

Housing Learning & Improvement Network

New Provision for Older People with Learning Disabilities

An introduction to the characteristics and needs of an emerging group to be provided for in developing new housing and services for older people. This includes extra care.

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The Health and Social Care Change Agent Team (CAT) was created by the DoH to improve discharge from hospital and associated arrangements. The Housing LIN, a section of the CAT, is devoted to housing-based models of care.

Other Housing LIN publications available in this format:

Factsheet no.1: Extra Care Housing - What is it? *This factsheet gives essential basic information, explains the various forms extra care housing takes, and describes key ingredients and central principles (28.07.2003 updated August 2004)*

Factsheet no.2: Commissioning and Funding Extra Care Housing *Summary of essential facts about commissioning extra care and other housing based solutions for care. Most important facts about funding, what is involved, who is involved, who has to be involved and how long projects can take.(28.07.2003 updated August 2004)*

Factsheet no.3: New Provisions for Older People with Learning Disabilities *An introduction to the characteristics and needs of an emerging group to be provided for in developing new housing and services for older people. This includes extra care (23.12.2003 updated August 2004)*

Factsheet no.4: Models of Extra Care Housing and Retirement Communities *An explanation of the different types of retirement community and examples of how key decisions about the choice of model are made (04.01.2004 updated August 2004)*

Factsheet no.5: Assistive Technology in Extra Care Housing *AT can play a part in supporting people in extra care housing. Summary of the most common applications, with examples and where to get more details (20.02.2004 updated August 2004)*

Factsheet no.6: Design Principles for Extra Care *Basic information about key design principles and issues to consider when designing and developing a brief for a new Extra Care Scheme. Variety of models and ways of developing a range of different sites (26.07.2004)*

Factsheet no.7: Private Sector Provision of Extra Care Housing *The private sector has had an involvement in the provision of extra care housing for at least 20 years. This factsheet is intended to help statutory authorities commissioning extra care housing and private developers work together with a better understanding (21.07.2004)*

Factsheet no.8: User Involvement in Extra Care Housing *The role of the users in the development and management of extra care schemes, linked to concepts of independence, self determination, control and choice, key themes in national policy (August 2004)*

Published by: Housing Learning & Improvement Network
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Essential Short Facts: Older People with Learning Disabilities

1. Introduction

This fact sheet outlines issues and good practice in relation to the development of supported housing specifically for older people who have a learning disability. This note has been prompted by interest in the Extra Care Sheltered Housing Fund announced in August 2003 (see below and pages 12 and 13 of this Factsheet for details of the Access and Systems Capacity Grant criteria).

2. Department of Health – Funding Extra Care housing and supported living

There are two distinct funds:

- i. In 2004/05, the Department of Health (DH) made available £29 m with a pre-allocation of £17.7 m to be spent on developing new extra care housing places. This leaves £40.3 m for year two funding 2005/6. In announcing the fund the DH made clear it wished to:
 - Develop innovative housing with care options
 - Stimulate local partnerships

Bids for schemes **which include learning disabled older people** and demonstrate good practice are particularly encouraged

- ii. There is a separate pot of £2.32 m in 2005/06 specifically for supported living schemes **for learning disabled people of any age** who have been living with family carers who are no longer in a position to provide support. Those are also in practice likely to be older people with learning disabilities

For further details see Department of Health Extra Care Housing Fund – Application Guidance Notes published 31 July 2004. Annex B refers to people with learning disabilities. www.changeagentteam.org.uk/housing

The development of Extra Care Housing for older people with a learning disability could usefully focus on:

- Those with disabilities living in services or with older carers who may need to move because of changing needs
- Those with a learning disability who need specially designed or adapted dwellings including provision of suitably enabling assistive technology
- Those with a learning disability who need enhanced housing, care and support
- People with Downs Syndrome because of the greater risk of dementia at a relatively early age

Additional details can be found in:

FPLD, 2002. Appendix 5. *Today and Tomorrow. Report of the Growing Older with Learning Disabilities Programme.* Foundation for People with Learning Disabilities (FPLD)

3. Where people are living now

The situation of people with learning disabilities differs from the general population in significant ways:

- More than half of all adults with a learning disability are cared for by relatives in the family home. “Younger” elderly adults may find their carers reach the point where, because of the carers own ageing or decline in health, they can no longer give the support needed
- Most of the remaining group will be in some form of congregate living whether hospital, residential care home, group home, or similar with care and support from Social Service or NHS Trust
- A small minority will be living independently in their own homes, very, very few are owner occupiers.

Where People Live	Approx
Adults living in the parental home	50
In residential care homes	30
In supported housing shared and self-contained	12
In adult placement	4
In NHS care	4
Total	100%

Source: Analysis by Housing and Support Partnership for Valuing People Team.

It is estimated that by the age of 60 less than 15% of those with learning disability will be living in the community or with their families.

As a consequence, the general thrust of policy toward older people to meet their preference of being supported at home is not generally possible because the vast majority of people with a learning disability as yet do not have their own home.

In each case therefore services will need to adapt as people age and a move cannot be ruled out. The fundamental policy and practice challenge is clearly those who are living with ageing carers and getting proper long-term housing, care and support plans in place.

4. What happens when we age – linking design and support

As people with a learning disability age they will experience just the same changes as anyone else. What is different may be the ability to explain, communicate or sometimes understand what is happening. Someone with a learning disability may also be less able to do something themselves to deal with the effects of ageing. This leads to consideration of what additional good practice in both design and support would appear in extra care housing for a learning disabled person.

We give a few examples below to illustrate but organizations seeking to support groups of people with a learning disability should consider the individual needs of each service users. A person-centred approach should not stop at a certain age. For example:

- As we age the tendency is to experience some loss of senses like hearing and vision. Action points might include checking for such loss regularly and finding means to counter e.g. hearing loops, hearing aids, cues to location by sound, texture, colour coding doors/floor, block etc. People with learning disabilities differ in their ability to use hearing aids and similar devices. The general practice must be to see what works best for each individual
- A similar decline in physical ability and strength is also a possibility. Living upstairs in a home may become difficult or extremely restrictive. Mobility and getting out can become more difficult with enhanced risks for example of breaking bones in a fall or lack of competence. Action points include recognition of these difficulties and plans to move to more suitable accommodation or adapt buildings
- Relatively few people with a learning disability will be “retiring” from work. An arbitrary, enforced, refusal to allow access to day services on reaching a certain age makes little or no sense for a disabled person. Day services or other activities may be an important part of the individual life and the source of friendships
- People with learning disabilities will have fewer friends and relatives to see or do things with. They are less likely to have children and more likely to have lost contact with family due to institutionalization. Action points include supporting vigorously any remaining contacts and friends
- People with learning disabilities living with other older people may be shunned by other residents keen to distance themselves in order to ensure their own continuing mental capacity is acknowledged
- Communication difficulties may make it hard to participate in or understand social activities or games enjoyed by other residents
- As we age our ability to sense when we are too hot or cold declines as does the body’s ability to regulate temperature. An older person with a learning disability in addition may not be able to communicate how comfortable they feel. This implies:
 - Greater vigilance and awareness by staff of environmental conditions

- A case for environment monitoring devices set to detect unacceptable variations. In independent living settings this could be through dispersed alarms and an array of linked sensors
- Illnesses may develop but not be detected or communicated. Regular health checks, commencing at a chronologically younger age than the general population could be part of the strategy
- Short term memory loss will probably be experienced. The disabled person will need more support and training to master aids that can be used to counter these impairments or reduce risks. For some people with a learning disability the task may be too great for example using an electric buggy. Again different or additional support will be necessary if the policy objective of enjoying as independent a life as possible is to be achieved.

Dementia

Dementia in people with learning disabilities is a significant issue. Advice on good practice for older people with dementia may conflict with good practice in relation to addressing other disabilities. As an example, Stirling University Dementia Centre did a lot of work on the use of colour for people with dementia. The RNIB point out that if you want to prevent someone wandering out of the front door, you do not highlight the door using ordinary low vision techniques like colour contrast. Rather you prevent someone finding the door by making it the same colour as the door frame and surrounding walls!

For a useful design checklist see pages 15/16 of this factsheet. Also, a further Factsheet on extra care housing for people with dementia will be available on the Housing LIN website. www.changeagentteam.org.uk/housing

Good practice in supporting Learning Disabled People with Dementia		
Early stage practices	Middle stage practices	Late stage practices
<ul style="list-style-type: none"> • Monitor and document change • Treat any medical conditions • Help the person, the family and support staff understand the probable diagnosis as appropriate • Focus on maintaining skills, keep independence by increasing staff supervision and 	<ul style="list-style-type: none"> • Keep the person appropriately mentally and physically active • Maintain physical health • Ensure adequate nutrition and fluids • Protect and maintain safety with regular risk assessments • Give appropriate help with self-care • Intervene to reduce agitation and 	<p>The emphasis in the later stages moves towards the provision of high quality 24-hour care. This will include particular attention to:</p> <ul style="list-style-type: none"> • Maintaining mobility and movement • Lifting and handling • Maintaining nutrition and fluids • Skin care and prevention of pressure sores • Prevention of

<p>prompting</p> <ul style="list-style-type: none"> • Keep changes in the environment and daily routine to a minimum; provide structure and supports to daily routines and to help orientation • Simplify routines and reduce choices • Keep verbal requests simple and clear • Help the person maintain self-awareness • Reassure the person daily 	<p>distress</p> <ul style="list-style-type: none"> • Adapt to significant differences in ability on a day-to-day basis; this can affect all aspects of their functioning e.g. mood, memory and self care skills • Work with families, carers and peers to understand the changes 	<p>infection and other physical health matters, e.g. constipation</p> <ul style="list-style-type: none"> • Ongoing attention to safety issues • Work with families carers and peers regarding terminal care and death
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Source: Dementia Resource Pack, Karen Dodd and Vicky Turk, BILD, 2003

5. Contrasting examples: misplaced and staying put

There is evidence that older people with learning disabilities are too often placed in older people's residential service not because of their own needs but for different and questionable reasons.

The National Service Framework for Older People referred to the possibility that disabled people may be "misplaced in older peoples' homes living alongside much older and more incapacitated people". Hospital closures have resulted in people being re-settled in older people's services, reorganization of community services also lead to people being passed from the Community Learning Disability Team (CLDT) to older people's services. There is evidence that the disabled incomers are much younger than fellow residents. For those living more independently or in small groups it is perfectly possible to "age in place" but the absence of suitable services can force a move from a familiar environment.¹

A recent survey² of people with a learning disability placed in older peoples care homes found proprietors of homes volunteering:

- They lacked suitable training
- They had inadequate staff levels
- Activities provided were unsuitable
- People did not fit in

¹ D.Thompson, FPLD Update Vol. 2 Issue 6, 2004 *People with Learning Disabilities Using Residential Services for Older People* Foundation for People with Learning Disabilities.

² Thompson D and Wright S (2001) *Misplaced and Forgotten*, Foundation for People with Learning Disabilities.

People “had very impoverished lives with few opportunities to get out”.

Almost Misplaced

Paul was 55 before he became known to Social Services having been cared for by his parents and, after their death, an aunt. When the aunt herself had to go into residential care it was initially suggested that Paul go into the same home despite being 30 years younger than most residents. Paul had gradually experienced more independence following the death of his parents and was able to assert he wanted his own place.

The family home was sold and a share of the estate was put in Trust for Paul. This was used to buy a small flat where he is now supported with a combination of a daily home help, support worker for 16 hours a week and emergency call system which he has never used.

Continuing to Live at Home

This London borough has a Senior Practitioner dedicated to assisting families with carers over 70 to put in place long term plans for adult relatives they are supporting at home.

John at 65 was still being looked after by his now frail and unwell mother who was approaching 90. There was some additional support from Mencap. In order to ensure his future housing was secure, he became a joint tenant of the two-bedroomed council house where he had lived for 30 years. Following his mother's death an intensive support package was provided in the morning and from mid afternoon until early evening with sleep in night carer and additional support at weekends. Support has been phased down as John's skills and confidence has been built up.

Sheltered housing is another option for older people. Letting criteria of sheltered housing may restrict lettings to those over 60 or 65 or by allowing someone with a disability in need of the kind of facilities or services on offer to take up residence despite being below the minimum age. This may well apply to someone with a learning disability. Practices in relation to placing people in registered care homes at a younger age varies. Some registration and inspection units have in the past permitted this, others banned it.

Re-modelling sheltered housing, most commonly combining 2 or 3 bedsits to produce self-contained flats, can be an opportunity for providing accommodation for a group of learning disabled people. In smaller schemes the process of re-modelling may reduce the number of units so that the scheme as a whole is seen as uneconomic to support with a warden service. A small block of 6 – 7 self-contained flats with some communal space may however make good sense for people with higher support needs. Alternatively, part only of a re-modelled sheltered scheme could be let to older people who also have a learning disability.

Alone in extra care – tackling the problem

The housing association concerned let one flat in a newly completed extra care scheme to an older person with learning disability. He was rejected by other residents who refused to sit with him at meal times and made disparaging remarks about him within his hearing to the effect “he should not be here”. Some residents also voiced their resentment at the additional help he received via the local authority Learning Disability Team. Staff found it difficult to manage when other residents were themselves often frail or unwell. One strategy adopted was to find two other residents who were more positive about the individual and less concerned with his disabilities to befriend and support informally.

6. Extra Care housing for people with a learning disability?

There is no precise definition of “extra care” for the general population of older people. There is even less precision at this time as to what extra care for someone with a learning disability means. General guidance is contained in Fact Sheet 1. in this series (Extra Care Housing. What is it?)

Extra care for older people is characterized by:

- Self-contained accommodation; residents are tenants or owners not licencees
- Grouped together on a site
- A much more extensive range of facilities than found in either residential care or traditional sheltered housing
- Provision of meals if required
- Individual packages of care and support
- Care and support available 24 hours a day
- Ability to provide high levels of care when required

For people with a learning disability this model fits well with the policies set out in the “Valuing People” White Paper on the future of learning disability services in that it is intended to foster independence rather than dependence. Support and care can be tailored to the individual user in an extra care setting, independence, control and choice are possible. Each person can have their own home.

Mildmay Park - Extra Care Sheltered Scheme for seven older people

There are seven older people with learning disabilities who live in six flats at Mildmay Park, London. There is a dedicated team of staff who work with these customers to support them to live independently within the extra care service. Community Support Officers attend regular training, both in-house and organised by Islington Learning Disabilities Partnership. In this way, the staff maintains specialised skills that are directed to addressing the particular needs of the client group.

Notting Hill Housing Group is contractor to Islington Council, and demonstrates care principles to meet the needs of customers with a learning disability. These principles include:

- To encourage customers' a maximum of possible choice of service within the boundaries of resources
- Promote maximum independence through adopting a non-institutional needs led approach
- Maximise the skills of service users and decision making opportunities
- Awareness of emotional support needs
- Acknowledgement and respect of gender; sexual orientation, age, physical or mental ability, race, religion, culture and lifestyle.

Key Workers

Community Support Officers take on key worker responsibilities, including devising a Care Plan resulting from a Community Living Assessment, which includes a detailed assessment of the customer's personal support needs, daytime and evening activities, social needs emotional needs and any special information required to enable the delivery of service. Included in this role is carrying out a risk assessment to ensure a safe environment, support to maintain contact with family/relatives and support to meet dietary requirements and encourage general healthy nutrition and lifestyle. The primary role of the key worker is to work with each customer and ensure that individual freedom and choice is promoted and protected. Key workers identify a variety of suitable day time/ evening opportunities. Support will include arranging transportation to services, escorting customers and liaising with the organisations to set up activities and functions. Key workers try to maximise opportunities to develop communication skills, literacy and numeric skills.

Customer Choice

Customers are at all times given the opportunity to express their views of services provided. This is done through:

- Customer group meetings which are held monthly
- Informal social gatherings and events
- Development of a tenants handbook
- Satisfaction surveys
- 1-2-1 interactions with the key worker

Common requirements of customers

Common requirements for customers at the Scheme include:

- 24 hour staffing
- Support for appointments, e.g. GP; counselling
- Support in ordering medication and prompting of medication
- Support in managing personal finances including budgeting
- Support to maintain tenancy
- Support to liaise with DSS and HB for benefit claims
- Initial extra support for orientation around the new building and locality.

Specific requirements for customers

Customers may have further additional requirements met based on individual care plans. At present this includes support for shopping trips, preparing meals, personal care, support with dealing with emotional issues, such as anger management.

The DH has made clear it does not rule out intentional communities as a choice for someone with a learning disability. However, given the level of funding available it is not anticipated new retirement villages expressly for people with a learning disability would be constructed.

The general thrust of policy is to **include** disabled people. People with learning disabilities have often been excluded from mainstream services and new services, including extra care housing, should be designed to be accessible by all older people. This means in larger purpose built developments for older people some thought should be given to the relatively small number of older people with a learning disability who might be housed alongside all other older people. Equally, many people with a learning disability may be better served in alternative, specialist provision designed to cater for their particular needs. Finally, some people may simply need the right package of support in an ordinary property.

Independent Living – three older people re-housed from hospital

Three elderly men had all lived in long stay hospital for most of their lives. One lived on a large ward the other two in bungalows with four or five other people.

In March 2003 they moved into a shared house with their own tenancies and support provided by New Support Options, the support arm of a specialist housing association. They each now have their own bank accounts. They are adapting to their new way of life and one man who loves to go out is taking particular advantage of all the new opportunities now open to him.

They all have health problems. This has required good partnership working between the support team, GP, community health team and at times additional appropriate specialists. Training was needed for staff before the men moved so that they had a good and thorough understanding of health needs and of the individuals so that support could be provided in an informed manner.

Specialised training and guidelines have been given on how to appropriately support for example epilepsy, asthma and prostrate conditions relevant to the three older people.

The men are not able to communicate verbally and therefore pictures and photographs were used to help make choices during the moving process and for staff to explain to the men what would happen during the moving process, with visits to their new home, shopping trips, etc.

One of the men was unwell after the move and this was felt to be strongly linked to the move and change in living arrangements. Staff need to be very supportive during such a time. Adapting to change can be a slow process and it may take a while for people to realise for themselves the benefits.

Supporting staff have got to know the GP and primary health care team very well. The GP has known the men for a number of years and this history and knowledge has been very beneficial. The men also have a good community LD nurse. It is felt strong support and joint working has led to the success of managing the health of the men during the move both physically and mentally. The care managers are also actively involved.

One resident is a recluse and only likes to go out when the weather is sunny and there is no breeze. Since moving however his confidence has built up and he has recently been for walks on days when the weather has been poor.

Before they moved a 'This is me' document was completed for each of the men, this contained all essential information about the person and was invaluable for staff to get a better understanding of the needs of each person.

The concept of a "community network" whereby people live in ordinary housing, in close proximity to one another is exemplified by an organization called "Keyring". They employ a project worker who lives nearby to provide a limited amount of support, co-ordinate other services, and help members develop mutual support. For example one member of a network who is not physically able can be helped by another who is fit but has no language. Together they can manage the shopping. Keyring networks normally consist of 9 or 10 people in ordinary housing but can be extended to include for example, someone living in sheltered housing who has a learning disability.

7. Using the Extra Care Fund

It is expected the general extra fund of £29m in the first year will primarily be spent on capital development of additional housing with care. The DH is looking for:

- Innovative solutions to the needs of older people – including those with a learning disability
- Good practice lessons

In the context of learning disabilities this might include:

- Re-modelling existing care homes or group homes
- Creating new models of self-contained sheltered housing but probably on a smaller scale than traditional sheltered housing scheme
- Re-modelling existing sheltered housing and letting some or all to people with a learning disability
- Schemes which mix disabled and non-disabled people
- Independent supported living specifically available for older people with a learning disability perhaps incorporating additional design features and with an appropriate package of care
- Introduction of a range of assistive technology to support independence, privacy, dignity, control or choice as part of a care package
- Purpose built and designed schemes for people with a learning disability who also have dementia
- Services which provide additional, specialist support to people with learning disabilities living in mainstream older persons accommodation or services

As with the mainstream extra care programme, examples that demonstrate partnership working or use alternative sources of funding are of particular interest. In the case of learning disabilities the latter could include:

- Shared ownership – part buy, part rent usually in partnership with a housing association, trust or relatives
- Joint ownership where a group of people combine resources to purchase a property together
- Privately financed developments
- Equity investment or other contributions from relatives
- Trusts
- Private sector leasing/renting working in partnership with a private landlord and/or housing association

Neither of the above lists is intended to be exhaustive. They are simply illustrations of the kind of initiatives that are possible.

8. Other Funding Options

Capital and revenue funding for older people with learning disabilities living in extra care is no different to any other occupant with the same range of renting and, in theory, owning options available.

Example of revenue funding – rented property	
Costs	Funding
Rent (including very limited services)	Housing Benefit
Home care	DLA/Attendance Allowance/Disability Premiums (Income Support)
Support	Supporting People Grant
Personal Care	Care Contract Funded By Social Services /Health
Meals, travel, domestic bills	Income Support/Premium

This is a simplified example. Social Services may fund support and similarly Supporting People Grant may not always be available. People on the highest rates of DLA may qualify for help from the Independent Living Fund subject to the Local Authority contributing £200 per week and the total package not exceeding ILF limits. It is also possible for older and disabled people to receive Direct Payments to meet assessed needs instead of having a package of care contracted for them by Social Services. Older people with a learning disability may need additional help to manage a Direct Payment (or ILF) but in principle Direct Payments can include an element for administrative help³. However issues of legal capacity combined with the absence of parents to assist the use of direct funding are in practice likely to mean these opportunities are seldom realistic.

Capital funding from the providers perspective will be a combination of:

- Social Housing Grant (if RSL provider)
- Department of Health Grant
- Borrowing – loans serviced by rents
- Charitable funding/own resources invested
- Cross subsidy from sales
- Charges for use of facilities, sub-letting to commercial users etc.

³ Guidance on Direct Payments for people with learning disabilities was issued by the DH in 2004. This is downloadable from the Valuing People Team's website www.valuingpeople.gov.uk

For people with learning disabilities generally there are a variety of particular circumstances that can be used creatively to extend the ways of funding housing – these are implied in the examples under the section “Using Extra Care Fund”. They include:

- Income Support Mortgage Interest Payments (ISMI) system
- Trusts now commonly established by parents of disabled children
- Direct investment/provision by families for disabled relatives

9. Some design considerations

The best extra care schemes are designed so that they anticipate and build in measures to counter:

- Mobility problems
- Access difficulties
- Some level of confusion/early onset dementia

The design principles carry over to people with learning disabilities in that throughout their lives these are all likely to be issues for many.

The RNIB produces useful design guidance, a version of which is reproduced below. Although intended to assist people with visual impairment many of the design suggestions are also useful for people with learning disabilities generally. It is useful to have a **process** as well as a focus of **design detail**.

Design Process Checklist

Stage	Look at
Review each room	Colour contrast, lighting and non-visual clues to find your way around
Function of room	A room used often in a similar way might have a ‘route’ defined by colour, sound, texture e.g. path from bedroom to bathroom. In a group home each person’s own room door might be given a personal colour
Overall themes of building	Consistent use of colour materials. Do all toilets have the same colour door? Do kitchens all have tiled floors?
Consistency	Light switches similar and at same height, handrails consistent in style and shape

What needs to be variable?	Lighting controllable – dimmer switches
Safety outside	Lighting at night, steps and paths illuminated and contrast with surrounding area

Design detail – room by room

<p>i. Front entrance</p> <ul style="list-style-type: none"> • Front door contrasts with surrounding area • Raised numerals at eye level • Door handles contrast with door, use of texture and colour, easy grip handles – ‘D’ or ‘L’ shaped preferable • Letterbox should have wire basket to catch mail • Avoid large areas of glazed material • Good lighting present inside and outside • Consider defining route from entrance door to other parts of the building with rails or floor coverings <p>ii. Corridors</p> <ul style="list-style-type: none"> • Limit obstacles, such as a radiator or cupboards <p>iii. Activity areas</p> <ul style="list-style-type: none"> • Introduce additional lighting <p>iv. Bedrooms</p> <ul style="list-style-type: none"> • Built in cupboards are preferred, again to limit obstacles in rooms <p>v. Bathrooms</p> <ul style="list-style-type: none"> • Use water-resistant coverings which are easy to clean • Matt finishes to walls and floor to minimize glare • Non-slip, waterproof flooring • Consider additional lighting focused on toilet area <p>vi. Kitchen</p> <ul style="list-style-type: none"> • Good lighting over cooker, sink and other task areas • Sliding cupboard doors to avoid walking into open doors • Non-reflective worktops in a neutral colour, against which both light and dark objects will contrast • Colour contrasts between wall and worktops, cupboards and floor • Raised edge at front and back of worktop to contain spillages • Non-reflective, slip resistant and waterproof floor finishes <p>vii. Living/dining room</p>

- Is there an easy way to orientate?
- Bright, but adjustable lighting
- Colour contrast between doors, walls and switches

viii. Stairs

- Handrails to give guidance on route of stairs
- Tactile cues to when top and bottom of stairs will be reached
- Good contrast between handrails and walls
- Good lighting
- Highlighted and tactile edging to steps

ix. External

- Contrasts between paths and parking and/or garden areas
- Check for dangers: low fences, dustbin stores, raised kerbs, overhanging trees and branches

10. Useful Resources

The single most useful recent reference work on older people with learning disabilities is *Today and tomorrow – the Report of the Growing Older with Learning Disabilities Programme – Foundation for People with Learning Disabilities*, 2002.

The GOLD programme supported 12 projects on older people with learning disabilities which are outlined in Appendix 2 of the above report.

www.learningdisabilities.org.uk

On design specifically for people with learning disabilities look at *Designing for Special Needs*, Maurice Harker and Nigel King, 2003, RIBA.

On design of social rented housing generally the Housing Corporation produces a mass of advice and regulations including Scheme Development Standards. www.housingcorp.gov.uk

RNIB – Multiple Disability Services produces two factsheets with useful guidance on design for people with learning disabilities, premature ageing and dementia not simply impaired sight:

- Improving environments for people with dementia and sight problems
- Improving environments for people with sight problems and learning disabilities

Telephone: 0207 388 1266 www.rnib.org.uk/multidis

Useful Contacts

Most important sites with relevant information on housing or learning disabilities.

www.housingoptions.org.uk

Housing information for people with learning disabilities

www.doh.gov.uk/learningdisabilities/

DH Learning Disabilities

www.valuingpeople.gov.uk

DH Valuing People Support Team

www.learningdisabilitiesuk.org.uk/

Choice Support

www.carestandards.org.uk/

National Care Standards

Commission

www.arcuk.org.uk/

Association of Residential Care

www.bild.org.uk

British Institute of Learning Disability

www.ndt.org.uk/

National Development Team

www.mencap.org.uk/

Mencap

www.housingcorp.gov.uk/

Housing Corporation

www.housing.org.uk/

National Housing Federation

www.nas.org.uk/

National Autistic Society

www.autismconnect.org/

Autism information

www.learningdisabilities.org.uk/

Foundation for People with Learning Disabilities

Some useful web sources on dementia include:

www.alzheimers.org.uk

www.dementia.stir.ac.uk/network

www.mhf.org.uk

www.rcpsych.ac.uk

Other sources on sensory impairment and learning disabilities include www.rnib.org.uk and www.rnid.org.uk

Other Factsheets in this series: see back of front cover

ANNEX A

The policy context – Older people with learning

The DH has recognized “*high health care needs can be met in non institutional settings if issues related to staff competence and skills are addressed*”. (DH, 1998, Signposts for success in commissioning and providing health services for people with learning disabilities).

Policy on learning disability services

The “Valuing People” White Paper sets out Government policy in relation to people of all ages with a learning disability. It particularly emphasizes the need to assist older family carers, to help them plan ahead and to consider supported living options.

It also highlights the needs of people over 75 who are misplaced in residential services for older people.

Policy in the White Paper of particular relevance is:

- Person-centred planning which takes into account the learning disability alongside ageing process. (This is similar in concept to NSF Standard: Person-Centred Care)
- Optimising the individual’s opportunities, choices and personal control

There are consistent themes in Government Policies towards older people but for older people with learning disability there are considerable challenges in making them applicable – the starting point is so different.

Policies for older people

In short:

- The NHS Plan stresses dignity, independence and services which encourage and support independence rather than dependence
- The National Service Framework for older people emphasizes:
 - Person-centred care including single assessment process and integrated commissioning arrangements (Standard 2)
 - Mental Health in Older People – integrated services to ensure effective diagnosis treatment and support for them and their carers (Standard 7)
 - Promoting an active healthy life in older age (Standard 8)
- Modernising Social Services proposes expanding support to allow older people to remain at home

- *Supporting People* and the associated grant regime has provided additional encouragement to assist vulnerable people to live independently with support
- *Quality and Choice in Housing for Older People* expects the majority of older people to remain in their own homes but with flexible services to provide support and care as well as provide adaptations when necessary. It refers to the majority of older people being home owners as a key

So few people with a learning disability have their own homes, let alone are owner occupiers, these policies cannot all be applied in a simple way. They imply:

- Support in the parental home and a suitable plan to “age in place”. This may include plans to continue support at home on the parents’ death
- That a move to some different provision, more suitable to their age may be the very first time the person has the opportunity to live independently rather than this being a continuation of an established lifestyle
- For some people they will have to continue to experience moving between services and/or accommodation in order to have a reasonable quality of life and be reasonably safe

Despite this there are common themes in these strategies where the focus is older people more generally and “Valuing People” concerned exclusively with learning disabilities:

- Independence
- Choice
- A person centred approach
- Focus on carers

ANNEX B

Facts and Figures

A distinction is commonly made in statistics between those with severe learning disabilities and mild disabilities. In the UK there are estimated to be:

- 230,000 – 280,000 people with a severe learning disability
- 580,000 – 1,750,000 people with a mild learning disability

People with a learning disability make up a small part of the general population of older people. People with a learning disability have a shorter life span than the general population; 75 for men, 80 for women⁴. As the Valuing People White Paper⁵ commented “Evidence of avoidable illness and premature death among people with learning disabilities is a major cause of concern”.

- Life expectancy for people with learning disabilities has been improving greatly, about half can expect to live as long as the general population⁶
- A case register⁷ shows 12% of those with learning disability over 60 but those with the most severe learning disabilities have limited life expectancy and survival beyond 50 is unusual
- People with Downs Syndrome make up 15% of all people with learning disabilities. Life expectancy has improved dramatically from less than 10 years in the early 1900's to the present when more than half will live in to their 50s or beyond. The average age of the onset of dementia is 54, average life expectancy from diagnosis to death is 5 years
- People with mild learning disabilities can expect to live almost as long as the general population

Lastly it should be noted that many people with a learning disability also have other difficulties which impact on health and care⁸. This includes:

- 48% have some sensory impairment
- 20-30% have a physical disability
- epilepsy is common affecting 20-30%

⁴ Office of National Statistics (2001) *Life Expectancy* HMSO London

⁵ Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*

⁶ Foundation for People with Learning Disabilities (2002) *Today and Tomorrow* FPLD

⁷ Parrot R et al (1996) *Future Demand for Residential Provision* Hester Adrian Research Centre University of Manchester

⁸ Emerson, E et al 2001 *Learning Disabilities Fundamental Facts* FPLD

The population of older people with a learning disability

Life expectancy for older people has increased significantly in recent decades. There is a corresponding increase in those with age related health problems. People with learning disabilities also have more chronic health problems than the general population: physical and sensory difficulties, epilepsy and mental health problems. For example:

- A person with **Downs Syndrome** used to be considered unlikely to live much beyond middle age. It is now quite reasonable to anticipate living to normal retirement age or beyond. However, premature ageing is to be expected and it is also common to be effected by dementia at a chronologically early age. In the general population only 5% of people over 65 have dementia but for those with Downs Syndrome it is at least 55%.
- **Epilepsy** also effects a disproportionately large number of people with learning disabilities. The cumulative effect of seizures may impact on general health and in some cases cause loss of what may have in any case been limited language ability
- Nearly a half of all people with a learning disability have either **physical or sensory impairments**. This means first, they may already resemble, in terms of need, the population of older people extra care is designed for. Second, additional disabilities may eventually impact on general health and this may be worse in that the learning disability exacerbates problems. For example, an inability to communicate may mean a condition or illness goes untreated or is misdiagnosed.

As people with a learning disability age – like the rest of us – sensory and physical limitations may appear. The population of people with even a mild learning disability may therefore come to need the same kind of accommodation and support for purely physical reasons as the general older population.

People with learning disabilities are now living into retirement age because of improvements in social care, diagnosis and health provision. About half of those with a learning disability now have a similar life expectancy to the general population. As with the general population the task is to develop care and support and if necessary adaptations that meets the individual needs – ideally at home in line with government policy and the preferences of the majority of older people.