Mencap NI Briefing Paper No.2

Ordinary houses in ordinary streets:

Independent social care and housing solutions for people with a learning disability

May 2018
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**Key statistics**

**In the UK**, there are approximately **1.4 million** people with a learning disability.

**In Northern Ireland**, there are approximately **42,000** people with a learning disability, including **31,000** adults.

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3. These approximate figures have been calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2017). Approximately 2.16% of adults and 2.5% of children in the UK are believed to have a learning disability.
Introduction

Mencap believes that people with a learning disability can attain equality in society by being empowered to have choice and control over their own lives.

Living independently in the local community with appropriate care and support has a key role to play in this. As such, through our strategic priority on social care, Mencap is committed to helping improve access to high quality supported living so that people with a learning disability can lead more fulfilled lives.

Access to safe, secure and affordable housing is a basic human need and essential for overall positive health and well-being. Housing shortages across the UK can highlight many social inequalities, most notably related to poverty and income. There are also a number of housing inequalities that are perhaps less well documented, including some particular challenges for people with a learning disability. Barriers to accessing suitable housing and social care support means that many do not have a choice about where and with whom they live. A recent assessment in Northern Ireland of housing outcomes across statutory equality categories\(^4\) reported that those with a learning disability do not always have an opportunity to live independently (Equality Commission NI, 2017a).

About this paper

This paper presents an overview of Mencap’s Personal Support service in Northern Ireland. It highlights the innovative, person-centred model developed with Golden Lane Housing to support more people with a learning disability to live as independently as possible. The paper also discusses the main barriers to independent living and makes recommendations for wider policy and practice.

Mencap established **Golden Lane Housing (GLH)** as an independent national charity in 1998. GLH tailors housing options (new build, leasing, partnership) to meet the needs and aspirations of people with a learning disability in locations of their choice, and is a Registered Provider of social housing in England. Its mission is to provide a quality home around which people with a learning disability can build their lives. The charity has so far transformed the lives of more than 1,700 people with varying needs in over 800 properties.

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\(^4\) Section 75 of the Northern Ireland Act 1998.
Only **15%** of people with a learning disability have some form of tenancy or ownership of their own home.\(^5\)

**Policy context**

Policy across the UK has generally shifted away from housing people with a learning disability in residential and nursing care, towards promoting independent living in supported housing models. While Northern Ireland is the only UK region not to have developed a specific strategy or plan on independent living, a wide range of NI policy recognises that it plays an important role in promoting social inclusion and enabling people to lead fulfilled lives (e.g. NI Executive, 2015; DHSSPS, 2012; OFMDFM, 2012; HSC, 2011; DHSSPS, 2005). Key to successful independent living, the urgent need for whole systems change to transform and reconfigure health and social care support has also been identified (Kelly & Kennedy, 2017; Bengoa, 2016).

**Where people live**

Learning disabilities are diverse in nature, ranging from mild to moderate, to more severe and profound. As such, adults with a learning disability have varying social care and accommodation needs. This includes those who require some additional support to maintain independent living, and others with multiple and complex needs who require access to more specialist care placements.

Across the UK, most adults with learning disabilities now live outside long-stay institutions. Their accommodation is wide-ranging, from residential and nursing care through to supported living, tenancies and home ownership, with the majority still living with their families (Hatton, 2017; Mencap, 2012). In Northern Ireland, there is limited data available across all living arrangements

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\(^5\) Golden Lane Housing [www.goldenlanehousing/whoweare](http://www.goldenlanehousing/whoweare)
for adults with a learning disability (Hatton, 2017); however, most of those known to statutory services (almost 80%) are living with family carers (Taggart & Hanna-Trainor, 2017).

A lack of choice in where people with a learning disability can live in NI, particularly access to supported living, is a priority issue (All Party Group on Learning Disability, 2018; Patient and Client Council, 2015). Family carers often provide unpaid full-time care as well as accommodation. 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 (Mencap, 2012).

Why independent living?

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides that people with a disability have the right to live independently and be included in the local community.

People with a learning disability are at greater risk of poor life outcomes compared to their peers. For example, they are more likely to experience social isolation and loneliness (Gilmore & Cuskelly, 2014), and have poor physical and mental health (Emerson et al, 2011). Their primary carers are also more likely to experience greater levels of stress, anxiety and depressive symptoms, and have less contact with family and friends (Seltzer et al, 2011). A range of physical health problems, including obesity and arthritis, is also more prevalent amongst family caregivers (Seltzer et al, 2011; Yamaki, Hsieh & Heller, 2009).

Supported independent living has an important role to play in helping improve outcomes for people with a learning disability and their families. Evidence suggests it has a positive impact on their overall health, well-being and quality of life (Housing Learning & Improvement Network (LIN), 2018; GLH, 2017 & 2015). It also reduces the social isolation of family carers and promotes positive mental health (GLH, 2017).

In addition, supported independent living is a cost-effective way of providing housing to those with the most complex needs (Housing LIN, 2018; GLH, 2017). Golden Lane Housing estimates it saves the public purse between £500 (residential care) and £2,500 (hospital setting) per tenant per week by supporting them to move out of more expensive accommodation and care settings (GLH, 2017).

The benefits of supported independent living include:

- More positive family relationships and social life
- Increased independence
- Increased community inclusion
- Improved living space and adaptations
- A better sense of personal safety
- Improved physical and emotional well-being of family members
- A cost-effective and sustainable approach

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4 Golden Lane Housing, 2017.
Provision of social care
It is projected that the number of people with a learning disability will increase by one percent each year over the next 15 years (RQIA, 2016). Continued growth in the learning disability population means more people will need housing and social care support (Mencap, 2012). This includes individuals with profound and multiple learning disabilities who often require more expensive care packages alongside their housing arrangements. Currently in NI, housing is generally regarded as a ‘peripheral activity’ in relation to adult care and support (Kelly & Kennedy, 2017).

Underpinning these challenges are significant difficulties relating to the quality, recruitment, retention and overall sustainability of the social care workforce; as well as fragmented delivery of core services such as health, social care and housing (Kelly & Kennedy, 2017). There are also increased, and currently un-resourced, costs relating to the higher rate for sleep-in staff in NI [See Text Box].

A good system of social care is vital to help people with a learning disability live independently and have choice and control in their daily lives. While funding pressures are undoubtedly challenging, the need for transformational change in the way that social care services operate and deliver in NI has been identified (Kelly & Kennedy, 2017; Bengoa, 2016). Effective change will need to include sustainable funding, workforce planning, and new approaches to care (NI Social Care Council, 2017).

Sleep-ins
Across the UK, various organisations provide a range of support and care to adults with a learning disability to enable them to live independently. For some adults this includes ‘sleep-in’ staff who are on call at night in case of an emergency and are generally able to sleep through the night. Employment tribunals and a subsequent change from previously accepted practice and guidance requires that in the majority of cases ‘sleeping time’ is considered as working time for National Minimum Wage (NMW) / National Living Wage (NLW) purposes.¹

Back pay: HMRC are indicating that providers must back pay all relevant ‘sleep-in’ staff, potentially going back a period of up to six years, and costing around £400million. The impact of retrospective payments presents a significant financial challenge to organisations who adhered to the regulations in place at the time; and has the potential to undermine vital services for people with a learning disability.

Increased costs: Sleep-in shifts are likely to increase care and support costs across the sector in the UK by over 4% every year, adding over £600 million to the wage budget by 2020. In Northern Ireland, some organisations are currently funding the additional costs of the higher rate for sleep-ins out of their own reserves.

¹ Mencap has paid the NLW for sleep-in shifts since April 2017.
Limited housing options

Difficulty accessing the crowded private and social housing sectors: Some private landlords lack understanding about people with a learning disability, and often do not accept payment of rent via Housing Benefit (GLH, 2015). A relatively small proportion of social housing is available for individuals with a learning disability, with priority given to those assessed to have the most complex needs. However, much of the mainstream social housing stock is not physically suitable for people with the highest support needs.

Lack of community-based supported housing: Developments in specialist housing seem to have considerably slowed in NI due to both a lack of funding and alignment with social care (Kelly & Kennedy, 2017). People with a learning disability most in need of supported accommodation include those who are living with ageing carers or waiting to be resettled in the community following a period in a long-stay hospital (‘delayed discharges’). It also includes a small number of individuals with particularly complex needs and challenging behaviours who are living in costly, specialist in-patient units outside NI. Notably, Transforming Care Partnerships (TCPs) have been set up across England with the aim of facilitating people with a learning disability, autism and/or challenging behaviour to move out of inpatient units into more appropriate support in the community.

Under-investment in home adaptations: Housing adaptations are cost effective and can promote independent living by making the home of a person with a disability more suitable for their needs (NI Executive, 2015). Evidence suggests they can:

- reduce the demand on social housing from other tenures
- prevent or delay entry into more expensive residential placements
- reduce the costs of home care
- improve quality of life for individuals and family carers.

Demographic trends indicate growing demand for home adaptation services as the population ages (NI Executive, 2015). Many people with disabilities in NI live in homes that are inadequate; and there is a need to streamline the adaptations and disabled grants process to reduce waiting times (Equality Commission, 2017b). Grants are also generally aimed at meeting the needs of existing tenants rather than those seeking to access and adapt a newly purchased property.

The average cost of providing home adaptations is four times less than that of residential care.

Lack of joined-up statutory approach to inform Local Development Plans: Council Local Development Plans include policies and proposals for the use and development of land in their area to meet the needs of the community. As these plans are informed by data which does not capture the significant number of adults living at home, and who are therefore not included on complex needs housing application lists, they generally do not reflect the supported housing requirements of people with a learning disability. They also do not consider the many individuals living in residential / nursing care for whom supported living in the community may be a better option.

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8 For example, a wheelchair-accessible flat, equipment such as a hoist, and enough space to enable the person’s support needs to be met.
Lack of forward planning

Demographics: There is a lack of comprehensive data about the learning disability population in NI. For example, the total number in each Health and Social Care Trust (HSCT) is unknown; this information is not collected in a single regional common information system with agreed data sets (RQIA, 2016). Without up-to-date, disaggregated data, or taking account of future population trends, statutory agencies are not in a position to plan strategically to meet the level of need.

Transition from child to adult services: There is an inconsistent approach to transition planning in NI, and the need to plan for the growing proportion of school leavers with more complex physical and behavioural needs (RQIA, 2016). A lack of joined-up planning, combined with limited housing solutions, can significantly reduce opportunities for people with a learning disability to lead a full, independent adult life.

Ageing carers: Compared to elsewhere in the UK and Ireland, NI has a higher proportion of older people with a learning disability being cared for in the family home by an ageing family carer (Taggart & Hanna-Trainor, 2016). In our experience, there is a lack of quality information, advice and support for families to make and implement plans for the future, including consideration of their home as a capital or physical asset. Alternative accommodation is often only considered when a crisis emerges, such as the death or illness of a family carer, resulting in a reliance on high-cost emergency housing solutions. Sometimes in these situations, the family may have been previously unknown to statutory services. It has been suggested that the hidden demand for housing support from people with learning disabilities living with older carers requires a more strategic and robust approach to needs assessment (DSD, 2015); and each HSCT should monitor and ensure that effective future planning is taking place in relation to older carers and their needs (RQIA, 2016).

Participation: Detailed planning helps ensure individuals with a learning disability can make informed choices about where they want to live. In a crisis, they are unlikely to be fully involved in decisions about their housing arrangements, or allocated accommodation that best meets their needs. The Personal and Public Involvement (PPI) approach\(^\text{12}\) has a key role to play in effectively engaging service users and carers with those who plan, design and provide services.

One third of adults with a learning disability who live with their families are living with a parent who is over 70 years old.\(^\text{11}\)

\(^{11}\) British Institute of Learning Disabilities (BILD) http://www.bild.org.uk/resources/ageingwell/olderfamilies/

\(^{12}\) PPI is a legislative requirement for Health and Social Care organisations as per the Health and Social Services (Reform) Northern Ireland Act 2009.
All Party Group on Learning Disability

In Northern Ireland, the All Party Group on Learning Disability (APGLD) held a stakeholder event focused on identifying current priority issues for people with a learning disability (APGLD, 2018). Limited access to supported housing options was a predominant issue of concern, with recommendations including the need for greater choice; a dedicated learning disability housing strategy; and an improved cross-departmental approach to housing and support.

“Everyone has a right to be happy and content in their own homes, we just need extra support to help us live a full, fulfilling life.”

“I cannot get a suitable home at present. On waiting list for many years, I am 37 this year and desperately want to be independent albeit with support. It would give my family peace of mind to know that I am settled and happy before anything happens that might cause a crisis.”

“Lots of our friends have severe learning disabilities who have specific behaviour issues that need special staff and living requirements. There is a lack of sufficient places... we need more specialised care out in the community.”

What works?

Mencap’s Personal Support service currently supports almost 80 people in NI to live independently in a mix of individual or shared flats / houses (generally accommodating up to 4 people).

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“I cannot get a suitable home at present. On waiting list for many years, I am 37 this year and desperately want to be independent albeit with support. It would give my family peace of mind to know that I am settled and happy before anything happens that might cause a crisis.”

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13 The 80 participants included a wide range of healthcare professionals, organisations, young people and adults with a learning disability, MLAs, parents and carers.
Key features of the service include:

**Integrated services**

Supported living provision ranges from one-to-one support for a few hours in their own home, up to 24-hour support in specially adapted accommodation. A LifeStyle Support service assists people within their own home with tasks such as daily living, finances, maintaining their tenancy and day opportunities. People also receive support to access services and activities within their local communities.

**Positive Behavioural Support**

With a strong evidence-base for its use, Positive Behavioural Support (PBS) is the most effective framework for supporting individuals who display challenging behaviour, including adults with a learning disability (PBS Coalition UK, 2015). Typical behaviours can include aggression, self-injury, withdrawal, and disruptive or destructive behaviour (NICE, 2015). They can affect an individual’s quality of life and opportunity to access and maintain independent living. Across the service, staff have received training in the principles of PBS, with managers also trained as PBS coaches. All staff work with tenants to help identify and avoid possible triggers for challenging behaviours, and implement appropriate strategies to reduce their frequency and severity.
Assistive technology can be cost effective, and has huge potential in the provision of adult social care (Kelly & Kennedy, 2017). Policy approaches such as self-directed support, person-centred planning and personalisation encourage their use in supporting independence, choice and control (Voices of Disability Group, 2013). Mencap’s supported living services increasingly use assistive technologies to complement the personal support provided, and enable people to live as independently as possible. These consist of personalised equipment, software and products to assist individuals with their daily needs. We are pioneering the use of 360° imagery and Virtual Reality technology in supported living in NI, to help tenants see and plan their new homes before moving in.

For example, door alarms, bed sensors, video monitors and home care calls.

Computer technologies that use software to generate realistic images, sounds and other sensations that replicate a real environment (or create an imaginary setting), and simulate a user’s physical presence in this environment. Funded by both the Northern HSCT and Building Change Trust (Techies in Residence) we are developing interactive social stories aimed at building a person’s confidence through virtual experience of a task before it is physically undertaken.

The service works in partnership with various statutory and voluntary colleagues in terms of identifying need and providing solutions. This includes the Health and Social Care Trusts, the Regulation and Quality Improvement Authority (RQIA), Golden Lane Housing, the Northern Ireland Housing Executive (NIHE), and local Housing Associations. We also work closely with education and training providers, community groups and other voluntary sector agencies.

Partnership working

Some models are designed to provide an environment in which both the individual and their support team have the best opportunities to implement and benefit from effective Positive Behavioural Support.
Meeting an individual’s specific accommodation and support needs is a core tenet of the Mencap Personal Support service. Most recently, we have been working with Golden Lane Housing in NI to develop innovative ways of providing person-centred social care and housing solutions. Consideration is given to all the potential ways in which housing can be provided, including: inheritance, succession, ownership, co-ownership and ethical private renting. There are a range of investors and investment opportunities, and less reliance on statutory capital investments. The model also clearly aligns with the draft Programme for Government in terms of improving the quality of life for people with disabilities and their families (Indicator 42).

It consists of **three** key elements:
Golden Lane Housing are responsible for the first charity bond ever listed on the London Stock Exchange. They raise Retail Charity Bonds\(^\text{16}\) (social investment) for the purchase and adaptations of property for people with a learning disability in their local communities, either as individuals or in groups. This scheme is often a preferred option for families to help prepare for the future when they can no longer give the same level of support, and so that young adults can gain independence. Combined with specialist support from Mencap, tenants benefit from having security of tenure and well-maintained, safe and appropriately adapted accommodation.

The Great Tenants Scheme enables people to rent a home through the private rental sector in a location of their choice, and tailored to their specific needs.

It is suitable for people living on their own or with others. GLH leases properties directly from the owners,\(^\text{17}\) and then liaises with tenants as the landlord. As well as ensuring tenants have good quality housing, this approach helps overcome barriers such as paying deposits, or a reluctance by some landlords to accept people in receipt of benefits. The provision of personal day-to-day support is commissioned by the HSCT and provided by Mencap.

Many families are keen to find a long-term housing solution to secure their loved ones’ future. The Our House scheme helps them put their money / property into a discretionary trust fund run by the Mencap Trust Company (MTC).\(^\text{18}\) After parents pass away, this enables their son or daughter to carry on living in the family home, or in an alternative suitable property. MTC enters into a lease arrangement with GLH, who manage and maintain the home for the beneficiary. They build a relationship with the beneficiary and their support team to make sure things continue to work, year after year, as their needs and ambitions change. With the introduction of GLH in NI, families living here can now benefit from this option.

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\(^\text{16}\) Retail charity bonds help established charities in sectors like supported housing access affordable finance and deliver their social mission.

\(^\text{17}\) This will normally range from one to seven years (or occasionally longer).

\(^\text{18}\) MTC is a fully owned subsidiary of Mencap; it has been successfully running hundreds of discretionary trusts on behalf of people with a learning disability since 1976.
Personal story: Bryan and Warren

Bryan (40) and Warren (38) are brothers who have a learning disability and complex needs that require 24-hour care. They had previously been living apart for 23 years due to a lack of suitable accommodation. While Warren lived at home with their parents, Bryan had lived in a nursing home over 30 miles away from the family home. Balancing the practicalities of caring for one son while maintaining regular visits to the other was often very difficult for the brothers’ parents.

Mencap’s Personal Support service worked closely with the family and the Western Health and Social Care Trust (WHSCT) to develop a successful supported living solution tailored to Bryan’s and Warren’s individual needs and aspirations. This involved Mencap accessing capital through Golden Lane Housing, using their innovative Retail Charity Bond, to purchase and adapt a suitable property. Bryan and Warren have since settled in well to a new bungalow near Omagh. They share their home with two other adults with a learning disability, and have 24-hour care and support.

“We can call and see our sons whenever we want, just for five minutes after shopping or for a couple of hours at a time. We don’t have to make an appointment or stick to visiting times. It is just wonderful. We are safe in the knowledge that our sons are content in what we can only describe as a home from home.” (Parent)
“The Western Trust had, for a considerable period of time, attempted to find a solution for Warren and Bryan; the lack of providers close to home and the wish for both brothers to live together brought challenges and barriers. However, Mencap and Golden Lane Housing were able to open a new door and provide a solution whereby both brothers could be reunited, and their parents were close at hand with reduced travel. A local solution has been delivered which makes perfect sense for all parties – the WHSCT, Mencap, GLH, and particularly Bryan, Warren and their parents” (WHSCT).
Liam is 22 years old and has a mild learning disability. He previously experienced some challenges living in shared accommodation, and needed more personalised support to live independently. The **South Eastern Health and Social Care Trust (SEHSCT)** worked with Mencap and Golden Lane Housing to find an appropriate housing solution, which entailed GLH taking out a lease on a detached property where Liam now lives as their tenant.

GLH spent time with Liam to discuss all aspects of the tenancy agreement, which was also provided in an Easy Read format. This supportive landlord approach ensures that Liam receives ongoing help from GLH to manage his tenancy. In consultation with Liam, especially in terms of considering compatibility, a second tenant has recently moved into the property.

Mencap provides one-to-one support with establishing daily routines, cooking, budgeting and life skills. This has helped Liam become settled, confident, and increasingly able to access the local community independently, where he has made many new friends. He would like to progress into paid work, and is participating in external courses aimed at building up his employability skills.

“We have worked collaboratively with Mencap and GLH to deliver integrated housing and social care provision for adults with a learning disability. The Great Tenants scheme has had the positive impact of providing them with secure tenancies in their own community.”

(SEHSCT).

“Golden Lane Housing were able to provide me with a nice house that is big and spacious. It was good fun to go go-karting with other tenants supported by Mencap. I get more time to go out independently, staff help to organise activities.”

(Liam)
Outcomes

Since 2016, the partnership in Northern Ireland between Mencap and Golden Lane Housing has delivered:

- **22 supported housing tenancies**
- **Privately rented homes for 12 people (‘Great Tenants’)**
- **£1.1m capital investment**
- **£5m capital projects in development**
- **Bespoke accommodation for 10 people (‘Ordinary Houses’)**

“"I love living on my own and I am happy in my new flat. I have more independence and I would like to live here for a long time.”

Key Features:

**Mencap NI Personal Support service**

- Supports people with a learning disability to make decisions about their own future
- Provides a responsive and person-centred approach
- Offers a range of cost-effective and sustainable social care and housing solutions
- Works in partnership with individuals, families and statutory, community and voluntary agencies
- Delivers services within an evidence-based framework of Positive Behavioural Support
- Complements personal support with innovative and pioneering assistive technologies
- Shares learning with practitioners and policy-makers
1. The NI Executive should ensure that health and social care reform is supported by appropriate levels of sustainable investment so that people with a learning disability can receive the quality and variety of care needed for them to lead fulfilled lives.

2. The NI Executive should ensure that the development of a social care workforce strategy includes staff being equipped with the necessary skills to support people with a learning disability, particularly those with complex needs. Social care staff should also be paid a wage that reflects their skills and responsibility, and be valued for the work they do.

3. The NI Executive should maintain a ring-fence on funding for the Supporting People programme, and provide the additional resource it needs to effectively support vulnerable adults to live independently, including those with a learning disability.

4. The Department of Health, Health and Social Care Trusts, Department for Communities and NI Housing Executive should:

   - develop a clear, joined up approach which ensures the social care and housing needs of people with a learning disability are identified and more closely aligned.
   - work more closely with Councils to ensure that people with a learning disability are identified, and their housing needs fully reflected, in Local Development Plans.

5. The NI Executive should develop an independent living strategy for people with a learning disability in Northern Ireland.

   The strategy should include:

   - consideration of changing demographics, and improved data collection about the local learning disability population.
   - a joined up approach which brings together existing strategy and policy recommendations across health and social care, housing, transport and other areas.
   - a review / mapping of existing housing options for people with a learning disability.
   - improved access to a more diverse range of sustainable and person-centred supported living provision.
   - improved provision of home adaptations across all tenures.
   - earlier identification of people with a learning disability who are living with ageing family carers, particularly those aged over 70, ensuring each has an agreed social care and housing plan for the future.
   - quality information, advice and support for families about options such as using the family home as a capital or physical asset.
   - improved planning for the transition from children’s to adult services.

6. The UK government should publicly undertake to fund the back pay for the historical liabilities on sleep-in shifts; and service commissioners in Northern Ireland should commit to funding the increased costs of sleep-in shifts.
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