

# Growing Older as People with Learning Disabilities

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# People with Learning Disabilities

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- 1.4 million people in the UK
- People with learning disabilities are now living significantly longer and are growing older in the community
- Many of the same age-related health and social care needs as other people but they also face some specific challenges. Many people with learning disabilities, especially those with milder disability, are not known to health or social services
- By 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.

# Right to a family life

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The right to respect for private and family life is enshrined in ARTICLE 8 of the European Convention on Human Rights.

As part of the Good Lives Framework people told us:

- Adult loving and sexual relationships are not prioritised and supported
- There is a concern that services will not value people's relationships long term
- Family relationships were not prioritised in the pandemic response and are often seen through the prism of support

# Support from family

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Two-thirds of adults with learning disabilities live with their families, usually their parents.

There are around 2 million carers in England and Wales who are aged 50-64 and 1.3 million carers aged 60 and over.

29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 1 in 4 of these cases have local authorities planned alternative housing.

# Being a Parent

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Estimated around 0.15% of people with a learning disability are parents

54 times more likely to have their child removed compared to nondisabled parents (2020-2022)

# Going for GOLD! Research

Inclusive research in Greater Manchester in 2020, carried out by a team of 16 older people with learning disabilities

**Aim:** reduce social isolation amongst older adults (aged 50+) with learning disabilities and to find out what makes somewhere an age-friendly place to live

Worked with MMU to hold interviews and focus groups with 59 older people with learning disabilities



# Key Findings

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We need to promote ageing well for people with learning disabilities so they can understand what it is to age positively.

People with learning disabilities need support throughout their lives to live healthy lifestyles to remain healthy longer.

Older people with learning disabilities need to be better supported to deal with the transition that often takes place when their parents die.

Important influences on what makes an area a good place for older people with learning disabilities to live are local amenities, the environment, transport links, local people and whether people feel safe where they live.



# Experiences of growing older

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Most participants viewed growing older negatively and as a time of loss.

Uncertainty and lack of clarity about the future suggests that many people did not have the opportunity to talk to people about physical changes associated with growing older, or their feelings and concerns about growing older.

The impact of the death or ageing of parents is a distinct and clearly important experience for many older people with learning disabilities.

Future planning with families is vital so that people can think about where they will live and the support they will need after they move out from the family home



# Housing Support

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Two-thirds of adults with learning disabilities live with their families, usually their parents.

Planning for your loved ones future for when you can no longer care for them can be really difficult.

Parents becoming ill or dying can result in crisis as no future planning is in place. This can mean people end up living in places that aren't right for them

Older people with learning disabilities are more likely to be placed in older people's residential services at a much younger age, even though this may not meet their preferences or needs, especially in relation to communication, support and activities.

# Talking about and planning a good death



## Dying to Talk



### What did we do?

MacIntyre wants the people we support, their families and our staff to feel ok talking about the future, so people don't need to feel worried or afraid of dying.

In 2021 and 2022 we worked with people in Chesterfield, Leicestershire, Herefordshire and Worcestershire.

We:

- listened to **79 people we support**
- talked with **70 family members**
- trained **134 staff** in 38 workshops
- worked on an **e-learning module**
- developed a **resource pack**, full of tips and tools
- trained **94 health and social care staff** from groups outside MacIntyre
- did talks and meetings to **raise awareness** with 413 people at MacIntyre and 508 people from other groups
- shared **newsletters**, blogs and tweets with about 1,500 people

We reached over 2,000 people

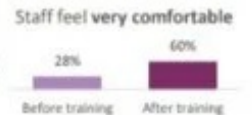


### What good things happened?

- **More people we support feel ok talking about dying.** At the start of the project most people felt a bit worried or scared hearing the word 'death'. By the end, more than half said it was not so scary any more. They could plan what they wanted

*"I liked talking about grandma. I liked talking about my best song. I liked having ideas on what I want. It made a lot of thoughts in me. I want to talk more. It is not scary or sad after all."* (Person supported)

- **More staff feel ok talking about dying** with people they support. Staff also liked having a chance to talk about things that affected their own families and friends.



- **We shared ideas so other organisations can help people too.** 80% of people from other organisations who took part in our training said they used something they learnt.
- People said we were doing good work. We were **nominated for three national awards.** We were 'highly commended' at the Women Achieving Greatness in Social Care awards.



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