

Living on the Edge



**enabling older owner occupiers
with moderate learning disabilities
to live independently**

by Lorna Easterbrook



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Executive summary

Increasing numbers of older people with moderate or mild learning disabilities live independently in their own homes – but some are facing crises that limit their abilities to continue to do so. Their house or flat is in need of often substantial repair, improvement or adaptation, and they have significant and ongoing support in terms of time and skills, knowledge and expertise.

Crisis may be triggered by factors ranging from debt problems, neighbour disputes, hoarding, illness or bereavement – but are often the cumulative result of the person not receiving support that might have helped them resolve the situation at an earlier stage.

These older individuals and their families are often identified simply as ‘difficult’ and are not known by statutory services. Isolated older people with moderate learning disabilities may be particularly ‘hidden’.

Positively supporting older people with moderate learning disabilities successfully to deal with such situations can be stressful, protracted, and difficult – but the outcomes can transform people’s lives.

Crisis Support Workers are one way of ensuring that such older people are properly supported. Without this, as the case studies in this report illustrate, individuals are left vulnerable to abuse, potentially homeless, facing repeated intrusive and distressing house clearances if hoarding of materials spirals out of control, or may have to leave their own home and move permanently into care or supported accommodation.

The policy agenda is rapidly moving from a focus on outputs in terms of numbers and types of services provided and received, to achieving what central government calls ‘genuinely better outcomes’ through broader forms of this type of support.

Local authorities and the NHS may already be involved in the lives of these individuals – but in haphazard, intrusive and expensive ways that ultimately fail to achieve positive or sustainable long term outcomes. That effort, and those resources, should instead be channelled into positive models such as Crisis Support Workers that will help local authorities meet the expectations of Transforming Social Care (LAC (DH) 2008 1).

For people highlighted in this report, who are living very near to the edge of managing to sustain their life in local communities, crisis is currently often the only route into support. Preventing crises occurring and recurring must become a clear priority.

Part 1:

Setting the scene

This section gives an overview of the current issues relating to ageing, housing and moderate learning disability within the current policy context.



Introduction

Increasing numbers of older people with moderate or mild learning disabilities live independently in their own homes – but some are facing crises that limit their abilities to continue to do so. This report looks at the situation facing older owner occupiers who:

- Live in homes needing urgent repairs and/or adaptations
- Have reached a point of crisis at home
- Lack some comprehension, or have behavioural difficulties, that adversely affect their abilities to manage their everyday lives
- Are living in complex situations
- Are facing the likelihood of crises recurring in the future.

Box 1

What is a Learning Disability?

A learning disability affects how people learn and understand things. This in turn may affect the ease with which they manage their everyday life. Some people's learning disability is mild, and means they successfully manage parts of their life but may need support with some aspects at some times. Others have a moderate learning disability, where support is needed on a more regular, ongoing basis in order to prevent crises from re-occurring or because of behavioural challenges.

Sometimes people with a learning disability also have physical disabilities. Where there is such a combination, this is often called profound and multiple learning disability (PMLD).

There are differences of opinion as to how many people in the UK have a learning disability. This is partly because there is not complete agreement about what is and what is not a learning disability. Nor has everyone

with a learning disability had this diagnosed or told to them, or are known to Social Services.

People who have autistic spectrum disorder (ASD) may also have difficulties making sense of the world, and experience problems with:

- Social interaction;
- Communication; and
- Imagination.

This creates problems understanding other people's behaviour, intentions and emotions.

Those with Asperger's Syndrome may not have an intellectual disability, but may still find difficulties in understanding language and in communicating. Of people with other ASDs (excluding Asperger's Syndrome), it is estimated that 70% may have some kind of learning disability (Fombonne, 2005)

Sources: [Foundation for People with Learning Disabilities website](#) and [Mencap website](#)

“Clients don’t always have a formal diagnosis of learning disability or mental health, so we don’t feel we can refer people on [to specialist organisations] because ours is only a layman’s view”

(HIA worker)

The featured case studies have been identified by home improvement agencies, with whom individuals became involved due to a need for support with housing disrepair or adaptation.

Some of the individuals described have been diagnosed as having a learning disability; most have not. All have some identifiable comprehension or intellectual difficulty, or challenging behaviour, which is having an adverse effect on their everyday lives (Box 1). These difficulties are making the crisis situation worse, and more likely to recur.

In the case studies in this report, some people receive social care support from either older people or learning disability Social Services teams; some have been told they are not eligible for support; some have never been in contact with Social Services. In the case of some older people, their disabilities appear to have been ‘hidden’ for decades. Some live alone; some live with family carers; some provide care for younger relatives with a learning disability.

However, they all have two things in common. Firstly, their home is in need of often substantial repair, improvement or adaptation. Secondly, there is a need for significant and ongoing support in terms of time and skills, knowledge and expertise – both to deal with the current ‘crisis’ (which may include, but not be limited to, the condition of their home) and, crucially, to ensure such crises do not occur again.

These crises may be triggered by factors ranging from debt problems, neighbour disputes, illness or bereavement – but are often the cumulative result of the person not receiving support that might have helped them resolve the situation at an earlier stage.

These older individuals and their families are often identified simply as ‘difficult clients’. They come into contact with a service or agency only at this crisis point – such as when decades of hoarding reach critical points and their homes are about to be cleared because of environmental and public health concerns. Responses to these crises involve agencies as varied as environmental health, the police, and animal welfare organisations, as well as home improvement agencies, and social and health care professionals.

Although such one-off crisis interventions may well help to resolve immediate issues, they leave the underlying problems untouched for the longer term. Indeed, if only the immediate or crisis issue is tackled, the unresolved problems may be so serious that even these efforts may be inadequate (Box 2).

Box 2

Responding to crises too late

Mr and Mrs S are in their early 60s and were living in a flat, which they owned, located over a fast food takeaway. Both have a moderate, undiagnosed learning disability and struggle to manage their finances, as a result of which they have large debts. The flat was in a state of serious disrepair and they were referred to a home improvement agency (HIA). They had been assessed as not being eligible for social services support.

Each time the HIA caseworker visited to discuss the housing repairs, the couple wanted instead to discuss their son's drug addiction problem. In addition, because she was morbidly obese, Mrs S underwent a stomach stapling surgery and needed significant post-operative care at home from

her husband. The HIA caseworker referred them to the Citizen's Advice Bureau (CAB) for debt management advice, and it was decided their debt was so large the only way they could repay it was to sell their flat.

The couple now live in a mobile (park) home, which is not in good condition. They still have significant unsecured debts. The HIA caseworker is trying to raise charitable funds for essential works to their mobile home. It is not clear, however, how this pensioner couple will repay any of their remaining debts, or if their new housing situation is sustainable over the long term – if not, homelessness or a move to supported accommodation are real possibilities.

By the time anyone became involved with this couple their financial crisis had already peaked. Had someone been able to spend time supporting them in the management of their finances and housing earlier, the loss of their flat and the move to a park home might have been avoided.

This report considers the issues facing older people with moderate learning disabilities in crisis, as they are supported to remain living in their own homes in the community. It explores situations for:

- People with learning disabilities who have aged 'in situ' in their family home with a parent who has now either died or entered the residential care system;
- People who are already over retirement age whose learning disability may always have been 'hidden'. This includes some older people whose hoarding habits are causing serious concern to neighbours or the statutory agencies;
- Older people providing family care to younger relatives with a learning disability.



Positively supporting older people with moderate learning disabilities to live in their own homes successfully can be a lengthy, complex process, and require ongoing support to maintain. Professionals and organisations may feel they lack the skills, the time or the knowledge properly to support the person or household (Anderson et al, 2005). However, this is a particularly critical issue because:

- More older people are living at home for longer, with higher levels of disability, difficulty and need;
- There are more owner occupiers, especially amongst older age and lower income groups;
- More people with learning disabilities are also living longer in their own homes.

It is also critical because the impact of not providing the right support can be costly in all senses – both for individuals and their families, and for statutory and other services.

This report considers the current demographic picture, housing trends, and the policy agenda. It draws on work to support complex cases over the short- and longer-term through the development of Crisis Support Workers, already established by Coventry Care & Repair, and being piloted in three other Care & Repair schemes (Stroud; Manchester; Bristol) as part of a national programme. It highlights issues for commissioners and planners of housing and social care support, and makes a series of recommendations.

Housing tenure

Increased home ownership amongst all adults is an overriding, long standing government priority. It was also identified as a top aim for people with learning disabilities in the White Paper, Valuing People (Department of Health, 2001); and this focus continues (Department of Health, 2007).

Around a third of all households contain at least one person of pensionable age – 72% of whom are owner occupiers (Department for Communities and Local Government, 2006). Owner-occupation has increased markedly in recent decades amongst all income groups, but particularly for those on lower incomes.

Housing tenure is an important issue since it affects both the services people can access as well as those they may need. For example, the ongoing financial responsibility for repairs, maintenance and improvements falls to the private owner occupier. Older people on low incomes are more likely to live in non-decent housing, and less likely to be able to afford to pay for repairs. There is no system of financial support to meet these costs available through the welfare benefit system for those on low incomes. In addition, help with everyday life skills such as can be provided through Supporting People funded 'floating support' is more likely to be made available to those living in social rented housing rather than to owner occupiers.

As older family carers die, it is becoming more likely that their adult children with learning disabilities will inherit and continue to live in the family home – but with no guarantees that it will be in good repair, or that support mechanisms will be put into place to enable independent living in that home.

With more people with learning disabilities living in the family home with older carers (Department of Health, 2001), and with the increased likelihood of inheritance, or of otherwise remaining alone in the family home, more attention needs to be paid to the housing- and life-skills-related needs of older learning disabled owner occupiers.



Kitchen (with dangerous DIY wiring) before and after renovation



Demography

Although the ageing of the UK's population is relatively well known, the implications of the expected increases in the numbers of older people with a learning disability have not been so well explored. This may be one of the reasons why no single set of figures contains all relevant details for the UK as a whole or for its individual countries.

For example, overall estimates of the numbers of people with mild or severe learning disabilities exist for the UK but are not broken down by country. It is estimated that between 580,000 and 1,750,000 people in the UK have a mild learning disability, and 230,000 – 350,000 people have severe learning disabilities (source: Foundation for Learning Disability website). Separate figures are not available for the numbers with a moderate learning disability. Although the charity Mencap estimates there are 29,000 people with a learning disability living at home with family carers aged 70 or over, this total is not then subdivided by severity of disability.

The best figures concerning projected increases in the numbers of older people with a learning disability relate to England, but do not distinguish between degrees of disability. Emerson and Hatton (2004) estimated that, in 2001, there are just over $\frac{3}{4}$ million people aged 20 or older in England with a learning disability.

Many amongst this total number, however, will not be known to statutory services. This may be particularly true for those older people who have a learning disability. The learning disability White Paper, *Valuing People*, suggested that around 25% of older families are 'hidden' and not known to services until there is a crisis (Department of Health, 2001); whilst Emerson and Hatton (2004) estimated that in 2001, only 15% of those aged 60 or older with a learning disability were known to services, compared to 23% of those aged between 20 and 64.

There are many reasons why older people with learning disabilities appear to have such limited involvement with statutory services. Although knowledge about and recognition of learning disabilities has arguably improved in recent years, the focus of services on those with the highest level of need means that many individuals may simply not be eligible for statutory support. In the case of some older people with a learning disability, their families may have avoided involving 'the authorities' for decades, if not all their life. Or, there might be other reasons why families did not seek support in the past, including the lack of carers' rights and of appropriate services. In addition, where individual older people have not been diagnosed as having a learning disability, any apparent behavioural and comprehension difficulties may be believed to be connected with the ageing process.



Bedroom before

Irrespective of their currently low level of involvement with statutory services, the numbers of older people with a learning disability are expected to rise significantly over the next few years, with a consequent rise in demand for services as more people reach a crisis, eg. as a result of the death or incapacity of an older carer.

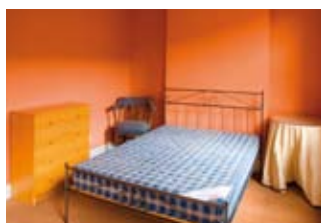
This rise is partly because of the overall ageing of the UK's population. The most recent 2006-based population projections show that the proportion of the population aged 65 or over is expected to increase from 16% in 2006 to 22% in 2031 (source: Office for National Statistics website). People with learning disabilities are also living longer in general.

On an extremely conservative estimate, Emerson and Hatton (2004) calculate a 37% increase in the numbers of people aged 60 and over with learning disabilities between 2001 and 2021, bringing total numbers to just under 240,000. They go on to suggest that this increase could be as much as 59%, to just over 290,000 older people with a learning disability. They further predict an increase of at least 36% in the numbers of people aged 60 and over with learning disabilities who are known to specialist learning disability services, to 36,160 people (Emerson & Hatton, 2004).

These age-related increases are in marked contrast to predicted changes for those aged 20-59 with learning disabilities, for whom the increase may be as little as 2% over the same timescale (Emerson & Hatton, 2004).

These figures are extremely significant for those involved in planning and commissioning housing, care or support services for adults of all ages, not least because of the information gap that may currently exist in terms of not being aware of the situation and needs of all older people with a learning disability.

These rises are taking place in parallel with increased home ownership, and within a policy agenda that remains focused on supporting people to remain living in their own homes for as long as possible. This has significant implications for service planning in the short, medium and longer-term.



Bedroom after clearance
and renovation

Policy agenda

The policy agenda across health, housing and social care for older people and younger adults is continuing to undergo a process of rapid and significant change. In social care and housing support in particular, it is moving from a focus on outputs in terms of numbers and types of services provided and received, to achieving what central government is starting to call 'genuinely better outcomes' (Department of Health, 2007: 29a) for service users and carers, based on three key factors:

- Independence;
- Well-being;
- Choice and control (Department of Health, 2006).

This change is taking place, however, within a context where one of the central tenets of the community care reforms of the 1990s remains intact. Nearly twenty years since the publication of the community care White Paper, *Caring for People* (Department of Health, 1989), the intention continues to be to support people to remain living in their own homes for as long as possible (Department of Health, 2007b).

What has changed is how this is to be achieved. The Audit Commission (1986) and the Griffiths Report (1988) both drew attention to the serious problems arising where only very limited services were available to support people in their own homes. Once an individual's needs increased, the only service solution was residential care – leading to many individuals entering care and nursing homes unnecessarily early, especially older people (Easterbrook, 2002). It was filling this gap that was one of the six key objectives of the community care reforms, by focusing the provision of domiciliary, day and respite services to those in greatest need (Department of Health, 1989).

In practice, an early and significant change to the then 3-year Transitional Grant to local authorities, and a series of major legal challenges to different aspects of the community care legislation over many years, helped translate this system into one where social care services are largely restricted to those meeting the critical and substantial eligibility criteria under local Fair Access to Care Services arrangements (Department of Health, 2007c; Commission for Social Care Inspection, 2008). This has resulted in significant concerns about the welfare of those unable to access services or support because their needs are not deemed sufficiently high (Wanless, 2006; Commission for Social Care Inspection, 2008).



There are many other factors that have shaped the current system. The past decade has, in particular, seen substantial tranches of major new legislation and guidance concerned with the NHS, local government, social and health care services, and with users' and carers' entitlements. In short, the current legislative and practice frameworks are a long way removed from those in place at the time of the community care reforms.

In December 2007 the government's concordat, *Putting People First*, set out the expectation that between January 2008 and March 2011, the requirements for social care services for those with the most intense (arguably the highest levels of) needs, are to be balanced by a preventative approach that enables people to remain independent at earlier stages. This is not the first time that the need to meet these potentially competing priorities has been highlighted. In 1998, the then Blair government issued an initial 3-year series of grants to local councils, aimed at promoting independence through the development of preventive services (Easterbrook, 2002).

In the current agenda, however, the emphasis on the importance of services is arguably matched by recognition of people's needs for support. Importantly, 'support' is being identified as something that is both broader than, and separate from, practical social care, housing or other services, and includes advocacy, brokerage, information and advice to self funders as well as those who might receive state financial support (Department of Health, 2007a; LAC (2008)1).

This type of support is highlighted as something about which the statutory sector has a clear and significant role to play, not least in its planning and commissioning. There is also a further broadening of outcomes to include outcomes for individuals, for specific groups within an area, and for the wider community. This community-based focus particularly builds on work around the idea of what constitutes 'an ordinary life' (Department of Health, 2006a), and on the importance of social inclusion (for example, Department of Communities and Local Government, 2006a). It is in addition to specific focuses within older people and learning disability services (Box 3).



Box 3

Client group priorities

The publication in 2001 of the Valuing People White Paper, and the recent consultation paper Valuing People Now (Department of Health, 2007) continues to set much of the agenda for learning disability services. Key amongst the early priorities were supporting patients to move from the last remaining long-stay hospitals into their own homes in the community; support for older family carers of people with a learning disability (especially for parents who are ageing); and a wish to increase home ownership amongst those with learning disabilities.

The 2007 consultation paper, Valuing People Now, reinforces these priorities, with a particular focus on access to home ownership (2007: 17), and on forward planning for people with learning disabilities living with older family carers (2007: 61). From 2008, a new cross-government indicator will measure the accommodation status of people with a learning disability, and whether they have control over their housing situation. This social inclusion indicator focuses on increased home ownership amongst people with learning disabilities, as well as on tenancies (Department of Health, 2007).

For older people in recent years, service priorities have tended to concentrate on avoiding either institutional care (such as places in residential care or nursing homes) or hospital admission. More recent initiatives, such as the Partnerships for Older People Projects (POPPs), have piloted ways in which resources might be used differently to support earlier, preventative, interventions. Initial indications suggest that these earlier interventions before people reach higher levels of need may be both more cost effective for health and social care services, as well as producing better outcomes for individual older people (LAC (DH) (2008) 1).

For all client groups, the policy agenda is firmly focused on the need for Adult Social Services to demonstrate that their work across local authority, NHS and other organisational and professional boundaries is translated into personalised responses, person centred plans, and self directed support. It is expected that, by March 2011, everyone eligible for Social Services support will have a personal social care budget allocated to them, with the intention that increasing numbers of people are then supported to take all or part of this personal budget as a direct payment (LAC (DH) (2008) 1).

Over the past decade, the policy agenda and resultant legislation have repeatedly moved the NHS and local authorities towards closer, more integrated, work and funding. This goes beyond the funding flexibilities offered by the Health Act 1999 and the new joint statutory duties outlined below. Various funding sources have increasingly been pooled, in order to create what are regarded as seamless services.

The Supporting People reforms (Department for Communities and Local Government, 2007) are a good example. This pulled together funding streams that included housing benefit, the Housing Corporation grant, and home improvement agency grants. From this, a single budget was formed to be used by local councils for housing-related support across client groups and housing tenure. More recently, Supporting People funds have in turn been combined with Disabled Facilities Grants, Integrated Community Equipment funds, social care money, the Independent Living fund, and Access to Work, in thirteen pilot Individual Budget (IB) schemes, to see if the IB approach creates a more joined up package of personalised support to individuals. The pilot schemes concluded at the end of 2007.



Although statutory agencies and funding sources have become increasingly integrated, concerns have repeatedly been raised about differences within systems of social care and welfare benefits for those whose disability and need for support arises before, as opposed to after, the age of 65. These and other concerns regarding equality for disabled people, form part of the Independent Living Review conducted by the Office for Disability throughout 2007.

The statutory sector still largely divides clients or users into groups defined by both type of disability and by age. There are some early indications that these current client and user divisions may be beginning to be blurred. Different sectors (and different teams within the same sector) are being encouraged to work more inclusively across client and patient groups – partly to achieve personalised support, and partly to avoid situations where those individuals fall between ‘gaps’ between teams (Department of Health, 2007d). This may prove extremely useful to the older people described in this report, who may find they currently fall between separate support for older people, from that for younger adults with a learning disability, or those with mental ill-health or challenging behaviours.

Planning and commissioning are crucial elements in delivering this much broader approach to care services, support, and demonstrating what is being achieved for users and carers. From 2008, therefore, planning and commissioning cycles, requirements, and approaches, are also undergoing major change.

Planning and commissioning

As outlined above, the planning and commissioning functions of both local authorities and the NHS are also undergoing significant reform as services move from reporting outputs to outcomes; as commissioners move from block contracts to more individualised support; and as planners' focus broadens from the higher level need of specific client groups to an approach that incorporates the whole local community. Overall priorities include the need for joint and/or integrated working and funding; the information required to support appropriate levels and types of commissioning; and a clear focus on the outcomes to be achieved (Department of Health, 2007a). Driving these changes are new duties to produce Joint Strategic Needs Assessments (Box 4).

Box 4

Joint Strategic Needs Assessments

Under section 116 of the Local Government and Public Involvement Act 2007, from April 2008 Primary Care Trusts and local authorities must produce a Joint Strategic Needs Assessment (JSNA) of the health and wellbeing of their local community.

Questions that local JSNAs must address include:

- what are people living with that makes their lives difficult?

- which groups are getting a raw deal?
- what help do the groups getting a raw deal want and need? (Department of Health, 2007e)

JSNAs are drawn up by councils and the PCT through their Local Strategic Partnerships. They should be informed by, and support, other plans such as the Sustainable Community Strategy, and local housing strategies.

The JSNA sets out specific outcomes for issues such as:

- hospital discharge arrangements;
- the provision of intermediate care;
- fall reduction strategies;
- packages of support with a health or nursing element;
- community equipment services;
- universal advice, information and advocacy (Department of Health, 2007b).

Commissioning decisions must be shaped by the local JSNA, which also informs the Sustainable Community Strategy (SCS). The SCS is a long term, overall plan, developed from what local people have said they want for their area in the future. From the objectives set out in the local SCS, a Local Area Agreement (LAA) is drawn up (Department for Communities and Local Government, 2007a).

The LAA is a 3-year agreement between the major statutory bodies and central government. It sets out the agreed local priorities and can identify national targets on which it hopes to improve in line with these priorities (Box 5). Up to 35 of the 198 new National Indicator set (or targets) published by the government in 2007, can be chosen for inclusion as 'stretch targets' in the LAA (this is in addition to 17 targets relating to education and early years targets). Which of the 198 are chosen depends on the objectives agreed locally in each SCS, and may also include those targets relating to the outcomes set out in the JSNA; the LAA contents must be agreed with central government through regional Government Offices.

Box 5

National Indicators (targets)

A new list of 198 National Indicators was published by the government in 2007, and replaces the existing 1,200 targets.

Relevant targets for older people with a learning disability include:

- People supported to live independently through social services (all ages) (PSA18, NI 136)

- People over 65 who say that they receive the information, assistance and support needed to exercise choice and control to live independently (NI 139)

Both of these National Indicators (NI) form part of Public Service Agreement (PSA) target 17.

Although the government monitors performance on all 198 target indicators, a major focus in each area will be on those chosen for the LAA as these will form some of the key funding priorities for the next 3 years.

These changes are important not least because, from April 2009, Supporting People funding will form part of a new Area Based Grant from central government for LAAs. It will therefore be important to ensure that housing-related support, and targets to support people to live independently in their own homes, are reflected in LAAs.

Other funding changes include the transfer, from 2009, of PCT funding for social care of adults with learning disabilities, and the Learning Disability Development Fund supporting the implementation of Valuing People objectives and targets, to local authorities. Importantly, in January 2007 the government also announced details of an allocated, ring-fenced, 3-year Social Care Reform Grant, to be used by local authorities to help redesign their systems of social care services and broader support by March 2011 (LAC (DH) (2008) 1).

One critical area for planners and commissioners will concern how they shape what is available locally so that it includes the wider issue of support, and not just services, especially around advocacy, advice and brokerage. This is an important issue since it is here that the government expects that some of the tensions experienced by Social Services departments between acting as a gatekeeper of budgets in order to provide care services for those with the highest levels of need, and acting as a broker, advocate, adviser or 'navigator' for others (Glendinning and Means, 2006) might be resolved (LAC (DH) (2008) 1).



Part 2:

People on the edge

This section examines the problems of, and possible service responses to, older people with complex problems who reach a crisis point, usually related to their housing.



“We see the housing need rather than the formal identification of a disability.”

(HIA worker)

Overview

As the following examples illustrate, many people with a learning disability (usually undiagnosed) only seek or are referred for help when a significant housing problem occurs.

Home improvement agencies (HIAs) specialise in helping vulnerable groups, mostly older and disabled home owners, who need help to carry out repairs or adaptations to their homes. They are often the only source of housing related support available to owner occupiers and consequently may be the first port of call for individuals or agencies seeking practical housing help for people with complex problems.

It is often only after the HIA has become involved with the client that the extent and complexity of the person’s problems and situation becomes clear. Whilst a skilled HIA caseworker may recognise a person’s lack of comprehension in dealing with day to day living and help them through the process of home repair or adaptation, most will not label a person as ‘learning disabled’ or diagnose a specific condition.

In trying to deal with the housing repairs or adaptations, the nature of the problems and the circumstances of the individual can mean that the HIA becomes involved in trying to provide support that goes well beyond the bounds of its usual housing-related assistance within a time-limited remit.

In a sample telephone survey of HIAs undertaken in December 2007, three-quarters (76%) reported that they were dealing with the sorts of complex cases described, below. There was limited understanding of the term ‘learning disability’, although discussing the nature of the complex cases they were involved with revealed that the term was relevant to many of their clients.

One-off home repair interventions in the case of people with moderate learning disabilities may be of limited value, if systems of support are not subsequently put into place to prevent repeated deterioration of the property. Some HIAs are now trying to address this issue through the appointment of complex cases workers who are able to offer both specialist help and broker or provide ongoing support.

As many of the following case studies illustrate, people with a learning disability, their families and carers, may live on the edge of a crisis. But an initial skilled intervention, followed by a relatively low level of ongoing support, can prevent future difficulties, and support and enable people to maintain independence in their own homes.

Hoarding and environmental health issues

Concerns about an individual who is hoarding materials at home are often raised because of public health fears, such as infestation, or other welfare and safety issues, such as the risk of a fire.

Materials hoarded can range from houses filled from floor to ceiling with unstable but tidy piles of newspaper, to months' or years' worth of rubbish collected from the streets, waste food matter, faeces and urine, and the dead bodies of vermin, or even pets.

Once concerns have been voiced, environmental health services usually become involved. They may ultimately issue an enforcement notice allowing them to enter and clear the property – thereby 'solving' the immediate problem.

This response raises several issues. Firstly, effectively forcing someone into behaving differently in order to stop what others consider to be a public hazard or nuisance may cause significant distress to that person. It may badly affect their mental or emotional health and well-being, especially because time limits mean they are not able to go through their belongings themselves prior to clearance. On the other hand, not intervening could cause continued distress to immediate neighbours or to the broader local community. If clearance is needed before urgent repairs can be carried out (for example, because contractors are refusing otherwise to enter the property), then the person's safety – and that of others – may be compromised unless this action is followed.

Secondly, this kind of enforcement can generate distrust and a refusal to have anything to do with any representative of what might be seen as 'officialdom'. This could include GPs and other health professionals, as well as social care services and the wider voluntary and community sector. In turn this may affect the person's health and overall well being, especially if they then miss out on health checks, financial advice and help (including welfare benefit applications), and support with housing problems.

A final problem is that this approach appears rarely to be successful in the long term. People who hoard may well do so habitually. Left to their own devices, people may simply accumulate more materials. Over time, if this reaches another crisis point, the environmental health team may become involved again and serve further enforcement notices. As the individual is expected to meet the costs of these clearances, this may cause further detriment to their well being. The cumulative problems of following this approach on its own may, over time, fundamentally undermine the person's abilities to remain living independently in their own home.



Case study

Miss L, who is in her 70s, lives alone in her own bungalow. She enjoys going alone to the local theatre, but does not socialise with people. She has no family or friends. She is often victimised by local children because she is 'different'. Whilst she has never been formally diagnosed, it is believed she has some mental health issues, and a learning disability.

Miss L does not throw anything away. This includes food rubbish; her kitchen floor and other surfaces are covered in food debris. There have been numerous infestations of mice and she has been served with enforcement orders several times by Environmental Health because she starts to hoard again as soon as the bungalow has been cleared.

Miss L trusts the local HIA staff who over the years have organised home repairs, raised funds to replace furniture, a fridge and curtains, made successful benefit applications, arranged for a telephone to be installed, fitted smoke alarms and secured the gas supply through setting up a budget plan. However, Mrs L is very reluctant to let anyone else into her home.

Since the appointment of the Crisis Support Worker Miss L has been visited regularly, encouraging her to keep her hoarding to acceptable levels. As a consequence there have been no further enforcement notices and no deterioration of the property. Thus Miss L is being enabled to live independently in her own home without the trauma, upheaval and cost of crisis interventions.

Case study

Mr G is in his 70s. He lives alone in the house he inherited from his parents and in which he was brought up. Although there is no formal diagnosis, it is believed he may have a learning disability and some degree of autism.

His house has no heating, hot water or laundry facilities. Mr G does not cook for himself. The local Environmental Health team have cleared the house several times, but because Mr G does not seem to think there is a problem, debris builds up again each time. He has been assessed as not eligible for Social Services' support.

The HIA was asked to help to organise replacement windows. On the day the

builders were due to fit the windows, they refused to enter the house because it was full of rubbish, half-eaten rotting food, faeces and flies. The decomposed body of his pet dog was found under his bed. The HIA helped to clear a sufficient space so the windows could be reached, provided air fresheners and face masks for the builders, and the work was carried out.

The HIA is frustrated that they can only offer very limited amounts of support, usually at a crisis point, because their current funding is dependent on reaching targets relating solely to numbers of clients and amount of building work completed.

Self-neglect

Self-neglect can be defined as ‘not engaging in those self-care actions that are required to produce socially acceptable levels of personal and household cleanliness and hygiene’ (Anderson et al, 2005: 3). Different professions perceive and respond to this issue in a range of ways. For example, where environmental health see this as a public hazard that needs to be stopped, housing workers give priority to the physical state of the property.

There is no single profession or agency that appears to have a comprehensive overview of the nature of the problem and possible different interventions. A multi-disciplinary approach may well be needed – but an individual practitioner still needs to take the initiative and to lead to ensure this is achieved (Anderson et al, 2005).

Case study

Mr H is a 67 year old who lives alone in his own home, which is in a state of serious disrepair. He was referred to his local HIA by a social worker from a neighbouring district who confirmed that Mr H has a learning disability.

There were concerns for Mr H’s safety, as it appeared he was being targeted for money by local criminals and his front garden used as a rubbish dump. Whenever there was an infestation of mice, his neighbours contacted Environmental Health who would then clear out the property and charge Mr H £2,000 each time (a charge is attached to the property with interest accruing). This had happened several times.

Mr H has poor comprehension, and a limited ability to carry out ordinary day to day tasks. He has no relatives or friends involved in his life. He will only eat food unheated and straight from tins, or occasionally from the chip shop. When his clothes become too dirty, he throws them away and buys new ones.

He took up an unsolicited offer received in the post of a credit card, because he believed the credit card firm were giving him ‘free’ money. He did not understand that he would have to pay back the money, and now owes several thousand pounds.

The local HIA has dealt with some of the immediate crisis issues. Security measures were installed and funds have been raised from the council to carry out a complete renovation. The caseworker successfully negotiated with the council to waive the charges on his property, and a local Age Concern debt counselling service has resolved the credit card debt. Benefit applications have increased his income.

The HIA’s newly appointed crisis support/complex case worker will continue to work regularly with Mr H to ensure that broader issues of self neglect, and lack of comprehension regarding daily living, are addressed and that he is supported to live in his own home for the foreseeable future, thereby avoiding admission to residential care or other supported accommodation.

Protection of and advocacy for vulnerable adults

Much of the emphasis on protecting vulnerable adults has centred on issues of abuse of those who are in receipt of care. But there are many other adults whose vulnerability and need for protection becomes evident only when they are facing crisis situations. In such cases specialist advocacy services with housing expertise can be difficult to find.

Case study

Mr R is in his mid 60s and lives alone in a leasehold flat. There are few – if any – people in his life. He has moderate (undiagnosed) learning disabilities; although he appears to understand when he is given information, this is not borne out by his subsequent actions. There are serious concerns that he lacks comprehension, particularly in terms of absorbing new information. He has developed very fixed ideas of what he should do, and will not accept anything that is at odds with those ideas. Because he does not have critical

or substantial needs he does not receive any help from Social Services.

All leaseholders in the block of flats where he lives have been told they must each find £20,000 for maintenance. He needs someone to help him sort out this issue, to deal with the freeholder and to look for ways to find the money. He cannot afford a solicitor and there is no one in the local HIA or other voluntary sector organisations with the skills and capacity to take up his case. Without advocacy and help Mr R may lose his home.

“One problem is that the council may be giving these clients a really poor service – but they are spending a lot of time giving them a really poor service”



Older carers of people with a learning disability

Older family carers of people with a learning disability were one of the initial priority client groups under the learning disability White Paper Valuing People (Department of Health, 2001). More recently, attention has become focused on how to help those younger relatives plan for their future after the death (or permanent move into care) of their older carer.

Case study

Mrs P is 72 and has a mild learning disability. She shares her home, which she owns, with two of her three adult daughters. The eldest is 48, has profound and multiple learning disabilities. Her youngest daughter, aged 38, also lives with her and has moderate learning disabilities. Her middle daughter, who has no disabilities, is married with children and has her own home.

The HIA became involved when Mrs P needed a Disabled Facilities Grant (DFG) to build a downstairs bedroom and level access shower room with hoist for her eldest daughter. Mrs P has arthritis, and mobility and incontinence problems. When the HIA caseworker visited, the downstairs flooring was found to be soaked in urine, and rotting as a consequence. She had unsecured debts totalling several thousand pounds.

As well as organising urgent home repairs and adaptations, the HIA's specialist crisis support worker helped Mrs P to get her debts under control; and obtained a

Community Care Grant and charitable funding for new flooring, furniture, a washing machine, towels and bedding.

The crisis support worker is now trying to raise charitable funds for a new front door to improve security and to decorate more of the house. She visits regularly to discuss day to day issues; and is beginning to explore possible options for the future of Mrs P's two daughters who live with her since, in the event of her death, she intends leaving her property to be shared equally between her three daughters.

The crisis support service has therefore prevented an impending housing crisis that could have resulted in all three women moving permanently to different care homes or supported accommodation; improved their quality of life and well-being; and is now helping to make positive future housing plans that will include use of home equity to contribute to future care costs.

Trust and access

One major aspect of working with people in complex situations concerns gaining access to them and their home, and gaining their trust.

The decision whether or not to trust anyone is extremely personal. It may have nothing to do with the person's job title, or the organisation for which they work (Anderson et al, 2005). Indeed, in some instances, job title or type of organisation can serve to perpetuate mistrust. Statutory and voluntary sector agencies will each have come across instances where the nature of their organisation both hindered, and helped, in gaining access and people's trust. Trust is often gained if something is quickly achieved for the person, particularly where this is a priority for the individual concerned, as this physically demonstrates that the person is being listened to and what is being promised will be translated into positive action.

Case study

Mr and Mrs B are in their 40s, and both have learning disabilities. They live in an inherited owner occupied home. They received ongoing support with everyday, domestic tasks from a social services care worker in their lounge and kitchen, but would not let her go upstairs into their bathroom.

They contacted the HIA because their toilet was leaking. A member of the HIAs Handyperson team visited, and the couple agreed that she could see the upstairs bathroom. Their house was in a very bad state of disrepair. The toilet had been leaking for some time, and there was raw sewage on the bathroom floor.

Because the Handyperson immediately repaired the leak to the toilet, she gained the couple's trust. They accepted her view that the bathroom needed completely gutting and replacing. Whilst the HIA caseworker is dealing with the grant and funding applications, it is the Handyperson who Mr and Mrs B trust and who is the link with the couple. When this work is completed,

and if the couple are happy, the HIA hope to be able to organise replacement of the kitchen, which is also in a very poor state.

The Handyperson is also involved in trying to sort out a dispute with the neighbours. Mr B was using a telescope in his garden to look at the stars at night, but neighbours thought he was a 'peeping tom'. When they challenged him, he was unable to explain himself fully because of his learning disability. This has led to some hostility towards the couple from their neighbours. The Handyperson hopes to support him to speak to the neighbours in order to end this conflict.

The difficulty for the HIA is that the Handyperson service funding is based on what are best described as 'volume throughput' targets – that is, the greatest number of clients supported in the shortest possible time. There is no funding for such involved, ongoing support. They hope that by securing funds for a complex case worker they will be able to offer a better service to people like Mr and Mrs B.

Families on the edge

A physical housing crisis can be the trigger for a family member to seek help. As the following cases illustrate, the combination of family finances, home ownership and the network of family relationships and mutual support mean that situations, and any solutions, can be complex.

Case study

Mr S is an 81 year old man who has a learning disability - or what his family call 'memory problems.' His daughter (47) and grandson (15) both live with him. His daughter is carer both to Mr S, and to her son who has Asperger's Syndrome. She herself has arthritis, is depressed and has mobility problems.

Because of Mr S's memory problems, he completed forms for council tax and welfare benefits incorrectly. This resulted in an over payment and a very serious debt problem which could have led to prosecution.

The HIA became involved because the house needed major repairs; there was a large hole in the roof and significant rain penetration in

the bedroom. The HIA resolved the debt problems with the council and the Pensions Service, and secured the correct benefits; obtained a charitable grant that enabled Mr S's roof to be repaired and the bedroom re-decorated; provided information about the Carers Centre for Mr S's daughter, and referred her to Social Services for a Carers Assessment.

The HIA, who do not have a specialist worker, are concerned that without practical help and ongoing support the house will deteriorate again, and financial problems recur. This could ultimately lead to the loss of the family home and the need for state funded supported housing for the three individuals.

The future of Mr S and his family (above), with no arrangements for ongoing support, contrasts with that of Mr M and his son (described on following page), where a specialist crisis support worker continues to be involved.

Case study

Mr M, who is aged 79, lives with his son who is 45. Both have some degree of learning disability. His son has been unable to hold down a job.

Mr M was referred to the HIA by his adult daughter, who lives some distance away. She was not in regular contact with either parent (and has no contact with her brother) following problems stemming from the time she was living at home as a teenager. However, following a recent visit to her mother, Mrs M (who has dementia and lives in a nursing home near to the family home), she visited her father at home, and was shocked at the deterioration in the property. She asked the HIA to get involved as neither she nor Mr M could afford to pay for the work needed.

The house was in need of extensive renovation, including repairs to the main roof and the flat roof over the kitchen, re-plastering of most walls, external re-pointing, completely rewiring, and Mr M needed a level access shower.

The house was also in need of a major clean, with the replacement of floor coverings, and provision of new living room furniture and beds a priority. Mr M and his son have extremely poor hygiene skills and these deteriorated significantly once Mrs M's mental health began declining some years earlier.

Because the house was jointly owned by Mr M and his wife, organising a loan was complex. As Mrs M had dementia, a solicitor had to be involved to apply for a Court of

Protection order on her behalf. Before the loan could be completed Mrs M died and new proceedings involving HM Land Registry had to take place to transfer ownership to Mr M.

Through regular, often lengthy visits, the HIA's crisis support worker; increased Mr M's income through Pension Credit, Attendance Allowance and council tax benefit applications; helped Mr M to arrange his wife's funeral (including making a claim on a funeral expenses insurance policy he held and, as this was not sufficient, paying the difference until it could be repaid from the housing loan); paid the solicitor's fees regarding the original Court of Protection order (this was reimbursed once the loan was secured); and made sure to visit when contractors came to tender for the works to the house.

The house had to be cleared and cleaned before the contractor would start work. This involved going through everything the couple had collected over many years of marriage. This was very distressing for Mr M, and took a long time to sort out.

The housing improvement work has now been completed. The crisis support worker visits Mr M and his son regularly, encouraging them to maintain their improved hygiene and housing standards, further develop their life skills, and plan for the future. This has included assisting Mr M's son to apply for social housing, as when Mr M dies the property will be sold to repay the loan and the son will otherwise have nowhere to live.

A service response model: Coventry's Orbit Care & Repair

Care & Repair England (C&RE) has been concerned for some time about the issue of the growing number of older people with moderate learning disabilities and the cumulative impact of this demographic trend, increasing owner occupation, and higher incidence of poor housing conditions.



In 2006 C&RE contacted Orbit Care & Repair in Coventry (Coventry C&R) to discuss the possibility of developing a service initiative that would aim to address this growing problem. Given their experience of the types of complex cases described above and the repeated return of clients in crisis, Coventry C&R were keen to develop a new way of working. In 2006, they successfully secured 2 years of funding from Supporting People (SP) for a Crisis Support worker who would provide crisis intervention followed by ongoing support to enable people with moderate learning disabilities to live independently in their own homes. SP recognised that this was an important innovation, particularly with regard to extending support for vulnerable groups in private sector housing.

The service has proved its worth – many of the cases in this report are from Coventry C&R's full time crisis support project. Following a Supporting People Service Review in 2007, continuation funding has been agreed to March 2009. The agency is now liaising with Learning Disability and Older People's Services with the aim of securing cross sector, long term funding.

As part of the research for this report, interviews were carried out in Coventry with the learning disability commissioner, an older people's contracts officer, Supporting People manager and, from Warwickshire, a further Social Services learning disability services commissioner.

Key concerns that emerged from these interviews included the need to support older carers, issues around younger relatives inheriting the family home, and joint working to ensure a smooth transition as clients reach the age of 65 and move from learning disability into the older people's team.

Lessons from the Coventry model

Prior to the development of the Crisis Support Service, Orbit Care & Repair Coventry had monitored these types of complex cases, and the repeated return of such clients in crisis, over a period of 10 years.

They identified that a growing number of older and vulnerable people with moderate learning disabilities, and some with mental health problems, were falling through the network of existing service provision, which is primarily available to tenants of social landlords rather than owner-occupiers and private tenants.

The demand for the crisis/floating support service has been high from its start. Through the detailed monitoring of each case (a condition of Supporting People funding), the service has demonstrated clear outcomes achieved for each client.

For example, when the service was launched in 2006, it identified 18 clients who had repeatedly used Coventry C&R for crisis intervention for up to 10 years. Of these, 11 people are now managing to maintain their homes and are generally more in control of their lives. This has been achieved with a limited level of regular, ongoing help from the Crisis Support Worker.

The current post holder has extensive expertise, skills and abilities across a range of areas. Clear goals and outcomes are agreed with the client as early as possible, with an emphasis on working together to enable the individual to become more independent. Regular progress reviews are carried out together.

During the process of supporting people to transform their current ways of handling everyday life, more than one crisis may occur. The person may need support from other professionals in order to address particular issues, especially if they have difficulties appreciating that they are in a very poor situation.

It is essential to provide the right level of ongoing support at the right time for each individual. Whilst this may be required over a long period of time – perhaps even for the foreseeable future - the level or type of intervention is not always high, nor does it make the client dependent on the HIA. The focus is always on supporting and encouraging self reliance.

“These are people where they don’t understand the world and the world doesn’t understand them. No one knows what to do with them. They don’t tick a client box until they reach ‘older age’, and then we discover all sorts of behavioural and comprehension issues that no one’s ever tackled with them before.”

(HIA Manager)

Coventry C&R's starting point was that although short-term crisis intervention was of some use, it was not tackling the root causes of problems. Through this initiative it is demonstrating the cost effectiveness of a long term, lower level, and preventative intervention approach. Through the provision of crisis support, Coventry C&R is helping vulnerable adults sustain their independence and well-being. By making sure that individuals have access to a range of services when needed, people are being enabled to live independently in their own homes, with the added security of knowing that there is help available to support them through any future difficult times as these first arise.

It is hoped that the Coventry model will become more widely applied, both by HIAs and also by other service providers. Help the Aged are providing funding for three further pilot schemes within HIAs (Stroud, Manchester and Bristol). The Department of Health and two charitable trusts are funding Care & Repair England to support and promote the initiative, raise its profile, and share the lessons learned with the wider Learning Disability and Older People's sectors.



Bathroom before and after renovation



Part 3:

Challenges, issues and recommendations



Challenges

There are two distinct challenges facing statutory agencies, and voluntary and community organisations, with regard to the issues raised by these examples of complex cases.

The first challenge is concerned with improving support for older people with moderate disabilities who are living in mainstream housing – in terms of skills, knowledge, and funding.

The second challenge relates to the potential impact of not providing adequate support – in terms of likely cost to the statutory sector, the impact on the individual and, increasingly, in terms of achieving the intended reform of adult social care.



Issues

Breaking the cycle of crisis

The highlighted cases of hoarding illustrate a number of issues. Although Environmental Health Departments can (and frequently do) charge individuals for the cost of clearing a property and removing waste and rubbish, the process is not without costs. The clearance process is both time consuming to enforce and is often repeated many times. Police resources may be called on to gain access, input from the RSPCA or other animal welfare specialists required – and other agencies such as HIAs may be needed to carry out urgent housing repairs. The process is also often distressing for the individual concerned and disruptive to neighbours.

As this cycle of hoarding and intervention repeats itself, the person may become more isolated within their community. The fabric of their flat or house may deteriorate further, ultimately making repairs more expensive and having a negative impact on the quality of life in the overall neighbourhood. This in turn may create more neighbour disputes and complaints about the person and their house, involving more police time and more input from the council – both of which take up resources that might be better used in a different way. This confrontational approach may also further isolate and alienate the person, making it less likely they will agree for anyone to be involved, whether from the HIA or any other agency. Homelessness or institutionalisation can be the end result.

The cases in Part 2 illustrate how a different approach can be taken to break this cycle, better support independent living and help to avoid crisis.

Prioritising prevention

For others living in their own homes who cannot easily manage daily life, the combination of running up ever-increasing debts, failing to maintain their home, and failing to look after themselves in terms of basic hygiene and eating, also creates real risks of homelessness, long term mental and physical health problems, and isolation within their local community.

Whilst many agencies may already be in contact with people in the situations described, including HIAs, difficulties in dealing effectively with them arise for several reasons.

In terms of statutory support, these tend not to be clients who have been assessed as being a high enough priority to be allocated social care services. This does not mean that they do not need help and support. Indeed, those working in statutory services may find they are consistently spending large amounts of time on a small number of people, who may not 'qualify' for ongoing, lower levels of practical care but nonetheless are repeatedly in contact with services or are being referred to them. These are people who appear to lack sufficient life skills and comprehension to successfully manage their lives, which may be spiralling – albeit slowly – out of control.

Over the past 15 years, social services have moved towards providing or arranging support packages for a smaller number of clients with higher levels of need. Consequently, their skills base in and knowledge of lower levels of need and preventative services and approaches, may also have reduced. By becoming increasingly specialised, staff may find they no longer know about broader community services and opportunities to increase a person's social engagement. By supporting those with the highest levels of need, they may have lost their understanding of how people with different degrees of difficulty might be most effectively helped.

Funding and performance frameworks

With regard to provision of housing help for disadvantaged, older home owners, HIAs are funded – in crude terms – to support the greatest number of clients through housing repairs and adaptations as quickly as possible. This is no reflection on the quality of the work HIAs carry out but a reflection of the funding and performance frameworks that are applied to them. But it does raise problems when complex cases, such as those outlined in this report, arise.



The people described in the case studies need far more time than HIAs are usually funded to provide. Sometimes months of contact are required before a person will even agree to anyone from the HIA entering their home. They may need someone to be there any and every time a building contractor is present. They may need support over a long time to clear their house because they would like to go through everything first. They may need ongoing support after the repairs and adaptations have been completed, perhaps to re-build relationships with neighbours, to manage other aspects of their daily lives and to prevent a repeat of the original crisis. But this need for time, and for long term and non-housing support, is not consistent with the provision of a core HIA service.

In addition, HIA staff may be concerned that they lack the skills or knowledge to support people with complex needs and to deal effectively with the root causes of problems. In these circumstances, and given the time constraints, they may focus solely on the main housing repair problem. This does not mean the other issues resolve themselves. Indeed, it is likely they will worsen and a further crisis may occur.

Unmet needs

Service commissioners and planners may not know as much as they now need to about the wider community of people with unmet needs for whom they do not currently provide services. Because of service rationing there is minimal contact with those who have lower level needs. This has major implications in terms of capacity to plan, in line with current policy trends, for the future of the whole community.

For example, the Disability Equality Duty requires local authorities to ensure that accurate information about the lives of people with learning disabilities is included in Joint Strategic Needs Assessments (Department of Health, 2007 – Valuing People Now). Local Learning Disability Partnership Boards are expected to identify how many older family carers (aged 70 or older) of someone with a learning disability live in local areas, so they can better plan future services. But data on the level of need is likely to be patchy and, if plans are based primarily on the current numbers being helped by social services, significant levels of unmet need will remain. Voluntary sector agencies and community groups which are working with individuals or households who fall outside statutory services therefore need to share knowledge and information about their experience of demand and unmet need with planners and commissioners.



Service divisions and boundaries

Another important issue facing the statutory sector concerns what might be called compartmentalisation in services and professions. As many of the cases illustrate, people's lives are complex, interwoven with family members and others from a range of ages and with many different problems. If statutory sector teams work with those individuals and households according to categories defined by age, type of disability or issue (such as older people, children, learning disability, physical disability, mental health), they will struggle to deal effectively with these real life complex cases that have little connection to such relatively neat divisions. This is one aspect where HIAs have a distinct advantage, working as they do with clients across age, disability, and – critically – housing tenure.



No quick fix

Where a specialist support service for complex cases can be set up, it is important that this is not seen as a 'dumping ground' for all 'difficult' clients. It has to be recognised that it will not be possible for a Crisis Support/Complex Case Worker to take very high numbers of active cases; 15-20 clients at any one stage seems the optimum number for effective intervention. In the case of such a worker located in an HIA, they would not be able to deal with the same level of live caseload as a traditional HIA caseworker, for example.

Ensuring that capacity is not exceeded is crucial. As the case studies illustrate, dealing with such situations can be stressful, protracted, draining, and difficult. It is essential that skilled workers do not take on too much and 'burn out'. One way to tackle higher numbers than can be handled by one worker is to follow the Coventry model. In that model, the Crisis Support Worker supports a maximum number of individual cases but also supports the HIA's mainstream caseworkers to themselves deal with one or two complex cases at any one time.

Who should develop the services?

The skills and knowledge of Crisis Support/Complex Case Workers is an important issue. Individuals will need to have some knowledge of learning disability as well as mental health, challenging behaviours, physical disability and ageing issues, amongst others. They need to know about and be able to access housing repairs, adaptations, and welfare benefits, as well as many other services and support systems. They need to be patient, and have excellent counselling, mediation, advocacy and information and advice skills.

Although this role is compatible with HIA provision because of the central issue of housing disrepair and adaptation, other local learning disability groups or older people's organisations may be better placed to develop appropriate services.

Not all HIAs will wish to develop such a service. In the sample telephone survey of HIAs carried out in December 2007, one-quarter (24%) said that they would wish to develop such a service if given specific funds to do so. It is therefore also important that learning disability services develop their capacity with regard to housing related support for people living in owner occupied housing. This could be developed in partnership with a local HIA in order to draw on their technical skills and expertise.

Focus on outcomes

There is a growing emphasis within statutory services on finding out what difference a service or support has made to a person's life.

The outcomes identified through the Supporting People Review of the Coventry C&R project were noted in Part 2 of this report. And, as the case studies amply illustrate, for older people with moderate learning disabilities living in private sector housing, the positive change in their circumstances that crisis support services bring about can be life transforming.

Over the next few years there will be a rapid increase in the numbers of older people with moderate learning disabilities living in owner occupied homes. Most will not – if current trends continue – come to the attention of statutory services until some kind of crisis occurs. For this group of people, even if dealing with the crisis is the only route into support, then the prevention of repeated future crises must become part of the service response.

Care & Repair England's recommendations

For all organisations and professionals

For people highlighted in this report, who are living very near to the edge of managing to sustain their life in their local communities, the prevention of crises occurring and recurring must become a key priority.

The current policy agenda clearly sets out that not all support needs are about practical care. For some people, a knowledgeable and helpful professional to act as an advocate, an adviser, and a broker of and support to their everyday life, is equally as important if a good quality, independent life at home is to be achieved.

All sectors need to consider how best to support older people who cannot easily be 'compartmentalised' into separate Learning Disability, Older People or Mental Health Sectors, but whose behavioural and/or comprehension difficulties are causing them to spiral into repeated crises that may lead to their needing costly care services or other interventions.

For Government

Approaches that enable older people with moderate learning disabilities to remain living independently in their own home must be comprehensively championed, especially at national levels. Relatively inexpensive, low level but long term interventions can produce life changing positive outcomes. But for long term security for individuals to be achieved, sustainable funding needs to be assured.

The housing repair and adaptation issues facing older owner occupiers on low incomes, especially those with moderate learning disabilities, must be addressed. For some, their home is in such a state of disrepair that there may be insufficient equity remaining in the property to fund even basic, essential work. The Government's emphasis on the importance of preventative approaches must be extended to housing and welfare benefits; including consideration of how vulnerable, low income older home owners are to meet the costs of home maintenance and necessary repair work.



For social care and health

The Crisis Support approach described in this report is already helping to deliver current policy imperatives, by supporting people living in complex situations to resolve and avoid crises, and enabling an independent life at home. Local authorities and the NHS may already be involved in the lives of these individuals – but in haphazard, intrusive and expensive ways that ultimately fail to achieve positive or sustainable long term outcomes. That effort, and those resources, should instead be channelled into positive models such as Crisis Support, and so help local authorities meet the expectations of Transforming Social Care (LAC (DH) 2008 1).

For Environmental Health

Long term strategies need to be put in place so that people at risk of repeated housing related interventions are identified, and support that is positive, long term and sustainable, provided. Working practice with regard to enforcement should be reviewed to ensure that strategies are put into place to prevent future crises requiring interventions to be repeated. Closer working relationships must be developed with NHS, Housing, Social Care, and Voluntary and Community sectors, to support vulnerable people facing a crisis in their home environment.

For Supporting People and future related arrangements

Enabling vulnerable people to live independently in their own homes through housing related support is at the heart of Supporting People. The needs of older people with moderate learning disabilities living in the owner occupied sector need to be better met by Supporting People, which still spends the majority of funding on people living in the social rented sector. Commissioning services that offer both crisis intervention and ongoing, low level support, such as the Crisis Support model described in the report, should be a matter of priority in terms of redressing this imbalance. This change is also relevant to the incorporation of Supporting People targets and funding into Local Area Agreements from 2009.

For the learning disability sector:

The need for support for older people with learning disabilities is increasing rapidly, especially amongst owner occupiers. This changing demographic and tenure profile needs to be planned for and responded to by a sector which often focuses more on the needs of younger people and on those living in the social rented sector. Close co-working across older people's services and teams, and with housing and housing-related support colleagues, will be essential to delivering both preventative and sustainable support.

For the older people's sector:

Responding to the complex cases described in this report requires advocacy, mediation, counselling and advice skills, as well as a wide range of knowledge and sufficient time to provide the careful and in-depth support that is essential to achieving positive outcomes. Older owner occupiers with mild or moderate learning disabilities are increasing. Older People's organisations and care services need to ensure they work proactively with Learning Disability, Housing, and Environmental Health colleagues in particular, so that such vulnerable individuals do not experience distressing interventions that may undermine their ability to remain living independently at home.

For the social housing sector

Increasing owner occupation for low income groups and those with disabilities means that floating support services should no longer be targeted only on social housing tenants. These approaches must be extended to include older people with moderate learning disabilities who are home owners and might also include links to home maintenance schemes and handyperson services. Increased development of supported housing for older people with learning disabilities which includes owner occupied and shared- ownership options is also required.

For home improvement agencies

Supporting older, vulnerable and disabled people who are living in complex situations and have related housing problems was, for many organisations, the reason they were founded. Service providers need to take stock of their role in supporting those in crisis in their local communities. They need to decide how their mainstream services could better meet the needs of older people with a learning disability – and take steps to put this in place. Where service providers are working with such complex cases, the issues and service shortcomings they reveal must be shared with commissioners and planners who may otherwise remain unaware of these essential support and life-skill needs, and not incorporate them into future service planning.

For commissioners and planners

The wider needs of all older people, including older people with a moderate learning disability and their carers, must be reflected through the Partnership Boards, and in the new Joint Strategic Needs Assessment. Planners and commissioners need to work closely with non-statutory colleagues to obtain information about such ‘hidden’ groups. They must ensure that new local arrangements go well beyond providing for those already known to social services or to social housing colleagues.

Improved planning and commissioning of cross cutting, sustainable services that enable older people with mild or moderate learning disabilities to live independently is urgently required. Services are needed as a matter of priority which enable independent living in mainstream housing, including owner occupied housing, and especially those which support people in complex situations at a point of crisis or where a crisis might recur.



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Websites

www.careandrepair-england.org.uk – free publications and resources relating to the learning disabilities project and information about older people and housing.

www.ons.gov.uk – the website of the Office for National Statistics (for population projections).

wwwFOUNDATIONS.uk.com – Foundations is the nation co-ordinating body for home improvement agencies in England. Can locate individual HIAs via website.

www.learningdisabilities.org.uk – the website for the Foundation for People with Learning Disabilities, part of the charity the Mental Health Foundation.

www.mencap.org.uk – the website for the UK learning disability charity, Mencap.

www.housingoptions.org.uk – a housing advisory service for people with learning disabilities.

www.icn.csip.org.uk/housing/index.cfm?pid=237 – resources, links and information about housing options for people with a learning disability.



Increasing numbers of older people with moderate or mild learning disabilities live independently in homes which they own. But some are facing crises that may limit their ability to continue to do so.

‘Living on the Edge’ aims to enable service planners, commissioners and providers to better understand:

- the main trends with regard to ageing and learning disability
- related policy developments across social care and housing
- current and emerging problems faced by people with moderate learning disabilities who are living in their own homes
- practical, preventative service responses to support independent living.

About Care & Repair England

Care & Repair England is a national charity established in 1986 to improve the housing and living conditions of older and disabled people. Its aim is to innovate, develop, promote and support housing policies and initiatives which enable older and disabled people to live independently in their homes for as long as they wish.

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