at different stages of our lives. When people in learning disability services talk about 'transition' they are usually referring to the transition from childhood to adulthood. The transition into old age for people with learning disabilities is equally important and needs the same sort of co-ordinated focus and joined-up, person-centred planning.

## Participants

This research would not have been possible without the help of the Growing Older with a Learning Disability (GOLD) group and older families from the Sharing Caring Project. The GOLD group came together in 1998 to support a project about getting older at the Foundation for People with Learning Disabilities. When the project ended in 2002, the group wanted to continue both to meet socially and talk about their experience of growing older. The Sharing Caring Project has been part of Sheffield Mencap for the last 15 years. The project supports over 600 families across the city, offering information, advocacy, group and individual support, and helping families to get the help they may need now and in the future. Both groups have provided invaluable support, inspiration and guidance. It is their priorities that have shaped this paper.

## Growing older with a learning disability

When John was born they told us he would not live long, that children like him died early. Well here we are altogether still 60 years later!

*(Older family carer, Sharing Caring Project)*

Like the rest of the UK population, people with learning disabilities are living longer than ever before. This is something to celebrate, and testimony to the fact that social conditions and life opportunities have improved for the majority of learning disabled people. Older people with a learning disability represent one of the fastest growing groups of the learning disabled population. Recent estimates suggest that, by 2030, the number of adults aged over 70 using services for people with learning disabilities is likely to have doubled (Emerson and Hatton, 2008). We also know that many older people with learning disabilities and their families are not known to these services until they are in crisis (Department of Health, 2010).

## Nothing about us without us - What matters to older people with learning disabilities?

A lot has been written about older people with learning disabilities and the challenges they face, but rarely has it been written from the point of view of older people themselves.

Older people with learning disabilities told me they valued the opportunity to speak for themselves, having someone spend time with them and listen to what they had to say. Sometimes this is especially difficult if people have communication difficulties.

The GOLD group have made a film about their experiences of growing older. The issues that are discussed here are the things that they say are most important to them – some of the quotes are taken from my discussion with them, and some come from the film.

The people the project supports and who come to the Sunday lunch club are all so different. Some of the older people with learning disabilities that come live on their own and don't get a lot of support from social services. They are okay but they can get a bit lonely and enjoy meeting up with their old friends. With some of the older families that come together, the parents are in their 80s and even one or two in their 90s. Some of them are still caring for a son or daughter with very high support needs. In other families the son or daughter is taking on a caring role for their older parent.

*(Sunday lunch club worker, Sheffield Mencap)*

People need to listen to us. We know about things.

*(John, GOLD group member)*

## Having a home

People live in all sort of different places. Some people live with their family. Some people live with other people. Some people live alone. Where you live is very important to you.

*(Pat, GOLD group member)*

Home, the place where we live, is important to us all. It is not just a place of residence but also a place where we want to feel secure; a refuge from the hurly-burly of the world.

People with learning disabilities find themselves growing older in many different places. They are more likely to have experienced institutional care from a young age, because at the time they were growing up public policy favoured institutional over community care.

Roger, for example, lives in a house with three other men with learning disabilities. He has lived there since he came out of a large hospital for people with learning disabilities that closed down over 20 years ago. The people he lives with now are not the same people he moved in with.

The majority of people with learning disabilities, however, are growing older in the family home, many with ageing parents. Sometimes, when parents have died, they live with other family members. Other people stay living in the family home or move into supported living, residential care or their own home.

One of the positive changes in recent years has been the opportunity for people with learning disabilities to have a greater presence in the community and live more independently. George lives in the flat that he used to share with his

It was hard living here on my own when mum died but I didn't want to leave my home. I like living here. It is good to share with Brian.

*(George, older man with learning disabilities)*

mum before she died. Now he shares the flat with his friend Brian. Social services and the Independent Living Fund (ILF) fund their support. Michael and Sylvia both moved out of group homes to get a flat of their own:

Twelve years ago I was living in a group home and, the weekends, I used to go home to my parents. Now I am an orphan but also now Sylvia and I got married. We like having our own place. Before that Sylvia used to live in a group home as well.

*(Michael, GOLD group member)*

But this independence has brought some new risks and people with learning disabilities are often exposed to bullying and hate crime. Although no one in the GOLD group said they had experienced this, people did feel that they had been taken advantage of by people that they knew, neighbours and support staff; often in relation to money.

I feel so embarrassed that I gave her so much money. I didn't like to tell anyone. It has made me very wary of people. She was paid to be my carer.

*(GOLD group member)*

## Planning for the future

What will happen to me when I get older? Will I have to move out like Billy did when he got ill?

*(Older man with learning disabilities in supported living)*

As people grow older, they worry about what will happen to them as their circumstances or health change. People with learning disabilities are no different.

When the GOLD group discussed what should happen if they became unwell and needed to move, Michael was clear: 'I want to stay where I am. I don't want to leave'. Roger did not want to move either. He had real concerns based on observing what happened to his grandmother years earlier: 'Not many people look after people. My Nan put in home. Didn't look after her. Not many care homes very good'. Pat, however, considered that a move may be necessary in certain circumstances: 'Sometimes if they need more help they have to move. Sometimes things change'.

In the past, many people with learning disabilities did not have any choice about where and when they moved if their health or mobility declined in later life. Research has shown that many people with learning disabilities were, and still are, being placed in older people's nursing or residential care inappropriately, at a much younger age than other residents and with a much lower threshold of needs (Thompson *et al.*, 2004).

Chris lived with his parents until they died when he was in his early 20s. First he lived in a hostel with 25 other people and after a few years he moved to a residential care home for six people with learning disabilities. A few months ago he moved to a nursing home for people with dementia. He is 59, but everyone else there is over 80.

### ***Ben's story: An example of person-centred planning***

Ben lived at home with his Auntie Mabel, who had cared for him since he was a child. Although known to services, he had not used any funded care since he was a child. Ill health had left his aunt with physical disabilities and she and Ben looked after each other and made a great team. Ben was supported by an older families project to develop a person-centred plan that included his life story, his likes and dislikes, how he liked to be supported and his fears and wishes for the future. All his family were involved, along with workers and friends who had known him for years. As a result of this planning, Ben was supported to build his independent living skills and social life, and his name was added to the tenancy. When his aunt died suddenly, Ben was smoothly supported to remain living in his own home with support workers he already knew, as planned. His worst nightmare of having to leave his home and 'go into care' never came true.

### ***Joy's story: Having a say in housing options***

Joy was living in a house with two other women but was having problems with her health and developed mobility problems which made it hard to climb the stairs. Social Services wanted to move her to a residential home for older people but she did not want to go there. Joy wanted her own home, something she had never had. Her support staff from the learning disability care provider fought for her to be moved into warden controlled sheltered accommodation for older people, and continued to provide 24 hour support for her there. For the first time in her life, Joy is not living with other people with learning disabilities. She takes part in many of the activities where she lives, has made lots of new friends and is very content.

Local authorities have been criticised for not planning with people who are growing older in the family home with ageing parents. In a worst case scenario, if a parent suddenly becomes ill or dies, a person can lose their home, their primary carer and all that is familiar to them on the same day; a traumatic prospect for anyone. However, there are some examples of good practice where local authorities have invested in supporting older families to prepare for the future (Department of Health, 2010; Magrill, 2007).

In my view, older people with learning disabilities need a wider choice of housing options so they can choose the one that is right for them. They, their families and the people that support them need more information about the options available and how support can be personalised to allow them to live in the place that suits them best.

Older people should have the opportunity to 'age in place' if this is important to them. This means ensuring the home environment can be adapted if necessary. It also means equipping staff to become more age aware and develop their knowledge and competence to support people in later life. Supporting people to continue living in their family home when their parents die requires identifying families and supporting them to plan for the future.

For the last 15 years, Sheffield has invested in building support structures into its existing statutory and voluntary sector services to meet the needs of ageing families of people with learning disabilities. Older families in Sheffield are now routinely identified, regularly visited and offered support, which includes making emergency plans and exploring long-term options. As one family carer said, 'We didn't know who to go to or where to go to before all this started'.

Ageing in place might not be right for everybody; some might need or want to move as they get older. The key is planning for transitions when needs change and ensuring support and care remains person-centred.

## The importance of family

Who's going to speak up for my son when I'm not here? Who's going to notice if he's not happy or if he needs a new winter coat or if someone's hurting him? He can't tell them so who will?

*(Maureen, older family carer from Sharing Caring Project)*

As we have seen, most people with learning disabilities still live at home with their families. Even when people move into other settings they still rely on family for practical and emotional support, as well as advocacy. As one mum said, 'she may have left the family home but she's not left the family!'

Whilst older parents celebrate the fact that their sons and daughters have survived beyond expectations and enjoyed a full life, worries about what will happen when they are no longer able to care are often overwhelming.

Older families have consistently said that they want:

- to be known to services before a crisis and have emergency plans in place;
- to feel confident that they have passed on all the information that people may need to support their relative in the future;
- support to make plans for the future and to stay together for as long as they want;
- positive partnerships between families, care workers and services;
- clear, up-to-date information, and support to make good use of it;
- to make their own decisions without feeling rushed into making changes or judged for the way they have cared; and
- to know that the person with a learning disability will be happy, safe and helped to speak up when older family carers are no longer able to support them.

Many people with learning disabilities are taking on increasing caring responsibilities for older relatives, usually parents. Many take pride in this; Michael, who looked after his mum with dementia at home until she was 91, says, 'I'm proud to be a carer. It's the most important thing I've ever done'. Tony is 69 and lives with his mum who is 91:

I try to help with the hoovering, cleaning and washing. Mum won't let me do the cooking, she's very independent. If she's ill or anything she doesn't mind but she tells me how she wants things done. I worry about how my mum is when she is out on her own. I'd rather go with her and know she is ok. She's my mum and she looked after me and now I look after her. 50:50 I call it.

*(Tony, Sharing Caring Project)*

All carers need to be able to access support in the right way. For example, information needs to be clear and accessible; carers should be supported to understand their rights to a carer's assessment, as well as signposted to sources of practical, financial and emotional support. It is also important that services treat family members as a unit, as the following examples illustrate.

Mutual caring does not only happen between family members – increasing numbers of older people with learning disabilities also care for their spouses, partners and friends. Pat in the GOLD group supports her partner Ray and is part of a national network of carers with a learning disability.

### *One pizza, two care workers: The need for joined-up solutions*

A community nurse was stunned to meet two different support workers in the course of her 90-minute visit to an older family. One worker was funded by older people's services to help Mum and cooked her half a pizza. The other worker was funded by learning disability services and supported the daughter to cook the other half of the pizza. The family thought it was strange and would have liked to eat a meal together sometimes, but they assumed the council knew as they were funding it. Once the nurse reported the visit to her manager the situation was highlighted and a joined-up solution agreed. Now the learning disability service funds just one worker for the same amount of time to support the daughter to cook a meal for her and her mother.

### *Barry's story: Support for family carers with learning disabilities*

Barry was struggling to cope as his mother's health deteriorated following a stroke. It was months before a doctor at the GP practice he visited regularly recognised Barry's stress and realised that he was doing most of the care himself as agency workers were only in for half an hour morning and night. Barry was supported by a local advocacy group to complete an accessible version of a carer's assessment and start thinking about what would help him and give him breaks from caring. As a result, his mum's care was increased and her medication was supported through a 'nomad system' so he did not have to worry about getting her pills wrong. An alarm was fitted so he could get help at the touch of a button, and a sitting service got involved so that he was free to go out and join a social club to make friends and play snooker for the first time in years.

### *Staying in touch with friends*

Some people get very lonely  
when they get older. I miss  
my friends from the old days.  
Friends are very important.  
Sometimes it is hard keeping in  
touch with friends. They live a  
long way away.

*(Betty, GOLD group member)*

There are many benefits to having friends in your life. Friends remember your birthday, share the good and bad times in your life and make you feel valued. They are people you can relax and 'be yourself' with. Older people with learning disabilities tell us they enjoy being a friend as much as having a friend. Yet for many people with learning disabilities, subject to multiple moves in their accommodation and daily services, friendship has not been something that services paid attention to and important relationships have not been sustained.

Older people with learning disabilities are at risk of being isolated in later life from anyone other than those paid to support them. Research shows being in contact with family and friends can help ensure people get the care that they need and provide an important safeguard against abuse and neglect. This is recognised in English and Welsh law, with the Mental Capacity Act requiring independent Mental Capacity Advocates (IMCAs) to represent individuals in critical life decisions which they lack capacity to make themselves, if they do not already have such a person in their life.

I am Joan's friend. We have  
been together 30 years. We  
have fun.

*(Margaret, GOLD group member)*



### **Edna's story: Staying connected with friends and family**

When Edna joined the GOLD group she was living in her own flat with support. She then suffered a number of falls, developed dementia and had a stroke. Edna moved four times, not including long stays in hospital. For the past six years she has been living in a nursing home. She has two sisters, who stay in touch by sending cards and presents, but they live in different parts of the country and their own health means they are unable to visit. The GOLD group has supported Edna to visit her closest sister.

The people Edna met through the GOLD group are the main link to her past and her only visitors. They keep an eye on the care she gets, making sure she gets regular baths and does not spend every day in bed. Because Edna had little opportunity to get out for several years, she had a lot of savings looked after by a health trust appointee. The GOLD group arranged for this money to pay for a carer to spend one-to-one time with Edna and to take her out. The same carer has supported Edna for three years now and they are both familiar faces in the local community, including the market, cafés and church.

The role of friends in enhancing quality of life for older people cannot be underestimated. Older people with learning disabilities should be supported to maintain friendships from the past but also helped to make new friends. One way of doing this is encouraging people to keep up their interests and be involved in activities in the community.

What we never expected when we started the lunch club was how many people knew each other but had not seen each other since school or the time when everyone was in one big day service in the city. It's been 30 or 40 years since some people saw each other and they are so happy to be reunited. It's been an unexpected bonus that we've been able to reunite people but we're sadly only too aware that if they didn't see each other once a month at the lunch club then they might not catch up with each other again.

*(Sunday lunch club worker, Sheffield Mencap)*

### **An active and fulfilling life**

Just because we are getting older doesn't mean we can't do things.

*(John, GOLD group member)*

It has long been recognised that staying active and engaged is important for us all as we get older. People with learning disabilities are no different. It is important they have opportunities to continue doing the things they enjoy and are not forced to stop purely on the basis of chronological age. Older age can also offer opportunities to try out new things.

Some people, like Edna, will become confused and distressed by being made to stop doing something they enjoy just because they have passed a particular birthday. There is a danger that they will spend more time indoors, becoming isolated and potentially depressed. John lives in a group home with three younger men but when he reached 65 he was 'retired' from the day centre

When people get older they can do lots of things. Sylvia cleans offices. John volunteers for the Salvation Army. Roger calls the bingo numbers at bingo. Tim is chairman of People First. Betty makes rugs at the Jewish day centre. Sometimes people have to stop. Edna used to go to college and then she didn't go there anymore. I don't know why.

*(Pat, GOLD group member)*

he had been attending for many years. The minibus still collects the other men each morning and John gets very upset. The staff say, 'He gets very angry and upset and we don't know how to explain it to him in a way that will make sense'.

Those who are growing older with their ageing parents are also at risk of not being able to get out as much as they would like. Many older family carers worry about this.

I worry about Gary getting old before his time because he is stuck indoors with me. It's not right. He worries about me see. He won't even go to the day centre anymore. I try and tell him. It makes me sad that he should be stuck indoors with me just because I can't get out anymore because of these legs of mine.

*(Stan, 86, lone parent and carer)*

Despite the barriers older people with learning disabilities experience, Pat from the GOLD group says, 'Getting old is not all bad. Some people are enjoying new things'. Michael and Sylvia, for example, have started their own pop band and play in pubs. John recently went on an aeroplane for the first time and had a holiday abroad.

It is now easier for more people to find themselves included in mainstream activities for older people, as older people's organisations work to be more inclusive. Age Concern England published a Good Practice Guide *It's good to be part of things* (Wertheimer, 2004) to encourage and support local groups to make their activities more accessible to older people with learning disabilities. Some learning disability service providers are developing new and creative ways of supporting people to take part in more meaningful and fulfilling activities.

Eileen is an older woman that we have supported for many years now. She has been in residential care more or less all her life and has no contact with her family. Over the years she has acquired a reputation for having some behaviour that is challenging. She wants to pick up everything on the floor or pavement she sees and can get very angry when anyone tries to stop her. Now we have found her a job where she picks up litter on the beach. She loves this job.

*(Team leader, Avenues Trust)*

## Staying well

For all of us, growing older is associated with increased health risks. Certain health problems are more common as we age, but not inevitable. Older people with learning disabilities should be

As we get older, we may have more problems with our health. It's important we look after our health.

*(Pat, GOLD group member)*

supported to understand how important it is to eat a healthy diet, take exercise and have regular health checks. It is particularly important that women with a learning disability are supported to understand the changes that accompany the menopause.

As you get older you change,  
and one day your periods stop.  
I might miss months and keep  
missing different months and I  
get worried but the doctors said  
don't worry about it; it happens  
to everybody.

*(Older woman with learning disability, quoted in Today and Tomorrow, Foundation for People with Learning Disabilities, 2002)*

[You] have to eat healthily and  
drink milk to keep [your] bones  
strong. I drink milk before I go to  
bed at night.

*(Older woman with learning disability, quoted in Today and Tomorrow, Foundation for People with Learning Disabilities, 2002)*

The GOLD group have done a lot of work on health issues and are very aware of what support they need in this area:

I go to appointments. I think it  
is important. I have the same  
doctor. They explain what's  
wrong with you. He is good.

*(Roger, GOLD group member)*

Help you stay healthy. Give you  
the right support. Look in my  
health book. Staff job is to help  
you speak at the doctors.

*(Betty, GOLD group member)*

Make sure people take the  
right medication. Sometimes  
they forget. I speak up for  
myself. I don't want another  
epileptic fit in the bath.

*(Roger, GOLD group member)*

Sadly this awareness is not the case for everyone. Many older people with learning disabilities can be slow to realise when they are unwell and may not know what action to take or have no one to discuss their concerns with.

My own experience has alerted me to the fact that support staff do not always know much about ageing and associated health needs. This can put people at risk. As Michael's mum, I find myself having to provide support staff and his GP with relevant information about potential risks to my son's health.

There are some people who face more specific risks. People with Prader-Willi syndrome are more prone to diabetes, osteoporosis and scoliosis. People with Down's carry a high risk of developing thyroid problems, sleep apnoea, gum disease and Alzheimer's. According to some researchers, people with Down's have a one in four chance of developing Alzheimer's from as young as 40 (Holland *et al.*, 1998).

As more people with learning disabilities and their families grow older, dementia is an important issue. It can affect people with learning disabilities in many ways. In addition to being at risk of developing dementia themselves, they may witness a parent change as they develop dementia, or they can experience the changing needs of friends or fellow residents who get dementia.

Whilst it is important that health and social care systems are in place to support early diagnosis and appropriate interventions, it is equally important that older people with learning disabilities are supported to understand what is happening – to them or others they are close to.

I noticed not long after my mother died that when I used to go back home to visit my dad that he was doing odd things. Once I saw him trying to eat his soup with a fork. Sometimes he would go out and not come back for quite a while, perhaps he got lost. After that he moved to a nursing home. No one told me he had dementia. He kept wandering out from the home and getting lost. One day we went to visit him and he wasn't there any more, he had moved; the staff were very unhelpful and didn't seem to know where he had gone. I was very upset and very angry. At about this time we began to do a project on dementia in the GOLD group and this helped me to understand what was wrong with my dad.

*(Michael, GOLD group member)*

Tim worried that he might be getting dementia. He had seen his notes during a review and noticed that they included something about a dementia assessment. He did not understand what this meant and no one discussed it with him. When he eventually asked, he found that this meant that because he was older it was important that he was checked regularly for signs of dementia.

## Facing death and bereavement

Dealing with death – both of the people we love and our own – is something we all face. The Palliative Care for People with Learning Disabilities (PCPLD) network was set up in 1998 in response to concerns that people with learning disabilities were not getting the same access to palliative care as others.

The PCPLD network makes an annual award for the most positive contribution to this work. Pat, from the GOLD group, is on the committee that selects the winning contribution.

Finding out my father was very ill with cancer, I was worried. I had once watched an episode of Brookside on television where a woman with cancer was dying at home and in excruciating pain, but she couldn't be given any more morphine unless she was in a hospice. This was very much on my mind as I didn't want my dad to suffer. We nursed him at home but in the end he went into a hospice and he died peacefully.

*(Pat, GOLD group member)*

Older people with learning disabilities should be supported to make end-of-life plans as part of the person-centred planning process. This includes helping people think about:

- where I live;
- who is important to me;
- likes and dislikes;
- what happens when I get ill;
- when I die;
- my funeral;
- what happens to my things.

The GOLD group are working on a project called *Making Plans* to help people think about and prepare for the future. Good planning can make such a difference. Becca had cancer of the bladder and was spending a lot of time in hospital. She was very clear that she wanted to return to her supported living home but they said that they could not provide the nursing care she needed. The acute liaison nurse at the hospital worked with the staff team and the community health services so that Becca could be supported to die at home in line with her wishes.

### **Linda's story: End-of-life planning and support**

Linda developed cancer and was supported by her family and health workers to decide her treatment plan. Sadly, it became clear that her cancer could not be halted and Linda worked with her family and friends to come up with a list of things she wanted to do before she died, as well as planning her funeral. Her dreams of 'lying by a pool on a posh holiday abroad with her family' came true, along with seeing a West End show in London. It was equally important that she had made a will and left the people she was closest to the treasures she deemed most valuable. After she died, it was a great comfort to her cousins to be able to plan her funeral knowing it was the way she wanted it to be, a real celebration of her life, complete with Abba songs and lots of funny memories.

Multiple loss features in the lives of many older people with learning disabilities. People living at home with an older family member risk losing family and friends, home, and the things that they used to do in the past. Ben's story (described earlier) highlights a pro-active way of avoiding some of these extra losses at a time of bereavement. Dealing with the emotions associated with loss can be very complex for people with learning disabilities. One way of keeping memories alive is to support people to create life story books with pictures of people and places that have been important to them.

Not only is this of value to the person but it also allows the staff to know them better.

It was quite a revelation when I saw the photographs in Oliver's book. There was one of him on his 21st birthday with his mum and his gran and he looked so happy. They are long dead, but he talks about them a lot now and it helps me understand more about him.

*(Carer from an older people's residential home)*

Sometimes people with learning disabilities have been denied the opportunity to express their grief. George, a man in his early 70s, tells people that both his parents and two of his sisters have died. He talks about his parents' deaths as though they happened yesterday. He will also explain that he did not go to the funerals, that his sisters did not tell him about them and that they left him out. The pain of being excluded seems to have almost exceeded the pain of losing his parents, as he has been denied the right to say goodbye. The hurt that this has caused George has interrupted his life. It is very difficult for him to talk about anything else, yet this happened almost 20 years ago.

All of the GOLD group went to Corinne's funeral. Michael and Sylvia's band played at the wake afterwards and all of Corinne's pottery and paintings were displayed all around the hall. There was one room which had a slide show of lots of photos of Corinne and all the holidays and fun times she'd had.

*(John, GOLD group member)*



John

Funerals are important rituals and can help people begin to grieve for the person who has died.

A higher percentage of people with learning disabilities experience more complicated grief than the general population and it is important that these people receive good support (Dodd and Guerin, 2009). Some people may take a long time to realise the full implications of what has happened and may take longer to grieve. New staff may not recognise that someone is still grieving. If grief has become complicated, and it has become difficult for a person to get on with their life even some time after the death, they may need specialised therapy.

### Summing up

In this paper, I have set out to highlight the experience of older people with learning disabilities and their families and the things that they themselves identify as being the most important issues – where they live, who supports them, staying in touch with family and friends, keeping active, staying well, coping with loss and facing death.

There is no one set of solutions to developing services that might support a better life for older people with learning disabilities, because of the wide spectrum of people's needs and the range of different places in which they are growing older. In many ways they are 'everybody's business' and the key is to develop a coordinated and informed response across local areas.

Current health and social care policies stress personalised approaches, human rights, inclusion and more choice and control. It is shocking that so few people with a learning disability are supported to plan their transition into old age and make it a smooth and successful one. We must ensure that the needs of older people with a learning disability are included and implemented in a joined-up and inclusive way.

In my view, and based on what so many people with learning disabilities and their families have told me, key areas for development and investment include:

- identifying older people with learning disabilities and their family carers in local communities as part of the local Joint Strategic Needs Assessment;
- investment in planning for future needs in a person-centred way for families growing older together and older people in supported living or residential care;
- joining up practice initiatives across learning disability and older people's services;
- equipping the workforce across a range of services to be aware of the age-related needs of people with a learning disability and to make adjustments to their practice to meet them;
- continuing to listen and learn from what older people with learning disabilities and their families have to say.

Perhaps most importantly, it is about attitude and values; we all need to recognise and appreciate the fundamental humanity of older people with learning disabilities. They have the same rights as anyone else to a better life, in later life. As a mum, thinking about the future, it is this that I long for above all else for my son Michael as he grows older.

## References

- Bigby, C. (2004) *Ageing with a Lifelong Disability. A Guide to Practice, Program and Policy Issues for Human Services Professionals*. London: Jessica Kingsley Publishers
- Bigby, C. (2010) 'Aging ... A Continuing Challenge', *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 7, No 1, pp. 1–2
- Department of Health (2010) *Valuing Older Families Now*. London: Department of Health
- Dodd, P. C. and Guerin, S. (2009) 'Grief and bereavement in people with intellectual disabilities', *Current Opinion in Psychiatry*, Vol. 22, pp. 442–446
- Emerson, E. and Hatton, C. (2008) 'Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England', *CeDR Research Report*, 2008:6
- Foundation for People with Learning Disabilities (2002) *Today and Tomorrow: The Report of the Growing Older with Learning Disabilities Programme*. London: Mental Health Foundation  
[www.learningdisabilities.org.uk/content/assets/pdf/publications/today\\_tomorrow.pdf](http://www.learningdisabilities.org.uk/content/assets/pdf/publications/today_tomorrow.pdf)
- Holland, A. J., Hon, J., Huppert, F. A., Stevens, F. and Watson, P. (1998) 'Population-based study of the prevalence and presentation of dementia in adults with Down's Syndrome', *British Journal of Psychiatry*, Vol. 172, pp. 493–498.
- Magrill, D. (2007) *Supporting Older Families: Making a real difference*. London: Mental Health Foundation
- Thompson, D. J., Ryrie, I. and Wright, S. (2004) 'People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK', *Journal of Applied Research In Intellectual Disabilities*, Vol. 17, No. 2, pp. 101–107
- Wertheimer, A. (2004) *It's good to be part of things: Working with older people with learning disabilities*. London: Age Concern England

## Resources

Blackmann, N. and Brooks, M. in collaboration with the GOLD group (2008) *Dementia and People with Learning Disabilities: Valuing Relationships*. Training pack (including two DVDs made by the GOLD group) available from Respond  
[www.respond.org.uk/shop](http://www.respond.org.uk/shop)

Easterbrook, L. (2008) *Living on the Edge: Enabling older owner occupiers with moderate learning disabilities to live independently*. Nottingham: Care and Repair England

Foundation for People with Learning Disabilities (2010) *Mutual Caring: Multimedia resources*  
[www.learningdisabilities.org.uk/publications/mutual-caring/](http://www.learningdisabilities.org.uk/publications/mutual-caring/)

Ward, C. (Forthcoming, 2011) *Growing Older with a Learning Disability: A practice development pack for support staff*. Association for Real Change (ARC)  
[www.arcuk.org.uk](http://www.arcuk.org.uk)

Watchman, K., Kerr, D. and Wilkinson, H. *Supporting Derek: A practice development guide to support staff working with people with a learning difficulty and dementia*. York: Joseph Rowntree Foundation  
[www.jrf.org.uk/publications/supporting-derek](http://www.jrf.org.uk/publications/supporting-derek)

### About this project

This paper forms part of a series of *Perspectives* commissioned to support the five-year research programme, A Better Life. This programme investigates what will improve quality of life for some of the most marginalised, and least heard, people in the UK – older people with high support needs.

A microsite based on these *Perspectives* will launch in January 2012. It will provide a unique digital platform to showcase the voices of older people with high support needs and features photos of people who contributed their perspectives and a poem by Sir Andrew Motion. To find out more visit [www.jrf.org.uk/work/workarea/better-life](http://www.jrf.org.uk/work/workarea/better-life)

Published by the Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP. This project is part of the JRF's research and development programme. These views, however, are those of the authors and not necessarily those of the Foundation. ISSN 0958-3084

ISBN 9781859358597

**Other formats available.**  
**Tel: 01904 615905**  
**email: [info@jrf.org.uk](mailto:info@jrf.org.uk)**