



ambition  
for  
ageing

# Going for GOLD! Growing Older with Learning Disabilities

Briefing



## Key learning

- 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.

## INTRODUCTION

**People with learning disabilities are living longer and most now live in community settings. However, they are at increased risk of social isolation, with older adults with learning disabilities at particular risk.**

The Greater Manchester Growing Older with Learning Disabilities (GM GOLD) project aimed to find out what older people with learning disabilities think about their local area, whether they feel part of their local community, what barriers exist to meaningful social contacts, interactions and activities, and their perspectives on growing older.

The GM GOLD project was an inclusive research project carried out by a team of 16 older people with learning disabilities (co-researchers) supported by 'research buddies'. The team conducted interviews and focus groups with 59 older people with learning disabilities from eight Greater Manchester boroughs.

This briefing is a summary of the findings of the research and highlights a number of recommendations.

Ambition for Ageing is a Greater Manchester level programme aimed at creating more age-friendly places and empowering people to live fulfilling lives as they age.

We do this by providing small investments to help develop more age-friendly neighbourhoods in Greater Manchester in addition to funding larger scale work across the city-region. As a research project, we are committed to sharing the learning we gain from the programme to help influence local, regional and national policy. Ambition for Ageing is part of Ageing Better, a programme set up by The National Lottery Community Fund, the largest funder of community activity in the UK.

## INEQUALITY AND DISCRIMINATION

People with learning disabilities experience more health inequalities than the rest of the population and are likely to experience long-term health problems.

*"[The people in my area] don't like people with a disability."*

They also experience social and economic disadvantage, such as harassment and barriers to paid work. This can make it harder to go out, take part in social activities or use public transport. These experiences may make people with learning disabilities more prone to negative impacts of growing older through the potential long-term impact on finances, self-esteem and confidence.

### Recommendations

- Health providers need to be accessible and proactive in ensuring that health needs are met. Older people with learning disabilities need support throughout their lives to live healthy lifestyles to remain healthy longer.
- We need to find ways of changing negative public perceptions and behaviours towards people with learning disabilities to improve their lives and sense of belonging and safety.



## GROWING OLDER

We found that most participants viewed growing older negatively and as a time of loss. Growing older was seen as preventing people doing things that they enjoy. Health and mobility could deteriorate, there were physical changes, such as hair going grey or getting thinner, the menopause, and people were concerned about their own mortality and death. Some people, however, felt that growing older was an inevitable part of life, that 'we all grow old', it is 'just one of those things', and that age was 'just a number'.

*"How do I feel about growing older – I don't want to. I want to stay as I am, independent, I don't want to be old and I don't want anything to happen to me."*

This 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. It also indicates a lack of future planning and discussions about people's preferences about their future living arrangements.

### Recommendations

- People with learning disabilities need information about growing older and having a good life. They need to hear good things about growing older.
- Older people with learning disabilities need to be better supported to deal with the transition that often takes place when their parents die.

The impact of the death or ageing of parents is a distinct and clearly important experience for many older people with learning disabilities. They may have lived with their parents for their whole life and still be living at home when parents die, or become too frail to provide them with practical support.

*"I used to go out shopping with my mum, I used to go on holidays with my mum and my dad and my stepdad until my mum died. And then when my mum died it all changed suddenly."*

This is a significant life change and it is important that they receive long-term emotional support as well as support with practical aspects of life and personal care. 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.

## SOCIAL ISOLATION

"I have good neighbours, when, when I'm on my own they'll check on me, see if there's anything I need or, you know, if I need anything to just go and knock on the door."

There were examples of people living busy, active lives and making positive contributions within families and communities. However, many participants considered themselves lonely, and expressed a desire for deeper, meaningful relationships. The research found that potential causes of social isolation were not being with or feeling rejected by family and friends, loss and bereavement.

"Isolation? Being locked in your own home, in your own bedroom. Having no meals. Having no friends. Having no one to talk to, just locking yourself away."

Often, people were not supported to keep in contact with family and friends, particularly after transitions such as leaving school, leaving institutional care and moving house. Older people with learning disabilities were less likely to be in a long-term intimate relationship than other older people, and may experience difficulties meeting people and maintaining social relationships. They were also less likely to meet new people, as the membership of self-advocacy groups and community groups is relatively static.

"When I lived with my sister – when she was out all the time. Neighbours did not bother with me."

### Recommendations

- People's social needs should be included in care plans and individual budgets. Support workers should be clear that their role includes supporting people to develop relationships and access local communities.
- The membership of existing groups and activities should be broadened to increase opportunities to meet new people.
- Initiatives supporting people to take part in social activities must be promoted to and accessible for older people with learning disabilities.

## ACCESSIBILITY, TRANSPORT AND FEELING SAFE

### Recommendations

- Support to travel could include: more help at bus stops, speaking timetables, stop announcements on buses and trams, training to use apps such as Citymapper, training for taxi drivers, taxi concessions for older people with learning disabilities, improved ring and ride services.
- We need to help older people with learning disabilities feel safer there could be more hate crime campaigns, more police who know how to help and know where people with learning disabilities live, better street lighting, more CCTV and training about personal safety for people.

"Bus stops. Not enough. Drunks at the bus stop. Brother drops at bus stops. Bus and tram are easy because they are close."

Being able to travel about is important to meet people and access places and activities. Whilst transport is a common concern for older people, people with learning disabilities may need additional adjustments, as well as support to get to places, particularly for the first time.

"I like going on the buses. I'm a bus enthusiast. All the buses – buses to town, to [another town]. I could get the tram but I don't do trams, I like buses. The nice old buses."

Ensuring that the physical environment is accessible also plays an important role in the social inclusion of older people with learning disabilities. Places, groups and activities within communities need to be inclusive of older people with learning disabilities. This goes beyond physical accessibility; accessible information and attitudes are also important.

"I don't feel safe going out. I get called names. It's not safe on the tram with school kids."



## CONCLUSION

Our research shows that later life transitions for people with learning disabilities can be particularly disruptive, and that they are at particular risk of social isolation and loneliness, and therefore, the potential impacts on independence and wellbeing. Older people with learning disabilities often do not have access to support or resources to age positively.

People with learning disabilities are citizens with the same rights to relationships and to participate in communities as the rest of society. In addition to the legal, moral and ethical implications, if society, neighbourhoods and communities do not become more inclusive of people with learning disabilities, they will not benefit fully from the contributions that they can make. It is likely that this would also increase demand for public services as more people with learning disabilities are living longer than in the past.

*This research took place before the COVID-19 pandemic and does not take into account the impact of COVID-19 social restrictions. Although, there are examples of communities coming together as a result of the pandemic, a major adverse consequence is likely to be increased social isolation and loneliness, especially for those who are already isolated or lonely. It would be interesting to conduct research to explore the impact of COVID-19 on people with learning disabilities, with particular regard to social isolation and community belonging.*

For the full reports and easy read reports from this project please visit [www.ambitionforageing.org.uk/GOLD](http://www.ambitionforageing.org.uk/GOLD)



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