

Housing Learning & Improvement Network

Care Services Improvement Partnership 

Health and Social Care
Change Agent Team

New initiatives for people with learning disabilities: extra care housing models and similar provision

This report explores the role of extra care housing models and similar provision of housing, care and support for adults of all ages with learning disabilities, with examples and ideas for commissioners and providers.

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New initiatives for people with learning disabilities: extra care housing models and similar provision

Introduction

Extra care housing developments are increasingly seen as a more suitable option than residential care for older people with care and support needs. Extra care models also provide opportunities to address the needs of adults of all ages with learning disabilities, whether younger or older.

The Housing LIN promotes partnership working and a whole systems approach between health, housing and social care commissioners and providers in the statutory, voluntary and independent sectors in the English regions and London. All of these have an essential role to play in addressing the housing, care and support needs of adults with learning disabilities.

People with learning disabilities have diverse and varied needs: Housing LIN Factsheet no. 3 outlines issues and good practice in the provision of supported housing and extra-care models for older people with learning disabilities, including funding and design, policy background and statistics. This report complements Factsheet 3, and provides examples from Housing LIN members of approaches to extra care housing for both younger and older people with learning disabilities:

- strategic approaches;
- specialist supported and extra care housing for people with learning disabilities;
- enabling people with learning disabilities to access to mainstream extra care housing.

The report is in five sections:

- Section One summarises the current policy context, defines extra care housing and discusses why it may be suitable for people with learning disabilities;
- Section Two provides brief details of over a dozen examples of strategic approaches and individual schemes;
- Section Three draws out the learning points from the examples, showing how commissioners and providers have tackled some of the issues that arise when planning, developing and managing supported and extra care housing provision for this client group;
- Section Four summarises the questions raised in the discussion and learning points in Section Three;
- Section Five contains full details of all the examples and contacts for further information.

Section One: Context, definitions, suitability

1.1 Policy context: learning disabilities

Recent and current policy initiatives provide the chance to extend the role of extra care and similar models for people with learning disabilities, and some opportunities for new funding across the housing, health and social care divide. The Department of Health has provided £2.3m for ten bids to develop extra care housing for people with learning disabilities, which were due to start on site by March 2006.

Valuing People (Department of Health 2001) is the key to current policy for people with learning disabilities. It takes a holistic view of the needs and aspirations of people with learning disabilities, and promotes four key principles:

- rights;
- independence;
- choice; and
- inclusion.

The housing objectives are to enable people with learning disabilities and their families to have greater choice and control over where, and how, they live. The circular on implementing Valuing People asked local authorities to:

- set up local multi-agency Learning Disability Partnership Boards with representatives from service users and the voluntary sector;

and, specifically on housing, to:

- expand the range of housing care and support services to give real choice;
- join with neighbouring authorities to encourage a wider range of provision;
- work with local housing authorities and providers to develop strategies, housing allocations, advice services and adaptations; and
- produce a local housing strategy for people with learning disabilities, and related plans for commissioning care and support services (by 2003).

The Foundation for People with Learning Disabilities GOLD programme (Growing Older with Learning Disabilities) started in 1998 and researched the needs of older learning disabled people and older family carers through a national programme of research and development projects and involvement of disabled people and their carers. It focused on a number of areas relevant to this report, including:

- early-onset dementia amongst people with Downs Syndrome;
- inappropriate placement of people with learning disabilities in residential care homes where they are living alongside people who are much older;
- end of life care issues; and
- the needs of older carers including those from minority communities.

Further details are available on www.learningdisabilities.org.uk.

1.2 Policy context: the broader disability agenda

As well as the specific work around learning disabilities referred to above, recent work across all types of disability is relevant. Improving the Life Chances of Disabled People (Cabinet Office 2005) has four policy priorities, two of which relate to housing and people with learning disabilities: independent living and transition to adulthood.

The Disability Discrimination Act 2005 created the Disability Rights Commission and introduced new regulations concerning the treatment of people with all forms of disability, including learning disabilities. The Act establishes the Disability Equality Duty which comes into force in December 2006. Public bodies are required to publish a Disability Equality Scheme to set out how they intend to implement the Duty. Guidance on implementing the Disability Equality Duty for local authorities and social housing providers is due to be published later in 2006. The draft guidance covers a wide range of housing-related issues including housing strategies, user involvement, design, adaptations, housing advice, homelessness, disability housing registers, lettings, harassment and anti-social behaviour.

1.3 What do we mean by extra care housing models?

Extra care housing, sometimes called very sheltered housing, is increasingly popular. It is a concept, rather than a type of housing, and can vary in size and purpose to meet different needs. We have used the term 'extra care housing *models*' in this report to stress that there is a wide range of provision that meets these criteria. Housing LIN Factsheet no.1 gives essential basic information, and stresses that:

'The most important fact is that extra care housing is housing first. It isn't an institution and should not look or feel like one. People who live there have their own homes. They have legal rights to occupy. This means there is a clear distinction between extra care housing and residential care as recognised by the Commission for Social Care Inspection.'

Care and support is available on-site (usually 24/7). Buildings are designed for the needs of people who are frail or have physical disabilities, and include flats or bungalows with one or two bedrooms. People have their own self-contained dwelling with their own front door. There is usually a range of communal facilities, often open to the wider community, including leisure facilities and a café or restaurant providing a midday meal.

Different tenures may be available, sometimes within the same development:

- rent;
- shared ownership (part rent, part buy);
- outright sale.

To date, most extra care housing has been provided by housing associations in partnership with local authorities, and has been mainly for rent. There is growing interest in ownership options, as in a number of our examples. Increasingly, extra care housing is also available through the private sector, usually for sale.

1.4 Why are extra care models and similar provision suitable for people with learning disabilities?

Valuing People stresses the need for greater choice and control. Factsheet 3 discusses the limited choices offered to people with learning disabilities in the past, and the advantages of extra care models. People with lower or higher support needs, and those with additional disabilities and impairments, can achieve much greater independence in extra care models than in residential care, and there is much more scope for user involvement in design and management, as in some of our examples. The range of tenures offers the same choices as those enjoyed by the wider population, and the benefits system and family money can make ownership

options possible for people with learning disabilities, as discussed in Section Three. Extra care schemes can also provide a very suitable solution where an older carer is finding it difficult to continue to care, but the learning-disabled adult and the older carer do not wish to live apart from each other: this is complex and will need careful advice about different options, as discussed further in Section Three.

Section Two: Examples of strategic approaches and provision

This section includes brief details of each example; Section Five provides full information and contact details. Learning points are picked up in the discussion in Section Three.

2.1 Strategic approaches

Some local authorities responded by saying that they were developing services for all vulnerable adults rather than specialist extra care housing for people with learning disabilities. Others gave examples of specialist provision, sometimes working closely with service users and carers.

Gateshead Metropolitan Borough Adult Care Services and Housing 21: extra care Courts, adjacent bungalows, flexible approach to contracting

Gateshead have developed four new-build extra care Courts for older people over recent years and there is a fifth scheme in the pipeline. They have worked with Housing 21 to enable people with learning disabilities to move into either the extra care Courts or into adjacent two-bed bungalows. The bungalows were developed as part of the overall housing strategy at the same time as the Courts. Gateshead has also adopted a flexible approach to contracting: a block contract for older tenants, and spot contracts for clients with learning and physical disabilities.

Staffordshire County Council: strategy for extra care for older people and vulnerable adults, including people with learning disabilities

Staffordshire's Health and Social Care Directorate is currently undertaking an ambitious county-wide plan over six years from 2006 to refocus provision for vulnerable adults. Staffordshire have decided not to develop any specialist extra care schemes for people with learning disabilities.

London Borough of Barnet/Notting Hill Housing Group: reprovioning across the Borough

An imaginative learning disabilities reprovioning programme is currently under way in Barnet. The new provision is on eight sites across the borough, formerly occupied by large care homes and day centres, hostels and a sheltered housing scheme which were outdated and not fit for purpose. The reprovioning will provide a range of supported housing, and smaller replacement care homes and resource centres. Notting Hill Housing Group are the development partners.

Wirral Metropolitan Borough Council and Wirral Methodist Housing Association: working with users and carers, shared ownership

Wirral MBC and Wirral Methodist HA are currently working with a local group of people with learning disabilities and family carers to plan a shared ownership supported housing scheme with provision for a mix of care and support needs.

West Sussex County Council and Mid Sussex District Council: housing strategy for people with learning disabilities, enabling officer

West Sussex (the county authority) has a housing strategy for people with learning disabilities which aims to move away from residential care towards supported living options. Joint work has resulted in a number of housing schemes, including Prescott House (featured below) which is a mixed extra care scheme for older people and people with learning disabilities.

Mid Sussex (the district council) has a supported housing enabling officer who works across all client groups. Allocations go through the Mid Sussex multi-agency panel for supported housing. There is a common housing register and a separate database for supported housing, used for both allocations and needs assessment for housing and support strategies.

2.2 Examples of mixed extra care schemes for older people and people with learning disabilities, with a quota of flats for each client group

Prescott House, Burgess Hill: West Sussex County Council, Mid Sussex District Council, Hyde Housing Association/Chichester Diocesan Housing Association

Prescott House is a new extra care scheme, opened in autumn 2003 and built on the site of a former residential care home already owned by Hyde/CDHA. There are 25 flats, five of them designated for people with learning disabilities and dispersed across the scheme. All the learning disabled tenants are in their 50s or 60s. Support is provided by Hyde/CDHA.

Steeple View, Stowupland, near Stowmarket: Suffolk County Council and Orwell Housing Association

This new extra care scheme opened in early 2006. Orwell have developed and now manage the housing, and provide the on-site care and support. There are 28 one-bed and 8 two-bed flats and the usual range of communal facilities. Six people with learning disabilities, aged from late 40s to 60s, have accessed flats and they are spread across the scheme, in both one and two-bed flats.

2.3 Examples of specialist provision for people with learning disabilities linked to, or within, extra care schemes or supported housing for older people

Mildmay Park: London Borough of Islington and Notting Hill Housing Group

Mildmay Park was opened in 2000. It is an extra care scheme with 40 flats for older people, people with learning disabilities (aged from late 50s to 70s) and intermediate care. The learning disabilities service is also featured in Housing LIN Factsheet 3 and is provided by a specialist staff team.

Three schemes in Newton Abbot: Devon Community Housing Association and Devon County Council

Powderham Court, built in 2004, is a new-build DCHS supported housing scheme. There are 19 flats (17 one bed, 2 two bed) for older people with additional support needs (including one wheelchair flat), a lift and communal facilities similar to a traditional sheltered housing scheme. Nearby are two blocks for people with learning disabilities (mostly in their 20s and 30s): Newfoundland Court, a block of four new-build one bed flats also completed in 2004, and East Street, another block of six one

bed flats completed in late 2005. These two blocks have no communal facilities and are to general needs design standards, with no lift.

A scheme manager and five support staff are based at Powderham Court and they support tenants across the three developments, so this is an interesting example of staff working across both client groups. Powderham Court and Newfoundland Court received funding from Supporting People, but there was no allocation left for East Street. The support hours were reconfigured to make space for supporting the new tenants due to move into East Street, at no extra cost to the Supporting People budget.

2.4 Examples of older people with learning disabilities accessing mainstream extra care schemes for older people

Coopers Court, Mile End: London Borough of Tower Hamlets and Ashley Homes

Coopers Court is an extra care scheme with 41 one-bed flats, built about five years ago. There have always been around five people with learning disabilities in the scheme through the normal allocations process: the age range of learning disabled tenants is from mid-40s to over 90. Ashley Homes is the Care and Support Services Division of Shaftesbury Housing Association who was the development partner. Ashley Homes staff and managers have experience of learning disability services as well as older people's services.

Stockton-on-Tees Borough Council and Endeavour Housing Association

This new extra care development is a flagship project in a regeneration area, currently on site with completion due in April 2007. A scheme manager started work in May 2006, almost a year before the scheme opens, to ensure full involvement up to and after handover. There are 50 dwellings, all with two bedrooms. Endeavour is a major provider of supported housing in the area and provide for a wide range of support needs, including people with learning disabilities.

Endeavour has been working closely with the commissioners, Stockton BC, which has a joint health and social care service. There has been in principle agreement within the Development Steering Group that people with learning disabilities as well as older people will be able to access the scheme through normal allocations criteria and the multi-agency panel, where they meet the access and need criteria. Where people with learning disabilities are allocated places, they will be dispersed throughout the service and not allocated a specific area within the building. There has been a great deal of discussion about design issues, especially access and security.

2.5 Examples of specialist extra care schemes for younger people with learning and other disabilities

Whitfield Lodge, Lancashire: St Helens Metropolitan Borough Council, Arena Housing Association, Creative Support, Step by Step

Whitfield Lodge was purpose-built and completed in 2004. It provides a block of ten self-contained one-bed flats designed around the extra care model specifically for learning disabled men and women in their 20s and 30s. The building is owned and managed by Arena Housing Association, and capital funding came from the Housing Corporation and St Helens MBC. There is a dedicated team of day-time, waking and sleep-in staff on site from the support provider, Creative Support, who are a specialist

learning disabilities and mental health support provider. An independent advocacy service, Step by Step, has provided a brokerage service since the scheme was in the planning stage.

Developing Whitfield Lodge demanded a completely different approach from commissioners and funders compared to a traditional scheme. There has been a very high level of user and carer involvement from the outset, including scheme design and support arrangements. All the tenants receive Direct Payments and some also receive funding from the Independent Living Fund. Funding comes from Supporting People, Social Services and Health. There are great variations in the care and support needs of different tenants, from a few hours a week to a high number of hours and waking nights.

Shared ownership and rented extra care housing for people with visual impairment, learning and other disabilities:

**Devon County Council, SeeAbility and Signpost Housing Association;
Hampshire County Council, SeeAbility and Atlantic Housing Association.**

SeeAbility is a specialist provider and works with adults of all ages who are blind or partially sighted and have additional disabilities. There is a high incidence of visual impairment amongst people with learning disabilities. SeeAbility has worked with local authorities and housing associations to develop specialist extra care provision, mainly for younger disabled people. Honiton and Eastleigh are rented; Exeter is especially interesting because it is a shared ownership development.

SeeAbility is also working with other providers (John Grooms, The Disabilities Trust, John Grooms Housing Association) in a new collaboration called 4ability. The aim is to produce more shared ownership extra care schemes, using private finance and no grant. Schemes will be open to all disabled people, irrespective of age, income, mental capacity or type of disability.

Section Three: Discussion and learning points

This section draws out learning points from the examples above under the following headings:

- Strategic approaches, creative commissioning, partnership working;
- Working with people with learning disabilities and their carers, facilitating choice;
- Financing the capital costs;
- Funding the support and care packages;
- Accessing mainstream or mixed extra-care schemes;
- Planning, design and build, Assistive Technology;
- Joint working and staff training ;
- Is there an ideal number of people with learning disabilities in a mixed extra-care scheme?
- How well do people with learning disabilities integrate with older people in mixed schemes?
- Extra care for older carers and adult offspring with learning disabilities still living at home;
- People with learning disabilities and dementia;
- Home ownership options: shared ownership or outright purchase.

3.1 Strategic approaches, creative commissioning, partnership working

Extra care housing for adults with learning disabilities is likely to cut across and relate to a number of different local strategies, including:

- the Partnership Board learning disabilities housing strategy;
- strategies for older people and/or vulnerable adults;
- Supporting People;
- the local housing strategy;
- local planning and regeneration strategies;
- local reprovisioning of learning disability services, including day services and residential care, and perhaps of hostel provision following closure of long-stay hospitals.

In some of our examples, commissioners and providers had been very creative in their approaches, including:

- offering different types of contract for care and support for older people and for people with learning disabilities;
- working with colleagues in planning and regeneration;
- recycling Supporting People funding;
- mixing funding sources for capital and revenue.

Provision of new extra care housing is usually undertaken with a development partner, either a housing association or a private developer, whether it is new-build or refurbishment of existing sheltered or other housing. The choice of development partner may affect the likely access for people with learning disabilities. Housing associations vary in the extent of their experience of working with people with learning disabilities.

A commissioner commented that their authority had to work hard with the senior staff and board members of their development partner to persuade them to try a mixed scheme for older people and people with learning disabilities, because it was outside their “comfort zone”.

One provider, mainly of housing for older people, had successfully integrated people with learning disabilities and the process had been helped by having a scheme manager with experience of working in learning disability services: she had acted as a resource for other scheme managers.

QUESTIONS:

Do the different strategies in your locality complement each other? Do your local strategies consider the role of extra care housing models for adults (of all ages) with learning disabilities?

How do you choose your development partners – do you look for experience of learning disabilities as well as older people?

3.2 Working with people with learning disabilities and their carers, facilitating choice

Some of our examples involved substantial user involvement in planning, designing and managing housing and services. The highest levels of involvement were in extra care schemes for groups of younger people with learning disabilities: examples include St Helens, Wirral and the Seeability schemes. In some cases family carers were also closely involved.

There was also considerable consultation in some of the mixed schemes where dwellings had been designated for people with learning disabilities. It should also be possible to consult on strategies, scheme design and service provision (with both service users and carers) through formal mechanisms such as the local Partnership Board.

There is a chapter in the CSIP Commissioning eBook (at www.cat.csip.org.uk/commissioningebook) on commissioning with service users and carers (Chapter Three: Involving people who use services in the commissioning process, by Nigel Walker). The chapter also has links and references to a number of other sources of guidance, including a pack to help organisations working with people with learning disabilities: "Shaping the Future Together" from the GOLD programme at (www.learningdisabilities.org.uk). The CSIP e-book is a unique, free, open access, online facility to help people who are commissioners of community-based health, social care and housing services.

In line with the aspirations of Valuing People, it is essential to facilitate informed choice, but housing advice for people with learning disabilities is under-developed in many areas. Extra care housing models may or may not be the best option for the individual. Housing choices are closely related to other aspects of someone's life. Person-centred planning should provide a useful tool to address someone's housing needs, alongside other aspects of their life including employment or training and social activities. The person-centred plan may provide the starting point but there will need to be more work to actually make things happen, as in the examples in St Helens and Wirral and the Seeability schemes.

If extra care models exist in a locality, this will widen the choice of housing, care and support options available to learning disabled adults of all ages, but they will need access to information, advice and support to enable them to benefit from this wider choice. If extra care models do not yet exist, people with learning disabilities, carers and professionals will need to find out about such models, and perhaps visit schemes. There is scope to work through Partnership Boards, user-led organisations such as People First and carers' groups, colleges and other settings to disseminate much more information about models of housing, care and support, including extra-care models, by:

- producing leaflets and information packs;
- providing better information on local websites;
- open days, events and discussion (at college, in day centres, at employment projects and meetings) so people with learning disabilities can learn and understand more about housing and support choices;
- advocacy and support for people with learning disabilities, especially those still living at home with older carers;
- information, events and support for carers;

- training for staff, especially frontline staff, on housing options (including extra care models) so that they can support their service users to make informed choices.

People with learning disabilities, carers and staff also need to be able to find specialist advice on some things that are more complex, like home ownership and shared ownership (see below). This can be achieved by using specialist national agencies like Housing Options (www.housingoptions.org.uk), and by having a specialist member of staff (as in our example in Sussex).

Q: To what extent do you involve people with learning disabilities in planning future provision, scheme design and management?

Q: How do ensure that people with learning disabilities, and their carers, receive information and advice and are supported to make informed choices?

3.3 Financing the capital costs

Most of the schemes featured have involved Housing Corporation funding through a housing association. In such cases the scheme will have been a high priority in local strategies in order to attract such funding. For some of our examples, other funding sources have been used as well as, or instead of, Housing Corporation Social Housing Grant, including:

- social services capital funding;
- recycling capital receipts and cross-subsidy from disposal of surplus sites;
- charitable funding;
- mortgages and family funds for the purchase element of shared ownership schemes.

There are a number of new initiatives to provide extra-care housing without the need for public funds, including SeeAbility (see above and Section Four), Housing LIN case study number 23 (Cheshire PFI), and the East Sussex PFI initiative (see Housing LIN Newsletter number 14, May 2006). Factsheet 2 has general information on funding extra-care housing.

QUESTIONS:

Is there likely to be Housing Corporation funding available?

Are there any other sources of capital funding?

3.4 Funding the support and care packages

Not surprisingly, there were a number of issues raised about funding care and support. Across all our examples, funding came from a combination of some of the following sources:

- social services;
- health;
- Supporting People;
- Independent Living Fund;
- people's individual disability benefits.

For both rented and shared ownership housing, the package needs to be agreed before the person can take up the tenancy or contract to buy the property, so the

processes for the housing and the support need to work in tandem. Delays with one process will impact on the other. At one new development, completion and hand-over was delayed for over six months, so that the support packages were also delayed.

People with learning disabilities may have very high care and support needs, sometimes linked as much to their physical or sensory impairments as to their learning disability. In an extra care scheme there are two approaches:

- provide a very flexible service from the on-site staff team; or
- provide additional care and support from an outside agency in addition to that from the on-site team.

Either can work and the route chosen will depend on the person's individual needs and the way that the service is managed and funded.

In our examples, there were a number of issues concerning Supporting People (SP) funding. Some of the support in extra care models would always be classifiable as housing-related, and this would be a significant percentage for people with lower levels of need. New extra care schemes that were completed under Transitional Housing Benefit arrangements, or with pipeline arrangements in the first year or two of SP, were still accessing SP funding although in some cases this had been reduced. In newer schemes, all the support costs had to be met by social services or health because the authorities had no spare SP funding available to new clients. In one case there was a creative reconfiguring of SP funding to spread it over more clients.

In one area, there were severe financial constraints. Social services funding could only be made available to existing clients with learning disabilities who were already in receipt of a care package, preferably where there would be savings. Everyone who moved to the scheme from residential care showed savings, but these could not be recycled for new clients. This meant that people with learning disabilities living at home with relatives were unable to access a new extra care scheme, even when it was ideal for their needs, because they were costing nothing or very little in their existing housing and there would be no savings. Some units that could have been available to people with learning disabilities were lost because of this funding constraint.

In another area, although people were living at home and the costs would increase, the funding authority was willing and able to commit to meeting their needs on the basis that they could not remain in their existing housing situation long-term, so this would enable a planned move in accordance with their own choice, rather than a crisis move in the future.

QUESTIONS:

What funding is available for support and care costs?

Is the availability of funding likely to impact on allocations for rented dwellings, or on purchase or shared ownership arrangements?

3.5 Accessing mainstream or mixed extra care schemes

In addition to those featured in Section Two, a number of other local authorities responded to the research for this Report by saying that they were not developing specialist extra care housing for people with learning disabilities, but expected them to access mainstream extra care provision for older people. The question here is: does this actually happen in practice?

In our examples, people with learning disabilities have been able to access both mainstream extra care housing, and mixed schemes with a quota of designated dwellings. Success factors included:

- commissioning schemes to include housing for people with learning disabilities;
- an accessible and effective local allocations system (housing register, multi-agency panel) for people with learning disabilities;
- publicity and encouragement to access extra care housing through front-line staff working with people with learning disabilities and carers;
- a willingness to take risks in allocations decisions.

One authority had been a pioneer in developing extra care models for older people and had a number of extra care schemes for older people. However, they had only one or two people with a learning disability across all their extra care provision. When the authority developed a new extra care scheme with some designated learning disability provision, senior staff were involved in the planning and scheme design. Front-line staff were aware of the new development and they actively trawled for possible tenants and supported them to move in.

Respondents stressed the importance of being willing to take risks and face challenges with tenants with a learning disability, even if it did not always work out. In one case, an extra care scheme had tried to support an older tenant with Prader-Willi syndrome and the scheme manager had sought expert advice and training from their local learning disability service. Despite extra support, the tenancy had failed because the tenant was unable to cope with budgeting, to manage her appetite and diet, and to maintain her tenancy. The tenant had previously been in residential care and despite high support, she was unable to adapt to independent living. Because of the risk of serious self-neglect she had to return to a care environment. However, the important lesson is that the housing association was prepared to give her the chance to succeed, and social services were prepared to fund the extra support needed.

QUESTIONS:

How accessible is your local allocations system (housing register, multi-agency panel) for people with learning disabilities?

Do you designate dwellings in new schemes for people with learning disabilities?

Are learning disabilities staff involved in the planning and design of new extra care schemes?

How do you ensure that people with learning disabilities (and front-line staff working with them and their carers) know about extra care provision in your area?

3.6 Planning, design and build, Assistive Technology

Some respondents expressed concerns about planning issues for extra care housing. General issues concerned the lack of understanding of planning officers of the concept of extra-care housing, and this can be a problem both for mixed/older people's schemes and for specialist schemes for younger people with learning disabilities. The Housing LIN is working with the Royal Town Planning Institute to produce an advisory planning note on extra care housing for local authority planners. This should be on the Housing LIN website later in 2006.

The other important issue for this report is the minimum age for extra care schemes for older people, typically 55 or 60. A minimum age can be specified in the planning permission. It is also specified in tenancy agreements for rented housing, and in leases for shared or outright ownership. Extra care schemes are usually leasehold, with the housing association or developer retaining the freehold. However, this can cause problems for people with learning disabilities who are under 55 or 60 but who may wish to access the scheme, either because of their care and support needs, or because they are moving in with their parent/carer but would want to stay if the parent/carer died.

Extra care housing for people with learning disabilities does not have significantly different design issues from extra-care for older people. Factsheet 6 sets out design principles for extra-care housing. Given the higher incidence of visual impairment among people with learning disabilities, it would be sensible to follow the RNIB design guidance.

It is very important for people with learning disabilities in a mixed scheme with older people that their dwellings are dispersed throughout the scheme. Respondents felt very strongly that there should not be a separate wing or area, such as the end of a corridor, because this would emphasise that they were different, and could encourage discrimination by other residents or by staff.

All schemes should provide some two-bed units. As in a number of our examples, these can be very appropriate, either for two people with learning disabilities who want to share, or for an adult with learning disabilities and a carer (parent or sibling) who want to remain living together in the same property (flat or bungalow).

Two women with learning disabilities had lived together for many years, supporting each other. Stress and ill-health meant that they had to separate, but with the opening of a new extra care scheme with some two bedroom flats, they were delighted to be able to share a flat and live together again, receiving the support and care they both needed.

Assistive Technology (AT: also known as telecare) should be considered in schemes for people with learning disabilities. The Preventive Technology Grant provides £80m over two years (2006/2008) for AT solutions. Factsheet 5 looks at AT issues for general extra-care housing. "Gadgets, Gizmos and Gaining Independence" is a new report produced in 2006, and funded by DH¹. It provides a comprehensive assessment of the role of AT for people with learning disabilities. The report features a tenant in an extra-care scheme in Sussex, Prescott House (see above and Section

¹ Advance Housing and Support (2006) Gadgets, Gizmos and Gaining Independence: Alternative Technology and people with learning disabilities. Available on Housing Options website www.housingoptions.org.uk

Five): she uses her video entryphone to check callers, has a personal PC and internet connection and uses e-mail to communicate with her care manager.

QUESTIONS:

Do you (or your partner organisations) have strict age limits which would discriminate against people with learning disabilities and their carers?

Do you provide some two bed dwellings in your extra care schemes?

Do you consider the use of AT for people with learning disabilities?

3.7 Joint working and staff training

There are a number of reasons why people with learning disabilities have not accessed mainstream extra-care schemes in the past. One factor is undoubtedly the extent to which learning disability and older people's social care teams have, or have not, worked together, because older people's teams have usually been in the lead in planning and developing extra care provision. Designating some units in a scheme can facilitate such joint working, from inception through to completion and ongoing management and allocation decisions.

A number of respondents, both commissioners and providers, commented on how helpful it was if all adult services were under the same directorate. In some of our examples, there is now a joint health and social care organisation. In some cases, this included responsibility for Supporting People.

Another factor is the training and experience of staff teams. Designating even a few units will encourage staff training. In some examples, scheme managers and some staff had been appointed because they already had learning disabilities experience and sometimes qualifications. This is clearly easier to do with a new scheme and a new staff team, but can also apply to existing schemes and teams. In other cases, staff with a background of working with older people accessed specialist training on learning disabilities. It was felt that in mixed schemes for older people and people with learning disabilities, it was especially important that support staff should encourage and promote independence amongst all tenants.

One manager commented that it was very important for the care provider to have a commitment to services for people with learning disabilities, and ideally to already have experience in this field. This would ensure that front-line staff and scheme managers would be supported by senior managers within the organisation, especially when problems arose.

QUESTIONS:

Does your organisational structure facilitate joint working?

Do staff have experience of learning disabilities, and access to specialist training?

3.8 Is there an ideal number of people with learning disabilities in a mixed extra care scheme with provision for older people?

Our examples of schemes designed for a mix of client groups generally have around five to six flats for people with learning disabilities, and up to one-fifth to one-quarter of dwellings overall. In schemes where people with learning disabilities have gone through the normal allocations process, they vary from one or two to five or six. In

other words, in no mixed scheme were people with learning disabilities in the majority.

The “How many?” question is delicate: some would say that the number does not matter and should be based on general allocations criteria for the scheme. Because people have their own self-contained flats, they do not need to mix with other people if they do not want to. However, respondents with experience of commissioning and managing mixed schemes said that for the scheme to work well, consideration should be given to the balance, just as there is generally a balance between older people who have greater or lesser care and support needs. Too few, and they could find themselves isolated, especially if someone moves out or dies, so a minimum of four to five can work well.

Respondents did not want to set an upper limit and stressed that the most important factor to consider is the attention to individual care and support packages so that individual needs and wishes would be met, with sensitive and empathetic support provided to everyone. The manager of a specialist service emphasised the need to support a tenant with learning disabilities to integrate into a "mainstream" service through proper communication, both one to one and with shared communal activities. He stressed the importance of championing central principles of care such as rights, independence, choice, inclusion and consultation.

Q: What steps do you take to ensure that people with learning disabilities are not isolated if they are in extra care schemes for older people? Do you aim for a minimum number?

3.9 How well do people with learning disabilities integrate with older people in mixed schemes?

Most residents in mainstream extra-care schemes for older people are in their 70s and 80s. Most people with learning disabilities in the mixed schemes in our examples were somewhat younger (in their late 40s, 50s and early 60s), although there were a few much older people: ages ranged from mid-40s to over 90. Before new schemes opened, and when people with learning disabilities were allocated to existing schemes, there was some concern about how well the different groups would integrate.

Factsheet no. 3 quotes an example of one learning disabled person who was housed in a new extra care scheme for older people. He was isolated and rejected by other residents: they would not sit with him at meal times and made disparaging remarks about him being there. Some tenants also resented the extra support he was receiving from staff from the learning disability team. Staff took steps to build relationships between him and two or three of the older people.

Some respondents with experience of setting up and managing mixed schemes were realistic about the risks of “camps” developing between different groups of residents. They were concerned not to “set people up to fail” and wanted to try to ensure a balanced and inclusive community, especially in a new scheme. Staff attitudes and experience are clearly important here. Similar concerns arose about including older people who had been homeless into sheltered or extra-care housing, but such problems were minimised where the scheme manager was welcoming and confident (see Factsheet no. 16). Factsheet 15 raises similar issues concerning older people with mental health issues. Mixed schemes where staff have experience and/or

training in working with older people and learning disability are likely to have fewer problems because staff will be able to understand and diffuse potential problems.

In mixed schemes for older people, some respondents commented on how support staff were able to support learning disabled tenants to play a full role in activities within the scheme, such as tenants' meetings, as well as in social activities. It was also stressed how important it was to facilitate links and social activities outside the scheme. This can be especially important for people with learning disabilities who are somewhat younger than their older neighbours. A high quality, person-centred support service will work with each individual.

One scheme manager stressed that it was important for the tenants with learning disabilities to support each other, and have a sense of their own identity, as well as integrating with the other older people in the scheme. Although they joined in with many of the activities in the scheme, they were younger than other tenants and also had a full and active life outside the scheme in their local community; this had been encouraged and facilitated by the specialist staff team.

Two respondents pointed out that in their mixed extra-care schemes, the people with learning disabilities in their 40s and 50s presented as much older than their age. They had lived at home with elderly parents, or in residential care homes following a crisis move from the parental home, so the extra-care scheme was a great improvement in terms of their independence and quality of life. Because they had lived very sheltered lives, they had similar interests and hobbies to older people. This made the age gap between them and the older people in the schemes less apparent than it might seem.

Another sensitive area concerns people with a learning disability and for example, challenging behaviour or very limited communication. Clearly, people should not be discriminated against because of their disability. There is evidence that appropriate housing and support can reduce or prevent challenging behaviour. For example, people with autistic spectrum disorders are often especially affected by noise and crowds, so a large hostel-type environment is likely to exacerbate any challenging behaviour whereas a quiet and self-contained flat will probably minimise it². There is a risk that someone with limited communication could find themselves very isolated, especially if they were to be the only person with a learning disability amongst older people who may not wish, or be able, to make the effort to communicate with them.

A person-centred approach considers the needs of the learning-disabled person and take all these factors into account. For example, living independently in a house, flat or bungalow in the community with additional support may be more suitable than a flat in a mainstream extra-care scheme for older people. In theory, anyone can "choose" to apply to rent, or buy into, an extra-care flat. In practice, the need to provide funding for their support package means that there is a degree of intervention from health and social care staff. The report on AT for people with learning disabilities (Advance 2006) has a number of examples of using AT to help manage behaviour constructively, both to help carers and to help the person with learning disabilities to self-manage.

² Harker, M. and King, N. (2004)

Tomorrow's big problem: housing options for people with autism. National Autistic Society. Full report available on www.nas.org.uk and www.housingoptions.org.uk

Two scheme managers reported successful work with learning disabled tenants with challenging behaviour, and another with limited communication who used Makaton signing. Staff had been able to work one-to-one with these tenants to assist their successful integration, both with other tenants with learning disabilities and with the other older tenants. These providers were convinced that the key to success was staff training and sufficient time to work with both the learning disabled person and other tenants, diffuse any problems early on, and support all the tenants sensitively.

3.10 Extra care for older carers and adult offspring with learning disabilities still living at home

Extra care schemes can provide a very suitable solution in some circumstances where it is quite clear that the older carer and their adult offspring do not wish to live apart from each other and choose to remain together. However, it is important that the adult with learning disabilities receives expert housing advice and advocacy to ensure that this is the best solution for them, rather than moving into independent housing (see also discussion above on housing advice).

Research for the GOLD programme (above) found that many older carers and adult offspring wished to remain together. However, in some cases the older carer is no longer able to cope. Their existing family home may present a problem (for example outside steps, stairs, no downstairs WC, need for a walk-in shower). One solution may be adaptations to the existing home but this is not always possible or appropriate.

If no solution can be found before serious illness or death of the carer, then it may result in a crisis move and great distress for both parties. Health and social care professionals often come across clients where either the carer, or the adult with a learning disability, or both parties, are not prepared to separate, even if the housing is unsuitable and the carer is unable to provide adequate care. Although the carer is usually a parent, it can be other relationships (for example siblings, or aunt/uncle and niece/nephew). There is often a degree of mutual care and interdependence.

Extra care can provide a good option in terms of both housing quality, and care and support. If the extra care route is chosen, there will need to be sensitive support for both the older carer and the adult with learning disabilities to prepare for the move. Extra care can offer care and support for the carer even if they are in poor health. It will also provide appropriate care and support, and a secure future, for the adult with a learning disability if the carer becomes frailer. After the death of the parent or other carer, the person with a learning disability can remain in the flat and does not have to add the trauma of moving to the distress of grieving.

In our examples, households comprising a parent and an adult learning-disabled offspring in their late 40s or 50s occupied:

- two one-bed flats in the same development; or
- a two-bed flat; or
- shared a one-bed flat.

However a strict age limit as imposed in some extra care schemes (often 55 or 60) would have prevented such imaginative solutions.

Two older mothers, both with adult sons in their late 40s or early 50s, were moving into a new-build extra care scheme. Because there were two bedroom flats this was possible, and because there were other people with learning disabilities in the scheme of a similar age, the two sons would be less isolated than if they were the only ones.

A mother in her 80s and daughter with Downs syndrome in her 50s had been separated for the first time in their lives through illness; the mother was temporarily in a care home. They were able to move into a one bed flat together in an extra care scheme: in their previous housing they had always shared the same bedroom. Within a year, the mother had died, but the daughter was able to remain in the flat. She received sensitive and appropriate support from staff and other tenants who already knew her, and she continues to thrive.

If a scheme is rented, or a mix of rented and shared or outright ownership, there should be no problem offering housing to two-person households (parent/carer with learning disabled adult) and also to individuals with a learning disability. However, if the scheme is only for sale, with no rented flats, then it may be less likely that there would be other individuals with a learning disability. In such cases there is a danger that the person with a learning disability may be isolated, especially after the death of the parent/carer. They may also need expert advice on benefits and finance issues (see 3.12 below).

QUESTIONS:

How do you ensure that people with learning disabilities, and their carers, receive information and advice and are supported to make informed choices?

Do you provide some two bed dwellings in your extra care schemes?

Do you (or your partners) have strict age limits which would discriminate against people with learning disabilities and their carers?

3.11 People with learning disabilities and dementia

There is a great deal of interest in providing extra care solutions to both early onset dementia, and dementia amongst older people (see Factsheet 14 and the recent report "Opening doors to independence", 2006, for Housing 21 available at www.housing21.co.uk). Because of the extent of dementia amongst people with learning disabilities (especially early onset dementia amongst people with Downs Syndrome), some respondents were exploring specialist extra-care provision for this client group. The problem they faced was the need to find people for a scheme in the months before an extra-care development was coming up for first letting, and this often proved difficult. If someone's dementia was too advanced, they were unlikely to be able to adapt to the level of independence needed in an extra-care tenancy. This was especially true if they had limited or no independent living skills because they had lived with family or in a care setting.

However, they found that it was difficult to get a diagnosis for someone in the early stages of dementia, when they would be more likely to be able to adapt and gain the skills needed. Respondents suggested possible reasons: perhaps health professionals were unwilling to make a formal diagnosis and attach the "dementia label" too early, because of the difficulty of distinguishing dementia in someone who also had a learning disability. Yet social care staff and carers who worked with the

person and knew them well were sometimes confident that dementia was indeed the problem.

The other dilemma for care managers was the desire that someone should be able to enjoy some years in the extra-care scheme and not need to move on (perhaps to full nursing care) if their condition deteriorated too much and too quickly. They feared that if someone's dementia was too advanced, a move from their current accommodation into extra-care would be disruptive and could precipitate a rapid deterioration.

QUESTIONS:

Have you considered extra care for people with learning disabilities and dementia?

How would you address the question of finding appropriate referrals to such a scheme?

3.12 Home ownership options: shared ownership or outright purchase

The examples above include different tenures. Ownership options are not always considered a possibility for people with learning disabilities. However, given the right advice and access to specialist services, it can be possible.

There are specialist mortgage brokers who can provide advice to potential shared owners and their families. In our examples, people who needed a mortgage have successfully raised interest-only mortgages; some have used family money (from inheritance or gift). As long as people remain entitled to Income Support, they can access mortgage interest for a mortgage of up to £100,000, and Housing Benefit will cover the rent. If people have significant levels of disability or are near to pension age, then it may mean that they are unlikely to want, or be able, to access paid work. However, if someone is likely to access paid employment then their ability to pay their mortgage could be compromised so this needs to be considered at the outset, especially for younger people. There is no problem if someone is working in a voluntary unpaid job (even full-time) because this does not affect benefit entitlement, as long as it has been declared and is approved. This was the case of one of the shared owners in one of our examples. For more discussion on shared ownership for people with learning disabilities, see Housing LIN Case study number 12 and the Housing Options website (www.housingoptions.org.uk).

A few people in our examples were able to buy into their new housing using family money, which could come from family members or from legacies; there is more information on this on the Housing Options website.

QUESTION:

Have you considered home ownership options for extra-care housing for people with learning disabilities?

Section Four

This section summarises the questions raised in the discussion and learning points in Section Three.

Strategies and development partners

Do the different strategies in your locality complement each other? Do your local strategies consider the role of extra care housing models for adults (of all ages) with learning disabilities?

How do you choose your development partners – do you look for experience of learning disabilities as well as older people?

User involvement, informed choice

To what extent do you involve people with learning disabilities in planning future provision, scheme design and management?

How do ensure that people with learning disabilities, and their carers, receive information and advice and are supported to make informed choices?

Capital and revenue funding

Is there likely to be Housing Corporation funding available? Are there any other sources of capital funding?

What funding is available for support and care costs?

Is the availability of funding likely to impact on allocations for rented dwellings, or on purchase or shared ownership arrangements?

Accessing mainstream or mixed extra-care schemes

How accessible is your local allocations system (housing register, multi-agency panel) for people with learning disabilities?

Do you designate dwellings in new schemes for people with learning disabilities?

Are learning disabilities staff involved in the planning and design of new extra-care schemes?

How do you ensure that people with learning disabilities (and front-line staff working with them and their carers) know about extra care provision in your area?

Planning, design and build, Assistive Technology

Do you (or your partner organisations) have strict age limits which would discriminate against people with learning disabilities and their carers?

Do you provide some two bed dwellings in your extra care schemes?

Do you consider the use of AT for people with learning disabilities?

Joint working and staff training

Does your organisational structure facilitate joint working?

Do staff have experience of learning disabilities, and access to specialist training?

Issues for mixed extra care schemes (older people and people with learning disabilities)

What steps do you take to ensure that people with learning disabilities are not isolated if they are in extra care schemes for older people?

Do you aim for a minimum number of people with learning disabilities?

Extra care for older carers and adult offspring with learning disabilities still living at home

How do ensure that people with learning disabilities, and their carers, receive information and advice and are supported to make informed choices?

Do you provide some two bed dwellings in your extra care schemes?

Do you (or your partners) have strict age limits which would discriminate against people with learning disabilities and their carers?

People with learning disabilities and dementia

Have you considered extra care for people with learning disabilities and dementia?

How would you address the question of finding appropriate referrals to such a scheme?

Home ownership options: shared ownership or outright purchase

Have you considered home ownership options for extra care housing for people with learning disabilities?

Section Five: Examples and contacts

This section contains full information on the examples summarised in Section Two, and contact details.

5.1 Strategic approaches

Gateshead Metropolitan Borough Adult Care Services and Housing 21

Gateshead have developed four new-build extra care Courts for older people over recent years. Each Court has around forty flats and the usual range of communal facilities and services. There is also a fifth development in the pipeline to remodel a multi-storey block of flats. Supporting the principle of social inclusion, Gateshead have worked with Housing 21 to enable people with learning disabilities to move into either the extra care Courts or into adjacent two-bed bungalows where they can also access the Court facilities, care and support. The bungalows were developed as part of the overall housing strategy at the same time as the Courts, and have proved very popular with people with learning and other disabilities.

The first extra care court had no-one with a learning disability, but subsequent developments have all had two or three people within the Courts, and/or in adjacent bungalows. One of the local scheme managers had experience of learning disabilities and has acted as a resource to other staff. The lower age limit is normally 55, reflecting Housing 21's policy and charitable rules, but there has been some flexibility, for example in the case of an older carer with learning disabled adult child. Housing 21 reported no problems with integration and attributed this to the careful work done by staff with both older tenants and those with a learning disability.

Gateshead has also adopted a flexible approach to contracting: Adult Care Services has a block contract with Housing 21 to provide care and support to older tenants, and spot contracts for clients with learning and physical disabilities who may be either in the Courts or the adjacent bungalows.

Contacts:

Rosemary Luckett, Head of Adult Care Services, Gateshead Metropolitan Borough
rosemaryluckett@gateshead.gov.uk

Lorraine Morrissey, Commissioning Manager, Housing 21
MorrisseyL@housing21.co.uk

Staffordshire County Council: strategy for extra care for older people and vulnerable adults, including people with learning disabilities

Staffordshire's Health and Social Care Directorate is currently undertaking an ambitious county-wide plan over six years from 2006 to refocus provision for vulnerable adults, moving away from institutional care towards "ordinary houses in ordinary streets" in accordance with Valuing People. There are up to twenty possible extra care schemes in the pipeline at various stages of development, including about ten with housing associations and others with private sector providers, for rent, shared ownership or outright sale. The schemes vary in size from smaller redevelopments of local authority sheltered schemes to larger retirement villages.

Staffordshire have decided not to develop any specialist extra care schemes for people with learning disabilities. They are hoping to encourage and facilitate a small number of older people with learning disabilities to access most or all of the future extra care schemes currently being developed across the county, although up to now this has not happened with existing extra care schemes. They are now actively trawling their own care homes and people with whom they work in the community to see who might be interested in having the opportunity to move into extra care housing.

Staffordshire, like others, are also considering whether some older carers with adult children still living with them may wish to buy into two extra care schemes for sale currently under development, so that their adult children, aged 50+, will be able to remain in the property if the carer dies first. They have also been in discussion with a private sector provider about the Possibility of some rented dwellings for people with learning disabilities in one extra care scheme.

Staffordshire are committed to funding the care and support packages that anyone already receives if they move into an extra care scheme. They stressed that they will not be "placing" people in extra care, but will be giving them information and helping them make their own choice to rent or buy into extra care if such a move is right for them.

Contact:

Trevor Edwards, Assistant Director for Joint Commissioning, Social Care and Health Directorate, Staffordshire County Council
trevor.edwards@staffordshire.gov.uk

London Borough of Barnet/Notting Hill Housing Group: reprovioning across the Borough

An imaginative learning disabilities reprovioning programme is currently under way in Barnet. The new provision is on eight sites across the borough, formerly occupied by large care homes, hostels and day centres for people with learning disabilities, and a sheltered housing scheme for older people, which were outdated and not fit for purpose. Because of the size of the older provision (including for example a day centre originally designed for 150 people), Barnet have been able to dispose of some sites. The aim has been to cross-subsidise the new buildings without further capital subsidy, although there will be some Housing Corporation funding for later phases of supported housing.

The reprovioning will provide a range of supported housing, and smaller replacement care homes and resource centres. The new service will also include a community based day opportunities programme that is not buildings based. There has been consultation with service users and with staff, and detailed community care assessments for each resident. The homes being replaced were larger (10-12 bedspaces) and did not meet current requirements. Most of the replacement housing is in supported housing schemes of around eight self-contained flats, with sleep-in staff cover. However, thorough assessment found that some of the long-stay residents of care homes still needed to stay within a care home environment and for them, the replacement provision will be in three small homes of around six bedspaces each.

Work is being phased, and the first new developments are on site, with completion later in 2006. Plans for further phases run up to 2009. Notting Hill Housing Group are the development partners for most of the new provision, and they will own and manage the buildings. The local authority will continue to run the services and provide the staff. In the supported housing schemes, as well as sleep-in cover, tenants will have their own support provided by local authority support staff on an individualised and person-centred basis, so that some may have quite high care and support needs but others will have much lower needs. Individual "moving-on" plans are being developed with each service user to ensure a smooth transition.

Barnet already had a local authority-run supported living service. The new supported housing provision is building on that model, and will be redeploying some of the staff who previously worked in care homes and day services. As the services change, Barne will be delivering training to ensure that staff are equipped to face the challenges within their new role.

The Service is managed and funded by Adult Social Services. There is no planned Supporting People revenue at the present time although this remains an option as new services develop. There is no direct health revenue, although as Barnet is a joint service, some tenants will have their support needs funded through Barnet PCT, especially for people moving on from residential care.

So far, there has been no need to move residents out of their existing homes: they are fully involved in seeing what is being provided, in some cases living next door to the new buildings as they are constructed. In future phases there may need to be some "decanting" to allow the redevelopments to progress, but it is hoped to keep this to the minimum because of the disruption caused. At present, all the dwellings provided through the reprovioning will be for existing residents of local authority provision. People with learning disabilities living in the community will only be able to access the new provision as vacancies arise.

The Barnet re-provisioning is interesting because it takes a holistic approach to learning disability services in the Borough, including rethinking day opportunities alongside housing and support provision. The large day centres were key to the whole redevelopment because of the land they were occupying. One has been closed altogether and replaced with community-based services. The re-provisioning will also enable Barnet to develop its three remaining building bases, which will deliver both specialist and community access day services, including facilities such as a hydrotherapy pool.

Contacts:

Alan Brackpool, Joint Commissioner (Disabilities) Younger Adults, London Borough of Barnet

Alan.Brackpool@barnet.gov.uk

Andy Lawrence, Project Manager, Young Adult Social Services – New Choices Project, London Borough of Barnet

Andy.Lawrence@barnet.gov.uk

Wirral Metropolitan Borough Council and Wirral Methodist Housing Association: working with users and carers, shared ownership

Wirral MBC and Wirral Methodist HA are currently working with a local group of people with learning disabilities and family carers to plan a shared ownership supported housing scheme with a mix of care and support needs. Group members are aged from 20s to 40s and have known each other for some time. WMHA have acquired a site for a block of 12 new build flats and are awaiting capital funding to develop the scheme, hopefully in 2006/7. WMHA already work with people with learning disabilities in a number of small shared houses.

WMBC will be working with the group to involve them in planning the housing and ascertaining their care and support needs: some have physical as well as learning disabilities. This is an interesting example because it has been largely led by service users and carers, and the extra care service model being developed has been advocated by the group. WMBC comment that they think this will impact significantly in respect of their commissioning of future services.

Contacts:

Martin Morton, Wirral Metropolitan Borough Council

martinmorton@wirral.gov.uk

Linda Tweedle, Housing Manager, Wirral Methodist Housing Association

Linda@wmhaltd.org.uk

West Sussex County Council and Mid Sussex District Council

West Sussex (the county authority) has a housing strategy for people with learning disabilities, "A Place to Live", which aims to move away from residential care towards supported living options. Joint work with local housing providers, the Older Persons Service Manager, the County Learning Difficulties Service and the district council has resulted in a number of housing schemes, including Prescott House (featured in detail below) which is a mixed extra care scheme for older people and people with learning disabilities. From the outset, the scheme was designed to provide ten flats for older people with care needs, ten flats for older people without care needs, and five flats for older people with learning disabilities. The original expectation was that

most of the new learning disabled tenants would be moving out of residential care, but in fact some came from their family home or from supported housing. Social workers from the learning disability team assessed potential tenants to ascertain their care and support needs.

Mid Sussex (the district council) has a supported housing enabling officer who works across all client groups. Allocations go through the Mid Sussex multi-agency panel for supported housing. There is a common housing register for the local stock-transfer association and over twenty other housing associations, with an extra one-page form for anyone with support needs. This feeds into a separate database for supported housing, used for both allocations and needs assessment for housing and support strategies. The database can be screened across different client groups.

There is an extra care review meeting every six months, where providers and stakeholders from all the extra care schemes in the area meet and discuss issues, problems and changes in legislation. They are also planning a promotional event for sheltered and extra care housing later in 2006.

In Mid Sussex, another new mixed scheme provides wheelchair flats for people with physical disabilities on the ground floor and other flats for older people (55+). On the top floor, there are five flats for people with learning disabilities, who are younger than those in Prescott House: the tenants have individual support packages and there is sleep-in cover.

Contacts

Andy Lane, Service Manager, County Learning Difficulty Services, West Sussex County Council
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Sarah Leppard, Supported Housing Enabling Officer, Mid Sussex District Council
SarahLP@midsussex.gov.uk

5.2 Examples of mixed extra care schemes for older people and people with learning disabilities, with a quota of flats for each client group

Prescott House, Burgess Hill: West Sussex County Council, Mid Sussex District Council, Hyde Housing Association/Chichester Diocesan Housing Association

Prescott House is a new extra care scheme, opened in autumn 2003 and built on the site of a former residential care home also owned by Hyde/CDHA. There are 25 flats, five of them dispersed across the scheme and designated for people with learning disabilities. All the learning disabled tenants are in their 50s or 60s.

Support is provided by Hyde/CDHA and there is now one staff team for all the tenants. Originally, there was a specialist daytime team for the tenants with learning disabilities but at night and weekends, all tenants were supported by the older peoples' staff and over time it was decided that it was better to combine staff into one generic care and support team. The scheme manager pointed out that staff in the older people's team were keen to get involved and receive training so that they could work with the learning disabled tenants. They looked on this as a career opportunity to improve their skills and employability by working with another client group. All staff needed training and support in adapting to the different needs of an extra care scheme, with the emphasis on promoting independence, because many had come

from a residential care background. Time was spent developing policies and procedures and behaviour management strategies so that staff felt supported. The success of the scheme is attributed to the time and resource put into the initial move-in and settling-in period, and the relationships developed between staff and tenants and between tenants.

Contacts as above (West Sussex and Mid Sussex), and:

Nichola Alexander, Manager, Prescott House, Hyde Housing Association/Chichester Diocesan Housing Association Nichola.Alexander@hyde-housing.co.uk

Steeple View, Stowupland, near Stowmarket: Suffolk County Council and Orwell Housing Association

This new extra care scheme opened in early 2006. Orwell have developed and now manage the housing, and provide the on-site care and support.

There are 28 one-bed and 8 two-bed flats and the usual range of communal facilities. The main block was funded with Social Housing Grant from the Housing Corporation. During the development phase, an additional four units (all one-bed flats) were “bolted on” with separate funding from Suffolk County Council. The original intention was that two flats would be for people with learning disabilities and early onset dementia, and two to provide respite care for younger people with early onset dementia. The four flats have full access to the whole scheme, although they are grouped together separately. The learning disabilities care manager has been involved in planning the scheme since the decision was made to add on the four units, and will continue to play a role in future management and allocations issues.

The same staff team works across all tenants, and the manager has qualifications and experience of learning disabilities as well as older people. Some of the people with learning disabilities have high care needs so will be receiving additional support from outside as well as from the on-site staff.

The scheme is now fully let. Because of funding constraints, the two respite units are now being let as normal flats. Six people with learning disabilities have accessed flats and they are spread across the scheme, in one and two-bed flats. Most attended the local day centre so they already knew each other. Day centre staff have worked with them and their families over many months to prepare them for independent living. This has helped them adapt to the changes to come, and has included accompanying them on visits to the scheme while it was under construction and working with family members. The care manager is sure that this has been very important in helping them settle in.

Contacts:

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aregent@orwell-housing.co.uk

Ann Laurie, Social Care Manager, Suffolk Social Services
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5.3 Examples of specialist provision for people with learning disabilities linked to, or within, extra care schemes or supported housing for older people

Mildmay Park: London Borough of Islington and Notting Hill Housing Trust

Mildmay Park was opened in 2000. It is an extra care scheme with 40 flats for older people, people with learning disabilities and intermediate care. The learning disabilities service is also featured in more detail in Housing LIN Factsheet 3.

At present, two people share a two-bedroom flat and four live in one-bedroom flats, these being scattered throughout the scheme. Most of these tenants were in a care home that closed down so they already knew each other before moving in. Their ages range from late 50s to mid-70s, and at present all but one is male.

There is a contract from Islington to support six people with learning disabilities through a specialist team, and they are currently providing just over one hundred hours of support a week, but with flexibility depending on the needs of each individual. The learning disabilities support service is to some extent separate from the extra care service for older people, with three specialist staff who do a great deal of one-to-one person-centred support. The manager has responsibilities for the learning disabilities and intermediate care services. The staff team's background is in working with older people, and they have benefited from a great deal of free training on learning disability issues through Islington's learning disabilities service.

The six tenants would access the same service as older people if needed at night, although they do not usually need to do so. They can choose to join older people at the optional lunch each day and often do so, depending on their other activities. They also access some of the other social activities of the scheme. They have integrated well within the scheme, and also have their own independent activities outside the scheme, facilitated by the specialist support staff.

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Devon Community Housing Association and Devon County Council: mixed provision for both client groups in Newton Abbot with creative use of Supporting People funding across both client groups

Powderham Court, built in 2004, is a new-build DCHS supported housing scheme near the centre of Newton Abbot. It has some aspects in common with extra care models, including higher staffing levels than a traditional sheltered housing scheme, and staff on-call at night (although not sleep-in). There are 19 flats (17 one bed, 2 two bed) for older people with additional support needs (including one wheelchair flat), a lift and communal facilities similar to a traditional sheltered housing scheme. Flats have a walk-in wet shower room and there is a bathroom for assisted bathing but with no hoist. Corridors and doorways are to wheelchair standard.

Nearby is Newfoundland Court, a block of four new-build one bed flats for people with learning disabilities also completed in 2004, and East Street, another block of six one bed flats completed in late 2005. These two blocks have no communal facilities and are to general needs design standards, with no lift.

A scheme manager and five support staff (two full-time and three part-time) are based at Powderham Court and provide around 130 support hours a week to tenants

across the three developments. The manager also looks after a nearby traditional sheltered housing scheme with 20 flats for older people. The same staff team provides support to the older tenants at Powderham Court and to most of the learning disabled tenants, so this is an interesting example of staff working across both client groups. A few of the learning disabled tenants receive their support from another provider: this is for historical reasons because the other support provider was already working with them before they moved in.

The staff team work across all the tenants to avoid over-dependency and there is a key worker system. Both older and learning disabled tenants have support plans for their individual needs. The scheme manager commented that all the older tenants have higher needs than the norm in traditional sheltered housing. Across all the tenants, support is provided for a wide range of needs including managing money and bills, emotional support, advocacy, liaison with other agencies, support with health needs and daily living skills. The scheme manager had experience of both learning disability and older people's services before taking up her post. DCHS provides a wide range of care and supported housing across both client groups.

There is no-one with a learning disability amongst the older people in Powderham Court, all of whom are aged from late 50s to mid-80s. They have support needs because of physical disabilities, sensory impairment, social needs and frailty. Some had to move because their previous housing was unsuitable because of frailty or physical disabilities.

The tenants with learning disabilities live in Newfoundland Court and East Street. They are all aged from early 20s to late 40s, and previously lived in a range of accommodation, including parental home, shared housing and residential care. Those from Newfoundland Court moved in at the same time as the older tenants in Powderham Court and have always been invited to attend the weekly coffee morning and other similar activities, where despite the age gap they get on well with the older tenants. Newer tenants at East Street are able to drop in if they wish but have not done so much. All the tenants with learning disabilities have a range of other activities including paid work, voluntary work, employment projects, college and leisure activities so their social life is mainly outside the scheme.

Powderham Court and Newfoundland Court received funding from Supporting People, but there was no allocation left for East Street. The intention had been to use East Street for people with learning disabilities and support needs, and there were over twenty people waiting for such housing. Yet without funding for housing-related support there was a danger that it would have to be let as general needs housing. This encouraged DCHS and their local authority partners to look again at the support needs of the four learning disabled tenants and the older people who had moved into the new housing in 2004. They found that tenants had become more independent, and so the support hours could be reconfigured to make space for supporting the new tenants due to move into East Street, at no extra cost to the Supporting People budget. Without the staff working flexibly across both client groups, this creative solution would not have been possible

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5.4 Examples of older people with learning disabilities accessing mainstream extra care schemes

Coopers Court, Mile End: London Borough of Tower Hamlets and Ashley Homes

Coopers Court is an extra care scheme with 41 one-bed flats, built about five years ago. The flats are constructed as i-pods with moveable walls and can accommodate a couple, or someone with physical disabilities. There have always been around five people with learning disabilities in the scheme, although this has happened because they met the normal allocations criteria, rather than being a policy decision to target them. There are two contracts with Tower Hamlets for care (with Social Services) and support (with Supporting People).

Although the lower age limit is usually 65, there has been some flexibility to meet the needs of people with learning disabilities, and an older carer and her adult daughter in her 40s occupy two flats in the scheme. The age range of learning disabled tenants is from mid-40s to over 90.

Ashley Homes is the Care and Support Services Division of Shaftesbury Housing Association who was the development partner. Ashley Homes staff and managers have experience of learning disability services as well as older people's services. At Coopers Court, the staff team work across all tenants and have accessed a wide range of training on issues concerning learning disability. The Area Manager reported that there have been no problems with integration between tenants with learning disabilities and other older tenants, and they participate in meetings, social activities and outings.

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Stockton-on-Tees Borough Council and Endeavour Housing Association

This new extra care development is a flagship project in a regeneration area, currently on site with completion due in April 2007. The scheme name will be chosen following a competition involving local schoolchildren.

There are 50 dwellings: 20 bungalows and 30 apartments. All have two bedrooms (one double, one single); this is Endeavour's normal standard for individual dwellings for supported housing. Endeavour is a major provider of supported housing in the area and provides for a wide range of support needs, including people with learning disabilities.

Endeavour has been working closely with the commissioners, Stockton-on-Tees BC, and there has been in principle agreement within the Development Steering Group that people with learning disabilities as well as older people will be able to access the scheme through normal allocations criteria and the multi-agency panel, where they meet the access and need criteria. Stockton BC has a joint health and social care service. The Head of Adult Strategy is responsible for commissioning all adult services, including older people, people with learning disabilities and all Supporting People services. The housing team have started to take referrals from older people in the local area where the service is being developed and staff in the learning disabilities team have already started to identify potential clients. Although the

normal lower age would be 60, this is flexible in cases where people are younger and where individual needs are assessed and considered. This should be done taking into account that the overall aim of the service is extra care for older people. This could also include older carers (who meet the assessment criteria) with adult offspring who have a learning disability. Where people with learning disabilities are allocated places, they will be dispersed throughout the service and not allocated a specific area within the building.

Endeavour is developing the scheme with Housing Corporation funding, and will be the landlord. A service specification is currently being drawn up, and care and support services will be tendered to local providers. A scheme manager has already been appointed, to start work in May 2006, almost a full year before the scheme opens, to ensure full involvement up to and after handover. The post is joint-funded for the first year between Stockton Supporting People and Endeavour.

There has been a great deal of discussion about design issues, especially access and security. The scheme is part of wider regeneration in the area and attention has been paid to how to separate the private areas (apartments and bungalows) from the public areas, which will be open to the wider public from the surrounding area. Facilities will include a bistro, gym and hair salon. The idea of providing day services and training opportunities for people with learning disabilities is being looked at. There is a desire to create a vibrant and diverse community but also an appreciation of the potential vulnerability of some tenants, including perhaps those with learning disabilities.

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5.5 Examples of specialist extra care schemes for younger people with learning disabilities

Whitfield Lodge, Lancashire: St Helens Metropolitan Borough Council, Arena Housing Association, Creative Support, Step by Step: self-management by tenants using Direct Payments and brokerage from an independent advocacy service

Whitfield Lodge was purpose-built and completed in 2004. It provides a block of ten self-contained one-bed flats designed around the extra care model specifically for learning disabled men and women in their 20s and 30s. The building is owned and managed by Arena Housing Association, and capital funding came from the Housing Corporation and St Helens MBC. There is a dedicated team of day-time, waking and sleep-in staff on site from the support provider, Creative Support, who are a specialist learning disabilities and mental health support provider.

There has been a very high level of user and carer involvement from the outset, including scheme design and support arrangements. A group of parents and service users approached the local authority some years ago with clear ideas about future housing, care and support needs. At that stage all were living at home with parents and all knew each other, both through attending local day services and because they

often socialised together as a group. Whitfield Lodge evolved from this group working together with staff from St Helens, Arena Housing Association and (after a tendering process) the support provider Creative Support.

There was a settling-in period during the first few months after the building was completed. Parents provided some of the sleep-in cover. St Helens staff from the day centre and the respite team who knew the tenants also worked at Whitfield Lodge alongside Creative Support staff and provided night cover, as did the St Helens commissioning manager. In this way the support provision was able to evolve around the tenants' needs, and everyone was able to work together to understand and overcome any problems. Some tenants now need less support than they did at the start, as they have developed more confidence and independence since moving into Whitfield Lodge. For example, one tenant no longer attends day services but has found employment locally.

The scheme was designed to be user-led and self-managed from the start. All the tenants receive Direct Payments and some also receive funding from the Independent Living Fund. Funding comes from Supporting People, Social Services and Health. There are ten separate contracts with the care and support provider and ten detailed individual plans. The contracting arrangements when support was commissioned stressed that the support provider had to accept Direct Payments. There are great variations in the care and support needs of different tenants, from a few hours a week to a high number of hours and waking nights.

An independent advocacy service, Step by Step, has provided a brokerage service since the scheme was in the planning stage; this was originally a direct contract with St Helens but is now dealt with through Direct Payments. The brokerage service provides a quarterly report from the tenants to the St Helens care manager in the learning disability team on how the care and support service is performing.

Developing Whitfield Lodge demanded a completely different approach from commissioners and funders compared to a traditional scheme. Both parents and service users had very clear views and there was a need for detailed discussion on the best way to proceed, with the scheme evolving from a more communal design to independent self-contained flats. Professionals were not sure whether mixing such a wide range of support needs in one building would work, but tenants with lower and higher support needs have been happy to live alongside each other. Both the support provider and the housing provider are exposed to more risk than in traditional procurement arrangements: the housing provider would have to manage any voids (there have been none to date) and the support provider could in theory lose one or more of the individual contracts, making the remaining contracts more difficult to staff. The brokerage arrangement has been crucial to the success of the scheme.

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Shared ownership and rented extra care housing for people with visual impairment, learning and other disabilities:
Devon County Council, SeeAbility and Signpost Housing Association;
Hampshire County Council, SeeAbility and Atlantic Housing Association

SeeAbility is a specialist provider and works with adults of all ages who are blind or partially sighted and have additional disabilities. There is a high incidence of visual

impairment amongst people with learning disabilities. SeeAbility has worked with local authorities and housing associations to develop specialist extra care provision, mainly for younger disabled people. Their accommodation is designed to enable easy access for people who have a visual impairment, making good use of colour and texture contrasts in décor, tactile information and lighting. There are some specialist facilities (eg electric windows, door key fobs). All the self-contained flats in the developments described below are ground floor and designed to meet the needs of people who use a wheelchair. Honiton and Eastleigh are rented; Exeter is especially interesting because it is a shared ownership development.

SeeAbility is also working with other providers (John Grooms, The Disabilities Trust, John Grooms Housing Association) in a new collaboration called 4ability. The aim is to produce more shared ownership extra care schemes, using private finance and no grant. Schemes will be open to all disabled people, irrespective of age, income, mental capacity or type of disability.

Willow Way, Exeter, Devon

This is one of two extra care schemes developed in partnership with Devon County Council. It is part of a much larger mixed tenure housing development on a former school site by Exeter Housing Society. The corner site was purchased by Signpost who developed the two-storey building with Housing Corporation funding. There are also eight shared ownership flats for non-disabled people on the first floor, with separate entrances. It was completed in March 2006.

The specialist provision on the ground floor comprises eight one-bedroom flats with common room, conservatory, gardens, staff room, sleep-in room and en-suite, and laundry. Each flat is spacious and brightly decorated, with fitted carpets and white goods (fridge, washing machine, hob) included in the purchase price. There is a fully height-adjustable kitchen and walk-in shower, except for those owners who have chosen a bath with over-bath shower. The design allows for direct access through swing doors from bedroom to bathroom, although where not needed there is a removable partition wall. Ceilings are reinforced for a hoist if needed. There is an on-site call system.

The ground floor flats have been offered for sale at £120,000 (£60,000 for a 50% share). The lease specifies that flats will need to be sold on to someone with a learning disability, with no age restriction. Seven were sold off-plan to people with learning disabilities and the final flat by May 2006. Six of the shared owners also have a visual impairment and three are wheelchair users. All are young people from 18 to 30+. In most cases, family members have been closely involved in supporting the person in their housing choice and the move was direct from the family home into the shared ownership flat.

Willow Way has been planned over a number of years and there was a steering group, which included local health and social care professionals. Shared owners have come from Exeter and elsewhere in Devon: one out-of-county person has come with their support package funded from their previous (and adjacent) home county.

There was plenty of publicity through community teams and parent/carer groups. Prospective shared owners have been involved for up to eighteen months prior to moving in, and have chosen colour schemes and some aspects of design. Shared owners will be responsible for internal repairs and maintenance, redecoration and

replacement of carpets and white goods within their own flat. The freeholder (Signpost) is responsible for the maintenance of the building fabric.

Care and support is provided by SeeAbility's specialist team based on-site, with around 20 staff (full-time, part-time, bank). The level of care and support varies greatly, with overall around 500 hours a week, and a range from around 30 hours a week to over 200 hours per week depending on the person's assessed needs (including waking night cover). Support is priced at an hourly rate so the cost per week is transparent for purchasers. Funding has come through health and social services.

Shared owners are committed to using SeeAbility as their support provider for the first three years. Arranging the mortgage and the support package and funding had to run in tandem, because people could not buy into the scheme until their support package was confirmed.

Windmill Court, Honiton, Devon

Windmill Court is similar to Willow Way and was also completed in Spring 2006. There are eight one-bed ground floor flats and communal facilities. Capital funding came from charitable sources and it is rented. SeeAbility is the specialist support provider, with funding from Devon County Council.

Meadowbank, Eastleigh, Hampshire

This was SeeAbility's first extra care scheme for people with learning disability and sight impairment. It was developed in partnership with Hampshire County Council and Atlantic Housing Association in 2003, using Housing Corporation grant and some cross-subsidy because of being part of a larger development. Support is provided by SeeAbility under a management agreement, with an on-site team and some tenants with very high support needs including 24 hour support. Funding is mainly from social services, with some funding from Supporting People and some tenants receiving Independent Living Fund payments.

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Other Housing LIN publications available in this format:

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- **Preventative Care: the Role of Sheltered/Retirement Housing**
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<u>Factsheet no.2:</u>	Commissioning and Funding Extra Care Housing
<u>Factsheet no.3:</u>	New Provisions for Older People with Learning Disabilities
<u>Factsheet no.4:</u>	Models of Extra Care Housing and Retirement Communities
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