



# The Housing Timebomb

*The housing crisis facing people with a learning disability and their older parents*

**MENCAP**

*Understanding learning disability*



# Contents

Executive summary	2
Findings of the <i>Housing Timebomb</i> survey	4
Introduction	5
The case for immediate action	7
A way ahead	14
Recommendations	17
Conclusions	18
Appendix: Methodology	19

## *Executive summary*

*The Housing Timebomb* provides a comprehensive and all too distressing picture of local authorities' failure to plan for the future housing needs of people with a learning disability living with older parents. The Government estimates that 29,000 people live in the family home supported by a parent who is aged 70 or over. Yet only half of local authorities are aware of how many older parents are living in their area. Even fewer are investing sufficient time or money into meeting their needs or have planned alternative housing provision before parents die or become too frail to care for their son or daughter. Only one in four local authorities are even beginning to address the problem.

The population of older parents is growing and many more of their sons and daughters are likely to outlive them. We estimate that, as a result, it will take 30 years to deal with the increasing backlog. Unless more places are planned, local authorities will be forced to act in a crisis situation, only arranging alternative housing when parents die, while people with a learning disability will be denied a choice of where they live and with whom. This has placed an unexploded timebomb under tens of thousands of older parents and people with a learning disability.

Older parents, in their 70s or 80s, have spent a lifetime caring. They expect and deserve a better deal from local authorities. They have made a vital contribution to their son's or daughter's well being. Their relationship will often span four or five decades, from their son's or daughter's childhood, through to their adulthood and growing older together. Even at an older age, parents remain the primary providers of care and are pivotal in ensuring that people with a learning disability can live an active life in the community.

Older parents are all too aware that their own ageing makes it impossible for them to look after their son or daughter indefinitely. Naturally, they are increasingly anxious about where their son or daughter will be living and who will be caring for them in five or ten years' time. These concerns become more pressing as parents become frailer and when they are no longer able to provide a home or sustain their caring role. They and their families need to plan for the future in good time. For their peace of mind, older parents need to know that arrangements for their son's or daughter's future housing and support have been made before they die.

*The Housing Timebomb* illustrates that local authorities view alternative housing provision for people living with older carers as a low priority. There is little indication that local authorities are planning to increase funding for residential care or supported living to meet the needs of people with a learning disability. This poses significant risks to the future security of people with a learning disability. It is critical to plan strategically for their housing and support needs. The Government and local authorities must act now to bring stability to the lives of anxious parents and reassure them and their sons and daughters about the future. At the very least, we owe as much to the tens of thousands of families who have spent a lifetime caring.

## *Findings of the Housing Timebomb survey*

- Only half of local authorities are aware of the numbers of people living with older parents aged 70 or over.
- Only 1 in 4 local authorities has planned alternative housing in 2002/03 for those living with older parents aged 70 and over.
- Local authorities have planned a total of only 227 places to meet the needs of those living with older parents aged 70 and over.
- At the current rate of only 227 places being provided per year, it will take 30 years to meet the needs of people living with older parents aged 70 and over. By this time, if they are still alive, the parents will be more than 100 years old.
- Only 1 in 5 local authorities has provided for any significant increase (greater than a 5% increase) in their budget for residential and nursing care for 2002/03.
- Only 1 in 10 local authorities has provided for any significant increase (greater than a 5% increase) in their budget for supported living for 2002/03.
- The information provided by local authorities is poor and the financial information systems are not always able to differentiate between residential and nursing care, supported living packages, and day care.

## Introduction

The last 30 years have witnessed significant changes in the types of housing provided for people with a learning disability. The 1971 White Paper *Better Services for the Mentally Handicapped* emphasised the direction of policy towards reducing the number of people with a learning disability in long stay hospitals and providing more independent, inclusive alternatives in the community. Many of the aims of the 1971 White Paper have been realised. The majority of large institutions have been closed, and it is now estimated that approximately 1,570 people live in long stay hospitals in England (White Paper, *Valuing People*, 2001).

The Government was right to prioritise the resettlement of people from long stay hospitals. But it is vital to realise that the majority of people with a learning disability have always lived in the family home – with care provided, predominantly, by their parents. There are now 145,000 adults with a severe or profound learning disability living in England. It is estimated that 87,000 or 60% of these live with their family carer – the same proportion as 30 years ago. Many are dependent on elderly parents; the Government has stated that a third of people living in the family home are living with a parent aged 70 or over (*Valuing People*). This equates to an estimated 29,000 people with a learning disability.

In the past it was assumed that parents would look after their son or daughter until the person with a learning disability died – usually by the time they reached their 30s. But people with a learning disability are living longer – many into mid life and old age. More and more are being cared for in the family home by parents who are themselves getting older and frailer. As people with a learning disability increasingly outlive their parents, remaining in the family home indefinitely will no longer be an option in a growing number of cases. Successive Governments and local authorities have failed to adjust to this change and have, as a result, neglected the needs of older parents and their ageing sons and daughters.

Concerns felt about the unmet needs of older parents and their sons and daughters are becoming more pressing in view of the total shortage of alternative housing and support places (outside the family home) for people with a learning disability. Research demonstrating the seriousness of the situation estimates a shortfall of between 25,000 and 30,000 housing

support places to meet the existing levels of unmet need (Emerson, 1996, *Residential Provision for People with Learning Disabilities*). It is suggested that existing provision will not meet increasing demands and that the need for an alternative to the family home is likely to increase as people with a learning disability live longer. People with a learning disability and their families now face a future in which planning ahead does not take place as the alternative housing options are not available. *The Housing Timebomb* illustrates that a move to an alternative home is rarely offered until some immediate point of crisis is reached or because of the death of the parent.

The Government now recognises that there is a concern about people with learning disabilities living with older parents. The Government's White Paper on learning disability services, *Valuing People*, states that people with a learning disability and their families need to be able to plan for the future in good time. It states that there should be better forward planning by local councils so that parents do not have to face uncertainty in old age and that their sons and daughters gain independence in a planned way. It states that finding alternative housing places for people living with older parents aged 70 and over should be a priority.



## *The case for immediate action*

Mencap's *The Housing Timebomb* makes the irrefutable case that local authorities should take urgent action to plan for the housing needs of people with a learning disability who live with older parents.

### **Case for action 1: Preventing a crisis**

*The Housing Timebomb* shows that in most cases social services do not try to find an alternative housing placement until there is a crisis in the household brought on by the death or ill health of the parent. When the move away from the family home occurs in this way, the consequences for the person with a learning disability will be negative. Moving home becomes inextricably linked with their parents' death. This sudden upheaval coupled with the unexpected separation or loss of a parent often causes stress, confusion and trauma.

Without proper planning, people are moved into inadequate or inappropriate placements determined by whatever resources are available at the time, rather than to more appropriate accommodation. We need to end crisis placements in which people are being moved at the wrong time to the wrong place. An additional problem is that local authorities rarely plan non-crisis moves because eligibility criteria give a low priority to non-urgent cases. People with a learning disability living with elderly parents in their 70s or 80s are not regarded as a sufficient priority for arranging alternative housing provision. This means that housing opportunities are missed and that people with a learning disability have their needs assessed too late.

*Who looks after my son if I become ill? When we die my son Jonathan will not only lose his Mum and Dad but he will lose his home as well. Jonathan deserves the same rights as other people to be independent and make choices with the right support.*

**Mr & Mrs Harris, Essex**

*My husband is 80 and I am 77 and we worry constantly that a crisis could develop at any time. At the moment there is little or no housing for people with a learning disability.*

**Mr & Mrs Frost, Gloucestershire**

*At the moment I am reasonably fit and able to cope. However, I worry what will happen to my daughter if I become ill or die.*

**Mrs Johnson, 73, Nottinghamshire**

*Being over 70, our greatest concern is what happens to our son when we are gone. Social service provision appears to be crisis led.*

**Mrs Peters, 74, Manchester**

## **Case for action 2: Helping lifelong carers**

### ***The unique caring role***

Older parents of people with a learning disability fulfil a unique caring role, spending much more of their time with their sons or daughters than would the parents of non-disabled adults. A very strong bond develops in childhood, which continues into adulthood. The lack of support networks and facilities means that people with a learning disability form a particularly strong attachment to the home.

Most people will need to provide or arrange care and support for a loved one at some point in their lives. Such caring is usually based on close personal relationships. A decision to take on that caring role stems from love, loyalty and recognition of the need to support an immediate member of the family.

*How long do we have to be full-time, lifelong unpaid carers? When does it end? When will someone listen to us and help us plan our daughter Jane's future?*

**Mr & Mrs Evans, late 70s, Essex**

*We are 73 and 76 and have not been in the best of health in the Past few years. We are finding our caring role more demanding as our daughter Susan gets older.*

**Mr & Mrs Davies, Liverpool**

The needs of parents of people with a learning disability are very different to those of carers of older people. The caring responsibilities of looking after an older person with dementia are relatively short term. In contrast, most parents of people with a learning disability are lifelong carers for whom caring is likely to be the dominant feature of their lives. They will retain responsibility for caring and decision-making beyond childhood into adulthood. Without this extensive caring, many more people would need the support of statutory services.

As parents get older they may have their own health problems, making it difficult for them to continue acting as full-time carers. Indeed, a lifetime of caring takes its toll on many parents, leaving them exhausted and anxious about the future. This is particularly the case with parents of people with profound and multiple learning disabilities; the high support needs of their sons and daughters put them under additional stress. As all such parents get older, it is inevitable that the anxiety, depression and social isolation associated with the caring role will increase.

### ***Smaller networks of support***

Older parents of people with a learning disability often have smaller support networks to help them carry out their caring role. This is often because when their son or daughter was born, social services were not able to provide the wide-ranging services they provide today. So, families learn to cope with

difficulties alone. A single-family member, followed to a lesser extent by siblings, provides the main support. They often have little practical support either from other family members or from the wider community of friends and neighbours. In addition, older parents may also become sole carers due to the death of a spouse, which puts additional demands on them.

*We are getting more and more concerned as we get older because we have no family living locally. We realise we may have to move to another borough to be near our other son so that he can help us look after our severely disabled son David.*

**Mr & Mrs Alexander, both in their 70s, London**

Many older carers struggle, not only because they have so few family members to help them, but also because of the lack of support from statutory authorities. This lack of regular contact contributes to a lack of planning for alternative housing. In fact, an estimated 25% of people with a learning disability are not even known to services until illness or death prevents a parent from continuing to care (White Paper, *Valuing People*, 2001).

Older parents may also be more reluctant to establish contact with social services or to seek additional help when their needs change. Many are very wary of approaching professional staff for help and are therefore at greater risk of being overlooked by under-resourced support services.

### ***Independence and mutual support***

Caring within a family context is complex. The relationship between the older parent and son or daughter is often intense and can develop into mutual dependency, particularly as the parent gets older. People with a learning disability take on responsibilities to help their parents, who in turn become increasingly dependent on their son or daughter for emotional and practical support with day to day care tasks. The lack of help from statutory

services means this help becomes essential. In some cases the traditional caring relationship is completely reversed with the person undertaking all personal and domestic tasks to support their parent in the home.

### **Case for action 3: Removing parents' fears for the future**

Many older carers struggle with the dilemma about what will happen when they are no longer able to provide the support their son or daughter needs because of their own ill health or old age. They face the dual stress and strain of coming to terms with their advancing age and worrying about the future of their son or daughter, who may well outlive them.

Older parents are all too painfully aware that their son or daughter ought to move to alternative housing before they grow too old to care. Many parents in their 50s express considerable concerns for the future. Anxiety intensifies as they reach their 60s, 70s or 80s. Parents also find it increasingly difficult to cope with the physical demands of a caring role as their own health begins to deteriorate.

Although this is a source of constant worry, parents often find the subject of alternative accommodation a difficult subject to face up to or to discuss with their son or daughter. Only a small proportion of parents, and in particular older parents over 70, have made formal plans for the future needs of their son and daughter. A recent study estimated that 82% of carers had not made concrete plans (Helen Prosser, 1996).

*Like all parents I am concerned about my daughter's life after I die or become unable to care for her. Her disabilities are severe and complex and suitable accommodation and care would be difficult to find.*

**Mrs Parry, 73, Northamptonshire**

*My husband and I are both over 60 and we are finding the physical aspects of looking after our son increasingly difficult. We also have the constant nagging worry of what level of care will be available when we are no longer able to care for him. What makes the situation more worrying is that my husband has been recently diagnosed with angina and one of the side effects is chronic fatigue.*

**Mr & Mrs Richardson, Northants**

*I worry that when the time comes when I can no longer care for my son whether suitable provision will be available or will he just be placed somewhere and forgotten.*

**Mrs Matthews, 74, Rochdale**

The majority of family carers of adults are committed to caring for their family member at home until they are no longer able to do so. Some of them will be ambivalent about their son or daughter leaving home and want to put off the inevitable. But it would be wrong to criticise them for being overprotective considering how little help and advice they get from social services in planning for the future. *The Housing Timebomb* shows that most parents have received little or no encouragement from social services to plan ahead and help their son or daughter gain their independence in the community.

Parents have insufficient information about the options for alternative housing and how to proceed. Some regard the lack of alternative residential or supported living places as a barrier to their son or daughter leaving the family home. Many lack confidence in the ability of anyone to provide a sustainable quality of life. After years of uncertainty and worry, the transition is unplanned and the choice of where to live is rarely fulfilled. Given the lack of support from social services, it is not surprising that parents and people with a learning disability often want to remain in the family home.

## Case for action 4: How people with a learning disability fear for the future

The current demographic research illustrates an increase in life expectancy for people with learning disabilities. Many more people with a learning disability now expect to live into mid life and old age. The number of people with a learning disability in their 40s or 50s living in the family home is therefore likely to increase and many will outlive their parents. This means that it is important to expand the availability of alternative housing options for those living with older parents in preparation for when the parent dies or is unable to continue caring for them.

Like their parents, many people with a learning disability are extremely anxious about what will happen to them when their parents are no longer alive. Many are worried about how they will adjust and cope with their new housing arrangements when they have to leave the family home and about what choices will be available to them.

*My future seems to be out of my hands. I'm told I have a choice, but it is very limited. I will be told to go somewhere I don't want to go. I do worry where I will live in the future and also worry about having to leave my day centre where all my friends are.*

**Roger Spencer, 45, Epsom**

*Ann gets upset when we talk about the future with her. She often tells us she doesn't want to live in a home. But what other options are available?*

**Julie Thomas, 73, Durham**

## *A way ahead*

People with a learning disability who are currently supported by older parents will inevitably become the responsibility of statutory services once they are unable to continue caring. *The Housing Timebomb* reveals that only half of local authorities are aware of the numbers of people aged 70 and over living in their area. Even fewer local authorities – only one in four – have plans in place. In too many cases, the first contact may be when a crisis occurs, usually the death or illness of the parent/carer.

A long-term view must be taken if we are to avoid highly stressful emergency placements. This should focus on what housing provision people with a learning disability and their parents want, and which services will achieve the best outcomes for all. The contacts that social services establish with older parents and people with a learning disability should be needs led rather than crisis led and should be long-term rather than a one-off exercise. It will take a considerable time to discuss the different options and to encourage parents and their sons or daughters to accept future housing provision outside the family home.

The key to success is forward planning long before the crisis arises. This will involve input from statutory services at an early stage, ideally when the parent reaches 50, even if the preferred outcome in the short term is to remain in the family home. This will enable moving home to become part of a process planned over a period of time and allows both parties to prepare psychologically for the event.

### **Identifying need**

Social services should work with families to draw up long-term care and support plans and prioritise the needs of people with a learning disability living with older parents. This planning process should ideally start when the parent reaches 50 so that they do not have to worry about their son's or daughter's needs when they are in their 70s.

It is important that planning takes into account the full range of housing and support options now available for people with a learning disability. To achieve this, housing departments and social services should work more



closely together in order to prioritise alternative housing. Working closely with families, they should develop joint housing and community care assessments so that integrated packages of support can be designed.

Social services should maintain up to date registers of the numbers of carers and people with a learning disability living in their area. They should not depend on an estimate of prevalence to judge the numbers of people living with older parents. The registers should include:

- the number of parents between 60 and 69, and 70 and over, and their family circumstances;
- how many of their sons or daughters may need a move in the next three to five years;
- the kind of new provision and support required and the estimated cost of an alternative placement.

An individualised support plan that ensures longer-term care needs are met should be agreed by all parties. This plan should be flexible to the changing needs and circumstances of both the parents and person with a learning disability. It should also include the continued involvement of the parent once their son or daughter has moved to alternative accommodation.

## **Information**

Parents and people with a learning disability need better information and advice about housing options available to them. Parents need access to information so they can plan for the housing, legal and financial care needs of their son or daughter. They should be encouraged to play a central role as partners in planning changes to services. The person with a learning disability and their parent should be given the opportunity to explore a range of alternatives so that an informed choice about the most suitable form of provision can be made. Similarly, social services should work with the family to plan short-term breaks away from the home that can prepare their son or daughter for a future permanent move.

## **Expansion of housing and support provision**

*The Housing Timebomb* shows that only one in four local authorities have developed alternative plans for the future. This calls into question their ability to deliver a comprehensive housing and support programme. Tightening eligibility criteria are already restricting access to housing services and waiting lists are common for residential provision. Given that local authorities only plan to provide an extra 227 places to meet the needs of people living with older carers, there is clearly unmet demand for alternative housing. On current plans, we estimate that it will take 30 years for local authorities to deal with the increasing backlog.

Mencap believes that more funding is needed from Government to meet the housing needs of people with a learning disability with older parents. Housing provision should be expanded by 6,000 places a year for at least the next five years in order to meet the future housing needs of people with a learning disability living with older parents.

## *Recommendations*

These recommendations are based on the overriding principle that adults with a learning disability should not be expected to stay in the family home for want of an alternative. Nor should parents be forced to continue caring in their 70s or 80s. People with a learning disability should have the choice of where to live and the care and support to enable them to live in the community.

- The Government should expand housing and support provision by 6,000 places a year to help meet the future housing needs of people with a learning disability living with older parents.
- Social services should have up to date registers that contain the exact numbers of older carers in their local area (split between ages 60 to 69 and 70 and over). These registers should contain information on their particular caring needs and their family circumstances, as well as their housing and support and other assessed needs.
- Social services should publish an annual plan containing the number of people living with older parents in the family home, the places currently available and the numbers of people they intend to provide with alternative accommodation for each of the following three years. They should set targets and develop an action plan to achieve them.
- Social services should work with parents when they reach 50 to identify the future housing needs of their son or daughter. They should record how they engage with parents and people with a learning disability in care planning as well as the outcome of care plans agreed by families.
- Housing departments should regard people living with older parents aged 70 and over as in greatest need when defining eligibility and priority for housing provision. This should be reflected by government guidance at a national level and mainstream housing programmes drawn up at a local level.
- Parents and people with a learning disability need better information and support to help them secure alternative housing and support.

## Conclusions

*The Housing Timebomb* shows that adults with a learning disability are being cared for at home by a growing population of elderly parents who are getting older and frailer. Government and local authorities have completely overlooked the needs of people living with older parents. This has to change. Unless action is taken it will mean that people with a learning disability will have no real choice but to continue living in the family home until there is a major crisis or their parent dies.

The challenge is for the local authority, parents and their sons and daughters to work more closely together towards identifying and meeting future housing and support needs. Procedures should be in place to encourage and assist non-crisis moves and safeguard the security of people with a learning disability. There is also a strong moral case for society to provide support to those who have taken responsibility for the care of their sons and daughters. These families have earned the right to a peace of mind for the future, after a lifetime of caring.

## *Appendix: Methodology*

Mencap obtained the agreement of the Association of Directors of Social Services to carry out a national survey of all local authorities in England. Its purpose was to determine the numbers of people living with older carers in every area and the extent to which the future housing needs of people with a learning disability living in the family home are met. Local authorities were asked how many people with a learning disability are living with carers aged 60 or over and 70 or over and how many people living with parents/carers aged 70 or over will receive alternative housing provision in 2002/03.

Research was carried out between January 2002 and May 2002. A survey form was sent to all 150 English local authorities with responsibility for social services. Replies were received from 92 local authorities, which is a response rate of 61%. Based on the population figure used by the Department for Transport, Local Government and the Regions\* (DTLR), these covered 20.8 million people: 62% of the 50 million population of England.

The report is based on responses received from the 92 local authorities covering 90,451 adults with a learning disability known to social services. This equates to 62.4% of the 145,000 adults with a severe learning disability. The average number of adults with a learning disability known to social services per 10,000 population was 30.1.

For the local authorities that provided figures, 7.5% of people with a learning disability live with parents aged 70 and over; extrapolated for the 92 local authorities that responded to the survey, this gives 6,784 people with a learning disability. The 227 additional places planned for 2002/03 by local authorities are to meet the needs of these 6,784 people. At this rate it would take 30 years to meet their needs.

The financial information provided by local authorities was limited. Many did not provide information for the current year 2002/03. There was little evidence of authorities addressing the funding needs of additional housing and support packages. Most had not provided for any significant extra funding (greater than a 5% increase) for either residential and nursing care or supported living.

\*Responsibility for local government has now been taken up by the Office of the Deputy Prime Minister.

Mencap also conducted a short survey amongst 150 older parents (aged 50 and over) of people with a learning disability. The aim was to ascertain the extent of their caring role, their concerns for the future and whether they had tried to secure alternative housing provision for their son or daughter. We also asked people with a learning disability how they regarded their own future and the extent to which they provided support for their mother or father. Mencap also talked extensively to local groups that had conducted their own surveys into the housing needs of people living with older parents.

For the purpose of this survey, Mencap has not named the authorities in the report. The names of the parents and people with a learning disability have been changed to protect their anonymity.



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June 2002

Registered Charity Number 222377