

Housing for people
with a learning disability

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Foreword



Less than half a century ago, people with a learning disability were locked away and kept a secret from the rest of society.

Most lived in large institutions – in settings resembling old hospital wards or prison wings, where abuse was rife and they had no contact with the outside world. A long fight, led by families, brought about major progress, which saw the last long-stay hospital in England close in 2009.

Driving the campaign was the view that people with a learning disability should be treated as equal members of society and empowered to have choice and control over their lives – a position that is central to Mencap’s core values. The campaign saw people’s housing conditions as a key part of the move towards real equality for people with a learning disability.

Although we have seen the closure of long-stay institutions, we still have a very long way to go to achieve full independence for people in the community. Worryingly, recent investigations into assessment and treatment centres have raised concerns that new institutional settings are being created, even if that was not the original intention.

I regularly meet people with a learning disability and their families who tell me about the barriers they face to living the lives they want. One of the greatest of these is their housing situation. Many people describe having no choice about where they live and who they live with, and older family carers describe the uncertainty they feel about their son’s or daughter’s future.

This report describes the current housing situation for people with a learning disability. While acknowledging how much progress has been made in supporting people to live independently, it also highlights the challenges that remain. We know that people with a learning disability can live successfully in different types of housing, but there needs to be more emphasis on different ways of providing the housing that people want, and the support they need to live in it.

I hope this report will help decision-makers understand current and future trends so that action can be taken to improve housing for people with a learning disability. We want to see those who plan and commission services looking to widen the housing and support options available to people with a learning disability, to create more potential for choice and to enable people to achieve their aspirations.

Mark Goldring
Mencap chief executive



Executive summary

This report is intended to support decision-makers on issues relating to the provision of housing for people with a learning disability in England. It provides a picture of where people live now and what the future may look like for them in terms of their housing.

Mencap commissioned Cordis Bright to present a detailed and accurate picture of the current housing situation of adults with a learning disability in England and Wales. Alongside this, Mencap also undertook research on the routes into housing services for people with a learning disability. Both pieces of research, and supporting case studies, have shaped the findings of this report. Results from the Cordis Bright study are shown in grey text throughout the document.

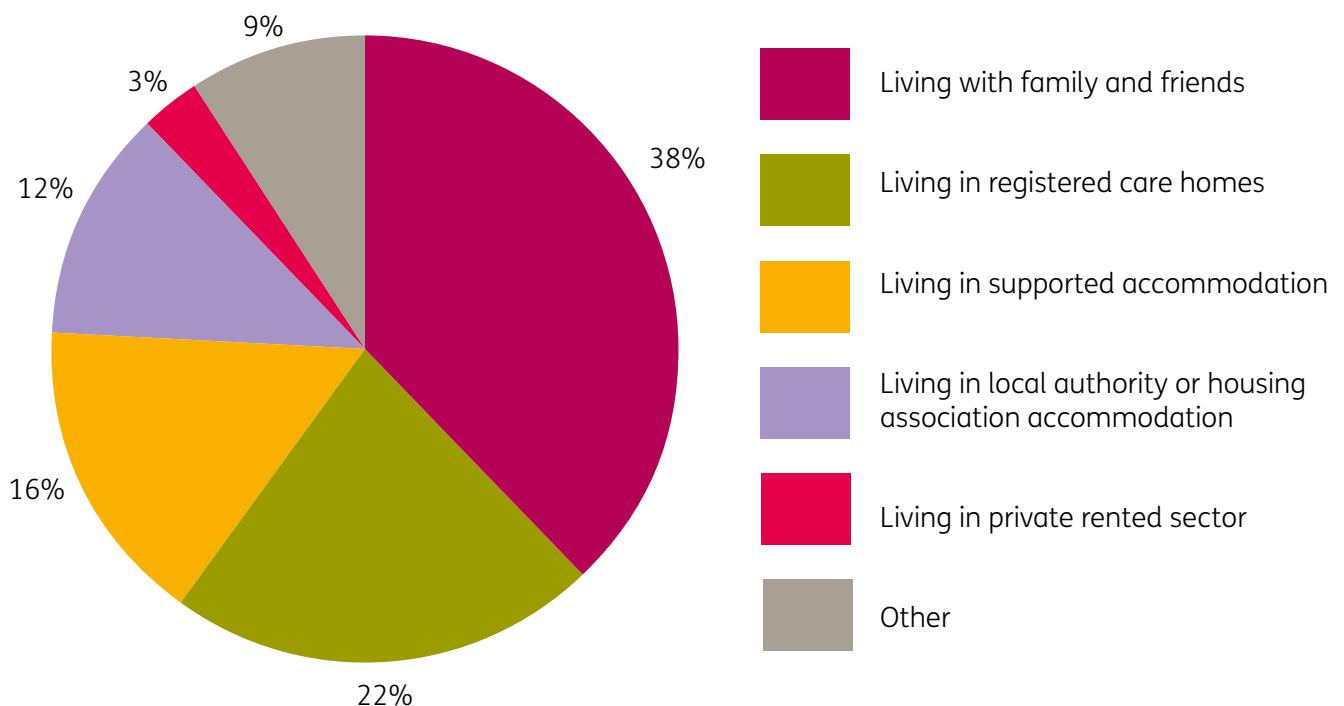
People with a learning disability have a right to live independently. Backed up by commitments in government and local authority policies, the last 50 years have seen significant changes in the way housing and support is provided. We have mostly moved away from an institutional model to one that promotes people living in ordinary houses in ordinary streets. However, we still have some way to go to achieve our vision of full inclusion in the community.

Key findings of the report

1. The report identifies the types of accommodation that people with a learning disability live in:

- The majority of people with a learning disability known to local authorities live in one of three types of accommodation: with family and friends (38%), in a registered care home (22%) or in supported accommodation (16%). 12% live as tenants in accommodation provided by a local authority or housing association and 3% in privately rented accommodation.

Where people with a learning disability known to social services live



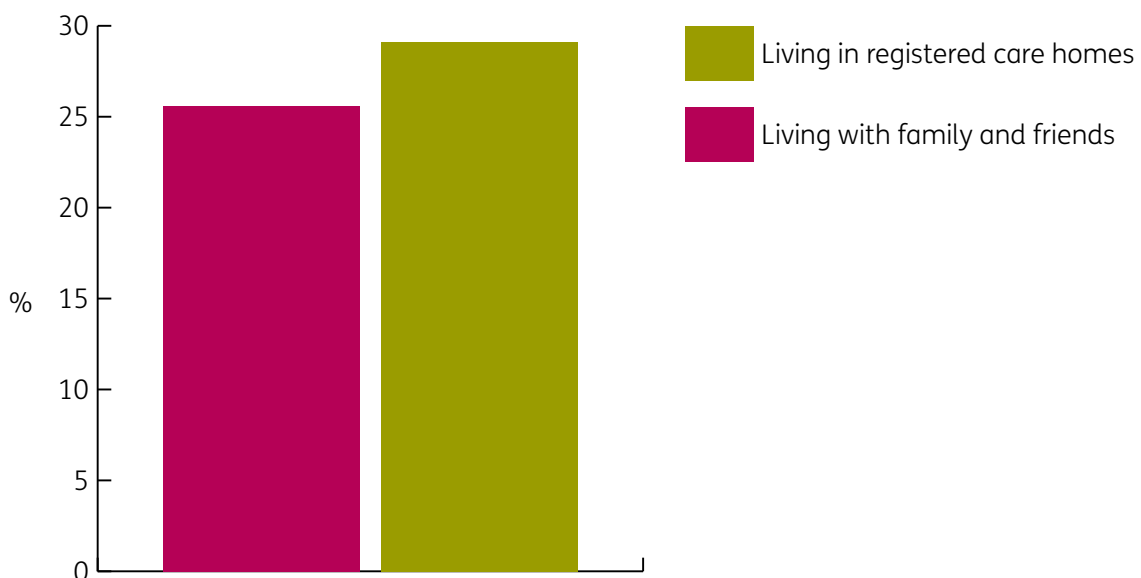
- In 2011, an estimated 8,578 people with a learning disability were newly referred to local authorities for housing support. Alongside this, nearly 10,000 people were on housing waiting lists.
- The demand for services is set to rise steeply. In 2011, there was a 3% increase in the number of people with a learning disability known to local authorities who needed housing with support. A further 5.7% increase is expected over the next two years. Research shows that to meet demand from the growing number of people with a learning disability, there would have to be an additional 1,324 registered care home places and 941 supported living places created every year until 2026. It also suggests that there will be an extra 2,257 people with a learning disability known to local authorities living with family and friends each year until 2026.
- Most people with a learning disability who live with family and friends want greater independence, with around 70% wanting to change their current housing arrangements to achieve this.

The majority of people with a learning disability want to live independently



- 89% of parents whose son or daughter lives with them want to see greater independence for them.
- Alarming, nearly 20% of people with a learning disability known to local authorities live in accommodation that needs improvement. This includes one in three people living in registered care homes and one in four people living with family and friends.

Percentage of accommodation of people with a learning disability that needs improving



2. Many people with a learning disability want to live a more independent life – something that requires housing arrangements that promote this. However, there are a growing number of barriers standing in the way of independence, including:

- **Resources:** With growing demands on housing and support services, alongside reductions in local budgets, local authorities are finding it increasingly difficult to house people with a learning disability and support them to live independently.
- **Planning:** Systematic failures in planning for the future of people with a learning disability are resulting in many areas not being adequately prepared. A lack of support for planning for the future by individuals and families may also lead to people with a learning disability reaching crisis point and, therefore, to high-cost emergency housing solutions.
- **Complex needs:** Some groups of people with a learning disability face greater barriers to independent living than others. This is largely due to a lack of planning, available appropriate services and resources. The groups affected include: people with profound and multiple learning disabilities (see page 22 for a definition of this term); people with a learning disability and behaviour that challenges; and people who live with elderly parents.
- **Lack of housing:** The lack of appropriate housing means we are failing people with a learning disability. 61% of local authorities believe that local housing arrangements do not meet the needs of people with a learning disability. This has led to long waiting lists, large numbers of people living far away from family and friends, and a high number of people living in arrangements that do not promote independent living.

3. Following the Welfare Reform Act 2012, changes to the way many housing options are funded will affect the ability of local authorities to support independent living for people with a learning disability:

- With less than 7% of people with a learning disability in paid employment¹, there is widespread reliance on benefits to support living arrangements. Changes in the Act place a greater focus on those with high-level needs, reducing the availability of benefits for those with low and moderate needs.
 - i. The new size criteria in social housing will force people to move or take a benefit cut if they have a spare room – even if they use it for their informal care and support arrangements².
 - ii. Government estimates show that changes to Disability Living Allowance (DLA) will see 500,000 fewer people getting help to cover the additional costs of disability. This will prevent individuals from being passported to other benefits – including the Severe Disability Premium (SDP) – leading to further loss of essential income.
 - iii. Tightening of Local Housing Allowance will make it harder for people with a learning disability to access housing that adequately meets their needs and will reduce choice and control for individuals.

¹ Of those known to social services.

² With only one exemption for people who require an additional bedroom for a non-resident carer who provides them with overnight care.

- iv. Future changes to exempt accommodation from Housing Benefit could be another obstacle to choice for people with a learning disability.

Although some of the changes will affect a relatively small number of people with a learning disability, most of these people are likely to be affected by a combination of several of these changes at any one time. This is very damaging to an individual's ability to live independently.

Many of the changes are subject to an element of local decision-making, giving local authorities the power to moderate the impact on disabled people where possible.

Recommendations

Although we have come a long way in supporting people to live independently, this report shows there is still work to do and significant future challenges to address. Demand for services is set to grow, which means we must address housing needs urgently if we want to support people with a learning disability to realise their right to live independently.

Based on the findings, the report makes two key recommendations:

1. The development of a national strategy on housing for people with a learning disability

The barriers to independence in this report are not exclusive to one area of England. A national strategy is therefore needed to pull together learning across local authorities and identify what action needs to be taken at the national level.

2. All local authorities to include specific plans for improving the housing situation of people with a learning disability in local housing strategies

Local authorities have greater influence over a person's ability to live independently than ever before. As this report identifies, local authorities will face growing pressures from increasing local need, so planning for the future is crucial. An action plan designed around promoting independent living should accompany any such plans.



Introduction

This report sets out to establish how far we have really come in supporting people with a learning disability to live independent lives. It is based on the results of two detailed research projects, which were specifically designed to look at the housing situation of people with a learning disability. The research findings outlined are supported by the stories and experiences of people with a learning disability and their families who Mencap supports and works with on a daily basis.

We look at where people with a learning disability live now and where they want to live in the future. The report also explores the challenges ahead for local authorities and central government in supporting people to live independently, identifying the progress of major government policy and the extent to which this has been put into practice.

One of the largest shake-ups in welfare for people with a disability took place in 2012, affecting access to housing services and the way these services will be delivered. This report looks at how we expect these changes to add to the challenges to independent living and whether any opportunities have arisen since. It also sets out two recommendations based on our findings.

What is a learning disability?

A learning disability is a reduced intellectual ability and difficulty with everyday activities. For example, household tasks, socialising or managing money, which affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

The level of support someone needs depends on individual factors, including the severity of their learning disability. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need full-time care and support with every aspect of their life. They may also have physical disabilities.

People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability.

Learning disability is often confused with dyslexia and mental health problems. Mencap describes dyslexia as a 'learning difficulty' because, unlike learning disability, it does not affect intellect. Mental health problems can affect anyone at any time and may be overcome with treatment, which is not true of learning disability.

It is important to remember that with the right support, most people with a learning disability in the UK can lead independent lives.



Background

Before we can improve the housing situation for people with a learning disability, we must look at the changes that have already been made and the policy that underpins the current system.

How far have we come?

People with a learning disability, families, campaigners and policy-makers should all be proud of our major achievements so far.

It was only 50 years ago that society generally expected people with a learning disability to live their life with other disabled people in segregated institutions, rather than with their families or independently in the community.

Initial resistance to this idea came in the 1960s, when it became apparent that the quality of long-stay hospitals (the institutions in which people with a learning disability lived) was often extremely poor and abuse was rife. A movement, led by families, to close these institutions saw changes to government policy, placing more emphasis on seeing disabled people as equal citizens.

In the 1970s, legislation was introduced to reduce places in hospitals and relocate people in the community. It saw many people moving to residential care homes or back with their families. This was the growing trend until later policy developments in *Valuing People*³ (2001) and *Valuing People Now*⁴ (2009) brought a greater focus on supporting people with a learning disability to live independently in the community. The last long-stay hospital in England closed in 2009.

Now, policy states clearly that people with a learning disability should have the right to live independently in the community. This has caused a general shift away from housing people in residential care homes and nursing homes, and towards supported housing models.

Government policy

The move towards a supported living approach for people with a learning disability has been underpinned by strong commitments in government policy. As a result, there has been a significant emphasis on the role that local services should play to support a person's right to live independently. The policy was introduced in *Valuing People* and later strengthened in *Valuing People Now*.

Valuing People

Valuing People (2001) reaffirmed policy to reflect society's changing expectations about how people should be treated. It provided a clear vision for people with a learning disability based on four key principles: rights, independence, choice and inclusion.

By the time *Valuing People* was introduced, most people with a learning disability lived with their families, having left long-stay hospitals⁵. However, more than 1,500 people still lived in long-stay

³ Department of Health. (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*.

⁴ Department of Health. (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities*.

⁵ Department of Health. (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*, p. 70.

hospitals, with a further 1,500 living on NHS campuses. *Valuing People* set about changing this. It began the process of separating social services from the NHS and introduced a target of April 2004 for all people to be relocated from NHS long-stay hospitals.

The *Valuing People* strategy sought to deal with some specific issues associated with housing people with a learning disability, including the growing number of people living with older carers and the need to give people greater choice and control over their lives. It also widened the Supporting People scheme (see page 24) to cover people with a learning disability.

Valuing People Now

In 2009, *Valuing People Now* introduced a three-year strategy to take forward the policy set out in *Valuing People*, recognising that much of the vision set out in 2001 needed to be put into practice. The strategy set out clear commitments and actions across government to enable change.

This new strategy placed greater emphasis on supporting people with a learning disability into supported accommodation. It introduced Public Service Agreement 16, which measured the number of adults with a learning disability known to social services who were moving into settled accommodation outside NHS campuses or registered care homes. This was a delivery priority for government and local authorities.

Independent living

Independent living is ‘about disabled people having the same level of choice, control and freedom in their daily lives as any other person’⁶.

It does not mean that someone has things done for them or that they live alone. Instead, it means that they have choice and control over the assistance and/or equipment they need to go about their daily life, and that they have equal access to housing, transport, health, employment and education, and training opportunities⁷.

The right to independent living is covered in international human rights law. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ‘Living independently and being included in the community’⁸, clearly states that people with a disability have the right to independent living.

Government policy backs up the direction of international law in its independent living strategy *Improving the life chances of disabled people*, introduced by the previous government. This report sets out commitments across government to meet the policy aims of independent living for people with a disability. The coalition government will replace this with a new disability strategy, which is currently being developed.

⁶ Office for Disability Issues. (2008). *Independent Living; a cross-government strategy about independent living for disabled people*.

⁷ Office for Disability Issues. (2009). *Independent Living Strategy, Improving the life chances of disabled people*, p. 11.

⁸ Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Housing and independent living

If a person with a learning disability has a choice about where they live and with whom, they are more likely to have access to independent living. This fact was recognised by government policies⁹ that set out commitments to increase provision of housing in the community and give people greater choice and control over where they live. Recent policy developments have focused more on moving people away from residential care homes and into supported living schemes. This significant change has seen large-scale deregistering of residential care homes for people with a learning disability.

Mencap believes that without access to housing and support services, many people with a learning disability would not be able to have an independent life.

Mencap has long argued for the right of people with a learning disability to live a more independent life. Our vision is a world where people with a learning disability – including those with profound and multiple learning disabilities – are valued equally, listened to and included. We want everyone to have the opportunity to achieve the things they want from life.

⁹ *Valuing People* (2001), *Valuing People Now* (2009) and independent living strategy (2009).



What is the housing situation for people with a learning disability?

Just 50 years ago, most people with a learning disability were segregated from the rest of society, living in institutions and long-stay hospitals.

But changes in society's attitude, followed by changes in government policy, have transformed the situation to what it is today.

This section outlines this current situation, highlights the increasing demand for services and identifies where people with a learning disability actually want to live.

Local authorities arrange housing with support or care home support for an estimated 63,000 people (36% of all people with a learning disability known to local authorities).

Where do people live?

The majority of people with a learning disability live in one of three types of accommodation: with families, in registered care homes or in supported accommodation¹⁰. These results are in line with existing data¹¹ and support general observations about where people with a learning disability live made by housing experts and service managers.

In 2011, three out of four people with a learning disability were found to live with families, in registered care homes or in supported accommodation:

- 38% live with family and friends
- 22% live in registered care homes
- 16% live in supported accommodation.

The remainder live in one of the following types of accommodation:

- 12% live as tenants in accommodation provided by local authorities and housing associations
- 3% live in privately rented accommodation
- 2.5% live in homes that they own (solely or jointly)
- 2.4% live in adult placement schemes
- 1.6% live in registered nursing homes
- 1.2% live in acute or long-stay healthcare residential facilities or hospitals
- 1% live in temporary accommodation
- 0.6% live in sheltered housing or extra-care sheltered housing.

¹⁰ Research by Cordis Bright identifies accommodation types for those people with a learning disability known to local authorities.

¹¹ Emerson, E. & Hatton, C. (2008). *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*. Lancaster: Centre for Disability Research, Lancaster University

Research also shows that there are significant numbers of people with a learning disability who are either on a waiting list for housing with support or allocated housing outside of their local authority.

- There are currently 9,996 people with a learning disability on waiting lists for housing with support. This amounts to 5.8% of all people with a learning disability known to local authorities.
- 13% of people with a learning disability known to local authorities are placed in accommodation out of their area (22,404 people).

While the evidence shows some progress has been made in the last decade, it is disappointing that there are still many people who are not being supported to live in accordance with their wishes. Today, over half of people with a learning disability known to local authorities live in two types of housing: with families, or in registered care homes. Our research shows that this situation is not in accordance with the aspirations of many people with a learning disability or their families, who want more independence and choice. This makes it hard to identify real progress in the government's commitment to independent living.

New referrals focus more on independent living

In 2011, 8,578 people with a learning disability were estimated to have been newly referred to local authorities. These adults were most likely to be living in the following types of accommodation:

- 48% with family or friends
- 21% in supported living accommodation
- 16% in social housing
- 7.5% in registered care homes

A comparison of housing arrangements for new referrals with the wider housing arrangements for people with a learning disability known to social services shows that there is some progress in moving people to independent settings.

However, further progress is needed, with local authorities reporting that 40.5% of these new referrals needed rehousing.

Local authorities also highlighted the fact that, in each local authority, four care homes are expected to be deregistered over the next two years. This will affect 3% of people with a learning disability known to local authorities.

Local authorities that took part in an interview emphasised the move away from the traditional registered care home model of housing provision, highlighting the lack of independence offered by this option. They outlined clear advantages for supported living arrangements as an alternative that offers choice and independence.

Future housing need

The number of people with a learning disability is higher than ever and is set to increase further in the next 20 years. Research by the Centre of Disability Research at Lancaster University shows that sustained growth in the number of people with a learning disability will see an average annual increase that equates to between 3.2% and 7.94% of those currently requiring social care services^{12, 13}.

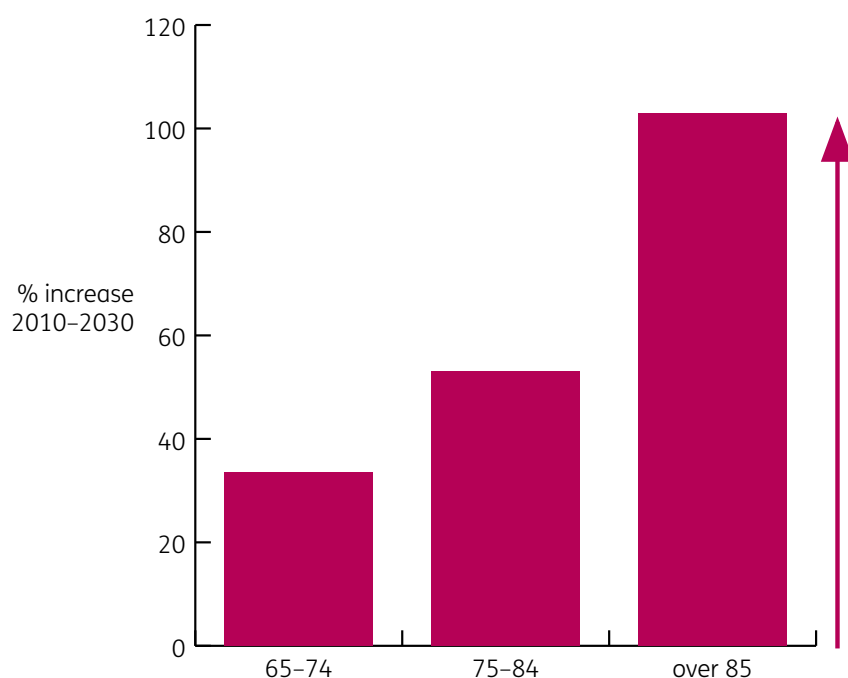
This will see more people needing support from social services and housing departments to live independently.

In 2011, there was a 3% increase in the number of people with a learning disability known to social services compared with 2010.

There is evidence of a growing number of people with profound and multiple learning disabilities (PMLD)¹⁴. It is expected that the current number of 16,000 adults with PMLD in England will increase to around 22,000 by 2026¹⁵. However, it is impossible to calculate this figure accurately due to a lack of adequate records and the varying definitions of PMLD used by local authorities.

People with a learning disability are also living longer. The number of people with a learning disability aged between 65 and 74 years is set to increase by 33.5% between 2011 and 2030. Likewise, by 2030 there will be an increase of 53% in the number aged 75 to 84 years and a 103% increase in the number aged 85 and older.

Increase in population of people with a learning disability aged over 65 from 2010 to 2030



¹² This annual increase will continue until at least 2026. It applies to people who would be assessed as having 'Critical' and 'Substantial' needs according to the Department of Health's *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care - guidance on eligibility criteria for adult social care, England 2010*.

¹³ Emerson, E. & Hatton, C. (2008). *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*. Lancaster: Centre for Disability Research, Lancaster University

¹⁴ Emerson, E. (2009). *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England*. London: Department of Health.

¹⁵ Lambeth PMLD Project. (2010). *Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth*.

Increasing demand for support

The growing number of people with a learning disability will see more people needing local authorities to make housing arrangements for them. For example, between 2011 and 2026, local authorities will have to provide an additional 1,324 registered care home places and 941 supported living placements per year¹⁶.

Many people with a learning disability need support to be able to live independently, and this support must be arranged by the local authority. Local authorities purchase or arrange places in accommodation, which provides additional support for one in three people with a learning disability.

Local authorities have highlighted a growing number of people who are requiring housing with support. There was a net increase of 5,171 people in 2011, equating to 3% of all people with a learning disability known to local authorities.

Local authorities estimate a 5.7% increase in the number of people with a learning disability who will receive housing with support or a care home placement in the next two years.

More people will live with family and friends

As well as the rising demand for local authority services, there will be an increase in the number of people with a learning disability living with family and friends. This will see an additional 2,257 adults with a learning disability living with friends and family per year until 2026.

This is also reflected in the growing number of adults with a learning disability who live with parents who are aged over 70 years.

What people with a learning disability and their families want from housing

Many people with a learning disability and their families are unhappy with their current housing arrangements, particularly if they are not living independently.

25% of parent carers are dissatisfied with the housing arrangements for their son or daughter.

The majority of people with a learning disability say they want to live independently, either by themselves (40%) or sharing a home with friends (30%).

People with a learning disability and their parents share a wish for current housing arrangements to change to enable greater independent living. Cordis Bright's survey of parents found that over three-quarters of parents whose children still live with them would like them to have an opportunity to leave home and live more independently.

89% of parents who report they are dissatisfied with their son's or daughter's current housing arrangement would like them to live more independently.

¹⁶ This estimate is based on the mix of housing arrangements remaining at the same percentile until 2026. However, it is likely that the breakdown of the number of placements for both types of housing arrangement will alter in the wider move towards supported living arrangements.

79% of parents whose son or daughter still lives with them would like them to have an opportunity to leave home and live more independently. Applied nationally, this represents 52,000 of the 65,000 people known to local authorities who are living with family or friends.

Need for improved accommodation

In a survey of local authorities that formed part of Cordis Bright's study, it was found that just under 20% of people with a learning disability are living somewhere that is not meeting their needs and should, therefore, have their housing arrangements improved¹⁷.

Those who live in registered care homes or with family are most likely to be found in housing arrangements that need to be improved.

19% of adults with a learning disability known to local authorities are in an accommodation arrangement that should be improved.

One in three people with a learning disability living in a registered care home are in an arrangement that should be improved.

A quarter of people with a learning disability living with family or friends are in a housing arrangement that needs improving.

Local authorities also report that 6.7% of people living in supported accommodation need to have the arrangement improved.

¹⁷ This figure may or may not include the 3,450 adults with a learning disability who were newly referred in 2011.



Barriers to independent living for people with a learning disability

Although we have come some way from long-stay hospitals and institutions, there are still many barriers to people with a learning disability living independently. For example, too many people with a learning disability do not have any choice over who they live with or where they live.

94% of local authorities agree that more needs to be done to meet the housing needs of adults with a learning disability.

There is a real danger that progress will be halted as both central and local government experience major challenges in providing housing for people with a learning disability. Mencap's research has identified five key challenges that, if ignored, will reverse progress made in the provision of access to independent living.

These challenges are:

1. Growing demand for housing and support services
2. Lack of future planning to meet growing housing and support needs
3. Specific barriers for groups of people
4. Not enough housing available
5. New challenges created by the Welfare Reform Act 2012.



Growing demand for services

One of the most immediate issues for the government and local authorities to address is the fast-growing demand for housing and support services.

89% of local authorities report an increase in the number of adults with a learning disability requiring housing support in the last three years.

At a time of increasing numbers of older people and people with a disability, local authorities are faced with rising demand for services across the board. And they are already feeling the pressure.

67% of local authorities say that it has become more difficult for adults with a learning disability to have their housing needs met in the last year.

82% of local authorities agree that there is a shortage of housing for adults with a learning disability in their areas.

As highlighted above, the growing demand for housing services is twinned with a growing demand for support services to enable people to live independently, placing a further strain on local authorities.

There has been a 3% increase in the number of people with a learning disability for whom local authorities arranged housing with support or care home support in the last year.

Who will pay to meet future demand?

Increasing demand for both housing and support services is set to put significant pressure on local authority budgets. But at a time when local authorities should be assigning extra money to meet growing levels of demand, they are seeing a reduction in funding from central government and having to make commitments to maintaining council tax freezes. This has led to budgets focusing on efficiency savings rather than on meeting demand.

In a 2012 study by the Learning Disability Coalition of learning disability services and local authority funding, 90% of local authorities stated that they have less funding than last year and 84% described funding for learning disability services as 'difficult'¹⁸.

Supporting People

Supporting People funds vital support to enable people to live independently. The scheme was highlighted in government policy as a central method for supporting people with a learning disability (*Valuing People Now*). Each year since 2003, Supporting People has supported an average of 32,000 people with a learning disability to move out of registered care homes or their families' homes to live in the community, and to choose where they live and with whom. In 2012, the government introduced a 12% reduction in funding for the Supporting People programme over a four-year period. As well as reducing the money for Supporting People, the government made the funding stream more vulnerable by removing its ring fence¹⁹.

We also know that while some local authorities have recognised the importance of Supporting People by not reflecting cuts in spending on front-line services, others have significantly reduced their Supporting People budget, helping fewer people to live independently.

All of this strongly suggests that local authorities are not going to be able to cope with a growing demand for housing and support services, limiting progress towards realising independent living for people with a learning disability.

¹⁸ Learning Disability Coalition. (2011). *Social care – the continuing crisis: from the perspective of local authorities in England, The Learning Disability Coalition Local Authority Survey 2011*.

¹⁹ Local Government Settlement (2010).



No one planning for the future

Because people with a learning disability are likely to depend on formal and informal support, planning for the future is crucial. Generally speaking, people with a learning disability, their families and local authorities should take part in detailed planning and assessments before any change in living arrangement is made. This is to make sure that the new accommodation meets the needs of the individual. Planning is also a central way of involving the individual in decisions about where they want to live.

However, evidence suggests that this does not often happen in practice. Where plans have not been made, it is likely that the individual, and their family, will be referred to the council when they have reached a state of crisis, by which point it is much harder to put beneficial arrangements in place.

Local authority planning processes

The research conducted by Cordis Bright looks at how local authorities responded to freedom of information requests and a survey. Based on these responses, it outlines the extent to which they strategically plan for the future housing needs of people with a learning disability.

When local authorities were approached for this information, all of the 174 top-tier local authorities in England and Wales said they were fulfilling their statutory obligation to have a local housing strategy that includes dealing with future needs of adults with a learning disability.

However, the evidence collected by Cordis Bright supported Mencap's opinion that there is a significant lack of knowledge about how many people with a learning disability live in each local authority area. Without knowing the numbers of people to plan for, or future population trends, local authorities will not be in a position to plan strategically for the future. Likewise, by not knowing accurately the total number of adults with a learning disability in England and Wales, the government and devolved administrations will be unable to address growing barriers to independent living.

Mencap believes that a key to understanding local and national population trends is the collection of data in the form of a register or alternative formal recording process. While registers are voluntary and there is no national standard for the data collected, recording information in this way is clearly a means of giving local authorities a realistic picture of the local situation.

We also believe that local authorities should use Joint Strategic Needs Assessments to look across the different client groups, as well as at the provision of services locally, and put in place plans for the future. We encourage all local authorities to ensure that they have robust plans in place to respond to the growing demand for local services as the number of people with a learning disability increases.

The quality of strategic plans varies among local authorities, and many undertake the bare minimum amount of planning.

Only 41% of local authorities say that they have a local register for adults with a learning disability.

Furthermore, the draft Care and Support Bill²⁰ proposes to remove the requirement for local authorities to keep a formal register of adults with a learning disability and, instead, simply give them the power to do so if they wish. This makes it less likely that local authorities will look to address future increases in demand or plan strategically to remove barriers to independence; they are more likely to stop keeping a register or formal record of adults with a learning disability than to start doing so.

Of the 59% of local authorities that do not have a register, 20% say that they have kept a register in the past.

These findings are concerning, providing evidence of patchy planning for adults with a learning disability. Mencap believes that more needs to be done to improve the quality, consistency and comparability of data held in adult learning disability registers.

Mencap is also increasingly concerned about the future of existing registers. While 98.5% of the local authorities that currently operate a register said that they plan to continue doing so, it is likely that some will stop keeping a register if the draft Care and Support Bill is passed into law unchanged.

Planning by families

Surveys of parents clearly showed that they felt excluded from the planning process. Whether it is because of a lack of awareness of their role in planning, a lack of support for parents to formulate plans or even a lack of confidence in local authorities, there are too many people with a learning disability who do not have plans in place for future housing needs.

73% of parents have not planned for the time when they are no longer able to care for their son or daughter to support their future housing needs.

²⁰ Department of Health. (July 2012). Draft Care and Support Bill.

83% of parents whose son or daughter with a learning disability lives with them have not planned for the time when they are no longer able to care for them.

Alarming, even parents who are over the age of 70 do not have plans in place for their relative's future care needs.

56% of parents aged 70 and over whose son or daughter lives with them have not planned for the time when they are no longer able to care for them.

This makes it significantly harder for local authorities to plan strategically for the future, and will only lead to an increase in the number of people who approach their council for housing and social care support in a crisis. In this crisis situation, councils will then find it impossible to fully involve individuals in decisions about their housing arrangements.

Mencap believes that it is imperative for every person with a learning disability living with parents aged 70 and over to have an agreed plan for the future. Local authorities should play a proactive role in this so they are aware of future demand.

Failings to plan properly in transition

There is a particular stage in the life of a young adult with a learning disability when several local authority departments have a real opportunity to work together to prepare them for an independent life in adulthood.

Many young adults with a learning disability (those aged between 16 and 25) are likely to study life skills in the education system, which will enable them to maximise their opportunities to live independently. During this time, housing and social services have the chance to work with them, their families and education departments to plan the housing they will have access to once they make the transition from children's to adult services. However, this is an opportunity that is not often taken up.

In a Mencap-run focus group of housing professionals and family carers, participants noted that many young adults with a learning disability are forced to move back home from supported living arrangements, with family or into a registered care home – losing the valuable independent living skills they had gained – because this opportunity to plan was missed.

Previous research among professionals and families undertaken by the PMLD Network in 2006 found that only 6% of respondents thought there was effective planning for the transition from children's to adult services.

Lack of information and support services

People with a learning disability and their families told us that one of the most common barriers to independent living is a lack of information, advice and advocacy.

If individuals are not aware of their options, they will continue to live somewhere they would not choose to. Furthermore, many people with a learning disability are unaware of their right to live independently and how to get the housing and support they need to do this.

Without a stream of allocated funding for the provision of information, advice and advocacy services, the access to and quality of these services varies across local authorities. Mencap believes that this is a central reason for individuals and their parents not having plans for the future.

In response to the draft Care and Support Bill's inclusion of a duty on local authorities to provide information services, Mencap has called for a legal entitlement to independent advocacy to be added to the future statute. Advocacy should be provided for any individual going through the assessment and care planning process for adult social care. Independent advocacy should also be available for anyone going through safeguarding procedures.

Where plans are in place, there is lack of confidence in them

Even for families who do have plans in place, there is a clear lack of a joined-up approach to planning between local authorities and families. Research shows that even if parents have plans in place, it is unlikely that they will have shared them with the local authority.

27% of parents do have a plan for the time when they are no longer able to care for their son or daughter. Of these parents, only 46% have informed the local authority of their plans.

This suggests that local authorities are only aware of such plans for 12% of the people with a learning disability known to them.



Some groups face bigger barriers to independent living

While much needs to be done to improve access to independent living for people with a learning disability generally, there are some groups that face greater barriers to housing than others.

Three of the most marginalised groups in housing provision include: people with profound and multiple learning disabilities (PMLD), people with a learning disability who live with older parents and people with behaviour that challenges.

People with PMLD

People with PMLD:

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need high levels of support
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge us.

(The PMLD Network²¹ short definition of PMLD)

²¹ For more information and the long definition of PMLD, see www.pmldnetwork.org

Local authorities have been very clear in highlighting the increased challenges associated with arranging housing and support for people with PMLD.

76% of local authorities report that they have had difficulty arranging housing for adults with PMLD.

This compares with 29% reporting difficulties arranging housing for people with a mild learning disability.

Meeting the housing needs of people with PMLD means ensuring they have the right physical environment and the right support.

It is important to get the physical environment right for people with PMLD. Adaptations will often be needed. For example, a wheelchair-accessible flat, equipment such as a hoist, and enough space to enable the person's support needs to be met.

Alongside a suitable housing arrangement, the right support is crucial. People with PMLD need high levels of support from staff with the appropriate skills. Too often, their housing options are limited because they cannot recruit staff to enable them to live independently.

Families have told Mencap what happens when these specialist skills are not available, describing how the health and wellbeing of their loved one has been jeopardised by poor care. Examples include unskilled staff not being able to give someone a drink properly, allowing pressure sores to develop and even failing to administer epilepsy medication regularly.

Meeting the housing and support needs of a person with PMLD will cost more than meeting the needs of someone without such a severe disability. Families of people with PMLD have told Mencap of occasions when they were advised by their local authority that certain housing types would never be an option, given the person's high support needs. Many of these families felt that independent living was rarely presented as an achievable outcome for such individuals. However, the extra costs associated with meeting the needs of a person with PMLD should never mean that they miss out on opportunities for independent living.

There are some excellent examples of people with PMLD achieving happy and fulfilled lives when funding and skilled support is in place. However, the majority of these examples have been hard won and harder still to keep in place.



Victoria

Victoria, who has PMLD, lives independently in a rented flat in London. She has 24-hour support, a circle of friends, a person-centred plan and she very much lives the life of her choice. Her mother Jean has consistently had to fight to keep this in place. Her local authority has now made the decision that it will never again fund individuals with complex needs to live independently, arguing the costs are too high.

Professor Jim Mansell's *Raising our Sights* report²² also includes examples of people with PMLD being supported to live independently and shows the benefits of this in their lives. It explains in detail the barriers faced by people with PMLD in getting their housing needs met, and makes recommendations on how they can be overcome.

Local authorities must plan strategically for housing people with PMLD in the future, as these individuals often require expensive packages of care alongside their housing arrangements. A lack of awareness of the number of people with PMLD at the local level will only impede local authority efforts. Research by Eric Emerson, *Estimating future numbers of adults with profound and multiple learning disabilities*²³, provides a guide to the number of people with PMLD in a local area of a given size. However, it is also crucial that this data is collected locally, as information on both the number and the specific needs of individuals with PMLD is needed in order to plan effectively.

People living with parents aged 70 and over

Published in 2002, Mencap's *Housing Timebomb* report highlights the large number of people with a learning disability living with parents aged 70 and over who are providing their full-time care as well as their accommodation. The report flagged up the risks associated with this situation and called for urgent action to be taken.

The government agreed with the findings and called for local authorities to invest resources in working with those in this situation²⁴. It was clear that their aim should be to provide housing and support to enable people to access independent living arrangements or to ensure plans were in place for when older parents could no longer care for their son or daughter.

Ten years on, not much has changed. While local authorities have told Mencap about efforts made to engage with parents aged 70 and over and seek ways to provide alternative housing arrangements, 7% of people with a learning disability still live with parents aged 70 and over – virtually the same percentage as in 2001.

Not only has there been little progress, but this group of people is set to get larger as the number of people with a learning disability increases and the general population is living longer.

By 2026, the number of people with a learning disability who will be living with parents aged 70 and over will have increased by around 40%, if housing is not opened up to them.

55.6% of parents aged 70 and over do not have plans in place for when they are no longer able to care for their son or daughter with a learning disability.

We know that local authorities tend not to begin finding alternative accommodation until a family reaches crisis point, usually as a result of the death or illness of the family carer. When the move away from the family home occurs in this way, the consequences for the person with a learning disability are profound. Moving home becomes inextricably linked with the death of the carer. This sudden upheaval, coupled with the unexpected loss of a carer, often causes stress, confusion and trauma. Without proper planning, people may be moved into inadequate or inappropriate placements determined by the resources that are available at the time.

²² Mansell, J. (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities*.

²³ Emerson, E. (2009). *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England*. London: Department of Health.

²⁴ Department of Health. (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities*.

People with behaviour that challenges

*'Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'*²⁵

Local authorities have reported that people who present behaviour that challenges are a particularly hard group of people to find suitable and appropriate housing for. Those who fall into this group are very likely to require housing with extra space. They are also likely to require 24-hour support. There can be a high turnover of staff in a team that supports people with behaviour that challenges because of the intense support required, and because staff do not always have the necessary training and support to enable them to provide this.

For many people with a learning disability who regularly display behaviour that challenges, the extent to which they do so is likely to be dependent on how well their environment is managed (for example, how effectively possible triggers are identified and avoided). It is very important that their housing and support is carefully designed and that they have 'capable environments'. This means that both the physical design of the service they live in and the support they are given respond to their needs. Capable environments should be developed on the principles of positive behavioural support.

Meeting needs in a personalised way can go a long way towards reducing behaviour that challenges. Personal budgets are one means of ensuring a truly personalised package of support, and it is important that people with behaviour that challenges are given the opportunity to have one.

There should also be a range of local providers that are trained to meet the housing and support needs of people with a learning disability who have behaviour that challenges. These providers should work closely with the individual, their family and/or advocate, and professionals who understand the person's needs and how best to meet them. These professionals may be part of a local intensive support team.

It is important that local authorities understand the importance of investing in the right support for people with behaviour that challenges, so that crises are avoided. We know that when the right support is not available locally, people are more likely to be sent far away from their families to inappropriate institutional-style services like Winterbourne View, where they are at risk of abuse and neglect. These issues are addressed in *Out of Sight*²⁶, a campaign report by Mencap and the Challenging Behaviour Foundation. The campaign is calling for the phased closure of large assessment and treatment units and the development of appropriate local services.

²⁵ Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. (2007). *Challenging Behaviour: A Unified Approach*.

²⁶ Mencap and The Challenging Behaviour Foundation. (2012). *Out of Sight*. London: Mencap. Available at www.mencap.org.uk/outofsight



Not enough housing available

One of the most concerning issues raised by individuals, families and local authorities is the lack of available housing for people with a learning disability – something that is a major barrier to independent living.

61% of local authorities believe that local housing arrangements are failing to meet the needs of people with a learning disability.

Too many people with a learning disability remain on waiting lists for long periods of time, housed miles away from family or living in housing arrangements that need improving. All of these factors can have a disproportionate impact on people with a learning disability.

If suitable accommodation is not available, people with a learning disability will be unable to live an independent life. And with the demand for housing services set to rise, this barrier needs urgent attention.

67% of local authorities report that it has become more difficult for adults with a learning disability to have their needs met in the last year.

The lack of available housing means that local authorities keep people in residential care homes, or people remain living with families.

One in four people with a learning disability still live in registered care homes.

38% of people with a learning disability live at home with family and friends.

While there is no simple solution to the supply problem, local authorities must ensure that no one is housed in unsuitable accommodation. They must also make sure that local housing strategies are addressing this problem and have plans in place to overcome this barrier to independent living.

Supply and suitability of housing

When providing housing for people with a learning disability, it is imperative that the arrangement meets both their physical and support needs. Every person has individual needs, which range from step-free access or an extra room for a carer, to being located near informal support networks. Finding a suitable home that meets these needs will have a positive impact on both the individual and the local authority.

However, housing departments are under significant pressure because demand for services outstrips supply. As a result, many people are being presented with limited housing options that often do not reflect their own aspirations and/or those of their families.

Around one in five people with a learning disability live in housing arrangements that need improving.

People living far away

Another symptom of the lack of available housing is the growing number of cases of people being housed outside of their local authority area.

22,000 people with a learning disability are placed in accommodation outside of their local authority area. This represents 13% of people with a learning disability known to local authorities.

Families of people with a learning disability often tell Mencap about the need to travel for more than an hour to visit a relative who has been accommodated in an out-of-area placement. By moving people far away from friends and family, local authorities are disconnecting them from informal support networks and long established social networks, both of which are key to their physical and mental wellbeing.

It is clear that for many people with a learning disability, the lack of housing availability is limiting their ability to choose where they want to live.

Long waiting lists

The current system of social housing allocation does not always work to the advantage of people with a learning disability.

While the government has said that people with a learning disability should be given reasonable preference on waiting lists, we are aware of many who remain on waiting lists for unacceptably long periods of time.

Around 6% of people with a learning disability are on waiting lists for housing with support.

This means that some are forced to remain in unsuitable and unsafe environments. Mencap has identified a number of specific groups of people with a learning disability who we believe should be treated as urgent cases when they request housing from their local authorities. These include people with a learning disability who are victims of hate crime, those whose community care assessments identify a need for housing and those living with elderly parents.

Victims of hate crime

Remaining on a waiting list for housing is dangerous for people with a learning disability who have been, or currently are, victims of hate crime.

Research shows that 60% of all disabled people have been victims of hostility, violence or aggression from a stranger²⁷. This includes up to nine out of ten people with a learning disability who say they have been bullied, harassed or harmed because of their disability, resulting in 32% of people with a learning disability not feeling safe in their homes²⁸.

There have been a number of cases where a person with a learning disability has died or experienced severe levels of abuse as a result of hate crime that could have been halted. Mencap believes that people with a learning disability who are victims of hate crime should be prioritised in housing services and on waiting lists, so they can choose to move away from the situation.



Peter and Jenny

Peter and Jenny are married and had lived together independently for six years. Jenny was forced to move out of their home and into residential care because of disability hate crime.

The couple had been victimised by local youths for three years when a serious incident brought things to a head in 2009. Although the community police team was helpful, Jenny remained traumatised by the abuse. She always felt nervous in her own home and no longer wanted to live there. She withdrew from activities she had previously enjoyed and became isolated. The couple registered with the local authority to join the housing waiting list.

After some time on the waiting list, Jenny suffered a breakdown and she had no other choice but to move into residential care, which was some distance from Peter.

Jenny is slowly recovering from her experience. She has moved to a supported living unit much nearer to home and has started taking part in hobbies and other activities again. She and Peter are spending a lot more time together. They desperately want to live together again but Jenny needs to live in a more supported environment for some time yet. The couple put their names on the list for a supported house or flat some months ago, but they are still waiting because they have been told theirs is not a 'crisis case'.

Experts involved in the case believe that if the couple had been treated as an urgent case, Jenny would probably not have suffered a breakdown and the couple would have been able to remain living in the same place.

²⁷ Scope discrimination survey. (February–March 2011). Scope/Com-Res.

²⁸ *Living in Fear*. (2000). London: Mencap.

People with a community care assessment

When a person's community care assessment identifies them as having a housing need, social services and housing departments should work jointly to ensure that all identified needs are met. In practice, we know that this joint work is patchy and, in places, non-existent.

A number of people with a learning disability and their families have told Mencap about care packages that have been put on hold until they are able to be housed. It is common for a family to have to wait for a house with a spare room before they can access a social care package, because an allocated room has to be available for a waking night carer. In these situations, families have been forced to wait months before they are allocated a new house with the extra bedroom, and can access their social care services. Another common situation is where an individual has to remain in a residential care home or assessment centre until a house has been allocated for them to live in a supported living set-up.

Mencap believes that individuals who are assessed as needing care and support should not be prevented from receiving this and should, therefore, be prioritised on housing waiting lists.

People living with older parents

As outlined above, the number of people with a learning disability living with parents aged 70 and over is increasing. Mencap believes that when these people ask to be added to the waiting list, local authorities should treat them as priority cases to make sure that they are allocated suitable housing at the earliest opportunity.



New challenges created by the Welfare Reform Act 2012

Significant numbers of people with a learning disability rely on support from the welfare state to fund their housing arrangements. Without access to this support, many of them would be unable to live independently. The recent changes to the welfare system seek to reduce government spending on welfare and therefore reduce the number of people who are financially supported. This will present a further challenge to people with a learning disability.

The next section of this report provides an analysis of the Welfare Reform Act 2012, setting out how we believe these changes will present further challenges, and their impact on local authorities.



The impact of the Welfare Reform Act 2012

The UK welfare system has recently seen one of the biggest shake-ups since its introduction, with a government focus on the creation of a 'fairer [and] more affordable' benefit system²⁹. The 2010 budget and spending review set out projected savings of £18 billion to the benefits bill by 2014–15, many of which were introduced through the Welfare Reform Act 2012. The government is also planning a further £10 billion of cuts, to come into effect from 2016.

As well as introducing a single working-age benefit – Universal Credit – to replace a range of existing means-tested benefits and tax credits for people of working age (from 2013), the act also makes other changes to the benefits system. These include changes to Local Housing Allowance, Support for Mortgage Interest (SMI), Exempt Accommodation and time-limiting contributory Employment and Support Allowance (ESA) for those in the Work-Related Activity Group, and the introduction of a new Personal Independence Payment (PIP) to replace DLA.

People with a learning disability and welfare benefits

Disabled people experience inequality and disadvantage in the form of things like lower employment and earnings potential, restricted access to goods and services, and higher general living costs.

Less than 7% of people with a learning disability known to social services are in any form of paid employment³⁰. Even when people do work, it is often for low pay and part-time hours. A third of disabled people live in poverty – double the rate for the rest of the population – and, as a result, are more reliant on benefits for basic income. Many people with a learning disability claim benefits, including ESA and Housing Benefit. In addition, many rely on DLA, which recognises the extra costs of living with a disability. The government's reform of the welfare system will therefore have a significant impact on people with a learning disability.

This section briefly considers some of the key changes introduced by the 2012 act and the potential impact on the abilities and aspirations of people with a learning disability to live independent lives.

New size criteria for social housing

12% of people with a learning disability known to social services have housing provided by either the local authority or housing association.

The Welfare Reform Act gives the government the power to introduce new size criteria (also referred to as 'under-occupancy' or 'bedroom tax') for the housing element of Universal Credit, when it comes into force. It is planned that the changes will be introduced in April 2013. Working-age Housing Benefit claimants living in social housing will face new size criteria rules, restricting Housing Benefit to allow for one bedroom for each person or couple living as part of the household. In effect, this will usually reduce the number of bedrooms that an individual is entitled to. As a result, tenants will either receive a reduced amount of Housing Benefit – and have to make up any shortfall between this and their rent – or be forced to move home.

²⁹ Department for Work and Pensions (2012). <http://www.dwp.gov.uk/policy/welfare-reform/>

³⁰ Social care and mental health indicators from the National Indicator Set – 2009–10 Provisional, August 12 2010: www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information

The government has estimated that 660,000 working-age people living in social housing will be affected, with 420,000 (66%) of these being disabled social tenants³¹. When the new rules are introduced, each claimant will see an average reduction in benefit of approximately £14 per week, taking into account forecast increases in social sector rents. The exception to the new size criteria will be in the case of disabled people who require an additional bedroom for a non-resident carer who provides them with overnight care. This will stop any reductions, based on under-occupancy, in Housing Benefit for these individuals.

Mencap is concerned about those people with a learning disability who rely on their spare room to support informal care arrangements, or who may be reliant on support networks in their local area. Forcing someone to move away from informal support networks, or use other (often limited) income to make up the difference in rent, will undermine their ability to live independently.

The issue is further complicated by the government's own admission that there is a lack of suitable homes in the social sector for under-occupying tenants to downsize to. Given the particular disadvantages that people with a learning disability could face as a result of this policy, Mencap believes that they should be prioritised for discretionary housing payments (DHP) by local authorities. However, the inadequacy of existing DHP funding will limit the support available to disabled people.



Jim is 43 years old and has Down's syndrome. He now lives in his own flat in Suffolk, but it has taken him more than 25 years to get a home of his own.

Jim has been living independently for just over two years in a social housing two-bedroom flat. He did not request a two-bedroom flat but it was the only one he was offered. He has finally settled in to his home and has adapted the extra bedroom as his office, complete with computer. The room also has a spare fold-out bed for when family and friends come to stay.

Jim and his parents are now very concerned that he may have to move as a result of the new under-occupancy policy. This would take him away from his local community and support networks, which they feel would be very disruptive and affect his mental wellbeing. Moving to the flat gave Jim his first real sense that he has rights and choice over his own life. Having to move would destroy his aspiration to live more independently and would probably have a negative effect on the many new skills he has acquired, as well as undermining his confidence.

Jim currently lives a relatively short distance from his parents, who support him as much as they can. He also gets 17½ hours' support from a support worker. If he was forced to move further away from his parents and support network as a result of changes to housing benefits, he would probably need more support paid for by the state.

³¹ This is made up of 390,000 local authority tenants and 270,000 housing association tenants.

See: *Housing Benefit: Size criteria for People Renting in the Social Rented Sector: Equality Impact Assessment*, June 2012, Department for Work and Pensions and *Housing Benefit: Under occupation of social housing: Impact Assessment*, June 2012, Department for Work and Pensions.

Localised schemes for Council Tax Benefit

The Welfare Reform Act introduces changes to the way Council Tax Benefit (CTB) is administered, passing decision-making responsibilities and administration to local authorities. Councils will also see a 10% reduction in funding, but have been told that the changes must not affect people of pensionable age.

Mencap is concerned that this reduction to already-stretched local authority funding will see the cut passed on to working-age claimants, with authorities having discretion over how savings are to be realised. We believe that, as a result, some people with a learning disability will lose out financially and not be offered any protection from the cuts. It is also likely that the localised decision-making will lead to significant variation in delivery, creating a postcode lottery of support.

Additionally, removing CTB from the pool of benefits that will be integrated into the Universal Credit, and therefore not including it in the calculations for an individual's Universal Credit amount, may well affect on the potential to reduce incentives to work. Yet this is the very thing the Universal Credit was supposed to improve because people may well be in the position of having to pay more Council Tax out of their other benefits or income from work.

Reform of DLA: a new PIP

The Welfare Reform Act replaces DLA with a new PIP for working-age adults, to be introduced in 2013. PIP will continue to be a non-means-tested benefit aimed at recognising the additional costs of living with a disability. All claimants will have to undergo a new assessment for PIP, including those already in receipt of DLA.

The government has estimated that 500,000 fewer people will be found eligible for PIP by 2015/16 than under the current DLA system³². While not directly providing for housing support, DLA – as a benefit that recognises the extra costs of living with a disability – is crucial to supporting the independence of disabled people. Mencap is concerned that the focus by government on those with the 'greatest need' will lead to people with more moderate (but still high) support needs living under major financial pressure to cover the additional costs of their disability themselves, should they lose eligibility for DLA or PIP. This would make it harder for them to live independently and even more likely that they will experience poverty. It is essential that the PIP assessment recognises the particular support needs of people with a learning disability, and that the assessment process is fully accessible to this group.

Furthermore, receipt of DLA acts as a 'passport', or gateway, to other support. This includes the Severe Disability Premium (SDP), Blue Badge eligibility and Carer's Allowance, as well as providing an automatic exemption to some of the other rules introduced by the Act, including the household benefit cap and under-occupation. While the government has stated its intention to maintain existing arrangements under PIP wherever possible, the reduced number of people eligible for the benefit will inevitably lead to a loss of additional entitlements for some.

³² <http://www.dwp.gov.uk/docs/pip-assessment-thresholds-and-consultation.pdf>



Frances

Frances has a mild learning disability and reduced mobility. She receives the lower rate of both the care and mobility components of DLA. Frances uses her DLA care payment for a supporter to come to her home once a month to help her go through her bills. This support means that she is able to live independently.

“I find it a struggle with my bills. Without support I get into a lot of debt – I could lose the roof over my head!” says Frances.

Frances uses her DLA mobility component to visit her family. She has difficulty walking, is unsteady on her feet and cannot stand for long, which can make things difficult on the bus.

“I have to ask people if I can sit down. Often they just stare at me. It is upsetting because it makes me feel different. I have been called names as well... even the ‘c’ word.”

Frances lives some distance from her sister and other family members. It’s a long bus journey, with too many changes for her to manage, so she has to take a taxi when she visits them. Without her mobility money, she would be unable to afford the cost of travel and be at risk of losing touch with friends and family.

Frances is really worried about how she would cope if she lost the money when DLA is replaced with the PIP. In the past, Frances got into debt when she had no one to help her manage her finances.

Other aspects of welfare reform

Other changes that could well affect the ability of people with a learning disability to lead independent lives include the following:

- **Time-limiting contributory Employment and Support Allowance (ESA) for some disabled people**

Contributory ESA applies to those people who have paid sufficient tax and National Insurance. The Welfare Reform Act is time-limiting support for those in the Work-Related Activity Group (WRAG) of people with ‘limited capability for work’ but deemed able to carry out some work-related activity to move towards work. The 2012 Act provides a maximum period of 365 days on this benefit.

This limitation will affect around 700,000 individuals by 2015/16. Of these, it is expected that 30% may receive a reduced rate of income-related ESA (depending on their other income), and 40% will not qualify for income-related ESA at all³³. The Department for Work and Pensions does not provide a separate figure for the number of people with a learning disability who are affected, but we do know that there are 146,000 people in the wider ‘mental and behavioural disorders’ category already receiving ESA³⁴.

³³ Department for Work and Pensions. (2011). *Time limit contributory employment and support allowance to one year for those in the work related activity group: Impact Assessment* www.dwp.gov.uk/docs/esa-time-limit-wr2011-ia.pdf

³⁴ This figure includes those in the Support Group of ESA, and does not include people with a learning disability still on incapacity benefits and awaiting their WCA.

- **Changes to Local Housing Allowance rates – private-rented sector**

Before the Welfare Reform Act came into force, Local Housing Allowance (LHA) rates were changed monthly to reflect the changes in real rents locally. Recipients of LHA would receive rates set at the 30th percentile of all rents in the local area*. The Act and subsequent regulations changed this and, since April 2012, the LHA has been reviewed annually. Every April, rates are set at the lower of the previous LHA rate, which is uprated by CPI inflation or the 30th percentile of local market rents.

*Before April 2011, LHA rates were set at the median of all rents.

Around half of those on Housing Benefit in the private rented sector have someone in the household who describes themselves as having a disability covered by the Equality Act 2010³⁵.

- **Household benefit cap**

From April 2013, there will be a cap on the total amount of benefit that people of working age can receive. The cap will be set at £500 for a lone parent or a couple, and £350 a week for those who are single. It will apply to combined income derived from benefits including Jobseekers' Allowance, Income Support, ESA, Housing Benefit, Child Benefit, Child Tax Credit and Carer's Allowance. If someone's total benefits assessment is greater than their cap, their local authority will reduce their Housing Benefit payments.

Households will be exempt from the cap if they include: a war widow or widower, someone who is claiming Working Tax Credit or the ESA support component, or a claimant, partner or child who is receiving DLA or a PIP payment. Mencap is concerned that adults with a learning disability who are not in the ESA support group and ineligible for PIP could become subject to a benefit cap reduction. This could mean they would struggle to meet rent liabilities and possibly be at risk of homelessness.

- **Universal Credit**

Universal Credit combines a number of key means-tested benefits, including income-based ESA, income-based Jobseekers' Allowance, Income Support, Housing Benefit and tax credits. Many disabled people will gain from the new system, but for others the change will lead to a reduction in support through the merger of tax credits and disability premiums in Universal Credit³⁶.

Mencap is particularly concerned about the loss of the Severe Disability Premium (SDP) in the future Universal Credit. SDP provides additional support to some disabled adults if no one is paid Carer's Allowance for assisting them. As a result, many disabled people will be worse off. This will cost disabled adults with no one to care for them, or with only a young carer, about £58 per week (over £3,000 per year).

Another change is the reduction of disabled child additions. Currently, families with a disabled child may get the disability element of Child Tax Credit, worth £57 a week. But under Universal Credit, such support is to be provided through 'disability additions' to household benefit entitlements, and the proposal is to cut this to just £28 a week. This will affect all families with a disabled child – unless the child is getting the higher rate of the care component of DLA or is registered blind – and is equivalent to a loss of around £1,500 per year. The government estimates that this change will affect around 100,000 disabled children.

³⁵ <http://www.dwp.gov.uk/docs/eia-hb-lha-cpi-uprating-wr2011.pdf>

³⁶ The Children's Society, Disability Rights UK and Citizens Advice Bureau. (2012). *Disability and Universal Credit*.

The government states that savings made from reductions in the disability addition for children and the SDP will be used to increase the means-tested addition for those in the Support Group of ESA. However, while couples with someone in the support group will gain, those in the support group who live on their own and do not have a carer will still be worse off under Universal Credit.

- **Abolition of the Social Fund**

The Welfare Reform Act abolishes the discretionary Social Fund, which provides Community Care Grants and Crisis Loans, from April 2013. The fund currently provides financial support for emergency expenditure and urgently needed items. Instead, an allocation of money will be given to local authorities for local delivery of assistance, but there is no new statutory duty placed on local authorities to deliver this provision, nor is funding to be ring-fenced. The amount that local authorities will receive is also lower than previous payment levels, by almost a third in some areas. The concern is that financially-squeezed local authorities will reduce or cease this support of adults of working age.

- **Changes to support for mortgage interest**

Outside the Welfare Reform Act, the government has introduced a number of other welfare reforms that affect financial support towards housing costs and other additional costs. These include changes to the Support for Mortgage Interest (SMI) scheme. The SMI scheme, which offers financial help towards mortgage interest payments, has provided another avenue of housing for many people with a learning disability, often filling gaps in local provision of accessible accommodation.

The reduction of allowable mortgage interest rates and the plans to end the government's Home Ownership for people with Long-term Disabilities (HOLD) scheme makes this an unaffordable option for many people and significantly limits the prospects of property ownership for people with a learning disability.

- **Exempt accommodation³⁷**

Many people with a learning disability require a level of support alongside their housing provision – through, for example, supported living schemes. The special treatment of 'exempt accommodation' dwellings enables Housing Benefit to meet the additional costs of providing this type of specialist housing.

Around 40,000 people with a learning disability depend on 'exempt accommodation' to live independently³⁸. This is set to increase by at least 14,000 extra supported accommodation properties over the next 15 years³⁹. This growth is due to several factors, including: the personalisation agenda in care services, the move away from large-scale residential care provision, and the intention to support more people with a learning disability to remain living near families or other social networks (and avoid long-distance care placements, for example).

The government recently consulted on changes to the rules around exempt accommodation and is expected to develop a new system over the next few years. Mencap believes that the government must ensure that any change will not result in people with a learning disability facing less choice in where they can live due to a lack of support services.

³⁷ Accommodation provided by a council, housing association, registered charity or voluntary organisation where that body or person acting on the claimant's behalf provides them with care, support or supervision.

³⁸ Boath, M., Baker, E. & Wilkinson, H. (2010). *Exempt and supported accommodation*. London: DWP.

³⁹ Cordis Bright

How will these changes affect the housing situation?

Many people with a learning disability will be affected by these changes and, worryingly, a large number of them will be hit by the cumulative impact of several of these changes. It is likely that people who are affected by one of the reforms will be affected by several others.

Where current housing options and life opportunities may already be limited for people with a learning disability, these reforms present a real challenge to the aspirations and future options available to these individuals. In terms of housing options specifically, these changes come together to reduce availability across the three main housing sources available to people: public sector or social housing, private sector and home ownership.



Recommendations

Although we have come a long way in realising independent living through the closure of institutions and long-stay hospitals, we have not achieved our goal. There are still barriers preventing people with a learning disability from living independently. Mencap fears that the recent changes to the welfare system will play a significant role in the creation of further barriers.

What is disappointing is that ambitions and goals set out in government policy in the last ten years have not been put into practice, and the current housing and support system is failing many people.

We may soon see a new form of ‘institutionalisation’ evolve, as people with a learning disability face a lack of housing options due to population growth and budget pressures. While they may not be physically separated from society, by being denied their right to choose where and with whom they live, they are not being treated as equal citizens.

When looking at the barriers to independent living, Mencap found that there was a lack of understanding at national and local levels about how to put policy into practice. Problems are also caused by not knowing how many people with a learning disability live in each area, which makes it impossible for local authorities to plan strategically for the future. This is why we make two clear recommendations, which we believe will start the process of improving access to independent living:

Recommendation 1 – There is a national strategy for housing people with a learning disability.

Recommendation 2 – All local authorities should develop specific plans for improving the housing situation of people with a learning disability in their housing strategies.

National strategy

It is clear that the government supports the independent living agenda, through its own strategies and the international human rights legislation it has signed up to. However, the problem lies in putting this policy into practice, which is why we need a national strategy with an action plan.

A national strategy should be introduced with the clear aim to increase the access to independent living for people with a learning disability. Pulling together existing government policy on independent living and housing for people with a learning disability, this strategy should set out an action plan to put this policy into practice.

This strategy will need to address the existing barriers to housing and support services – in particular, reducing the impact of the Welfare Reform Act and the wider pressures on local housing authorities. Mencap believes that the strategy must identify how the government can work with local housing authorities and service providers to ensure that we are all working towards a shared goal. Furthermore, it will be imperative for the strategy and action plan to address the growing need for housing-related support, especially in light of planned reforms to exempt accommodation.

Local planning

As well as adopting the national strategy, local authorities need to take a leading role in promoting independence in their own areas. With a greater emphasis on localism and recent changes to the welfare system, this role is imperative.

To support the national housing strategy, we believe that top- and lower-tier local authorities should work together to create a local strategy and action plan aimed at increasing the number of people with a learning disability living independently. In particular, the local strategy should include plans to:

- understand the local population of people with a learning disability and their housing needs
- cope with growing demand for services
- promote joint working between local authority departments and other agencies, including those in the private rented sector – in particular, encouraging an enhanced cooperation with adult social care departments
- prioritise people with a learning disability in the spending of discretionary funds
- amend housing allocation policy to prioritise people with a learning disability who have been victims of hate crime, those assessed as having care and support needs and people who live with parents aged 70 and over
- work with families on planning for the future and increasing the number of people who have plans in place for when families are no longer able to care for them – in particular, having a target of an agreed plan in place for every adult who lives with parents aged 70 and over
- incorporate set priorities across local authority services and departments
- provide information, advice and advocacy services
- implement the national strategy.

Conclusion

Housing arrangements for people with a learning disability have come a long way since the 1960s, when people were housed in institutions that kept them apart from the rest of society. This is a result of national government and local authorities working together with people with a learning disability and their families to move towards a system founded on the principle of independent living.

However, there is further to go to reach a stage where independent living is the norm. Today, there are too many people with a learning disability living in inappropriate housing arrangements that do not enable independent living.

Mencap looks to local authorities and national government to be bold and take the steps that are required to reach our common goals.

Appendix – Methodologies

The observations and positions in this report are based on two thorough research projects, supported by a number of case studies providing evidence on the current housing situation for people with a learning disability.

The first research project was a report by Cordis Bright, commissioned by Mencap, to establish where people live and the barriers associated with housing. The second was a research project undertaken by Mencap to establish a clear picture of the routes into housing services for people with a learning disability and their families.

The housing needs of adults with learning disabilities in England and Wales – Cordis Bright, 2011

In this report, Cordis Bright combines numerous sources of data and makes a number of extrapolations to derive estimates applying to the population of adults with a learning disability known to local authorities. Full details of individual calculations can be found in footnotes within the main body of the report. The data sources include the following:

Primary data	Secondary data
<ul style="list-style-type: none"> - Freedom of information requests to all 174 local authorities in England and Wales - Survey of 32 local authorities in England and Wales - Telephone interviews with seven local authorities - Survey of 27 residential care providers - Survey of 496 parents and carers 	<ul style="list-style-type: none"> - Review of existing literature and data - Collation and analysis of data from ten local authority learning disability registers

A full breakdown of the study’s questions, data and methodology can be found in the full report.

Routes into housing – Mencap, 2011

The research was conducted over a three-month period from June until the end of August 2011.

Following a call for people to come forward to share their experiences – or the experiences of those they care for – of finding housing, we identified 11 case studies. We conducted semi-structured telephone interviews with seven of the case studies and received detailed written correspondence from the four others. We also received copies of four individuals’ community care assessments. Respondents included people with a learning disability and their family members, carers and advocates. The case study subjects received varying levels of support from social services, ranging from 24/7 and two-to-one support, to those who received no regular social services input.

We also ran a focus group with a range of housing professionals and support staff. The group discussed the issues raised by our secondary research and interviews in great depth, to understand what steps could be taken to improve the process of moving into independent living for people with a learning disability.

Given the nature of our methodology, data is primarily qualitative.