



Consultation Response

Health and Social Care Strategy for Older People

**The Scottish Commission for
People with Learning
Disabilities**



The Scottish Commission for People with Learning Disabilities (SCLD) welcomes the opportunity to respond to this consultation on its Older People's Strategy.

SCLD is an independent charity and non-governmental organisation. Our vision is of a fairer Scotland where people with learning disabilities are able to live full, safe, loving and equal lives. SCLD aims to make a significant contribution to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities are empowered to live the life they want in line with existing human rights conventions.

At SCLD we base everything we do on what people with learning disabilities tell us. In responding to this consultation, SCLD has held one to one interviews with older people with learning disabilities, and held focus groups with service providers and service commissioners of learning disability services, including Scottish Borders HSCP, East Renfrewshire HSCP, South Ayrshire HSCP, Aberdeen City HSCP, Hansel, Hillcrest Futures and Fife College.

Summary

SCLD believes the Scottish Government's Older People's Strategy must include a specific focus on older people with learning disabilities. We make the following recommendations for inclusion in the Strategy:

- 1.** There is a need for improved health and social care that is adapted to the needs of people with learning disabilities and people with Down's Syndrome, so that appropriate and effective interventions are made and people with learning disabilities grow older in good health.
- 2.** GPs, hospitals and other universal health and social care services must have an understanding of the different ageing profile of people with learning disabilities, and identify these effectively.
- 3.** Recommendations in the Strategy about healthy living should make explicit reference to increasing access to exercise and active leisure for older people with learning disabilities, both specialist and mainstream.
- 4. The Strategy should include plans to promote inclusivity within community groups and civic life in general, so that these are more accessible both to older people and to people with learning disabilities.**
- 5.** The Strategy should take an explicitly human rights-based approach, which recognises the right of older people with disabilities to services that support inclusion and prevent isolation
- 6.** The Strategy should recognise that older people with a disability have the same right of access to community services and facilities as any other older people, and commits to developing a plan to address this inequality.
- 7.** The Strategy should commit to reinforcing the links between housing and support at home services, recognising that for older people with learning disabilities is likely to come from Adult Learning Disability Services.
- 8.** The Strategy should emphasise the need for better data and intelligence on older people with learning disabilities to inform Housing Needs Assessments and Housing Contributions Statements as part of local strategic planning processes.
- 9.** The Strategy should reinforce that strategic planning processes and housing allocation policies need to recognise older people with learning disabilities as a heterogenous population and consider their particular needs including physical accessibility, accessible design, additional space for carers, scope for adaptations as well as place and location.
- 10.** The older people's strategy must propose measures to ensure that HSCPs make reasonable adjustments to their services under the Equalities Act (2010), so that older people with learning disabilities have the same health outcomes as other older people.

- 11.** The Strategy should include a clear focus on the life experience of people with learning disabilities, and a commitment to address the particular issues raised by this life experience
- 12.** A response to the transitional issue faced by many people with learning disabilities as they get older must be included in the Older People's strategy
- 13.** A detailed and inclusive Equality and Human Rights Impact assessment is completed as an integral part of developing this Strategy, in line with the requirements of the Equality Act 2010 and public Sector Equality Duty.
- 14.** The Strategy reflects and addresses the different incidents of various health conditions experienced by people with learning disabilities as they get older
- 15.** Working with carers' centres, HSCP social work teams should identify families where people with learning disabilities over 40 are living with their parents
- 16.** HSCPs invest resources in anticipatory care planning with this population. This includes providing accessible information to people with learning disabilities and their parents about future options
- 17.** Working with social work teams, local authority housing must include the needs of this population in their financial assessments and five year planning
- 18.** Carers' centres should use the [Active Connected Included](#) pack to improve their accessibility and inclusivity
- 19.** Support for eligible people with learning disabilities must be available to claim the Carer's Allowance
- 20.** As a priority, respite care should be offered both to carers of adults with learning disabilities and to adults with learning disabilities who themselves have caring responsibilities
- 21.** Local authorities must include 'caring responsibilities' as a criterion for receiving self-directed support.

SCLD believes the Scottish Government's Older People's Strategy must include a specific focus on older people with learning disabilities including those with Down's Syndrome. The reasons why this is so urgent are laid out in the answers below.

Health Inequalities

People with learning disabilities experience significant health inequalities. Life expectancy for people with learning disabilities in Scotland is 20 years lower than for the general population. Often they die from preventable diseases¹ ([NHS Health Scotland 2017](#) and SLDO 2020²). For people with Down's Syndrome life expectancy is up to 28 years lower than the general population.

A particularly important issue for this consultation to consider is the early onset of dementia for people with learning disabilities, and what this means for the Older People's Strategy. The mean age of dementia diagnosis in people with Down's Syndrome is 55. This compares to a 'typical' diagnosis age in a person's 70s or 80s.³ People with learning disabilities other than Down's Syndrome also develop dementia on average 10 years earlier than people without a learning/intellectual disability.⁴

A longitudinal study of ageing in Ireland by the Trinity Centre for Ageing and Intellectual Disability (TCAID) has found that people with learning disabilities have a different cause of death profile⁵. Respiratory diseases and circulatory disease were the main underlying causes of death, with cancer a less common underlying cause of death than in the general population. For people with Down's Syndrome respiratory illness, congenital heart defects, dementia and Alzheimer's disease were more common causes of death than in the general population.

The research concluded that people with learning disabilities were more likely to die from causes that were amenable to healthcare intervention. These findings have significant implications for older people's health services. GPs, hospitals and other

¹ [Health Scotland \(2017\)](#)

² [SLDO \(2020\)](#)

³ [Sinai et.al. 2017](#)

⁴ [British Psychological Society 2015](#)

⁵ [IDS-TILA \(2017\)](#)

universal health services need to understand the different ageing profile of people with learning disabilities.

The same research from TCAID found that:

- 85% of people with learning disabilities aged 40+ were sedentary or underactive
- 80% were overweight or obese
- 74% have poor bone health

A national survey of people with learning disabilities in Scotland called *How's life?*, carried out by SCLD in 2019, showed that only 52% of survey respondents had taken exercise in the last few weeks. This compares to 80% of adults in the general population.⁶

Further analysis from the *How's life?* survey data shows that, as with the general population, participation in exercise declined with age. Only 33% of those who responded to the survey who were over 65 had taken part in exercise over the last few weeks. In the general population, 66% of those over 60 had undertaken exercise in the last four weeks.⁷

These findings highlight the importance of older people with learning disabilities taking more exercise that is appropriate to and enjoyable for them. In our *How's life?* survey, for example, many respondents told us they enjoyed Boccia, a precision ball sport for those athletes with high support needs, that has no 'mainstream' equivalent.

Increasing provision of exercise opportunities such as Boccia is only part of the answer. Leisure Centres provide a wide range of locally-available fitness and exercise opportunities, but these are inaccessible to many people with learning disabilities. There are many factors that contribute to this inaccessibility (see Community Inclusion section below).

Therefore, the strategy for older people should include the following points for integrated health and social care services:

⁶ [SCLD \(2022\)](#)

⁷ [Scottish Household Survey \(2019\)](#)

1. There is a need for improved health and social care that is adapted to the needs of people with learning disabilities and people with Down's Syndrome, so that appropriate and effective interventions are made and people with learning disabilities grow older in good health.
2. GPs, hospitals and other universal health and social care services need to have an understanding of the different ageing profile of people with learning disabilities including Down's Syndrome, and identify these effectively.
- 3.
4. Recommendations in the Strategy about healthy living should make explicit reference to increasing access to exercise and active leisure for older people with learning disabilities, both specialist and mainstream.

Good practice examples of the 3rd sector working with the public sector

Service Commissioners that we spoke to identified two examples of communities, voluntary/third sector and public sector organisations working together to improve older people's health and wellbeing:

[Talking Points](#) is a 'one stop shop' provided by East Renfrewshire Council that can signpost people to over 60 organisations, including community groups, 3rd sector organisations and the Health and Social Care Partnership. It can be accessed online, by phone or email, and also holds regular in person events across the local authority.

Scottish Borders Council have a number of drop-in [What Matters](#) hubs in all its main towns, where people can meet with community groups and voluntary organisations as well as social workers and occupational therapists

However, while signposting to other resources or groups is a positive step, many people with learning disabilities find that these groups are themselves inaccessible⁸

⁸ [SCLD \(2016\)](#)

SCLD has produced a resource - *Active Connected Included* - to help community groups become more accessible⁹. There is more information about this resource in the answer below.

One of the individuals we spoke to identified a group that they attend as an example of good practice:

[Perth Six Circle Project](#) is a community project based in Perth and Kinross. They 'deliver activities aimed at reducing loneliness and social isolation and improving resilience for disadvantaged and challenged adults, many of whom have mental ill health, autism, learning difficulties and for some a combination of complex issues.... The activities are wide ranging and may include: lunch clubs, baking/cooking, cycling'. The project prioritises creating a sense of belonging and family with an extremely diverse membership. The programme of events includes some strenuous activities, and the group has adapted its programme and its way of working so that older people and people with physical disabilities can still participate and feel that they belong.

An additional benefit of being part of the Six Circle group is that this person would find it very easy to call them up if they needed help to contact medical professionals and services for help with their physical or mental health. The importance of being connected to an individual or group that can help with this cannot be overstated - people with learning disabilities repeatedly tell us how hard it is to find accessible information about services.

4. The Strategy should include plans to promote inclusivity within community groups and civic life in general, so that these are more accessible both to older people and to people with learning disabilities.

⁹ [SCLD \(2022\)](#)

Loneliness, relationships and community inclusion

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states:

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.¹⁰

The experience of many people with learning disabilities is that they are not included in mainstream community activities, and that these activities/groups are often not accessible to people with learning disabilities.

Therefore, the experience of ageing is different from that of many other people in the population: the imperative is not to provide support for people with learning disabilities to maintain the community connections that they have made over the years; rather, it is to enable them to make connections that they have never had.

Unfortunately, many good practice examples of community/3rd sector initiatives do not benefit people with learning disabilities because they are (sometimes unintentionally) excluded. A number of barriers prevent this kind of community inclusion that could help maintain the health and wellbeing of older people with learning disabilities.

The Scottish Commission for People with Learning Disabilities (SCLD) has developed a resource called [Active Connected Included](#). This practical resource is aimed at a range of audiences including community groups, learning disability support providers, family carers and people with learning disabilities themselves. It provides practical help to reflect on and change attitudes and practice. It helps ensure that activities that are 'for all older people' benefit older people with learning disabilities too.

¹⁰ [United Nations \(2006\)](#)

In North Ayrshire, every library has been given this pack. Leisure/sports centres, museums, and community groups would also benefit from using this pack to maximise their inclusivity.

SCLD fully supports a preventative approach to people's health and wellbeing, and is pleased to see that the Strategy recognises the importance of relationships as a social determinant of health in older people. SCLD's *How's life?* survey found that 52% of people with learning disabilities occasionally, sometimes or often felt lonely. This compares to 46% of the general population. 9% of survey respondents said they often felt lonely. This compares to 5% of the general population ¹¹ Around one in five did not see their friends as often as they would like, and the same number did not see their family as often as they would like.

The *How's life?* survey also found that very few people were in intimate relationships. People in older age groups were less likely to be in a relationship than younger cohorts. 28% of people aged 16-24 were in a relationship compared to 9% of those over 65. Though there is not a directly comparable figure for the general population, figures from the 2011 Census suggest that this trend is reversed. In the general population, people in older age groups were more likely to be married or in a civil partnership than those in younger age groups.

Where older people are in relationships, consideration must be given as to how to ensure these relationships are maintained. A quote from *How's life?* demonstrates the importance of this:

"Not living with my husband makes me feel lonely a lot. He lives in a care home he doesn't like. I really want to see my husband more and have him living back at home."

How's life? found that people living in mainstream accommodation were more likely to be in a relationship than those in supported accommodation and those in care homes (with people in care homes the least likely), which suggests that rules and practices, as well as limited privacy in these settings may be factors that hinder relationships.

How's life? demonstrated the important role that support and choice plays in the lives of people with learning disabilities, in particular. But crucially, it must be the

¹¹ [SCLD \(2020\)](#)

right support. The survey found that people who got enough support were more likely to see loved ones as much as they liked and less likely to be lonely because of this. People who had lots of choice over their free time were much more likely to see family, friends and/or partners as much as they liked than those who had little choice. People who had lots of choice over their free time were much less likely to be lonely.¹²

- 5. The Strategy takes an explicitly human rights-based approach, which recognises the right of older people with disabilities to services that support inclusion and prevent isolation**
- 6. The Strategy recognises that older people with a disability have the same right of access to community services and facilities as any other older people, and commits to developing a plan to address this inequality**

Housing

SCLD supports the recognition in the Strategy of the impact someone's home can have on their wellbeing.

Housing solutions for older people with learning disabilities need to reflect the diversity of the population through person-centred approaches which take into account individual choice and personal preference and are informed by an individual's level of need.

In supporting the Scottish Government's policy to support independent living and to enable people to stay in their homes for as long as they want and are able to do so, it is important that the Strategy recognises the following principles for fundamental change in delivery of adaptation services: self-direction, person-centredness, prevention and enablement.

In our engagement one person told us that the house she moved into twenty years ago already had widened doors and other accessible features, even though she did

¹² [SCLD \(2020\)](#)

not need them back then. Now, she is able to use her walker indoors when she needs it. This foresight and longer-term planning makes it more possible for people to feel that they are in a home that can accommodate their needs as they get older.

The same person said that they will stay in their own home until they are unable to cook for themselves. This is a support issue more than an adaptations issue. Service commissioners that we spoke to agreed that there needs to be closer planning between housing and Health and Social Care Partnerships, so that planning for accessible housing and planning for people's home support can be more closely coordinated and budgeted for.

Another person lives in a bought house and has had to wait a long time for adaptations, so their ability to leave the house is restricted. The difference between this person and others we spoke to who had adaptations carried out quickly seemed to be that he wasn't sure where to go to ask for the adaptations to be carried out, rather than that he lived in a bought house.

People were not very interested in the question of who should provide their housing or housing adaptations, or the support to access these. They were more concerned that information and support should be available, and that the information should be accessible, and the support readily available.

Another person lives with their partner who has dementia and uses a walker. The doors are not wide enough for him to use his walker indoors. He is going to have to move to another house shortly and she and her partner won't be able to live together any more, in contravention of her human rights. In a previous section we quoted a woman in a similar situation, who was continuing to live at home after her husband had been moved into a care home. The quote is repeated here because it highlights a housing issue as much as a loneliness issue:

"Not living with my husband makes me feel lonely a lot. He lives in a care home he doesn't like. I really want to see my husband more and have him living back at home."

This evident impact on someone's wellbeing is the result of a failure to provide the right support and a properly-adapted house.

SCLD is concerned that the experience of older people with learning disabilities seeking adaptations varies widely, with tenure, location and local funding conditions as significant as need in determining outcomes. There needs to be better data and intelligence on the specific adaptation needs of older people with learning

disabilities to inform local planning processes. There is a need for an integrated approach to meeting needs which consider the physical design of housing, use of space, geographical location, and links to public transport and amenities.

7. The Strategy should commit to reinforcing the links between housing and support at home services, recognising that for older people with learning disabilities this is likely to come from Adult Learning Disability Services.

8. The Strategy should emphasise the need for better data and intelligence on older people with learning disabilities to inform Housing Needs Assessments and Housing Contributions Statements as part of local strategic planning processes.

9. The Strategy should reinforce that strategic planning processes and housing allocation policies need to recognise older people with learning disabilities as a heterogenous population and consider their particular needs including physical accessibility, accessible design, additional space for carers, scope for adaptations as well as place and location.

The role of health and social care services

Many people with learning disabilities living on their own receive support to live independently from Adult Learning Disability services. So their experience of receiving support will be different from most people in the general population who start to receive support from Older People's services, only as they develop conditions related to ageing e.g. dementia.

This is a crucial distinction which needs to be acknowledged and reflected in the Strategy. It means that there may be a transition which may involve care and support being transferred from one social care team to another within a Health and Social Care Partnership: as people with learning disabilities grow older and develop conditions related to ageing the question can arise whether they should be moved over from Learning Disability Services to Older People's Services. Such arbitrary system based decisions often result in people feeling lost or abandoned in a depersonalised care system.

From the focus groups SCLD held with commissioners and providers of support services, and interviews with people with learning disabilities, it is clear that a

move from learning disability services to older people's services is problematic for a number of reasons:

- Many staff who work in older people's services do not feel skilled or confident about working with older people who have learning disabilities
- A move from one service team to another can lead to information about the person not being passed over effectively
- As stated elsewhere, the ageing profile for people with learning disabilities is different than that of the rest of the population. For example, the incidence of early onset dementia is higher, particularly among people with Down's syndrome, than in the general population. This can lead to people with learning disabilities who are (relatively) younger and more mobile being moved into care homes which are designed primarily for an older less mobile client group. So as well as any staff development issues, there are systemic service design issues, including staffing ratios.

In some HSCPs, there is pressure to move people from Learning Disability services into Older People's Services to reduce spend on larger support packages.

One HSCP had commissioned research to compare outcomes for older people with learning disabilities living in a mainstream care home for older people to a specialist learning disability care home. The research notes a significant difference in quality of life and other outcomes, with people in mainstream care homes dying 2 years earlier. There was anecdotal evidence that associated a lower staff ratio in mainstream care homes with a higher incidence of choking.

The commissioners we spoke to have addressed these issues in different ways. One HSCP has made the strategic decision to support people within the Learning Disability Service for their whole lifetime. Others ensured that there was specialist support in care homes or nursing homes that people with learning disabilities moved to. One HSCP ensured that where an older person with a learning disability moved into a mainstream care home they would take with them some of their previous support.

A number of voluntary organisations recommend and promote the use of 'passports' (ref PAMIS). These can be incredibly helpful in ensuring the consistency of care for people with learning disabilities.

SCLD asks that:

- 10. The strategy includes a clear focus on the life experience of people with learning disabilities, and a commitment to address the particular issues raised by this life experience**
- 11. A response to this transitional issue is included in the older people's strategy**
- 12. The older people's strategy proposes measures to ensure that HSCPs make reasonable adjustments to their services under the Equalities Act (2010), so that older people with learning disabilities have the same health outcomes as other older people.**

The Strategy includes some positive ideas about increasing or maintaining people's wellbeing as they get older. SCLD welcomes the recognition that healthy ageing is not solely a health issue, but rather a set of interconnected factors, including social, economic and environmental factors, that all influence health and wellbeing. The focus on positive ageing aims to change the narrative of ageing away from one focused on decline towards one that highlights the contributions of older people to society and that sees later years as a time of new opportunities.

However, the strategy very much treats older people as a homogenous population, which they are not. This approach risks older people with additional needs being excluded from the benefits which we hope the strategy will bring. SCLD would recommend that a detailed and inclusive Equality and Human Rights Impact assessment is completed as an integral part of developing this Strategy, in line with the requirements of the Equality Act 2010 and public Sector Equality Duty.

Research suggests that the ageing experience for people with a learning disability may differ from the general population, and that issues associated with ageing may occur for people with a learning disability at an earlier age than for the general population. Research has shown that not only is prevalence of certain conditions higher among a younger age group, but different patterns of disease are present for people with an intellectual disability compared to the general population.

Constipation and respiratory conditions tend to be higher than in the general population, whereas the incidence of cancer tends to be lower. For people with Down's Syndrome, incidence of heart conditions is higher, and people with learning disabilities can age differently from the general population in a number of ways.

These differences must be reflected to ensure that the policy meets the needs of everyone including people with learning disabilities.

13. A detailed and inclusive Equality and Human Rights Impact assessment is completed as an integral part of developing this Strategy, in line with the requirements of the Equality Act 2010 and public Sector Equality Duty.

14. The Strategy reflects and addresses the different incidents of various health conditions experienced by people with learning disabilities as they get older

Carers

The life expectancy of people with learning disabilities has increased over the years. The average life expectancy for people with learning disabilities has advanced from an estimated 18.5 years in the 1930s to 66 years in the 1990s (Bradock 1999, cited in [British Psychological Society 2015](#).)

This means that nowadays there is a reasonable expectation that people with learning disabilities will outlive their parents. This has raised support issues that did not exist a generation ago.

A 2019 study found that ageing carers did not receive enough support or information from professional services regarding care alternatives, at-home support, respite care or information about government or local legislation. This lack of information resulted in carers feeling isolated, anxious and fearful about their future ([Mahon et. al. 2019](#)).

Carers and support providers have both reported situations where increasingly frail and elderly carers continue to care for their adult children with learning disabilities with no support to provide somewhere else for the adult child to live. As a result, these situations end when a crisis arises e.g. the death of one or both parents.

Reasons given are:

- A lack of strategic planning

- A lack of suitable housing
- A lack of support provision.

Carers report a lack of information which makes anticipatory care planning both scary and impossible in practice.

Another aspect of this family dynamic is that people with learning disabilities sometimes take on caring responsibilities for their ageing parents. We know the risk of carers becoming isolated and ill because of their caring responsibilities. There is a high probability that these unwanted outcomes will affect carers with learning disabilities if:

- Information for carers about social connections is not accessible
- The social opportunities themselves provided by carers centres etc. are not accessible because of transport difficulties or other reasons
- Information about benefits for carers, and/or the application process, is not accessible
- They are already isolated and have no social network of their own to call on
- They are digitally excluded and have no access to social media and other digital technology that could connect them to other people
- relationships made and sustained by social care support are lost when the support is cut because they have reached a cut-off point e.g. some people are 'retired' from their day service when they reach 60 or 65.

Therefore, SCLD suggests that the following recommendations should be included in the older people's strategy:

- 15. Working with carers' centres, HSCP social work teams identify families where people with learning disabilities over 40 are living with their parents**
- 16. Social work invest resources in anticipatory care planning with this population. This includes providing accessible information to people with learning disabilities and their parents about future options**
- 17. Working with social work teams, local authority housing includes the needs of this population in their financial assessments and five year planning**
- 18. Carers' centres use the [Active Connected Included](#) pack to improve their accessibility and inclusivity**
- 19. Support for eligible people with learning disabilities is available to claim the Carer's Allowance**
- 20. As a priority, respite care is offered both to carers of adults with learning disabilities and to adults with learning disabilities who themselves have caring responsibilities**
- 21. Local authorities include 'caring responsibilities' as a criterion for receiving self-directed support.**



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