

Appendix D

Expert testimony to inform NICE guideline development

Section A: Developer to complete

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Guideline title:	Care and support for older people with learning disabilities
Guideline Committee:	Meeting 9
Subject of expert testimony:	Support at home for older people with learning disabilities
Evidence gaps or uncertainties:	[Research questions or evidence uncertainties that the testimony should address are summarised below]

Our review of evidence about care and support at home for older people with learning disabilities was based on the following questions:

Q. What is the acceptability, effectiveness and cost-effectiveness of care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities?

- What are the views and experiences of people using services and their carers in relation to care and support at home, in supported housing and in accommodation with care and support?
- What are the views and experiences of health, social care and housing practitioners about care and support at home, in supported housing and in accommodation with care and support for older people with learning disabilities?

To answer these questions, we conducted a search of bibliographic databases (as outlined in our review protocols). The systematic reviewers screened the results of the search and then extracted data from the included papers and assessed the quality of the methodology in the reported studies.

The evidence that was located and included in the review related to two main areas; **supporting adults with learning disabilities in group homes as they grow older** and **supporting adults with learning disabilities in residential care for older people**.

The review highlighted a significant gap in evidence about the effectiveness of care and support in the family home for older people with learning disabilities. Also, about people's views and experiences of care and support provided in the family home. This meant that the guideline committee felt unable to develop recommendations about this area of care and support and they agreed to seek expert testimony to plug this gap.

Members are seeking information about the nature of care and support provided to older people with learning disabilities when they live in their own or in the family home and in particular, how well different types of support meet people's needs and achieve positive outcomes. The committee would find it especially helpful for the testimony to be underpinned by evaluation or service monitoring data derived using before and after or comparison group methods.

In addition, the committee needs to understand what older people with learning disabilities and their families think about care and supported provided at home; whether it is acceptable and accessible and they also need to develop an understanding of what practitioners think of care and support provided at home for this population.

In summary, evidence on the following aspects of care and support for older people with learning disabilities would enable the Guideline Committee to develop recommendations or it may enable them to add weight to recommendations already drafted:

- The effectiveness and cost effectiveness of care and support at home for older people with learning disabilities. In the absence of cost effectiveness analyses, cost data and cost savings evidence as a result of care and support provided at home.
- Emerging models and approaches to care and support at home for older people with learning disabilities and associated outcomes.
- The self-reported views and experiences of older people with learning disabilities, their families and supporters about the care and support received at home, including what works and what does not work well.
- Whether older people with learning disabilities, their families and supporters think that care at home is personalised and coordinated across health, social care and housing services.
- The views and experiences of people delivering, organising and commissioning social care, health and housing services including what

works and what does not work well in care and support at home, including what works and what does not work well.

Section B: Expert to complete

Summary testimony: [Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

I have worked with people with learning disabilities for the past 20 years, with the majority of that work being to help people with learning disabilities and their families make choices about where they live and the support they get to live there on a practical or policy level. I have particular expertise in alternative housing and support options to residential care or supported housing. I have helped many individuals and families create bespoke housing solutions and have helped older family carers create solutions that involve using the family property, capital or inheritance to create long term solutions for their relative with a learning disability.

In relation to older people with learning disabilities living in the family home, there are clearly fewer examples because it often becomes impossible for a family to care for an older person in the family home when they are older themselves. To my knowledge, there is little in terms of data and evaluation on this subject so my views are formed by my experience of working with this group of people and their individual experiences.

In 1998- 2001, I led a project with Ealing Mencap to identify people with learning disabilities living with older carers in the London Borough of Ealing and plan the future with them. I have also worked with the housing advice service, Housing Options as an advisor since 2000 (this organisation later became Learning Disability England) where we provided independent advice to up to 3000 families of people with learning disabilities per year, some of whom were families caring for older relatives with learning disabilities.

Some examples of the experiences I have had of people in this group;

- It has been fairly common for people with mild/moderate learning disabilities to remain in the family home with parents or siblings as they get older, but I recall few experiences of people with learning disabilities and higher support needs remaining in the family home as they get older.

- It is common to see older people with learning disabilities living in the family home take on a companion and/or a caring role with a parent carer/s
- It is also common to see the income of the person with a learning disability being a valuable contribution towards running the home in a household where state benefits /pension or low earnings are the main household income.
- Parents and siblings of older people with learning disabilities are fearful about their future – some avoid dealing with it all together. Many are afraid to ask for help because they worry about because they worry about the family unit being broken up if they are seen not to be coping and they worry about whether the alternatives to living in the family home will not be right for the relative with learning disabilities.
- Some families are content to keep their older relative with a learning disability in the family home for as long as they can provide the support they need or adapt their housing situation to better meet their needs, but support and housing offered is usually not flexible enough to support this situation.
- Sometimes the older person with a learning disability and their family carer both need care and have to access different health, housing and social care systems to get this care. This can mean that no one organisation looks at them as a family unit and their housing and care needs as a whole.
- Social services and/or primary health care professionals look at their needs individually within the context of either older peoples or learning disability services and services offered that cannot meet both needs.
- This group of people often own property, have trust funds or money to create good solutions around the individual and family to enable them to remain in the family home but they do not routinely get information, advice and support to do this.
- Early planning based on good knowledge of how to enable older people with learning disabilities to stay in their family home does not routinely happen. This is sometimes because systems only respond to crises so solutions are often found in crises that are not ideal. It is also sometimes because of the fear of the family to plan for the future.
- It is common for families in this situation to expect a sibling or other family member to deal with the situation when they die and ensure that the relative with learning disabilities is cared for.

Emerging models and good practice need to be made more widely available;

- Shared Lives

- Homesharers
- Home ownership options
- Specialist homecare to meet the needs of entire family
- Assistive Technology
- Good neighbour schemes
- Home adaptation- DFG needs more flexibility
- Extra care for families
- Specialist information/advice/support and brokerage

Example 1

John was a 55 year old man with learning disabilities who lived with his parents who were both in their early eighties. He wanted to remain living with his family but they were concerned about what would happen when they die and they wanted to plan for the future.

After much planning with a housing broker, the solution was that they sold the family home and John bought a flat in an extra care retirement community and his parents also bought one in the same community. This meant that they could still live together and his family continue to provide support but when they became less able, John could access more support through social services.

In my experience, there are emerging and established models that can both meet the needs of the individual and family and be more cost effective than a care home, but they require robust and early planning to put in place. Most local authorities do not have the knowledge, expertise or capacity to do this type of planning and older peoples, learning disability and housing professionals do not work within co-ordinated enough systems to make this easy for the individual and family to navigate and achieve.

References to other work or publications to support your testimony' (if applicable):

Choice Based Lettings Report
BILD publication

Expert testimony papers are posted on the NICE website with other sources of evidence when the draft guideline is published. Any content that is academic in confidence should be highlighted and will be removed before publication if the status remains at this point in time.