



all about people

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BILD Factsheet:

Older people with a learning disability

This factsheet provides an introduction to the issues around ageing and people with learning disabilities.

Summary

- People with learning disabilities are living longer
- The number of older people with learning disabilities is growing
- Older people with learning disabilities are a diverse group
- Future generations of older people with learning disabilities will have more complex needs
- Most people with learning disabilities live with their parents and these families are growing older together
- Older people with learning disabilities and their families do not always get the right support
- Older people with learning disabilities share many of the same experiences of growing older as everyone else
- Older people with learning disabilities can face specific challenges and disadvantages as they age
- Older people with learning disabilities face a 'double jeopardy'. They face discrimination as disabled people and age discrimination as older people
- Older people with learning disabilities need to be supported to age well, to understand their age related needs, and to remain active and healthy for as long as they can
- It is important to listen to what older people with learning disabilities and their families tell us is important to them
- Many services are not well prepared to support older people with learning disabilities and their families; these include services for people with a learning disability, older people, carers and health care. Better information, joint training and planning are needed to meet people's needs at a local and national level

“The good news is that people with learning disabilities are living longer. The bad news is that their needs are in danger of being misunderstood, overlooked, or poorly met.”

(Kerr 2007)

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

(Gold group member quoted in Ward 2012)

People with learning disabilities are living longer

The life expectancy of people with learning disabilities has increased over the course of the last 70 years. This is despite the fact that people with learning disabilities are 58 times more likely to die before the age of 50 than the rest of the population (Emerson and Baines 2010).

People with learning disabilities face many disadvantages in relation to health (Emerson and Baines 2010, Department of Health 2001). However, better social conditions and access to medicines like antibiotics have meant that more people are surviving beyond childhood and adulthood into older age. For example, people with Down’s syndrome have seen a dramatic rise in their life expectancy from seven years in the 1930’s to their late 50’s today (Holland et al 1998).

The number of people with learning disabilities aged over 60, in England, is predicted to increase by over a third between 2001 and 2021 (Emerson and Hatton 2008). Recent evidence suggests that older people are one of the fastest growing groups of the learning disabled population (Emerson and Hatton 2011). The most recent predictions suggest

that by 2030 the number of adults aged over 70 using services for people with learning disabilities will more than double.

However, this is likely to be an underestimate of the actual numbers of older people with learning disabilities both now and in the future as many people with learning disabilities are either not known to services or indeed do not use learning disability services in adult life.

Older people with learning disabilities are a diverse group

Older people with learning disabilities are not all the same and the support an individual will need to make a successful transition into later life must be person centred and tailored around their individual needs. This is because people’s capabilities vary greatly as do their needs for support and community based services. Each person will have had a different life experience and a different set of hopes and fears for the future.

Some people admitted to the old long stay mental handicap hospitals when they were younger, say in the 1950s or 1960s, find they are now not eligible for learning disability services today, because they do not reach their local authority Fair Access to Care criteria. When they have been resettled into the community some have found it difficult to access appropriate support in later life. Today, many older people with learning disabilities who are living in residential care or supported living will have spent much of their life in institutional settings. People in this group are often seen as a relatively able and healthy group, but they have been denied many opportunities over the course of their lives.

The profile of older people with learning disabilities in the future will be even more

diverse than it is today. This is because the population profile of people with learning disabilities is changing. Not only are there more people with learning disabilities from black and minority ethnic communities, but many more people with complex health needs are living longer and will present a different set of challenges for services as they age (Emerson and Hatton 2011).

Where older people with learning disabilities live and who supports them

Families are growing older together

Two thirds of adults with a learning disability live with their families, the majority with their parents. Of these, 40% live with a parent over 60 and 33% live with a parent over 70 years old (Emerson and Hatton 2008). Given the increase in the ageing population the number of people with a learning disability living with a parent over the age of 70 will also rise. Many family carers are caring alone; others are caring for more than one person.

Many older family carers worry that their son or daughter is living a prematurely 'old' lifestyle because they share the social networks of their parents. As family carers grow older, and sometimes frailer, their social and support networks shrink exposing them to the risk of growing isolation (Magrill 2007).

In many of these older families the parent carers are becoming increasingly frail and the person with learning disabilities adopts a caring role. There is a growing awareness of the growth of mutual caring or increased interdependence in these families. Many families will need support to adjust to these new roles, which will require services to take on a more coordinated and family focused approach. It is also important that the person

with learning disabilities is recognised, and gets support, as a carer in their own right (Foundation for People with Learning Disabilities 2010).

The need to plan for the future remains a priority for all families growing older together. Many people with a learning disability and their family carers face increasing challenges as they age and many are continually worry about the future when the family carer is unable to provide care (Walker and Walker 1998). Sustained support is often needed to help families do this (Walker and Magrill 2002). Up to 25% of people with learning disabilities living at home with older family carers are not known to services until there is a crisis (Department of Health 2001). As a result there has been no formal planning for their future care. ***The need to identify these families before a crisis is crucial.***

A number of people with learning disabilities remain living in the family home when their parents die; more would like to do so. This can be a very vulnerable group if they don't get the support they need. This is particularly true for people with more moderate learning disabilities who are not eligible for support because they do not meet local social services Fair Access to Care criteria. They can fall through the net of local support services until there is a crisis. This group can be particularly vulnerable to hate or mate crime (Easterbrook 2008).

At present around 12% of adults with a learning disability live with a family member other than their parents (Emerson and Hatton 2008). As more people with learning disabilities outlive their parents the role of siblings and other family members will increase. Often these siblings lack the experience of services that their parents have and will need information and support in their own right.

People with learning disabilities growing older in supporting living or residential care

Many older people with learning disabilities find that they have little choice or control about where they live and how they are supported. Of the 30% of adults with learning disabilities who live in residential or nursing care many are aged over 45. The majority of staff in these learning disability services are inadequately trained to meet the needs of ageing residents. They can find themselves having to move when their needs change, Bigby (2004). This can also lead to older people with learning disabilities being inappropriately placed in older people's residential services at a much younger age than the rest of the population (LDAS 2010 and Thompson et al 2004).

Older people with learning disabilities share many of the same experiences of ageing as other older people

All older people need to be valued, seen as individuals and treated with dignity and respect. People with learning disabilities are no different. Older people with learning disabilities have the same needs as other older people. Like others, people with learning disabilities have the potential to age successfully and have choice and control over their lives. They can lead healthy and productive lives with the right individual and community support.

For all older people their continued inclusion, participation and engagement in the community are a vital aspect in the maintenance of their health and wellbeing. All older people need opportunities to live full and

productive lives; continuing to work if they wish or enjoy an active retirement. When older people do not have these opportunities they are at a greater risk of depression as a result of social isolation and exclusion (Age UK accessed 2012).

Older people with learning disabilities face a 'double jeopardy': discriminated against as disabled people and facing age discrimination as older people

A European study showed that ageism is the most frequently experienced form of discrimination (Age UK 2011). Studies of the health and social care system in the UK have highlighted the systematic discrimination that older people face, leading in some cases to neglect of basic needs and abuse (Department of Health 2009).

Older people with learning disabilities are not exempt from experiencing age discrimination. There is substantial evidence that they experience a 'double jeopardy' as they age.

Age discrimination operates in learning disability services in a range of different ways (Walker et al 1996). Services have failed to recognise that people have many transitions in their lives, including that into older age, and not just 'the transition' from childhood to adulthood. All transitions need planning for in a proactive way and the transition into later life is no exception.

Many learning disability services have simply not planned for this later life transition. They have failed to invest in understanding the age related needs of the people they support and the consequences for the organisation.

Many older people in learning disability services are supported by staff who are not 'age aware' and therefore not equipped to meet people's changing physical, emotional or social needs. Staff may have ageist

assumptions about what the people they work with can and cannot do. They may make assumptions based purely on the person's age not their abilities, needs or aspirations. This can limit the social and domestic opportunities of older people with learning disabilities. It can also affect the way staff work with an older person with learning disabilities because they tend to focus on physical care needs rather than on providing support aimed at retaining skills and independence.

Older people with learning disabilities face specific challenges and disadvantages as they age

Although people with learning disabilities face many of the same issues as the rest of the ageing population they also face some specific challenges and disadvantages.

Health and wellbeing

Overall, people with learning disabilities share the same age related physical and psychological changes as other older people.. With some of these changes come age related health risks and it is important that all older people have access to high quality public health and medical services.

People with learning disabilities are 2.5 times more likely to have health problems than other people but are often poorly served and discriminated by health services (Department of Health 2001, Emerson and Baines 2010; Mencap 2012). Because of their earlier life experiences adults with learning disabilities embark on the ageing process from a position of vulnerability rather than strength as they are often already in poor health (Bigby 2004, 2010).

As a result of unhealthy lifestyles throughout their lives, older people with learning disabilities are more likely to experience lower levels of fitness, unhealthy diets, and be less mobile leading to greater risk of obesity and age related diseases such as diabetes, hypertension, heart disease, stroke, arthritis and respiratory disease (Emerson and Baines 2010; Royal College of Nursing 2011).

Some people with learning disabilities have a specific genetic makeup which carries higher risks as they age. People with Fragile X syndrome have an increased risk of musculoskeletal disorder; people with Prader Willi syndrome an increased risk of diabetes, cardiovascular disease and obesity (Bigby 2004). People with Down's syndrome show patterns of premature ageing; they are at high risk of early onset Alzheimer's disease, with a one in four chance of developing the disease 40 years earlier than the rest of the population as well as facing a range of other health related risks (Holland et al 1998).

All people with a learning disability are at greater risk of developing dementia as they get older compared to the general population. (Cooper, S.A. 1997) (Alzheimer's Society 2012)

Research shows that psychiatric conditions increase with older age though it is less likely to be treated (ELSA 2002). Older people with learning disabilities have a higher risk of psychiatric disorder than their younger peers, which is two to four times more common than for other older people (Bigby 2004, 2010 and Mental Health Foundation accessed 2012).

Social needs

Older people with learning disabilities are more likely to be living on low incomes and in poor housing than the rest of the older population as they have had less opportunity to work and save money through their lives. They are more likely to have been dependent on welfare benefits.

Older people with learning disabilities are at greater risk of losing their homes and being moved into residential or nursing care when their needs change or when their family carer is no longer able to support them. This may lead to loss of contact with friends, staff and family.

Older people with learning disabilities are less likely to access a range of community facilities and leisure facilities and engage in the communities where they live or to have the opportunity to make and sustain friendships. Together with restricted mobility, this can lead to them living increasingly isolated lives.

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 older families and the challenges they face, but rarely has it been written from the point of view of older people themselves or their family carers.

Older people with learning disabilities tell us that they value the opportunity to speak for themselves and it is important that services continue to invest in self advocacy as people age. It is also important to invest in support and advocacy services for older families as they are often isolated and vulnerable and need support to plan for the future (Ward 2012).

“People with learning disabilities, estimated at approx 60 million worldwide, represent one of the largest groups of people with lifelong disabilities. As they age, most – those with minimal difficulties – continue to live independent lives, yet others - those with more severe life difficulties – remain dependent on lifelong support from their families and friends or from charitable organisations. As a result, because of their compelling needs associated with ageing, special attention needs to be given to this segment of the world’s growing elderly population.”

IASSID 2002

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