Housing and Older People with Learning Disabilities

This fact sheet gives an overview of the issues facing older people with learning disabilities and their changing housing needs.

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1. Introduction

This factsheet aims to give a general overview of housing options for older people with learning disabilities. It is aimed at family members, support staff, managers in housing and support services for people with learning disabilities and more general older peoples services, as well as commissioners.

About housing for older people with learning disabilities.

The housing issues for older people with learning disabilities are similar to the issues we all face when we age:

* Reduced mobility means that sometimes the physical environment needs to adapt or change
* If we need higher levels of care, where we currently live may not be suitable to allow for that
* We may be faced with greater loneliness and isolation if we can't get out and about as much.

The only real difference for older people with learning disabilities is that they often start from a different place. Whilst most older people live in their own homes alone or with a spouse or partner and have always lived independently, many people with learning disabilities already live in residential care homes and other group living arrangements and have had a level of dependence on care and support for most of their lives.

This means that older people with learning disabilities often have different expectations when they age and do not always have an independent lifestyle that they want to maintain. As more people in the current generation of people with learning disabilities live more independently in the future, this will of course change and they will have similar expectations to the rest of the older population.

2. The housing options for older people

Staying in your own home

Many older people want to remain in their own homes, within the communities that they know well. When we say 'own home', we mean a property that the person has bought or rented, living alone or with others. There is no reason that people cannot remain in their homes when they get older and less able.

The major issues in remaining in your own home are:

* Getting enough support to stay safe and well
* Getting the funding for that support
* The environment being right if you are less physically able.

If all of these issues can be dealt with then people with learning disabilities should be able to stay in their own homes in the same way that any older person should.

For older people in the general population, funding has always been an issue in staying in their own homes when needing more care. This is partly because older people's care has lower levels of funding than care for people with learning disabilities, and because there has been little exploration in the alternatives that allow older people to stay in their homes in the same way there has been for people with learning disabilities.

Local authorities have a duty to assess and meet eligible care needs. They also must take into account what the person and their family want. If this is a 24 hour care package that the council feels is too expensive, then they can offer an alternative that meets the person's needs.

In this situation, it is important to consider other ways that the person can get the round the clock care that they need:

- ✳ Employing carers directly through a personal budget or direct payment
- ✳ Sharing your care with a housemate or neighbour
- ✳ Having a Homesharer or Support Tenant as part of your support package
- ✳ Having a live in carer (or 2 or more live in carers that rotate)
- ✳ Using assistive technology
- ✳ Physically adapting your home
- ✳ Living in a network (such as Keyring).

Residential or Nursing care

There are many residential care homes for older people in the UK. They often look very different to residential care for people with learning disabilities because generally, there are more people living in them. It is common to see residential care homes for 20-60 people. Of course they will vary in quality but even in good quality homes, there can be a culture shock for people with learning disabilities, families and supporters, who have been moving away from large congregate settings for some years.

There is no reason that a good quality residential care home can't support people with learning disabilities well with the right conditions. The residential care model itself restricts the amount of choice you have in your life but for some people, this restriction is acceptable.

The main issues for people with learning disabilities living in residential or nursing care for the general population are:

* ✳ A lack of understanding of the specific needs of people with learning disabilities
* ✳ Low levels of staffing
* ✳ No choice and control over who you live with
* ✳ No choice and control over who supports you
* ✳ Very little personal income.

Extra Care Housing & Assisted Living

Extra Care Housing and Assisted Living is where older people have their own flats within a development of flats or houses especially for older people. There is usually care connected with the housing and this care should be flexible to meet the needs of the older people. This type of housing can be rented, purchased outright or purchased through shared ownership. There are some schemes aimed just at people with learning disabilities and some that are aimed at a mixed population and include people with learning disabilities.

As some people with learning disabilities age earlier than peers without learning disabilities, extra care schemes often accept people with learning disabilities from when they are in their fifties. If the support provided on site does not meet the needs of the person, there is no reason that additional support cannot be provided and a bespoke package of care be built around the person.

Extra Care housing can be purchased outright, purchased through shared ownership or rented. Some schemes are developed by housing associations, whilst others are provided by charities and private companies.

Older people with learning disabilities can access mortgages to purchase a flat in an extra care scheme and have the mortgage interest payments1 paid through Support for Mortgage Interest. There are examples where an older family carer and their family member with learning disabilities have both bought flats in the same extra care scheme so that they can continue to support each other.

Real Lives : Netta Jenkins

Netta Jenkins *is 63 years old. She lives in an Extra Care scheme called Prescotts in Burgess Hill, West Sussex. The scheme has 26 x 1 bedroom flats and a communal dining and social area. Most of the people that live there are older people, 6 of those people like Netta, have a learning disability. Before Netta moved to Prescotts, she lived in a 24 bed hostel for people with learning disabilities. Netta had also lived in a long stay hospital before that.*

The service is run by a housing association and has a communal area with a dining room where tenants can buy a hot meal during the day and a light meal in the evening. Tenants can order their meals each week. Netta gets support every morning to have a shower then she gets her own breakfast. Support staff help Netta to prepare an evening meal between 5 and 6 pm every day. Netta pays a cleaner to clean her flat for 1 hour every week to do all the basics like hoovering and polishing.

Pam, Netta's best friend lives next door to her. Freda, another friend sits with Netta at dinner time.Netta works in the workshop at a local day service 4 days a week and has Mondays off to go shopping on her own. Netta likes goin to the local pub but had some problems with having to leave the pub early so support staff could help her get ready for bed. They resolved the problem by helping Netta get into her pyjamas and put her clothes on top before going out to the pub which meant that she could come home whenever she liked.

What Netta says…It's nice, I can go out when I like, I can come back when I like. I can go out and do things on my own and with my friend, Pam. Some things, like when I go out on a Saturday there is a long queue when I get my money, are difficult for me so a bit more help is good

Specialist residential or nursing care

Specialist residential or nursing care means residential or nursing care especially for older people with learning disabilities. Many people with learning disabilities moved from institutions into communities in the 1980s and 1990s, often when they were close to retirement age already. As those people aged, some services were set up to meet their needs as older people and had specialist support for dementia and ageing.

Whilst there may be a need for some specialist residential or nursing care homes, they were often developed as a result of learning disability providers not knowing how to cope with changing needs as people grow older. Some residential care homes for people with learning disabilities are learning about dementia and ageing and changing the way they support people so that they can keep people in their homes for as long as possible.

Specialist supported housing

Real Lives : Stephen

Stephen *was 38 years old and lived with Shirley, Tom and Margaret who were all in their early 70s. They were all tenants in a 5 bedroom shared house. It sounds like an unlikely mix, but for these tenants the arrangement worked well. Stephen did many of the lifting and carrying tasks in the house, Tom was a very active so often went out and about with Stephen and was a good male role model to him. The ladies liked to 'mother' Stephen by making him cakes and helping him with the domestic chores he hated. They all enjoyed watching certain TV programmes together, but at other times did separate activities.*

Staff regularly reviewed the arrangement, but always found that everyone was happy with the how they were living, who they were living with and the roles that they played in each other's lives.

Specialist supported housing means a shared housing arrangement set up for older people with learning disabilities where people are tenants and the housing and care arrangements are separated. There are very few specialist supported

housing schemes specifically for older people with learning disabilities but there is no reason that older people with learning disabilities can't live in shared supported housing arrangements which are not age specific.

Fewer older people want to go into residential care homes because of the lack of choice and control they face. This is likely to be true of older people with learning disabilities that have lived more independently.

The key benefit of shared supported housing over residential care is that the care is provided separately from the housing, this means:

✳ As a tenant, you have rights to remain in your home even if your care needs change

✳ If the care provider is not meeting your needs, the care arrangements can be changed

✳ You are able to claim a full range of welfare benefits

✳ You have some control over who you live with.

Shared Lives and Homesharers

Shared Lives is where a person with a learning disability lives within another family and is treated as a member of that family. Homesharers are people who come and share your home with you and provide some support in return for lodging.

Homesharers are often used to enable older people to stay in their homes when they need some extra help and could do the same for older people with learning disabilities. Shared Lives are less often seen as a solution for people with learning disabilities who have more complex support needs but there are examples and they do work if the person and family are well matched.

More info: www.sharedlivesplus.org.uk

Real Lives : Henry

Henry, *aged 94 with learning disabilities, wanted to leave the hostel where he had lived for 20 years (previously he had been in a large, long-stay hospital from the age of 17). The other residents were too noisy, and Henry wasn't allowed to come and go when he wanted. Ann worked at the hostel where Henry lived. When Ann's husband Gary picked her up from work, Henry would often show him his photographs. Occasionally Henry went to events at Ann and Gary's home.*

Ann had heard about the scheme, and when she became increasingly unhappy working at the hostel, she and Gary agreed to talk to Henry about living with them. After a number of visits organised through the scheme,Henry said he didn't want to go back to the hostel any more. At Ann and Gary's it was quiet, he had his own room, and he could go out and about whenever he wanted.

This is a shared lives case study is from: SCIE Guide 8: Adult placements and person-centred approaches **www.scie.org.uk/publications/guides/ guide08/files/guide08.pdf**

Supported living network

A supported living network is where several people living alone or sharing, form a network over a geographical area and provide mutual and peer support as well as share support from a volunteer network member. The most well - known model is Keyring Living Support Networks. The Keyring model has usually supported people with mild learning disabilities but can be easily adapted to support people who have higher support needs to connect together and take part in their communities.

More info: www.keyring.org

Bespoke housing and support solutions

Older people with learning disabilities can set up bespoke housing and support solutions in the same way that anyone with a learning disability can.

The housing options could include:

* Buying a home outright or through shared ownership
* Using a Trust or money left in a will to purchase a property
* Adapting the family home with a self -contained extension so that the person can remain in the family home and receive the care they need
* Renting social housing through a council or a housing association
* Renting from a charity
* Renting from a private landlord.

More info: www.bit.ly/hsa-housing-options

3. Design, Technology and Adaptation considerations

Whether an older person wants to remain in their own home or get a new home, their changing needs may mean that thought needs to go into the design of the house and whether adaptations and/or assistive technology can help people to live more independently.

Design considerations for older people are likely to include:

* Technology, adaptations and aids for those with hearing impairments
* Technology, adaptations and aids for those with visual impairments
* Technology, adaptations and aids for those with reduced physical mobility
* Making the home safer to reduce falls and accidents
* Technology and aids to support people with dementia to live more independently
* Design that promotes more privacy and independence where people are sharing.

The key in getting design, technology, adaptations and aids right for individuals is understanding whether there is a need for the following and whether any of these needs can be met by a design, aid, adaptation or technology solution:

* Maintaining independence
* Creating greater independence
* Better privacy and dignity
* Better safety and security.

Housing design, aids and adaptations

Although legislation has helped make new homes more accessible, many of the accessibility changes that have taken place focus on mobility issues, such as the creation of Lifetime Homes and part M of building regulations. However, there are a number of basic design features which can also be incorporate into any property or scheme which will breakdown unnecessary barriers and exclusions enabling people who have visual or hearing impairments to also better orientate around their environment.

These features need not look institutional; sighted people should not immediately notice any specific differences in the development's design and specification and many of the changes suggested will also be helpful to everyone else irrespective of their ability, age or gender.

Some of these changes include:

* Internal and external finishes which are comfortable to the touch for people 'feeling' their way around. Designers should consider how and where texture can be used provide information about the environment
* Using materials that reduce reverberation, particularly in larger spaces where acoustics can become a problem
* Internal and external circulation routes that are short and uncomplicated and ideally without dead-end routes
* Features, such as radiators, being recessed or positioned so that they do not become obstacles
* Handrails being located each side of hallways and being as continuous as possible
* Stairs or steps are consistent in height, in depth and in width from the wall and internal
* Thresholds that are flush
* Fitting lever type door handles which are easy to use. Door furniture consistently placed throughout the building aids use through familiarity
* Hearing loops in communal spaces
* Worktops, surfaces and tiling in matt rather than glossy to minimise glare

* The capacity to have different types of lighting - incandescent, fluorescent, tungsten halogen, and lighting that can be switched and dimmed to create different atmospheres and cater for the differing needs of individuals, even within the same household
* Maximise the use of natural light particularly on circulation routes and in task areas such as kitchens
* Installing a higher than usual number of electrical socket so that task lighting and other powered aids and adaptations can be used wherever necessary
* Differentiating the colour between walls, floors and doors so that people can better navigate through buildings
* Avoiding the use of irregular, busy or geometric patterns on walls and floors
* Contrasting small features such as sanitary ware, handrails, door handles, sockets against their background
* External paths that are wide enough for side by side support and wheelchair users (1200mm or wider), fully accessible, level or gently sloping, well lit and barrier free
* Assisting orientation by varying the gates and boundaries between properties where relevant
* Distinctively shaped, coloured or fragrant plants can also aid orientation and act as memory cues
* Raised planters allow people to enjoy gardening activities if they wish.

Many of the features for new housing listed above can also inspire changes in existing accommodation. Simple changes to increase/enhance lighting, redecoration to assist with orientation and easy use fittings need not be difficult to achieve or expensive.

Also think about other changes which may help people to remain in their existing accommodation:

* Internal and external threshold ramps to make some thresholds easier to manage. These can be portable or fitted
* Internal and external handrails
* Window dressings and task lighting which enhances light and reduces or eliminates confusing shadows

* Purchasing contrasting furniture and placing it appropriately to ensure logical routes that are free of obstacles
* Purchasing specialist furniture such as bed, chairs which can be helpful for people with limited mobility/movement
* creating logical, unclutter routes
* Using objects of reference, tactile stickers, pictures, colours to provide sensory or memory cues
* Introducing tactile, audible and easy to use appliances, technology and personal aids to enable people to remain independent for as long as possible

Other, more costly, changes to the existing environment may include:

* Adaptations to the bathroom such as the creation of a wetroom, installation of an assisted bath, bathlift, enlarging or re-siting a bathroom to enable better access or support to be provided.
* Adaptations to the kitchen such as lower work surfaces and basin/draining board
* Installation of a stairlift or platform lift to allow access to upper floors
* Creation of ramps and widening doorways to allow increased access
* An extension.

Items of community equipment which a person is assessed as needing as a community care service, and for which the individual is eligible, should be provided free of charge. All minor adaptations costing £1,000 or less (which includes the cost of buying and fitting the adaptation) should also be provided free of charge. An Occupational Therapist (OT) in Social Services will be able to provide further information about this.

For adaptations over £1,000 a Disabled Facilities Grant (DFG) may be possible. It is a means tested grant provided by the local Housing Department for necessary and appropriate adaptations. Usually an Occupational Therapist from Social Services will visit to assess need and recommend what work should be done. Further information is available on the Age UK website.

Assistive technology

Assistive technology is the umbrella term given to a number of devices which can help support people less intrusively, create a safer environment or enable people to be more independent. The use of assistive technology in a personalised way could enable someone to remain in their own home for longer (whatever their tenure) or reduce their length of stay in hospital or respite after an accident or illness.

There is still a lot of fear and uncertainty around the use of technology, but it does not have to be complicated and need not replace staff or leave someone socially isolated. If considered sensitively and in a person centred way, it can enhance support already being received and help someone to maintain their independence and dignity.

There are millions of piece of equipment available, some are specialist but many are everyday technologies which can be used in creative ways. Most equipment is wireless, so can be retro-fitted making a personalised package of equipment more achievable than ever.

Some of the types of equipment could include those which:

✳ **summon help** such as panic buttons, pull cords, falls detectors, epilepsy sensors

✳ **create a safer environment** by monitoring extremes of temperature, carbon monoxide levels or smoke detection. By detecting whether gas, water or electricity have been left on and shutting off the supply. Devices to shut off small appliances such as a toaster or kettle if/when they should not be used

✳ **assist carers to provide more reliable support** or less intrusive support such as chair or bed occupancy sensors and pressure mats. Door sensors and beams, proximity detectors, infrared sensors and other devices which allow staff to know where someone is or what they are doing so that they can offer support if/when necessary.

✳ **gives someone control, independence and confidence** by allowing them to continue to do certain tasks but in a different way. This could include tasks such as opening or closing curtains or doors, biometric (finger print reader) locks if people struggle to use keys, are likely to forget their keys or want to give regular carers direct access. An intercom or door entry system so they can see who is calling and can give people direct access. Voice prompts and timers aid people who are likely to forget things/tasks or become confused

✳   **help someone to (self) manage conditions** such as taking medication, monitoring health conditions, reporting vital signs, monitoring/reporting changes of routine

✳   **aid communication** such as easy use phones and mobiles, GPS enabled devices to locate people, online programmes to help people stay in touch with others such as Skype and Facebook, aids to amplify sounds, devices to help people with communication disorders to express themselves

Most devices can be paired with a voice prompt, visual or sounder beacon, vibrating alert/pillow so that people who have hearing or visual difficulties will know when an event is taking place. For example, a flashing light (visual beacon) or a vibrating alert could be added to a doorbell so that someone who has hearing difficulties is still able to answer their front door. A voice prompt and timer could be teamed up with a door sensor so that someone is reminded to take their keys before they leave home and also an alert is sent to someone else (carer or family member) if they are away from home for longer than expected or the door is opened late at night.

Consideration also needs to be given to where the alert or message is being sent. It could go to on-site staff if someone is living in a property with full-time care. It could go to on-site or on-call carers at certain times and to a call centre or family member at other times – usually any combination is possible!

There are some stories of older people using technology in Using Assistive Technologies to support personalisation in Social Care

http://bit.ly/assistive-report-pdf

For example, **Jan is 97** and has a sensor mat under her mattress which is linked to a light so that when she gets out of bed at night, a light automatically comes on in her bathroom. The pressure mat has a timing set according to how long Jan needs to get in and out of bed on her own. If she hasn't returned within a given time, an alarm alerts staff who can check she hasn't had a fall. The bathroom light goes off when she is safely back in bed.

Dorothy, aged 92, uses Skype to keep in touch with her family.

Jeremy, an 84 year old with dementia described using a pill dispenser as "dead easy".

4. Considerations for providers

The following are for providers to consider when housing older people with learning disabilities:

✱ Vary your services so that the people can remain in their own homes for as long as possible.

✱ Look at ways that people can retain community links, relationships and friendships – additional transport, alternative meeting places, different means of communication?

✱ Be prepared to work in partnership with different and non-learning disability specific service providers. For example, think about the service that your staff (and their older relatives) use and how they may benefit the people you support?

✱ How can families and friends help to provide additional support or to make personal budgets stretch further? Tasks around the home, shopping, transport, timebanking?

✱ What assistive technology can help each individual to remain as independent as possible?

✱ Explore options for physical changes to the environment

✱ Explore aids which will help people remain independent

✱ Be aware of the alternative housing options for people who do need to move and be able to support them through this transition as smoothly as possible

✱ What training, support and processes/procedures do you have in place to ensure new ways of working and/or assistive technology become effectively embedded in your service provision?

✱ Capture your creative approaches, costs and benefits and use these to promote your services to commissioners and potential service users.

5. Considerations for commissioners

The following are for commissioners to consider when housing older people with learning disabilities:

* Be clear about your expectations of provider to enable people to remain in their own homes for as long as possible

* Make links with Older Persons Services and other non-learning disability specific services

* Raise awareness and provide information about the possible housing and support options – including non-learning disability specific services

* Encourage community inclusion, the retention of friendships, relationships, networks and mutual support

* Challenge negative attitudes and professional scepticism about the use of non-traditional and non-learning disability services

* Work with knowledgeable and creative providers that can demonstrate their ability to work with this group of people in a person-centred and dignified way

* Encourage and expect diverse models of support.

6. More help and resources

Housing and Support Alliance website

The Housing & Support Alliance has information about the various housing options mentioned in this factsheet. They also run a free and independent housing advice service for people with learning disabilities, families and organisations that are members.

www.housingandsupport.org.uk

Tel 0845 456 1497

Housing LIN website

Housing LIN provides information to housing, health and social care professionals in England involved in planning, commissioning, designing, funding, building and managing housing with care for older people.

www.housinglin.org.uk/Topics/type

Widening the Choices for Older People with High Support needs.

This study examines the experiences of older people with high support needs involved in support based on mutuality and reciprocity. Including some personal stories and examples of mutual support in appendix 4

www.jrf.org.uk/publications/widening-choices-high-support-needs

Using Assistive Technologies to support personalisation in Social Care

The stories in this report reveal how the lives of people of all abilities and ages and their families have improved as a result of assistive technology.

http://bit.ly/assistive-report-pdf

SCIE Guide 8: Adult placements and person-centred approaches

www.scie.org.uk/publications/guides/guide08/files/guide08.pdf

Designing the domestic environment for people with visual and hearing difficulties

Contains more detailed suggestions about housing design for people with visual and hearing difficulties.

www.clairehall.com/housing/publications.html

Housing for people with sight loss: a practical guide to improving existing homes.

Checklists for changes that can be made for each room in the home are in the guide.

http://goo.gl/hR2WjH

Age UK factsheet: Adapting your home: Your guide to services and equipment

http://goo.gl/1OZNIQ

Age UK Factsheet: Funding repairs, improvements and adaptations

http://goo.gl/vi6Iog

Age UK factsheet: Disability equipment and how to get it

http://goo.gl/7BoUDE

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www.housingandsupport.org.uk