A Measure of Success
an evaluation of the Department of Health's Extra Care Housing Programme for People with Learning Disabilities
January 2008
What is the Housing Learning and Improvement Network?

The Housing LIN brings together groups of staff within local authorities, primary care trusts, registered social landlords, the private sector and others interested in forging closer partnerships in delivering housing with extra care solutions for older people. It is part of CSIP Networks, which is itself part of the Care Services Improvement Partnership.

Anybody with an interest in the field can join the network free by registering at www.icn.csip.org.uk/housing

Care Services Improvement Partnership

The Care Services Improvement Partnership (CSIP) was launched on 1 April 2005 after a formal public consultation. Our main goal is to support positive changes in services and the well-being of:

- People with mental health problems
- People with learning disabilities
- People with physical disabilities
- Older people with health and care needs, and
- Children and families.

The Integrated Care Network offers advice on partnerships and integration that cut across all services in health and social care. It works closely with other networks and programmes across CSIP to maximise improvement.

About the author

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Acknowledgements

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Special thanks are due to the many families who prompted, steered, questioned and shaped many of the initiatives.

Finally, we would particularly like to acknowledge the help of all the residents who allowed us to visit their homes and share their experiences of moving into a new place.
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Executive summary

In 2004 the Department of Health allocated £2.3 million to 10 projects that were to provide extra care housing specifically for people with a learning disability. Most are now complete. The lessons should be of interest to those involved in re-modelling services, campus closures or trying to create new provision for the small but growing number of older people with a learning disability. The ideas about both particular forms of provision and the processes used should be of value to both providers and commissioners of services.

The wider policy context includes the aim of the Valuing People White Paper to extend the range of housing choices available and the targets in the more recent White Paper *Our health, our care, our say* (DH, 2006) to end NHS in-patient campus provision.

The schemes are diverse. They range from bungalows shared by two people to a collection of re-modelled sheltered housing schemes. Four are based on private sector housing or ownership.

Each example is the basis for detailed lessons set out in the report including points about design, legal agreements, care service etc.

**Themes repeated across projects included:**

- Gains from partnerships between the leading agencies.
- How helpful local ‘champions’ are, including involvement of family carers
- The projects often contributed to building better understanding between social care and housing colleagues with long term benefit
- The high costs of care and support in independent living. The need to think creatively about alternatives to reliance on professional, paid support. Ideas included mutual support, support tenants and assistive technology
- Someone to project manage and also help with a myriad of small, practical tasks that will be required in moving from one form of service to another, and
- The potential in re-cycling existing housing stock. This included sheltered housing, derelict general needs property, using the private rented sector and obtaining property from the owner occupied sector in three projects.

The developments have produced new housing for disabled people across the country – a clear tangible result. Nearly all are judged a success by the agencies and people involved. The Department of Health grant has frequently served as a catalyst for action or change.

At the same time, many have also emphasised the difficult challenges which often need to be overcome in putting in place effective housing strategies for disabled people.

Local authorities and their partners have, in many cases, been tempted to experiment, take a limited risk or do something beneficial sooner than they would have in the absence of a grant to underpin plans. This includes experiments with home ownership and tenure mix. Having a local ‘demonstration’ of sometimes novel approaches had the effect in several areas of creating demand for better services and giving people confidence in an unfamiliar alternative.

The smaller projects are mostly little different to well-conceived independent, supportive living. Compared to mainstream extra care housing for older people these developments have similar features except:

- They are smaller in scale
- Not exclusively for those over a certain age
- Have more limited facilities related to scale, and
- Often do not have a restaurant.

We draw from several of the developments in this report to describe a possible model of clustered extra care.
Introduction

For several years the Department of Health (DH) has been funding a programme of extra care housing for older people. It has been a catalyst in making this modern form of purpose-developed housing with care, support and facilities more common. It has encouraged local authorities and their partners, such as Registered Social Landlords (RSLs), to develop this option.

The programme is supported by the Housing Learning and Improvement Network (LIN) in the Care Services Improvement Partnership (CSIP) at the DH.

In 2004, the DH invited bids from Local Authorities with Social Services responsibilities for a small, new programme of extra care specifically for people with a learning disability.

Ten bids for the £2.3 million available were successful and received a grant from the DH. They ranged from £50,000 to over £375,000 and had to fit with the wider, learning disability policy context set out in the Valuing People White Paper, A new strategy for learning disability in the 21st Century, (DH, 2001).

This said:

- Housing was important – the aim is for a choice of where and how you live
- The Government wants people living with their families to be able to plan for a home of their own
- People with learning disabilities can live successfully in many types of housing: from individual self-contained properties, housing networks, group homes and shared accommodation schemes, through to village and other forms of intentional community. They can cope with the full range of tenures, including ownership
- Local authorities should expand the range and choice of housing, care and support services, and
- Draw up a housing strategy by 2003 addressing the aims of Valuing People.

These messages have been repeated in the consultative Green Paper, Independence, well-being and choice, (DH, 2005) and then developed further in the White Paper Our health, our care, our say (DH, 2006). The latter confirms the Government’s vision of “high quality support meeting people’s aspirations for independence and greater control over their lives, making services flexible and responsive to individual needs” and the commitment towards “fitting services around people not people round services”.

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It is this plan which explains there are an estimated 3,000 people with learning disabilities living as in-patients in ‘NHS Campuses’ and says “we finally want to see an end to this type of institutional provision”. It gives a target date for all NHS Residential accommodation (NHS Campuses) to be closed by 2010.

Valuing People Now: From Progress to Transformation, a consultation launched in December 2007, sets out the next steps for the Valuing People policy and its delivery. The priorities include:

**Personalisation** so that people have real choice and control over their lives and services.

**Access to Housing** housing that people want and need with a particular emphasis on home ownership and assured tenancies.

To further support the importance of housing there is a Public Service Agreement, PSA 16, to ‘increase the proportion of socially excluded adults in settled accommodation and employment, education or training’. This includes ‘adults with moderate to severe learning disabilities’.

www.hm-treasury.gov.uk/pbr_csr/psa/pbr_csr07_psaopportunity.cfm

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**Brief for this report**

The brief was to provide a short résumé and evaluation of the results. The focus is on the lessons that can be learnt from this innovative programme.

Only one scheme is exclusively for older people who also have a learning disability but most of the schemes are oriented toward those who have been living with older carers or previously in residential care.

The learning points are likely to be most helpful to those re-modelling services, involved in NHS campus closure programmes or trying to develop modern provision for the growing number of older people with learning disabilities whether in social housing, the private rented sector or owner-occupation. It was hoped that describing this modest programme might help commissioners and providers in thinking about ever wider choices for disabled people.

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**What we did**

This review is based on:

- The original proposals submitted to the DH
- Input of CSIP staff most involved in overseeing the programme
- Visits to two schemes and discussions with residents, staff, commissioners and housing providers
- Detailed case studies of three further projects, and
- Telephone/email interviews with all the other projects.
The programme

The ten successful bids were:

**Birmingham**  
Re-modelling flats on several sites

**Dudley**  
Purpose-designed two bed bungalow by conversion

**Hartlepool**  
New build flats and shared ownership

**Lambeth**  
Purpose-designed two bed bungalow for complex needs by purchasing and extending property

**Newham**  
Shared ownership

**Norfolk**  
Private sector leasing

**Redcar and Cleveland**  
Shared equity

**Salford**  
Re-modelling sheltered housing to extra care

**South Tyneside**  
Small development of new build houses and bungalows

**Wakefield**  
New build flats in mixed tenure development

Redcar and Cleveland is the one scheme that has not progressed.

The schemes are diverse but have these characteristics:

- All are based on self-contained accommodation for people living independently with care and support
- Four are based on private ownership or leasing
- The two smallest projects both involved a single bungalow shared by two people. None of the projects involved more than two people sharing a property
- The two projects which most closely resembled established models of extra care housing for older people were based on re-modelling existing sheltered housing
- Schemes were mostly targeted at people with learning disabilities living with older carers – although some residents moved from residential care homes into extra care rather than directly from the family home and at least one resident was re-housed from n NHS service
- A wide spectrum of needs is catered for - from a relatively low level where no personal care is required to some people with extremely high and complex physical and learning disabilities
- Several of the projects mix disabled and non-disabled people together on the same site or building, and
- A common thread is installation of assistive technology (AT) as part of a modern support package.
The Projects

In this section we describe each scheme and some of the key lessons.

Birmingham

- Remodelling flats on two sites for rent to people with a learning disability along with a 3 bedroom bungalow.
- Provision targeted at people moving out from residential care.
- Part of a wider plan to have a range of options.
- At present over 900 people in residential care.

Birmingham City Council is the country’s largest Social Services authority. It has ambitious plans to close many outdated residential care homes, re-providing 400 new places for people with a learning disability over the next four years.

The City Council is also still a major landlord with a large housing stock, including a number of difficult to let sheltered housing schemes. There are plans to extend options for older people generally by building a network of 11 extra care housing schemes, including several larger village scale developments.

The essence of this project was to take a number of dwellings in three sheltered schemes, where plans were already in hand to re-model or upgrade the accommodation to extra care and let them to people with learning disabilities. The DH grant was used to provide assistive technology.

The first building is a sheltered scheme and was re-modelled in partnership with Birmingham Mencap and now provides 24 self-contained flats. Four of these were still occupied by the original older residents; the remainder are now let to people with learning disabilities. A package of AT was installed, mainly based on sensors. In part this is to provide greater security because of the large number of doors into the building. Staff can be paged if a sensor alerts them to a problem or directly by the resident, who needs assistance.

In this scheme, there are staff on-site 24 hours a day as in any traditional extra care housing development. Three different care providers offer a domiciliary care service so residents have a choice of providers. Housing management is separated from care provision.

The AT package installed:
- assisted residents to achieve more independence
- reduced staffing requirements, and
- was useful in initial assessments.

As is usually the case, some care managers were initially concerned about ethical issues of monitoring by AT, as though this is somehow more intrusive than direct monitoring by staff. One of the benefits of the project has been to have and get past these debates1.

The second building is a three bedroom bungalow linked to a small extra care housing scheme. Residents are wheelchair users. AT has been used to enable individuals, by installing automatic door openers, as well as a package of sensors, to manage or reduce risk and improve security. This includes video monitored door entry.

The third building is described as ‘mini-extra care’. This is new build and has been provided by a local housing association and accommodates 12 people.

In summary the project has used the DH grant to enhance its’ AT provision. Two of the buildings used were refurbished older person’s housing; the third was a new extra care scheme funded by the Housing Corporation. The results are judged ‘a real success’.

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1 A discussion of these issues can be found in “Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home”, Magnuson, Lord Hanson E.J., Health and Social Care in the community in volume II, Number 11, September 2003 and “Living in the state of switch; how assistive technology impacts the lives of people with disabilities”, Scherer, M.J., Brookline Books, 2005 and “The ethical use of assistive technology” Wey, S., downloadable at www.atdementia.org.uk. The latter is a succinct statement of principles.
Older carers concerned about the councils' closure programs have been won round and for example have appeared on local radio shows saying how happy their relatives are in their new housing.

As is often the case the social care staff have been struck by the range of positive gains possible from different AT applications and how relatively inexpensive much of the more useful Telecare is.

Lessons

1) Extra care housing of the type developed is viewed as a positive option.

2) One of the preferred ‘products’ for the future for disabled needs group is ‘mini-extra care’. The authority would not seek to repeat the scale of the re-modelled sheltered scheme albeit that all three projects are judged a success. It is also apparent from the Person Centred Plans that some people continue to choose congregate living but this needs to be part of a wide range of options including supported living arrangements and shared ownership.

3) In scale ‘mini-extra care’ would typically be around six self contained dwellings. It would have, as do the three services developed, the core characteristics of ordinary extra care for older people as set out in the Housing LIN fact sheet 4 – ‘Models of extra care and retirement communities:
- Self-contained accommodation
- 24 hour care on-site
- Catering facilities and/or meals provided
- Range of communal facilities
- Facilities for staff
- Special design features
- Individual package of care and support based on assessed needs, and
- Provision for extensive assistive technology.

The scheme could, as with many ordinary extra care housing schemes, cater for diverse needs. Communal facilities could serve a wider community not simply those who live in the building.

4) Operating costs have turned out to be higher than expected and the authority would be keenly interested in cost comparisons particularly comparing residential unit costs with supported living; it is planning to carry out further financial modelling on these different care models.

Dudley

- The scheme involves the improvement and adaptation of a pair of semi-detached one-bedroom bungalows owned by the local authority to form a single, two-bedroom property.
- It comprises two large bed-sitting rooms, a large kitchen/utility room, shared bathroom and separate, secondary toilet and a large living room. The focus is on ensuring personal space for the two sharers.
- Two men were originally living with older carers and, prior to moving, were placed in a residential setting. They have positively chosen to share and were good friends prior to the move.

The principal partner agencies were the local authority, which is responsible for both Adult Social Care and Housing along with the Langstone Society, a local support provider. Rather unusually the support provider is not registered with CSCI as no personal care of the kind which would trigger registration is required, only support.

The DH grant of £50,000 has been used to combine two very small, one bedroom bungalows, which were not let and were in poor condition, to create a single, larger bungalow.
The two men were previously living in residential care and wanted the chance to live more independently. One also needed ground floor accommodation. They were already friends and professed a willingness to live with each other at an early stage and so were involved in the design and refurbishment of the property from the outset.

The layout places the bedrooms at opposite ends of the building with the kitchen, living and dining room in the centre. A small wooden summer-house has been constructed in the back garden for one of the men who smokes. The capital cost of refurbishing and re-modelling the building was £70,000. This investment brought two derelict buildings back into use.

The men are both articulate and relatively able. Some physical disabilities, including the frequent epileptic seizures of one of the men, means at present 24 hour support is provided in three shifts, although there is no sleep in room for staff. The residents provide a degree of mutual support, sharing domestic tasks fairly and making meals together while one takes responsibility for the garden. Lack of equity in division of work was a source of grievance for one man in his previous placement.

As with many of the other projects in the pilot, the relatively high cost of supported living, in both absolute terms and compared to some of the alternatives, is a concern for the authority.

As explained, the need for 24 hour presence is driven by the epilepsy of one resident. It is possible that the other resident could learn what to do to help his friend and/or that an epilepsy alarm combined with a rapid response service could be introduced and substantially reduce costs. Additional assistive technology is in the process of being installed.

One of the men says “there is too much staffing”. He would like them to be left alone more and to become even more independent. Achieving this, given different physical requirements, is one of the challenges.

This links to one of the unusual features of this project. The support provider has a strong commitment to the principles of supported living; working with the residents to extend what they can do for themselves. Residents choose the staff who work with them. The provider is conscious of maintaining a culture that prevents institutional practices. As noted, Langstone provides no personal care as one manifestation of this style. However, one of the residents needs regular medication and treatment. It has been difficult to persuade the District Nurse that this is a service that they should provide but this is rather being provided by the Community Nurse for learning disabilities.

Current costs exceed the per person cost of the previous residential provision, which was £706 per week. This had been configured as four, shared flats, accommodating 18 people in all. The Commissioner observes, however, that the true costs for each individual are disguised in residential care. It is likely that the real costs of staff time caring for the resident with greater physical needs and epilepsy would have been much higher than the “average”.

The two men now receive 168 hours of support. Initially costs were based on a relatively high hourly rate to allow for set up costs and some agency staff while a permanent staff team was selected. There was no Supporting People funding. It has now been agreed that Supporting People will contribute and that a lower hourly rate adopted by Supporting People will apply. This means that the cost to Social Care now comes very close to the previous cost i.e. around £1400 per week. Thus the costs before and after the move are not too dissimilar and for Social Care are virtually the same.

What are the results?

The project is judged a success but it is anticipated that it will evolve further and may possibly become part of a planned Key Ring community network.
Given that initial concerns by the relatives of one resident have not come to anything, this project has raised the question of larger-scale movement out of residential care. The agencies involved talk about ‘pump-priming’ and ‘getting the ball rolling’.

Within the local authority, the project has had the effect of prompting closer working between housing and social care staff. They who are now all part of a single directorate. As a concrete example, the Housing Department will draw attention to properties becoming available that they now appreciate might be particularly suitable for those with a learning disability.

The term ‘extra care supported living’ is used by the support provider. For them the project drove the creation of a fresh support model between the two extremes of low level support to the relatively able and residential care, which had been the two staple products.

For the two men there has been an opportunity to exercise a whole set of choices and they are now much more in charge of what they do and how they live their lives. There is said to be, ‘a much sharper focus on what each individual needs’.

Lessons

1) The factors that led to these positive results included:
   • Having a manager to co-ordinate and lead
   • Established relationship with Langstone, who became the care provider and who already had detailed knowledge of the two residents
   • Advocates
   • A clear understanding that either of the intended occupants could change their mind about moving at any time
   • A three month contingency to meet cost of running two services in parallel
   • Involving the two residents from a very early stage and
   • Recognition that the pilot may fail and also that the service will not last forever.

2) Adult Social Care’s relative lack of capacity in housing and housing-related matters is a hurdle to this kind of project; ‘project management is not linear’. There were numerous, apparently minor, matters which were potentially significant enough to derail the scheme. Extra capacity is needed to tackle these. There was no money for furniture and the scheme did not get a Community Care grant; the two men would not get income support until they moved into the bungalow. Filling this housing gap or engaging housing colleagues is important.

Hartlepool

• This scheme is shared equity supported housing.
• Owners are given an option to own up to 75% of the value of the property.
• The scheme offers two-bedroomed accommodation for single people and couples with on-site support staff.

This project is based on a partnership with Three Rivers Housing Association which was also involved in a bid by Redcar and Cleveland for a similar shared equity scheme.

The basis of the building was the re-development of a vacant church site to provide six flats for people with learning disabilities to be sold, along with 12 general needs properties and a parish hall. This was for the local community but could also be used by residents, thus providing part of the ‘facilities’ associated with extra care housing.

Eighteen months on, building work has yet to start. One of the lessons for those involved is how long acquiring church land can take.

The properties are aimed at disabled people living with older carers. The concept is to create a small mixed community in a lively area of Hartlepool. The local authority will have 100% nomination rights to all the properties.
The DH grant is £300,000. The balance of the cost is to be funded by:

- Part sale of some properties using Income Support Mortgage Interest (ISMI) as in similar shared ownership projects for disabled people
- Private loan taken out by Three Rivers Housing Association re-paid from rents, and
- Some investment in the shared equity properties by individuals or their relatives.

Consultation with relatives has found them willing to put money in if necessary and there are local examples where families have already taken action to acquire properties or pass on the family home in different ways.

An issue has been the difference between cost and value. Three Rivers builds to Housing Corporation standards. As a consequence the expected unit cost is about £110,000 – £115,000. This compares to a market value of £90,000; thus in Hartlepool low values mean part of the grant is being used to simply bridge the difference between cost and value. Values are creeping up and the gap between cost and value is being reduced.

In keeping with the extra care housing concept, all apartments are two bedrooms to allow a carer or support worker to sleep in or live with the disabled person if this becomes necessary or simply to allow a friend or relation to stay. On this basis and the design and layout of the flats, it is anticipated that it will be possible to support most people in this scheme for many years, unless they become physically very frail and live on the first floor. (The small scale and cost of development has not permitted the installation of a lift.) Facilities include the provision of staff office and accommodation on site.

Residents will be able to access Direct Payments and shortly Individual Budgets to arrange their own package of care should they wish and will not be tied to using a particular care agency.

Lessons

1) We have already mentioned the lesson around time and the cost-value equation and consequent grant required if Housing Corporation standards are to be achieved.

2) It has also been found that it is difficult to engage carers until there is something real to show. Showing plans, even of 3D designs, is not sufficient.

Lambeth

- This site identified two people with learning disabilities who would like to live together more independently.
- They both use wheelchairs and have very high physical care needs.
- Their needs could best be met in a bungalow, which needed adapting.
- Building formed from an existing bungalow and substantial new-build extension.

Partners include Golden Lane Housing, a charitable subsidiary of Mencap, as the housing provider and Lambeth Mencap as the care provider.

The building is a two bedroomed bungalow in a linear layout. There is an open plan kitchen and lounge, two bathrooms and an office/sleep-in room for staff.

Bungalows are extremely hard to find in Lambeth. The project took four years and depended on considerable trust and persistence of all the agencies, including Housing Benefit and Occupational Therapy. It is a good example of how difficult it can sometimes be to balance the ideal and local reality in striving to meet people's needs.

Golden Lane viewed a large number of ground floor flats and maisonettes but judged all would be unsuitable for the two people with complex needs, including high physical needs.
They found leaseholders and landlords in blocks of flats very resistant to accepting the kind of changes to access that would be required.

Eventually one of very few came on the market. Originally built by a housing association, as part of a small general needs development, the vendor had acquired the property and was now selling.

Golden Lane eventually purchased this for £236,500 and then added a large extension to create a spacious bungalow to wheelchair standards at a cost of £157,000. It incorporates a specially designed kitchen, storage for the extensive equipment and to house the wheelchairs, with a track and hoist system in the bedrooms.

The residents are two women with special needs, that include, for example, peg feeding. One had lived on a hospital site, staying with ten other people for 35 years. The other was living with her father who was in his 70s.

The results for the two are judged to be very positive. The treatment in the hospital was described as “health and safety maintenance only”. Three staff had to look after all ten clients and could give little individual attention, stimulation or activity. This person had consequently learnt to simply scream to gain any attention. This behaviour is now decreasing. Each resident now gets one-to-one support. They get out more, are enjoying more activities and get personal attention.

Rather than have everything brought to them in their home and things done to them they get out to see therapists and doctors and use community facilities and shops. There is 24 hour support available. This is based on:

- One person sleeping in
- Two staff on duty when both are present in the building during the day and
- One staff member in the intervening periods.

Due to the individual needs this is an expensive service, costing the authority £4000 per week for two people. The rent met by Housing Benefit is £261 per person per week.

This rent compares with a local reference rent for self-contained accommodation of £139 per week. This level of rent is claimed by the residents under what is widely known as old ‘Regulation 11’ which has recently featured in two decisions by Social Security Commissioner Turnbull. This regulation allowed higher rents in properties managed by certain classes of landlord to be met by Housing Benefit where this was for a disabled person and there was no cheaper suitable accommodation available in the locality, provided the landlord also offers an amount of support.

The rent meets management and maintenance costs but also services the mortgage taken out by Golden Lane to meet the balance of the total capital costs of £410,000.

Other sources of capital funding included:

- Disabled Facilities Grant of £25,000 which was approved in advance, and
- DH Grant of £200,000.

The project took so long largely because of the near impossibility of finding a bungalow or any other suitable building. Golden Lane incurred significant design and development costs amounting to around 10% of the eventual build cost over the four years. Their belief in the local authority and other agencies was necessary to take risk. An important element of this was their on-going relationship with Lambeth Mencap, who knew the two ladies the bungalow was planned around.

Lessons

1) Partnership, commitment and involvement of an unusually wide range of agencies are critical. The eventual success of the project depended on the close relationship and trust between the parties. There was no formal agreement or protocol and it is suggested that if this was repeated or in the absence of the strong, positive relationships, this would be helpful.
2) Linked to this, there is a question of what would have happened or how well the project would have gone had it been the case that the support or care service was simply to be tendered at some future point. It is thought unlikely that the strong partnership with all the agencies working together would have existed. The family carers involved would also have had a very different and less positive attitude had they thought it was not going to be the agencies they knew and had confidence in that would eventually provide support services.

3) The scheme is seen by all to have delivered positive outcomes. There are others with complex needs, some supported by a large and growing number of older carers, who will eventually no longer be able to provide support. The council has a strategy of helping those placed out-of-borough back in Lambeth. There is an accepted lack of suitable housing, ideally bungalows. Similar projects have been set up on a one-off basis by the learning disability team. The authority is working closely with Supporting People to develop independent homes based on self-directed support.

A legal agreement was required between the local authority and Golden Lane to pass on the DH grant. This involved protracted negotiation and significant legal fees for both Golden Lane and the Council.

4) There is no way people with the high level of disabilities of these two residents could achieve similar housing without considerable support.

5) Golden Lane is a relatively small but dedicated housing provider. The local housing associations would ordinarily be considered the most likely source of this kind of purpose-designed special needs housing. Here they did not engage in the bidding process.

The advantages of an organisation like Golden Lane are seen to be:

- Focused specialist – they understand needs. Their surveyor works across schemes and can help achieve continuous improvement in design/problem solving
- Deal with people as individuals and able to design around individual requirements rather than focused on producing standard ‘units’
- Willing to take some risks and be tenacious
- Turn up at meetings – involved
- Staff knowledgeable about needs of customer. Some have worked in social care; some in housing
- Strong value base regarding equal opportunities for people with learning disabilities, and
- An understanding of the social care system.

Although attention was paid to the detailed design, layout and equipment, little telecare was installed. This is to be retro-fitted by the landlord with a grant of £8,000 from Lambeth Council.

Newham

- To help two people living with older carers to purchase a property up to the value of £180,000 on shared ownership terms.
- Share of property to be between 25% and 50%.

Newham Borough Council worked with East Living, a housing and support provider, part of the East Thames Group, an RSL.

Two properties have been purchased on the open market. The criteria narrowed the field of applicants:

- Living with an older carer
- Wanting to move, and
- Eligible for Income Support Mortgage Interest (ISMI).
Initially three people expressed a positive interest and were identified by a member of staff who works specifically with older carers. The two individuals who proceeded are both Afro-Caribbean. One acquired a 45% share; the other, with a cheaper property, a 55% share.

- Enabled two people to buy a share. Property values have continued to rise.
- They are successfully living independently, despite having lived with their parents for many years.
- They were able to choose the property. The right location was very important to a successful move from home, particularly in the context of the ethnicity of the two purchasers. One man fixed on a certain bungalow and held his ground when others tried to persuade him to a different house. This demonstrated a clear, personal decision, recognising home-buying can also have an emotional element.

The DH grant clearly acted as a catalyst. Shared ownership could have been done before but there were no local examples of disabled people owning. Since this project, others have moved to ownership and the ability to demonstrate success locally means interest in this option is now greater.

The project has also built up links with financial advisers, solicitors and others who now understand the model and will work with people with learning disabilities and their families.

Both men have quite complex needs. The care package is consequently based on 1:1 support. This costs Adult Social Care about £1600 for each person per week. The assumption is that this will reduce over time. Unlike some of the other extra care housing schemes in the pilot, assistive technology was not used much but it is now thought that this could play a role. Support and care are among the aspects under review. There is thought to be scope in shared support, natural supports and other creative approaches.

Lessons

1) The project demonstrated that people with learning disabilities with complex needs can make positive choices in buying. Buying facilitates choice of area in particular. It demonstrated that house ownership can be a real possibility. If the exercise were repeated the authority would take a slightly different approach aiming the option at a wider group of people.

2) In setting up support packages the authority would now prefer to use an In-Control approach to give a further boost to ‘citizenship’.

The engagement of families was critical to success. Having a worker who already knew the families - who they in turn trusted - enabled the authority to target the opportunities very effectively and successfully.

Norfolk

- This is a pilot ‘private sector leasing scheme’ across Norfolk for 15 people.
- The project offers a ‘lease premium’ to private sector landlords to enable them to adapt and improve their properties.
- There is portable assistive technology.

A detailed case study is available from the Housing LIN in Annex One, Other Useful Information www.icn.csip.org.uk/housing/index.cfm?pid=533&catalogueContentID=2523

The unique feature of the Norfolk project is the use of 15 properties leased from private sector landlords. This model has been used for other needs groups, in particular homeless families but is not widely used for people with learning disabilities.

The arrangement in this case is that Saffron Housing Association leases properties for a period of five years from private sector landlords.
Saffron then manages and maintains the properties and at the end of five years hands the properties back to the landlord in the same condition as they were originally. Saffron acts as the landlord.

The advantages of this model are that:
- It enlarges the potential stock of housing, adding to choice
- It is possible to move quickly – and initially care managers saw this as a solution to ‘crisis’ situations, and
- Sometimes it is the only way of getting the right property, in the right place. A suitable property may simply not be available in the public sector or there may be a long and unpredictable wait.

The key disadvantages are:
- Lack of security of tenure – private sector landlords normally offer only an Assured Shorthold Tenancy. The involvement of an RSL improves security but this is not guaranteed permanent housing for ever, although some landlords may renew the lease
- Reluctance of private landlords to agree to let to people on benefits, and
- Reluctance of landlords to agree to adaptations.

These issues were dealt with so that some private landlords were willing to offer properties:
- The RSL leases the properties so the landlord does not need to worry about the benefits status of the resident
- Saffron found Housing Benefit Departments willing to be flexible on rent levels acceptable for Housing Benefit
- Norfolk County Council provides a rental guarantee
- A lease premium of £5,000 is paid to landlords to fund any adaptations required, including additional safety and security, decoration and user-friendly white goods, and
- The intervention of an RSL gives residents some greater reassurance that for around five years they are reasonably secure in their tenancy.
Outcomes

The scheme is judged a success. Initially the focus has been on those with mild or moderate learning disabilities although two tenants receive 24 hour care. The results for individuals are obvious in some of the things they and their families say:

- Adrian, Richard’s father. “It’s fantastic”, “I’m glad he is doing this while we are around to help”
- Bob, Martin’s brother. “He is over the moon”, and
- Brian. “Fantastic to have own independence and do what I want”.

Individuals’ conversations and experiences tell the familiar story of people growing in confidence and independence as a result of having their own home “Brian has started taking the ordinary bus – even though he has a much longer journey time as he wants to use public transport”. A family “went from initially(being) unhappy to (being) very happy and positive about the scheme”.

The key parties to make this happen have been:

- A housing project worker in Norfolk Learning Difficulties service
- A dedicated housing worker from Saffron Housing association, and
- Lead staff within joint Health and Social Services.

Others have played a part: in particular PACT (a local charity) whose Occupational Therapist and an Assistive Technology Support Worker were very important. The latter post oversaw the installation of a basic assistive technology package consisting of the following, plus individual devices according to needs:

- Keysafe
- Video/ phone entry
- Easy and safe to use appliances
- Connection to a community alarm service
- Standard environmental detectors – smoke, flood, heat, and
- Prompt devices e.g. electronic clock reminds to take keys, take medication.

Each resident gets six hours of basic support per week funded by Supporting People. Additional care packages based on an assessment of needs are then provided by Adult Social Care. Some residents use Direct Payments and employ their own staff.

The housing association built up relationships with smaller private landlords and letting agents. The latter were initially less helpful as they see the RSL taking management work from them. Some landlords, on the other hand, have been attracted by stability and a guaranteed income. They also appreciated that someone with a learning disability who was being supported could be a good tenant. Some smaller landlords, perhaps simply doing ‘buy to let’ as an alternative investment and not ‘professional landlords’ liked the idea of doing something to support people to live more independently.

Building a network of landlords and sympathetic letting agents is a key to success.

Lessons

1) Difficulties in finding suitable flats in the private rented sector. This needed an RSL who will work to create good relationships with managing agents, identifying the ones that will embrace the idea of housing disabled people.

2) Time needs to be spent with the person to look at what they want, priorities. Also, time must be invested with families to help them feel confident about the scheme. This also means being accessible to the families and the individual when they ring. Families feel they can offer support and be there for their son or daughter, they feel reassured saying “It’s better it happens while I am still around”.

3) Good partnerships.

4) Initially the OT and housing worker got very involved in the practicalities of the move for people, buying goods and smaller practical tasks. Dedicated support worker time is needed to take that on and for their role to be more advisory.
5) AT did not cost as much as expected. Using some of the money for training proved a good idea.

6) People became more independent. Not only could they do more when living alone, when coupled with increased confidence it impacted on other areas of their life. One man now wants to leave his day centre and work with rescued animals.

Redcar & Cleveland

- Shared equity supported housing.
- Three one-bed units, two two-bed units, one one-bed wheelchair accessible property.
- Owners given option to buy up to 75%.

This project, like that in Hartlepool, is in conjunction with Three Rivers Housing Group as the housing provider. A development officer was appointed on a temporary contract to oversee delivery of two shared equity schemes, one in each authority.

The proposal explained: “There is sufficient mid-range accommodation for more able learning disabled people but this is limited to rented accommodation.” It continued that the scheme “is intended to be an attractive option for individuals who cannot raise a full mortgage but could qualify for a small loan with the majority of their contribution coming as a gift from parents or family.

The buildings are to be purpose-built and included one property to full wheelchair standards and installation of assistive technology. Sleepover accommodation was incorporated in the design.

Support on site was planned as follows:
- 8 hours per day – early morning and evening.
- Safety call out – the principle is that staff can reach and access properties within 5 minutes of a call from residents.
- Sleepover.
- Residents were to be involved in selecting support staff.

Salford

- This involves remodelling a small sheltered scheme from bedsits to one-bedroom flats
- This is a phased process but four of the flats are for older people with a learning disability
- The design takes into account the needs of people with dementia, to enable people to continue to live there as they age and if they develop mental health problems.

A detailed case study is available from the Housing LIN. See Case Study No 29 – Pennine Court: Remodelling sheltered housing to include Extra Care for people with learning difficulties. For details, see Annex One, Other Useful Information.

Partners are Salford City Council and English Churches Housing Group.

This re-modelling of an existing 23 bed-sit sheltered scheme includes specific provision of four extra care dwellings and some facilities for older people with learning disabilities. It stands out as actually being intended for people with learning disabilities as they age, not simply those with older carers. Of the four initial tenants, the youngest is 49 and the oldest 82.

The DH grant contributed £225,000 towards the provision of the four Extra Care units and related facilities, and a further £100,000 was provided by the landlord. The total cost of the initial phase of upgrading the sheltered scheme, including the Extra Care elements, approached £1,000,000. The re-modelling was to turn the scheme into 17 one and two bed flats. All dwellings are to full wheelchair standards.
Scheme facilities included two lounges and a dining room with kitchen, laundry, treatment/guest room, sleep-in room and staff facilities and assistive technology. Special attention was paid to the design and fittings of the four ground floor flats earmarked for people with learning disabilities but the whole scheme and communal facilities are designed to be accessible and ‘dementia friendly’.

The AT is based on a standard environmental monitoring package and then sensors, such as fall detectors, are added according to individual needs. The emergency alarm links first to staff on-site with calls routed to Central Control as a back-up.

An extra care housing support service was commissioned jointly by Supporting People and Community Health and Social Care. The contract awarded to a private sector care provider, Creative Support, has clearly defined, measurable outputs and targets including:

- Integration within the scheme itself
- Developing community links
- Developing and encouraging relationships and friendships
- Increasing take-up of education and leisure activities
- Reducing social isolation, and
- Improving the quality of life and self-esteem of service users.

The four flats for the extra care housing (learning disabled) tenants are clustered together close to those communal facilities thought particularly relevant to this group of residents. Although the living units are clustered in this way, it was intended that the residents with learning disabilities should be fully integrated within the life of the scheme and that there would be shared use of communal facilities. There are other schemes in the pilot which mix people with different needs together. In this case the disabled tenants visited the scheme on a number of occasions prior to moving in. This was to:

- Confirm their decision
- Prepare for a move, and
- Get to know existing tenants – who had remained in residence while major works took place.

The scheme manager and care staff have worked hard to promote integration and encourage shared use of facilities and a sense of shared community. Those involved say: “This seems to be working” and “First names are now in common use”.

Outcomes are judged as positive so far. One un-anticipated result of the move has been improvement in family relationships and contacts for two of the four disabled tenants. “Visiting a self-contained flat in Pennine Court is very different to visiting someone in a care home”.

Lessons

An appendix to the case study write up contains extremely useful lessons and tips on design, which are commended. There are additional, broader lessons:

1) Service-user and Parental Involvement. The timescales of the project made it particularly difficult to carry out meaningful consultation with service-users and parents/careers. Salford’s ‘Where People Live Group’ (a professional working/planning group) was involved throughout the whole process as was, once identified, the first group of learning disability tenants. Wider consultation on design and the décor/furnishings/equipment of the scheme and flats with people with learning disabilities would have been better and this is something Salford would do in any similar initiative.

2) Handover to Care Provider: All four of the tenants had lived in Salford’s in-house supported tenancy network for a number of years.
Each had very strong supportive relationships with the staff from the houses they had lived in. In order to support the tenants' transition from the group home model to the self-contained model, and to allow Salford the time to carry out a full, robust, tender exercise for the care provider at the scheme, a transitional staff team was appointed from the existing staff within the group homes each tenant had lived in. It was agreed that the transitional team would work at the scheme for four months with the last four weeks of that period being a planned handover period with the new staff team of the care provider who had been awarded the contract.

The lesson learnt is that it was not beneficial to the tenants and staff to have such a lengthy lead in period to the handover. Tenants became used to having their support provided from staff they knew well and they became anxious about the inevitable changes to their staff team. Equally, the staff had supported the tenants through a major change and this made their relationships stronger than ever. Leaving the scheme and handing the service over then became difficult for the staff and they felt quite saddened. If repeated a short handover period of four weeks only or having the long-term care provider in place from the outset of the service being opened would prevent staff and tenants having to go through long periods of change.

4) Research assistive technology in depth. This was done thoroughly for this project but even so, as needs have changed, the recording and monitoring ability of the assistive technology has not been able to keep pace. It has proved costly and time-consuming to get the manufacturer to develop the devices installed further.

5) Have faith in your project and determination to succeed. Partnership working is extremely productive: building trust and developing an understanding of each others areas of business is invaluable in project development. Partners have to be flexible, as the timetable will change. The concept of ‘Extra Care’ is difficult for some professionals, service users and relatives to understand; expect some negativity, change is very difficult and can be very worrying for those involved. Be patient, understanding and supportive of each other. Keep talking.

3) Always have a ‘B List’: Identification of prospective tenants focused on those adults with learning disabilities who were older/aging and suffering from dementia. Work began with these tenants and their relatives and plans were agreed and put into place. Unfortunately, as noted in the case study, there were rapid deteriorations in the health of the identified tenants and one passed away, a second was taken into hospital and later had to be placed in residential care and a third changed their mind. A new group of tenants to move into the scheme had to be identified. This meant care managers, staff, people supported and their families experienced a level of anxiety over the speed at which the project was developing. The lesson was there should be a ‘B List’ of tenants and their families who had already been consulted and informed that they are on a reserve list.

South Tyneside

- Small-scale, new build development of three terraced houses and two bungalows to rent.
- Wheelchair accessible and to Lifetime Homes Standard, on a mixed tenure site.
- Creative use of assistive technology, including use of webcams, to keep people in contact with their older family carers.

A detailed case strategy is available from the Housing LIN. For details, see Annex One, Other Useful Information.
The leading partners are South Tyneside Metropolitan Borough Council, South Tyneside PCT and Places for People. Two carers were also closely involved in the Project Management Group from the start.

This is a development of three, two-bedroom terraced houses and two bungalows along with communal facilities. It forms part of a larger new build scheme. The properties have been constructed to Lifetime Home Standards which means they are more suitable for physically disabled people. They can be more easily and cheaply adapted as needs change. Flexibility includes incorporation of reinforced ceilings for hoists and a knock through panel between the bathroom and bedroom in the bungalows.

The development has been successfully targeted at the 180 people with learning disabilities who are supported by older family carers estimated to be living in this small local authority and who want to live independently. Providing two-bedroom accommodation means a number of permutations are possible including having a live-in carer or support tenant or simply sharing the property. The bungalows could be re-let as family housing or to another older or disabled person. The design and installation of AT means the scheme could be suitable for people with complex needs including higher physical needs. In practice, most residents have low or moderate disabilities.

Places for People has extensive experience of using AT to support older people living in ordinary extra care housing and the project was able to use that organisation’s assistive technology co-ordinator to support the installation of AT and assess individual needs. There are three strands to this:

- Installation of a telecare and alarm system linked to the support team. As usual the installation allows additional devices and sensors to be added according to individual requirements. The standard installation in the bungalow includes:
  - Fire, flood and similar environmental sensors
  - Electric window opener in kitchen
  - Hands-free entry system linked to the phone
- The installation of a broadband, open line audio/visual link between the family carers’ home and the new property. The system is based on webcams in both properties, touch screens and a PC. This is an unusual and novel application which allows the tenant and the family to keep in direct touch at a distance. The tenant can turn the PC off so it is not an intrusive monitoring system but simply a better and visual means of communication, and
- Provision of a very simple mobile phone with pre-programmed speed dial keys to call for help when needed. This incorporates GPS tracking which has the effect of promoting greater mobility and independence outside the home with a degree of safety.

The running cost of the core AT system is £4-5 per week. This is funded by Adult Social Care as an integral part of each care package.

There was strong initial partnership working with ‘champions’. This was particularly true in Places for People and a joint social care/PCT post. The partners were committed to collaborating and shared a belief in the importance of housing as a key to independent living and a willingness to innovate. Changes in personnel and roles partly because of re-organisation in the NHS had some impact on the project with Places for People now very much a lead partner.

Lessons

1) The scheme grew from local champions and good partnerships. One post worked across the PCT and Social Care and linked with the RSL.

Halfway through, this post was pulled back into the PCT. A good team and a determined RSL person, carried it forward, helped by some strong carers on the Learning Disability Board.

The reorganisation of the PCTs and the job change has meant that it has mainly been the RSL keeping the project going. The RSL is now working to rebuild what was a strong partnership.
The bid was the result of strong partnerships between the RSL, social care and health. Changes in personnel and restructuring meant that this was weakened initially but is now being quickly rebuilt. The scheme itself has played a role in this, illustrating the benefits of partnership working.

2) Involvement of family carers has been key in getting other carers interested in better but different services.

3) More time should have been spent sorting out some of the AT prior to people moving in. There were problems with the telecoms provider, particularly about getting lines connected when people did not have a credit history.

Wakefield

- This scheme comprises 12 new build apartments.
- It combines housing for people with learning disabilities with general needs housing in the same block.
- The building is designed to look like any other block of flats that happens to have flats set aside for people with a learning disability.
- Intended for people with learning disabilities who live with older carers.

The housing provider was Yorkshire Housing and the care provider is Avalon.

Wakefield carried out an analysis of needs and also a specific consultation exercise on the extra care model. The idea was to develop supported accommodation to enable a careful and inclusive transition to independence for people with learning disabilities living with older carers.

The authority was also aiming to:
- Provide more independent supported accommodation to replace residential care, and
- Increase provision of affordable housing in an area of high demand.

The original proposal was for 12, two-bedroom flats but in order to make cost savings this was changed to six two-bedroom flats for general needs housing and six, one-bedroom flats for tenants with learning disabilities. A ‘communal’ guest room with access to toilet/bath so that family members could stay over was added to compensate.

The support model anticipated support could be provided to both the older carer and the disabled resident. Individual care packages are the basis of the model but with provision in the building for night time support on site. It was anticipated that a ‘support tenant’ might occupy one of the flats at a reduced rent to provide some low level support to the disabled resident. By deliberately mixing general needs housing with six flats earmarked for disabled people older carers have an option of also moving to their own place in the same building.

The development incorporates a staff support room and guest suite as part of the facilities – the latter primarily intended for older carers. There is also a communal lounge for residents and a laundry used by staff, primarily to deal with washing bedding used in the guest suite and bedding from the sleepover room. Residents have washing machines in their own apartments.

Support is based on two members of staff being present on site 16 hours a day each plus a sleep-in carer. Additional care is available if required and residents can call for assistance, using a mobile phone at any time. Assistive technology was not installed initially as “we did not know what was needed”. It is now being fitted and linked to a call system, which fortunately was included at the outset.

The total weekly cost is £2960 for the six tenants. Part of what are perceived to be initially high running costs is due to managing the transition. Another factor is supporting people to use ordinary community services rather than simply attend a day centre.
The project manager notes: “Avalon were also contracted to facilitate a minimum of six hours ‘natural support’ per tenant per week e.g. family support, peer support from other tenants, unpaid support from within the community – for example staff at voluntary work placements. This is going well, and there are some really positive examples of tenants sharing their skills with each other – and feeling good about being able to do so e.g. helping another use the local bus."

All those who have moved in previously lived with older carers; one moved directly from residential care. The average age is 43.

The project is judged a success, with residents growing in confidence and independence.

This authority has already taken the good practice step of completing an evaluation of the project with residents so they already have some firm evidence of results.

Findings included:

- All residents have a doctor and dentist and would know who to tell if they were unwell
- All tenants reported doing more exercise
- All said they liked their homes and felt happier. No one wanted to return to their previous place
- Most liked the greater control and responsibility, even including cleaning and housework!
- All reported learning new skills since moving
- One said he sometimes was alone and another did not like having sometimes to wait for staff attention
- All felt they now had more things to do, and
- People liked having their own money and doing their own shopping (with support). Only one of the six had previously done his own shopping.

Lessons

1) A clear transition plan is needed. There are numerous practical tasks to be done to help people move: equipping and furnishing their home and arranging finances and benefits, for example. Simply asking care managers to do this alongside their normal work does not work well. Wakefield appointed a project manager.

2) There was a lot of excitement among individuals about moving but also anxiety amongst relatives about how well people would manage. The practical issues have to be addressed.

3) Do costing on shared ownership carefully. In retrospect it has been quite positive for the group of disabled residents to move in and settle first but this is by accident not design.

4) The communal room for residents to meet together and socialise “works really well”. It has promoted some natural friendships and support. If one person forgets how to do something they can easily ask each other rather than staff.

5) Important lesson about AT. It would have been most useful when residents first moved in. The care manager involved at the time did not see the need or have the knowledge.
Evaluation

Overview

The ten developments have produced (or will shortly produce) new housing for disabled people across the country; a clear tangible result. Nearly all are judged a success by the agencies and people involved. The Department of Health Grant has frequently served as a catalyst for action or change. Local authorities and their partners have, in many cases, been tempted to experiment, take a limited risk or do something sooner than they would have in the absence of a grant to underpin plans. This includes experiments with home ownership and tenure mix.

In a few cases where the grant has helped to bring forward action it is possible that essentially the same project would have eventually come to fruition but the grant has added a dimension or enhanced the service in some way – the programmes in Birmingham and Salford are perhaps examples of this.

Overall, a striking feature of the programme is the diversity of schemes broadly considered to be extra care by both those putting the proposal forward and those approving the grant. The main extra care housing DH-funded programme and this, much smaller programme specifically for older people with learning disabilities, should encourage innovation and new thinking in any future funding rounds. The diversity of projects suggests the grant has been successful in this aim.

Looking at each project in isolation, at one level there is little that could be said to be absolutely original or completely new.

Shared ownership for people with learning disabilities is a mainstream model for several housing associations; a model of leasing from private landlords has been used for some other needs groups and to a limited extent for people with learning disabilities; re-modelling sheltered housing and letting some or all the scheme to disabled people has been successfully implemented by a number of organisations.

The programme has however often served to introduce a new option or way of working to that locality. This is seen to be a valuable outcome in many respects by the agencies and individuals.

Those involved in social care particularly singled out the importance of the improved partnership working with housing colleagues or agencies and how these projects had contributed to better, closer relationships. A frequent theme was the difficulty of getting suitable housing in the absence of these relationships or housing expertise within a social care authority.

Several projects emphasised the value of having something concrete and tangible in the locality for people – including staff, councillors, carers and disabled people – to see, visit and talk about. Having the first ‘demonstration’ was having the effect in several areas of creating demand or giving people confidence in an unfamiliar alternative.

Most of the projects were recognised locally as examples of excellence of their type or to learn from. It was anticipated that there would be some follow up and replication. Occasionally the strategic thinking to build on the lessons or example seemed to be lacking. Changes of personnel during the pilot had sometimes had detrimental results and meant some of the benefits of the experiment were lost.
Detailed lessons have been set out in describing each project. Lessons repeatedly apparent are:

- The importance of, and gains from, ‘real’ partnership between the leading agencies. Also how helpful local ‘champions’ are, including involvement of family carers
- Difficulties of social care and housing collaborating and understanding each other’s requirements and constraints. A number of the projects are reported to have had positive longer term effects
- The high costs of care and support in independent living and the need to think creatively about alternatives to complete reliance on professional, paid support. The ideas apparent in the pilots included mutual support, support tenants and a substantially greater role for assistive technology
- Allocating someone a post to project manage but also help with a myriad of small, practical tasks that are required in moving from one form of service to another, and
- The potential in re-cycling existing housing stock to meet the needs of an emerging group of older, disabled people. This included sheltered housing, derelict general needs property but also using the private rented sector and – of course – the potential for obtaining property from the owner-occupied sector in the three projects based on shared ownership.

Issues

Some issues recurred in talking to the individual projects.

Cost

All the local authorities and the care or support providers involved were committed to independent living principles. Several were using Direct Payments or Individual Budgets to help maximise the residents’ control and choice over daily living and support matters and others anticipated moving in this direction. At the same time a number of the authorities in the pilot were finding the high cost of care in these new extra care services a challenge. In one case costs were about a third higher than expected.

High costs found in some supported living are not new. These are all new services and the hope is that there may be a reduction in costs to Adult Social Care over time, certainly in those services where there is a realistic possibility of residents doing more for themselves, needing less intensive or 24 hour assistance. Careful examination of costs – such as in Dudley – and adjustments after the initial setting-up period may also lead to the conclusion that costs to social care are not too different to those in residential care, at least for those with higher care needs.

Several projects volunteered they had not looked sufficiently carefully at alternative support mechanisms and recognised they needed to do this. There would clearly be interest in a sound, sophisticated mechanism for comparing costs of service provision based on independent living.

Assistive Technology (AT)

The use of AT was variable but often projects had majored on it. The feedback was very positive. People were impressed by how much could be achieved by AT to enhance independence and manage risks like epilepsy and also how relatively cheap mainstream telecare applications were.

Two projects said they had not given much attention to AT but one has now received a budget of £8000 to retro-fit an array of AT and the other was doing the same.

In most areas the pilot was having the effect of stimulating interest in AT.
It was seen as a tool to help square the circle of independence, privacy, control and choice, while producing economic benefits for the commissioner (or individuals where they already controlled their own budget).

Lack of knowledge about AT and the possible devices and applications amongst care managers was singled out as a hurdle to progress that the pilots had helped to address. The absence of a credible, independent Which-style evaluation of available products was remarked on by several authorities.

Housing strategy and partnership

It is not a new point but the programme did again bring out the difficulties of putting in place effective housing strategies for disabled people.

Extra care is a form of housing provision. Housing developers are used to thinking and working long term. Bids for Housing Corporation finance, for example, are now on a three year cycle. At least one of the projects reported as a lesson for them how long even just the land acquisition stage can take. The need to think, act, and plan development taking three or four years often does not sit well with a Social Care Department wanting a response in days to a particular ‘crisis’.

One of the housing providers involved in the pilots referred to a review of local authority housing strategies in the region they had completed and the paucity of specific, quantified assessment of how much, of what type and where, housing needed to be provided. The lack of proper, evidence-based, measures of need brought together in a coherent strategic plan is a continuing weakness. It helps to explain some lack of interest amongst RSLs in finding social housing for this group of people. Why it takes a DH grant to act as a catalyst for this kind of new housing.

What also began to emerge was a tension between the situation with Individual Budgets and In-Control with individuals all taking their own individual decision and attempts like those in the pilot, to work in a strategic way to create a new kind of service which a range of people might use now and in the future. The initiatives often depended on trust, partnership work and people prepared to take a degree of risk. It was not clear that this would happen were there not a degree of understanding between the agencies.

This concern aside, two specific lessons are:

- Housing strategies for people with learning disabilities may still need to be strengthened in providing clear, numerical, evidence-based assessment of housing required.

Housing Needs surveys commissioned by local authorities could be stronger in their measurement of the housing requirements of disabled people and quite possibly other, numerically smaller, vulnerable needs groups.

What makes the pilot extra care housing?

A recurring question was whether the projects really constituted ‘extra care housing’? Were they something qualitatively different or simply independent supported living?

The fundamental distinguishing feature is that while mainstream extra care housing is for older people, only some of this pilot caters directly for people over normal retirement age. The emphasis is more on the ‘relatively’ older disabled person, recognising that they are likely to have characteristics of a chronologically older group. For example, people with Downs Syndrome are likely to begin to develop early onset dementia in their late 40s or early 50s. The second emphasis in the pilot has been on relieving older carers.
Mainstream extra care housing for older people does not have a precise definition. Projects vary enormously in scale, care and support services, funding, facilities, accommodation and management arrangements.

**Features which tend to characterise extra care housing are:**

- Self-contained flats or bungalows – a defining characteristic distinguishing extra care from residential care. Dwellings will incorporate design features to facilitate independence
- Provision of an appropriate package of care, in the individual's own dwelling, to a high level if required
- Catering facilities with one or more meals available each day
- 24 hour care staff and support available
- More comprehensive and extensive communal facilities than in ordinary sheltered housing
- Staff offices and facilities
- Domestic support services including help with shopping, cleaning and possibly making meals
- Specialist equipment to help meet the needs of frail or disabled residents, and
- Social and leisure activities/facilities and additional individual or shared services.

**Key features that distinguish extra care housing from traditional residential care homes are:**

- Self-contained accommodation
- The provision of care can be separated from the provision of accommodation, and
- Care is based on an individual assessment of needs and can be more easily tailored to the individual.

**What distinguishes the extra care housing model from sheltered housing are:**

- High levels of care available
- 24 hour staffing, and
- Extensive facilities.

Extra Care schemes vary because there is no accepted statutory or other definition. It is however possible to tease out the main ways schemes vary from each other.

**Four key variables combine to create the particular model. These are:**

1) Housing and care provider relationships
2) Buildings – this encompasses such characteristics as the origin of the building, scale of development, range and dispersion of facilities, type of accommodation
3) Allocation and eligibility criteria – the lettings or sales policy
4) Tenure and, related to this, the financial basis on which residents occupy their accommodation.

These can be used to construct a typology of extra care housing. (For details of the typology see ‘Models of extra care and retirement communities’ Housing LIN Factsheet No 4.). The matrix used for traditional extra care for older people is reproduced on the following page.
Each level of the matrix represents an option on which a strategic decision is required. Most lines can be treated as independent so a ‘pick and mix’ approach is possible. However the range of facilities and scale are normally linked, as are some other variables.

So the bottom line is that:

- These pilot schemes mostly can be fitted into this typology although it ‘stretches’ the concept
- They do have similar features to extra care except:
  - They have tended to be much smaller
  - Not necessarily only for those over a certain age
  - More limited communal facilities as a result of small scale
  - Meals not provided in a separate restaurant or café but more often prepared for or by residents in their own home, and
- There is more often sharing with one other person although dwellings are all self-contained.

The smallest schemes like the bungalows are little different to any other supported living. Those that are qualitatively different and closest to ordinary extra care are the two projects based on re-modeling sheltered housing.

The diversity of the projects suggests we are some way off being able to describe another form of provision particularly suitable for older people with learning disabilities to match the emerging mainstream extra care provision. Taken together however, they add further weight to the case that extra care housing has a sound future in housing this client group in mainstream provision. Later rounds funded through this grant have begun to mainstream provision for older people and vulnerable adults.

### Two concluding observations on the future:

First there is of course no reason in principle why older people with learning disabilities should not access other housing provision provided for older people generally; including new mainstream extra care housing. This indeed was the basis of several of the developments and it is often the case now that some lettings in new extra care housing are made to disabled people as a matter of routine.
Second, from several projects there is a suggestion that what one termed ‘mini-extra care’, might be an attractive choice for some older, disabled people. The basic characteristics emerging of what might be described as small, clustered, extra care are:

- About six self-contained flats and/or bungalows clustered together
- Specially designed for older or disabled people, including giving some thought to the needs of those with dementia
- On-site care team/staff and or support tenant
- Some communal facilities – probably a large kitchen, office for staff, storage
- Core AT package installed at outset with facilities to adapt to individual needs
- Built to Lifetime Homes Standards with some properties to full wheelchair standards – most likely ground floor flats and/or bungalows
- Stand-alone cluster or incorporated in larger development, and
- For rent or sale.

In principle this is little different to cluster flats already developed by some organisations. The differences would lie in some of the finesse and detail. It is likely for example, if purpose built, then developments would:

- Have more extensive communal facilities
- 24 hour on site support or care, and
- Additional or different design and construction detailing within both the dwellings and communal areas to make life easier for a range of abilities and to anticipate growing frailty.
Other useful information from the Housing LIN Reports:

**Reports**
- Housing LIN Report: *Enhancing Housing Choices for People with a Learning Disability* (November 2006)

**Factsheets**

**Policy briefings**
- Housing LIN Policy Briefing 6: *Learning Disability and Housing* (November 2006)
- Housing LIN Policy Briefing 5: *Disabled Persons (Independent Living) Bill* (June 2006)

**Case Studies**
- Housing LIN Case Study no. 29: *Pennine Court: Remodelling sheltered housing to include Extra Care for people with learning difficulties* (August 2007)
- Park View Housing for people with a learning disability in South Tyneside (January 2008)
- Norfolk Private Sector Leasing Scheme for People with Learning Difficulties (January 2008)

**DVD and resource packs**
- *Embracing Diversity* (DVD+CD-Rom) (March 2006) OUT OF STOCK
- *Housing Now: Choice, Control and Independence for People with Learning Disabilities*