

Growing Older



Getting support right for people with a learning disability as they and their families age

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Put in place a strategic plan to identify and support people with a learning disability as they and their families grow older

The need to plan strategically to support people with a learning disability as they grow older was first highlighted over two decades ago, including in [Valuing People](#) and Mencap's [Housing Timebomb](#) report, but there are no current specific policy requirements to ensure that this occurs.

[Recent research](#) shows that 37% of adults with a learning disability and autistic people live with family and friends; a statistic that is largely unchanged over the last decade.

Beyond this, the much-welcome [increase in average life expectancy for people with a learning disability](#) means that people with a learning disability who live with and/or are supported by family members will do so for longer. This has in turn led to cases where families continue to support their relative into their old age, which can result in physical and mental health issues for the family carers and in the person with a learning disability not being able to get the right support.

People with a learning disability also face particular health issues relating to ageing. For instance, people with a learning disability (and particularly people with Down Syndrome) are [significantly more likely to a\) develop Alzheimer's/dementia than the general population, and b\) to develop these at a younger age](#).

Without strategic planning to a) identify, and b) work with people with a learning disability and their families to plan for the future, housing and support for people with a learning disability can be jeopardised. By identifying people with a learning disability and their families early on, and working with them to put in place plans for the future that suit everyone, quality of life can be improved and crises caused by abrupt and unplanned changes can be avoided.

Local authorities need to:

Ensure that they are aware of the number of people with a learning disability within their area

Introduce a mechanism for recording and monitoring the ages of people with a learning disability within their area and their families

Identify any people with a learning disability within their area who is a) living with, and/or b) supported by family members

Have a policy for contacting people with a learning disability and their families to create plans for the future, e.g., if a family carer is no longer able to provide support, if health and/or support needs change, if there is ill-health or bereavement, if mobility needs mean that the family home needs to change

Ensure that this policy includes reviewing and updating these plans at regular intervals

Ensure that people with a learning disability who live with ageing family carers are highlighted within local housing strategies

Integrated Care Boards need to:

Work with local authorities within their area to support them with planning for the future, and provide monitoring and oversight to ensure this occurs

The Department of Health and Social Care needs to:

Collect and monitor data on the number of people with a learning disability living with and/or supported by family carers

Collect and monitor local authority data on the percentage of people with a learning disability and their families who have received support to plan for the future

Analyse and publish national level data

Collect and distribute good practice examples to a) local authorities, and b) ICBs

Resources

[Confronting a Looming Crisis: People with learning disabilities and/or autism and their carers growing older](#)

(Dr Rachel Forrester-Jones)

We have worked to co-produce these actions and asks, building on years of work that has gone before it.

We are happy to engage with policy makers at a local, regional, and national level about how we can get things right for people with a learning disability whose behaviour challenges.

If you would like to talk about any of the actions in this plan, or any work you are planning on doing, please email actionplan@thecbf.org.uk