

Leaving Home, Moving On

Housing options for people
with learning disabilities



THE
FOUNDATION FOR PEOPLE
WITH LEARNING DISABILITIES

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If you are the parent of a teenager or an adult with a learning disability who is living at home with you, this booklet is intended for you.

It is written to help you understand the different ways in which housing and support can be provided when you start planning with your son or daughter about leaving home.

It explains what you need to think about when considering a move, what choices may be available, and how you can go about trying to get the kind of housing and support which will best suit your son or daughter.

Although the booklet is directed at you, it is important that ways are found to discover the wishes of your son or daughter. If they have no speech then pictures, photos, visits and consulting others who know them well may help to find out what they would like.

You may wish to follow up some of the ideas in this booklet. To help you do this, a list of useful organisations and publications is included at the end. Checklists have also been included which you may wish to use.

The alternatives described, apply in England and with minor variations in Wales. There are more significant funding and legal differences that will modify some options in Scotland and Northern Ireland. We have included addresses in Scotland and Northern Ireland, on pages 20 and 23, which you can contact for further information.



When should we start to plan?

Leaving home is probably the single biggest life change that your son or daughter will make so it's important to spend time considering the kind of life you would like for them, and what you think they would like.

Many people with learning disabilities are able to express clear views of their own and it's important that you talk with and involve your son or daughter when you start planning for them to leave home. If they find verbal communication difficult or do not use speech at all, you will probably have got used to finding other ways of understanding what they are "saying". There may also be other people (grandparents, school teachers, for example) who know your son or daughter and can be consulted.

You may have always envisaged that your son or daughter would leave home when they became an adult. Or you may have planned to continue caring until ageing, illness or other difficulties make this impossible.

Whichever is the case, for most parents, being a carer has been a positive choice and an enjoyable experience, and you may be reluctant to start even thinking about change. All parents tend to feel anxious when their children leave home, and change can feel daunting, even when it's likely to benefit everyone in the long run.

Planning and preparing for a move means you're more likely to get the right kind of housing and support. It can take a long time, even several years, to find the home your son or daughter would like. You have to be persistent. You may have to consider compromises. If you give yourself time, you are likely to get closer to what you want. Waiting until illness or some other crisis forces you to act quickly, will almost certainly mean you have fewer choices and less time for everyone to get used to the idea (though short-term breaks can help).

When beginning to think about planning your son or daughter's move, it will be helpful to gather information about possible housing and support options; and think about how, where and with whom they might want to live. You may find the checklist on page 16 helpful.

Living alone or with others?

At this point, you may want to think about whether your son or daughter would be happier living alone or with others. Shared housing is often more widely available, particularly for those requiring more support but it is possible for them to live on their own with a team of carers. This option of support living is worth thinking about and should certainly be discussed with your son or daughter who may have strong views about whether they want to share with others or would prefer their own accommodation (and support).



Some people with a learning disability live on their own because it gives them more choice and control over their lives, even with support staff coming in. It also means they don't have to share with people they don't get on with. If your son or daughter lives alone, however, it's important that they're safe, and have access to people and activities in the community so they're not isolated.

Rebecca lived in a group home but she became very withdrawn and would not join in activities with the other residents, preferring to wheel her chair into a corner. With her parents' help she now enjoys life in her own purpose-built bungalow, supported by a team of round-the-clock carers.

The advantages of shared living can include mutual support, opportunities to develop friendships with other residents, and more organised activities. In addition, care staff may be better trained and more experienced, though this is not necessarily the case and you will need to ask about this when looking at possible homes.

The main drawback of shared living may be restricted choice - not only when it comes to choosing meals or bath times but who you live with and who supports you. If you are looking round a home, it's worth asking whether residents are involved in things like selecting staff, choosing new residents, and deciding how the house will be run.

What are the main housing options?

The range of housing options is increasing all the time but people in some areas will have more choice than people in other areas. We have tried to describe the main options as clearly as possible, but people sometimes use different terms to describe the same thing, which can be confusing so if you're not sure, ask. It may also be possible to tailor an option to suit circumstances.

Registration

Homes are vetted and registered to ensure that the care provider is suitably qualified and experienced to care for disabled people. Larger homes are inspected twice a year; smaller homes may be inspected less often.

Inspection covers specific areas: building standards; space and equipment; staffing levels and staff training and experience; care and support; food; record-keeping and medication; complaints; health and safety.

The registration arrangements are changing and in England and Wales will be the responsibility of a new National Commission for Care Standards. You can check out the current arrangements with your local authority.

Registered care homes

Registered care homes are generally larger than group homes (see below) and can sometimes have 20 or more residents although many are much smaller with typically three to six residents. Personal care and full board are provided, and there's usually 24-hour staff cover.



Group homes (or shared housing).

Group homes are usually smaller than registered care homes, with three or four people sharing. Support staff either visit regularly, or are there during the day and sometimes also overnight as well. Residents may do their own shopping, cooking and housework, with help from staff. If accommodation, personal care and board are all provided the home will be registered (see above), but many group homes are not registered.

Living in a group home

Jacqui shares a group home with three other people. She moved there about 18 months ago, having decided she'd like to try a move from the family home. She already knew one of the other people she now shares with and when a room became available, Jacqui was offered it. It's only about a mile from her parents' home so she drops in to see them quite often. Her married sister and children who live in the area also visit Jacqui at the group home. Since moving in, Jacqui has been learning to cook and do her own laundry, both of which her mother used to do for her. A support worker comes in four half-days a days a week to help Jacqui learn these new tasks and one night a week she goes out with a volunteer from the local befriending scheme.

Cluster housing

Cluster flats or bedsits are self-contained units, either on one site (like sheltered housing for older people) or occasionally spread across a neighbourhood. Support staff are usually on hand and there may be shared facilities such as a laundry and communal lounge. This type of housing is often suitable for people who want to live more independently than in a home but still have some support.

Living in a cluster flat

Sally lives in a one-bedroom flat in a building which has 15 similar properties. The building belongs to a housing association, which specialises in providing accommodation with support to people with special needs. Although Sally is able to look after herself, the warden calls in twice a day to make sure Sally has taken her medication and see that she is okay.

Each flat also has an alarm system so Sally can call for help if she needs to. The building has a communal lounge and there are regular social activities. Sally attends college two days a week and on the other days she usually goes to the day centre where she meets up with her friends or stays at home and does her housework.

Individual placements

In an **adult placement** (sometimes called “**adult fostering**”), the local authority supports and supervises families who provide a place in their own home. Someone less disabled may be in **supported lodging** where they rent a room or bedsit in a family home and receive minimal support.

Renting

More people with learning disabilities are now renting properties from local authorities, housing associations, or private landlords. There are also a few companies who specialise in renting to people with learning disabilities (see Sources further of help, pages 19 to 24). Alternatively, if the family home is rented, your son or daughter may be able to take over the tenancy. Renting is not just an option for less disabled people, as there are several ways in which funding can be obtained for round-the-clock carers (see pages 13 to 14).



Home ownership

This is becoming more common, although still not particularly widespread. The various options for home ownership are set out in the box below.

Home ownership

- **Inheriting a property:** either directly or by setting up a trust.
- **Obtaining a mortgage:** using benefits for repayments; a couple are more likely to be able to afford this than an individual.
- **Joint ownership:** a group of parents or relatives combine resources to purchase a property for their sons and daughters.
- **Shared ownership:** using part-buy, part-rent arrangements from a housing association.

Who provides housing?

Local authorities

The housing department is responsible for the provision of **housing** and the social services or social work department is responsible for the assessment and provision of **care and support**. If you're in a large urban area, the housing and social services or social work department will be part of the same local authority but if you have a county council, they will be responsible for social services and housing will be the responsibility of the (smaller) district councils.

Housing departments have the most properties but usually have long waiting lists. Some applicants are given a higher priority because of their particular needs and your social worker may be able to advise you about this. Local authorities will have nomination rights with housing associations. In some areas, the local authority will no longer have any housing of its own because it has transferred the properties to a housing association. In this case, your son or daughter may need to apply directly to the housing association.

Nomination rights means the housing authority has the right to use a proportion of a housing association's properties.

Social services or social work departments may have their own residential homes but are increasingly likely to contract with other organisations including charitable organisations and private providers for both care and accommodation. Alternatively they may contract only for care, leaving the housing department - or individual - to provide the housing.

Housing associations

Like local authorities, housing associations receive Government funding and rents are partly subsidised. You can apply directly to a housing association or ask your local authority if they can nominate you for a tenancy. Some associations specialise in housing people with a learning disability.

The voluntary sector

Some voluntary organisations have set up charitable housing associations, often running smaller homes using ordinary housing. A few charities have built larger “village communities” for people with learning disabilities, often in rural or semi-rural areas. Some, but not all of these have a clear vision of the preferred lifestyle of the group and you will need to check on this.

The private sector

Property can be rented directly from private landlords. Alternatively, some private companies provide a range of housing with care, not unlike what is offered by some housing associations. You can make a direct approach to these companies but more usually contact is made via the social services or social work department.



How do I get the support my son or daughter needs?

How can support be provided?

If your son or daughter has always lived at home, you have probably been their main support and you will undoubtedly want to make sure that they are well supported after they move out.

Housing and support can be provided as a “package” but “pick and mix” arrangements which match individual requirements are increasingly common, particularly if someone lives on their own.

Pick and mix housing and support

John moved into a two-bedroom housing association flat after a long discussion involving John, his family and professionals who've been working with him. John was clear he wanted his own home but because he also has mental health difficulties, he needs round-the-clock support. Part of the planning before he moved was working out with him, how he wanted to be supported. John has a team of support workers but has recently been spending two hours a day without support. He is also visited regularly by a community nurse. John goes down to the pub two or three times a week with another man who has a flat in the same block. He also sees his girlfriend regularly and they support one another.

Registered care homes, group homes and cluster housing (see above) usually provide some kind of support alongside accommodation. This may be 24-hour staffing, or where people require less support, staff may visit several times a day or week according to people's needs.

Who can provide support?

Support can be provided by one or more of the following:

- paid staff, usually employed by a housing or care provider
- paid staff employed by the person with disabilities (see below)
- relatives and friends
- volunteers such as befrienders or advocates
- support tenants who live with the person and provide support in return for rent-free accommodation and a small payment.

People can also use services such as home care or meals on wheels which are not specifically for people with a learning disability.

How is support paid for?

Support costs are usually met through a combination of welfare benefits and local authority funding (and for some people with very high support needs, by the NHS).

Residential care placements

The local authority may purchase a residential care placement for your son or daughter which will include meals, clothing and domestic bills plus care costs. Any welfare benefits they are entitled to may be “clawed back” by the local authority except for a small personal allowance, plus the mobility component of Disability Living Allowance (DLA) if they receive this.

Independent living using benefits

Someone living more independently (i.e. not in a registered care home) can claim a range of welfare benefits to help pay for food, clothing and domestic bills like heating and lighting. Some local authorities charge for services such as home care. They may also be entitled to claim Housing Benefit from the local authority (see box below) which helps meet the cost of rent and services.

Other ways of funding support in independent living

If your son or daughter needs the level of support generally provided in care homes but lives in their own home, it may still be possible to get the local authority to fund the care package. Otherwise you may want to consider one of the following:

Local authorities can make **Direct Payments** to enable a person to purchase their own care services, although they are not obliged to do so and practice varies depending on where they live.

Your son or daughter is eligible to apply to the **Independent Living Fund (ILF)**, a central government fund administered by trustees. If they receive the highest rate DLA care component and receive local authority support to a value of at least £200; and their total care costs do not exceed £500 weekly, the ILF can consider an application for funding.

Independent living (using ILF and benefits)

Jane uses a wheelchair and lives in a ground floor flat. She has a mortgage from a building society, which has a special relationship with the local authority. Her support is funded in two ways. Money from the Independent Living Fund enables her to employ her own support workers and she receives additional support from the local authority's home care service for which she pays a contribution. Jane works a few hours a week and continues to spend some time at the local day centre where she can meet up with her friends.

Housing Benefit

- **Is your son or daughter eligible?**

You must: either be renting your own separate property or living in an unregistered group home; have less than £16,000 savings; and be on a low earnings or claiming Income Support.

- **Does it pay for rent and service charges?**

Housing Benefit will pay your rent and may also pay service charges relating to occupying the property, if the amount is reasonable, and payment is a condition of occupying the property.

- **Which service charges *may* be met by Housing Benefit?**

Communal cleaning; window cleaning; warden and/or caretaker; garden and property maintenance; emergency alarm systems; a charge for furniture and household equipment; low level support and counselling. Housing Benefit has occasionally been used to fund an element of personal support and additional services for disabled people.

- **Which service charges *cannot* be met by Housing Benefit?**

Water rates; heat and light within the individual's property; meals; medicines, nursing and personal care; daily living expenses (e.g. transport).

What steps do I need to take?

This booklet provides an introduction to housing for people with learning disabilities. It is intended to help you get started and you will undoubtedly want to find out more. The checklist on page 16 can help you get started.

The sources of help listed overleaf will be able to provide more detailed information and advice. You may also wish to obtain a copy of the fuller version of this booklet: *Living Alone or with Others: Housing and Support for People with Learning Disabilities*. Please contact the The Mental Health Foundation, Publications Department on 020 7535 7441.

What information do you need? and who could you talk to?

1. Contact Social Services to find out about your local authority's policies on housing and support for people with learning disabilities. Getting hold of their current Community Care Plan is a good starting point.

2 Find out what housing and support for people with learning disabilities is currently being provided in your area. Your local authority and/or organisations like Mencap can probably tell you.



3. If you have a social worker, ask to discuss plans for your son or daughter moving into other accommodation. If you don't have a social worker, ask social services to find someone you can talk to.

4. Talk to parents whose sons or daughters have already made this transition. Ask them about their experiences and obtain any useful information and contacts they may have found useful.

5. Contact local and national organisations with relevant experience (see list on pages 19 to 24).

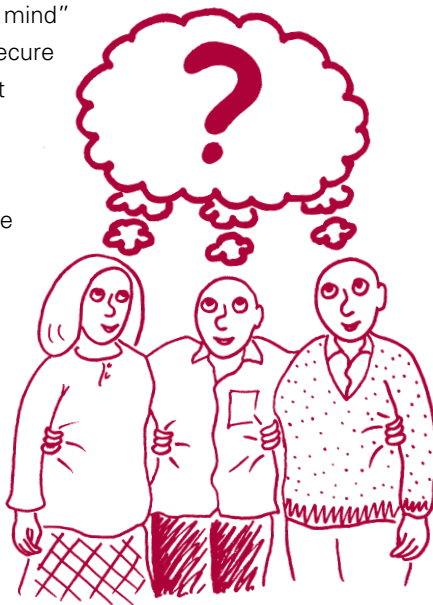
6. Check what benefits are available to meet housing and support costs and whether your son or daughter would be eligible to claim them.

7. Ask the local authority what financial contribution they would be likely to make towards housing and support costs and how flexible they are prepared to be if you are looking for services tailored around individual needs.



While gathering the kind of information described in the checklist you also need to bear in mind what sort of housing and support you and your son or daughter would really like. It may not be possible to find exactly what you want. You may have to make some compromises along the way, but it's important to keep your "ideal in mind" so that as far as possible, you secure the accommodation and support which best suits your son or daughter.

When you have some idea of the kind of housing and support you are looking for, find out from your social services or social work department if your son or daughter is eligible for an **assessment**. Local authorities are obliged to assess anyone who may need "community care", including housing and care.



Each local authority has its own system for carrying out assessments so you'll need to find out how this works in your area. If the local authority refuses to carry out an assessment (or if you disagree with the results of the assessment) you can appeal against their decision. The local authority is required to tell you about the appeals process.

When the assessment has been completed, the local authority will decide whether your son or daughter is eligible for services. If they are, there will usually be a **care plan**. This sets out what services they will provide themselves or arrange with someone else to provide.

If you are looking for some form of shared accommodation (registered care home, group home, etc.) your social services or social work department will usually help you find somewhere. If not, you could talk to them about other possibilities such as renting from a housing association as well as the kind of support they may be able to provide or arrange.

Sources of further help

Publication

Living Alone or with Others: Housing and Support for People with Learning Disabilities by Nigel King

This publication covers the issues in this booklet in greater depth. Please contact the Mental Health Foundation Publications Department on 020 7535 7441.

Advice

Housing Options

78a High Street
Witney
Oxon OX8 6HL
Tel: 01993 705012
Website: www.hoptions.demon.co.uk

A specialist independent housing advisory service for people with learning disabilities, their relatives and professionals.

ARC

ARC House
Marsden Street
Chesterfield S40 1JY
Tel 01246 555 043
Website www.arcuk.org.uk

A national umbrella charity of organisations providing residential and other services to people with a learning disability.

For Northern Ireland

Mencap in Northern Ireland

4 Annadale Avenue
Belfast BT7 3JH
Tel: 01232 691351

For Scotland

The Information Service

ENABLE

7 Buchanan Street
Glasgow G1 3HL
Tel: 0141 226 4541
Fax: 0141 204 4398
Email: enable@enable.org.uk

For more sources of information on a variety of topics including housing consult "A practical guide for people with learning disabilities" available free from:

Department of Health

PO Box 777
London SE1 6XH
Fax: 01623 724524
Website: www.doh.gov.uk

Benefits

There are a number of publications on benefits. One of the most relevant and accessible is “Disability Rights Handbook” available from

The Disability Alliance

Universal House
88-94 Wentworth Street
London E1 7SA
Tel: 020 7247 8776

For details of the Independent Living Fund contact:

Independent Living Fund

PO Box 183
Nottingham NG8 3RD
Tel: 0115 942 8191

Housing providers

The first two organisations are registered housing associations that specialise in accommodation for people with learning disabilities. They operate over most of England.

Advance Housing & Support Ltd

2 Witan Way
Witney
Oxon OX8 6FE
Tel: 01993 772885

New Era Housing Association Ltd

1-3 Dufferin Street
London ECIY 8NA
Tel: 020 7786 5550
Email: info@new-era.org.uk

The next two are not housing associations but specialise in accommodation for people with learning disabilities.

Golden Lane Housing

123 Golden Lane
London EC1Y 0RT
Tel: 020 7696 6902
Website: www.mencap.org.uk

Established by Mencap to develop property based initiatives to meet the needs of people with learning disabilities.

Renaissance Social Housing Ltd

Dobson House
Regent Centre
Gosforth
Newcastle upon Tyne NE3 3PF
Tel: 0191 285 5888
Email: rshlimited@aol.com

Renaissance Social Housing Ltd (RSH) is a not for profit based company which provides housing nationally for people with learning disabilities.

The National Housing Federation

175 Gray's Inn Road
London WC1X 8UP
Tel: 020 7278 6571
Website: www.housing.org.uk

The National Housing Federation produces a simple illustrated form of lease for people with learning disabilities. They also publish a directory of housing associations.

The Housing Corporation

149 Tottenham Court Road

London W1P 0BN

Tel: 020 7393 2000

Website: www.housingcorp.gov.uk

Provides local housing association contacts

For details of adult placement services contact:**National Association of Adult Placement Services**

51A Rodney Street

Liverpool L1 9ER

Tel: 0151 709 1200

Email: audrey@naaps.free-online.co.uk

Publishes a directory of adult placement schemes.

Home ownership

For an explanation of different approaches to home ownership for people with learning disabilities look at "Ownership Options

- A guide to home ownership for people with learning disabilities" published by the National Housing Federation or "My Home, My Life" by Ken Simons available from:

Values into Action

Oxford House

Derbyshire Street

London E2 6HG

Tel: 020 7729 5436

Website: www.demon.co.uk/via

Ownership Options, Scotland

Unit 2, John Cotton Centre

10 Sunnyside

Edinburgh EH7 5RA

Tel: 0131 661 3400

Trusts and Wills

A booklet called “Leaving money by will to people with learning disabilities” is available from Mencap at:

Mencap

123 Golden Lane
London EC1Y 0RT
Tel: 020 7454 0454
Website: www.mencap.org.uk

MIND publish a similar booklet called “Making provision” which covers different types of trusts. They are at:

MIND

15-19 Broadway
London E15 4BQ
Tel: 020 8519 2122
Website: www.mind.org.uk

HOUSING OPTIONS (see details above) also produces a fact sheet specifically about discretionary trusts.

Adaptations

For information on adaptations contact the Housing Department of your local authority. Advice can also be obtained from:

Care & Repair (England)

Castle House
Kirtley Drive
Nottingham NG7 1LD
Tel: 0115 9799091
Website: www.care-repair-eng.demon.co.uk