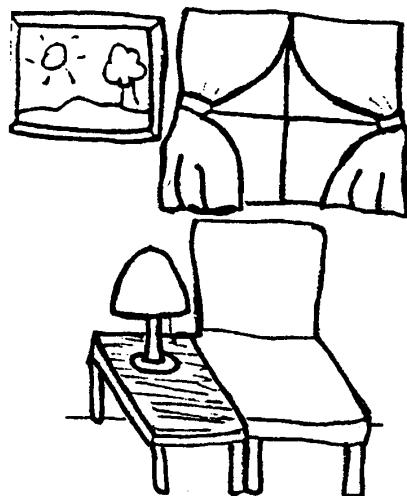


## CHAPTER 9

### A place to live



*I can't speak on behalf of all parents, but I think it's the natural process with young people of 19 – 20... to live in a flat like my daughter who is sharing with two other people. It's what you want for them, to live with their young peers.*

*Tommy's done four months and sees it as his home now with his peers and he has his own lovely room overlooking the whole of Brighton.*

Like many parents, you might be finding it difficult to imagine your child not living with you when they are older. You may be worried that no one else will be able to care for them and love them in the way that you do. They may want to leave home and you may feel you're ready for them to leave, but are worried that there is no suitable support and provision for them.

Many parents feel they don't have the information about how their son or daughter can have their own home with the support they need. This chapter covers what the housing options are for young disabled people in Brighton and Hove. You can read about the experience of other parents and young people who have made that move and pick up some tips about how they've gone about it.

What comes across clearly is that it's important to think and start planning early for this major move. Where we live, how we live and who we live with are among the most important decisions in our lives. You can start discussing housing options when your child is still at school as part of their transition planning annual review meetings.

*Letting go, that isn't easy. I suppose that's because I have massive love for Tommy. I just wanted the right thing for him. I did ask what would happen about him coming back home again and they said maybe he needed a bedding in process for a few weeks and so on. I said I didn't know if I could do this so I sort of wangled it so that Tommy comes home every Sunday night.*

*He's always done lots of things out of home and at college and he's watched all his brothers and sisters leave home and he wanted to leave home. I suppose it's a natural thing wanting to leave home.*

## WHERE DO PEOPLE LIVE?

Housing arrangements for disabled people have come a long way since the 1960's when people were housed in institutions that kept them apart from the rest of society. Since then thousands of people have moved out of long stay hospitals, campuses and residential care. This is thanks to disabled people, their families and supporters who lobbied for disabled people to have the right to live in the community like everyone else. This has led to changes in society's attitude, followed by changes in government policy that have transformed the situation to what it is today. But according to a recent Mencap report '*Housing for people with a learning disability*', there's still some way to go to ensure everyone lives in housing they like, with the right support that really meets their needs. So what are things like in Brighton and Hove?

*I don't think there was a terrific amount of choice. It was where he had friends and it wasn't too far away and he could go to college and back.*

### Housing in Brighton and Hove

Housing of all types is in short supply in Brighton and Hove. The city is the fifth most densely populated area in the region and there are higher than average housing costs and higher than average levels of homelessness. Brighton and Hove has the sixth largest private rented sector in the country, with 28,000 homes (23%) and only 19,000 homes (15%) in the social rented sector - that means council housing or housing association properties. Average house prices are high, meaning affordable housing is limited and there are problems with housing quality and overcrowding. (B&H Housing Strategy 2009-2014).

Approximately 800 adults with a learning disability use services that are funded through the council's Social Care.

The majority of people with a learning disability live in one of three types of accommodation: about 30% with their family, 30% in registered care homes (residential care) and about 30% live in rented or owned accommodation (of this group around half live in supported living accommodation). Rented or owned accommodation includes people living in supported accommodation, people who rent from the council and housing associations, tenants in privately rented accommodation and people who own their own home (solely or jointly). Approximately 9% live in adult placement schemes – called 'Shared Lives' in Brighton and Hove. The other 1% live in registered nursing homes or very specialist placements. We explain more about all of these later in this chapter.

The growing number of disabled people means that more people will need the council to make housing arrangements for them. Brighton and Hove have a Housing Strategy which includes targets to support people with learning disabilities to live as independently as possible.

*So eventually, Clare (Transition worker) said that she had found somewhere that would be suitable but he would have to live with three others because they weren't going to fund for one or two it had to be four. You know that autistic children have huge problems with relationships and friendships. But Tommy had a real shine with one of his classmates at Downs View and they seemed to have a link to each other. They seemed to communicate in their own language and have affection for one another. So they are living together and the other two came in a bit later and they are quite a bit younger. They are 17.*

### Planning for the future

Because disabled young people are likely to depend on formal and informal support, planning for the future is crucial. Generally speaking, disabled young people, 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 young person. Planning is also a central way of involving your young person in decisions about where they want to live and who they want to live with.

When looking for housing for your young person, it's really important that the arrangement meets their physical and support needs as well as their social needs. Every person has individual needs, which may range from step-free access or an extra room for a carer, to being near informal support networks, like your family and their friends.

*There was a fair bit of paperwork and people you had to see from that organisation. They had to know every detail, obviously, about your young person.*

### **Eligibility criteria for support from adult social care and funding for accommodation**

As we explained in the chapter on social care, for your young person to get support from adult social Care they will need to meet the council's 'eligibility criteria'. Not everyone with support needs is eligible for support. People who meet the council's definition of 'critical' and 'substantial' needs are able to get funding to pay for their support and accommodation needs. This means that the council recognises that there will be risks to the young person's independence if they do not get support from adult social care, and that these risks are assessed as high. People with 'moderate' or 'low' needs are not generally funded.

If your child has support from the Children's Disability Service or from a Transition Worker you can talk to them about doing this assessment. If you haven't had any support from the

council's social care team up to this point, contact the council's Access Point on 01273 295555 and ask for an assessment of need.

There is help with housing options for people over 16 who have lower support needs. Contact the Council's Learning Disability Housing Options Officer on 01273 293412 or ring the Housing Options Advice Line on 01273 294400. You will be able to discuss your son or daughter's situation and be offered either advice on what you could do yourselves or assistance to move into suitable housing. Note this service is only available to people who are over 16.

### **How the council commission (buy) services**

Brighton and Hove have a large range of housing and social care providers who have been 'approved' through an accreditation process. Providers are monitored by the council's contracts team. Commissioners (people whose job it is to buy these services) work with providers to ensure the services are what is required and ensure value for money.

## **TYPES OF HOUSING FOR YOUNG PEOPLE**

### **Continuing to live at home with their family**

Most young people live with their families until some time in their late teens or early twenties, when they begin the journey to independent living. They often begin in shared flats or student accommodation before moving on to living alone, with friends or partners. However, for most young people with disabilities and other support needs, this does not happen.

Official statistics show that the majority of adults with learning disabilities live with their families or in residential care. The council is keen to support the young person to stay living in their family home, for as long as the family are able to sustain this and can meet the young person's needs. The council can

offer help to make this work. Some support can be provided through 'outreach' support, day activities, short breaks/respite or access to social clubs. This includes services specialising in working with young people, autism, complex health needs and other needs.

There is a council residential short break service, Beach House, for adults with more complex needs. But be warned that this provision is for all ages so your young person may not always be with people their own age.

Some young people have a Personal Budget that can be used creatively to employ personal assistants or meet their needs in other ways. We'd suggest that it's really important to think about what's best for your son or daughter in the long-term and don't wait until there is a crisis when they may have to move out of the family home.

Support at home costs around £15.00 per hour but provider prices vary. The money to pay for this can come from the 'package' of support agreed by adult social care and can be arranged by the council or managed by the young person or their family as a Direct Payment. Read more about Direct Payments on page 145.

## **Supported Living or Housing**

Supported living or supported housing, as it's sometimes called, generally means living in accommodation where there are staff on site. There are two main forms of supported living in Brighton and Hove: living in a 'group' home, where people have their own room, but share other facilities; or living in a self-contained flat or studio. For both forms, support may vary widely; from 24 hours staffing to just a few hours a day.

*They have a whole package of lovely staff, all very young and motivated. Three guys and four girls on a rota system. One stays overnight, possibly sometimes two. There is always one overnight and three in the house at all times for the four of them.*

In supported living or housing the young person can have a tenancy which gives them more housing rights. They can claim housing benefit and keep most of their benefits like Disability Living Allowance or Personal Independence Payment, Jobseekers Allowance or Employment and Support Allowance.

There is a focus on gaining skills and independence and sharing responsibility for things like cooking, cleaning and shopping. The positive side of this form of accommodation is that the young person will have company as well as the security of a service and staff team. However, like all young people, it's important to remember they can be friends one moment and fall out the next and trusted staff can leave.

*The best thing is that they get to do what they want to do with their friends. Getting to do things that old people like me don't want to do!*

*Well they are teenagers and they do get up to trouble sometimes and they have arguments as well. I've had quite a few times when I have worried about Stephen because he has come home saying Daniel is this and Daniel is that and now he wants to go on holiday with him! The staff have said don't worry; they are friends but they do have ups and downs and now they want to go on holiday together.*

*Now there is someone staying overnight who knows them. That's the most important part. If someone doesn't know them they don't know how to deal with them in an emergency.*

### **Who can use supported living schemes?**

To access supported living/housing schemes, a young person will have to be assessed by Adult Social Care to see if they are eligible for the service.

### **Choosing the right supported living scheme**

The amount of supported living for people with learning disabilities in the city has grown dramatically over the last few years, due to the demand for more independent, personalised accommodation services. There are now over 35 services, which vary in size from two-person services to eight-person services, and supported living is provided by a range of providers.

Despite this greater choice, it can still be difficult finding the right place for the right person at the time that they need it. This can be for various reasons, for example, a vacancy might be taken up by someone from another area. Once again, good early planning is the key to identifying the right service for your child. Care managers or transition workers can help with this.

*They are trying to expand on their independence skills. They all have a lovely bedroom with double beds, they are very lucky, they have a lovely home to live in and Clare (Transition Worker) did a very good job at finding that particular property.*

Details of supported living accommodation in Brighton and Hove and further afield can be found on the Care Choices website at [www.carechoices.co.uk](http://www.carechoices.co.uk). You just put in your postcode and the type of care you are looking for and you can browse the results.

Supported living is registered as 'Services in your home' with the Care Quality Commission and so is subject to a different inspection regime to residential care. You can look up their latest checks on local supported living services on the Care Quality Commission website at [www.cqc.org.uk](http://www.cqc.org.uk)

*You can pop in at any time, it's not like school, and it's like an extension of your home. That's where they live.*

The council acknowledges that there are some gaps in provision for people with more complex needs. For example, people with challenging behaviour and autism have less options, but they are developing new services to address this.

### **Supported living for young people with less 'critical' needs**

There is some supported accommodation for young people who have lower needs but who may have some mental health support needs and a moderate learning disability. There is not much of this accommodation available and waiting lists can be long. The young person does not normally need to meet the 'critical and substantial' level of need to access these services but they will still need to be assessed by the council's Learning Disability Housing Options Officer to see if they meet the criteria for these services.

Some of these services are in large, hostel type accommodation and some are based in smaller group homes of five or six rooms. These services tend to offer low to medium support. Some houses may have staff on site during office hours and some have no staff on site. As these are low to medium supported placements, the young person needs to show they have the necessary daily living skills to live there and be quite independent.

It's important to know that this is not a service just for people with learning disabilities. Other people living there may have mental health support needs and no learning disability needs.

Most of these projects have a time limit on how long people can live in them, up to two years. During the time the young person is there they will be helped to make a plan for moving on. The young person can claim housing benefit in these services.

Contact the Learning Disability Housing Options Officer or go into the Customer Services Centre in Bartholomew Square and ask to make an appointment to speak to the officer. Priority is given to people who are homeless or threatened with homelessness.

## **Shared Lives**

Shared Lives is when the person lives with another family in their home with the support of that family. Shared Lives is like an adult version of having a foster family. The schemes recruit, assess and support carers who offer accommodation or care and support in their family home.

*I decided to move home because I was getting to the age where I wanted to move out and my social worker looked at loads of places, then she found this person from Shared Lives....I was OK when I moved in because I'd stayed there three nights a week anyway, so it was sort of like I was there already. Becky 18*

Shared Lives schemes can be a good stepping stone for a person with a learning disability or autism moving towards living more independently. Some young people who still live at home with their parents might live with a Shared Lives carer part-time, for example a few days a week.

*The social worker suggested that Becky go and live with the Shared Lives carer full time, but not permanently, while she investigated possibilities for longer term supported living. So the whole idea has been that Becky just lives there short term.*

She is supporting Becky with cooking skills but I think she could be doing more helping her manage her money.

## **Who can use Shared Lives services?**

To access Shared Lives, a young person needs to be assessed by the council's Adult Social Care team to see whether they are eligible for this scheme so if your child has a social worker or transition worker talk to them about this option.

In Brighton and Hove there are two providers of Shared Lives services – the council and the Grace Eyre Foundation. Shared Lives placements cost around £300-£450 per week, which will be funded by the council for people with eligible needs. A financial assessment will be carried out by the council in order to see if the person needs to make a financial contribution.

*I have a lot less responsibility which is actually one of the best things, because it was very demanding and very time consuming and very draining and wearing and that is better. And so the involvement that I do have with Becky is on a more personal level, just me and Becky, rather than dealing with all the bureaucracy and the form-filling and phone calls and meetings and all of that. I don't miss that.*

*The best thing for me is that Becky is happy where she is. If Becky was living independently, but she was unhappy, I would find that very difficult. But because it's what she wants, it's what she decided and it's going well, that's the best thing.*

As a step towards further independence and included within Shared Lives, there is the Kinship scheme. In Kinship schemes, the carer living in their own home will support the person with a learning disability who lives in their separate home.

## **Residential care**

Residential care offers specialist services with high levels of staffing 24 hours a day. It's for people who need high levels of direct support with personal care and daily living. If a young person is quite independent in these areas then residential care is probably not the right option for them.

Residential care almost always involves living with other disabled people who have been 'placed' there. So there is less choice of the people the young person will live with or the people who will support them. Because this was often the only housing option for people with learning disabilities in the past, who, for whatever reason, could no longer live in their family home, these homes now usually cater for older people rather than young people. The exceptions to this are some residential care homes for younger people with complex physical/health needs or those with complex or challenging behaviours.

Residential care homes vary in size from three or four to 10 or 12 rooms in a house. Most are ordinary homes on ordinary streets. You have to find the right vacancy and compatibility with other residents can be an issue. In a residential home the young person will not have a tenancy, they will have a licence, which means they have less rights and the landlord can access their room, or change their room.

#### **Who can get residential care?**

To access residential services, young people will need to be assessed and meet Brighton and Hove's 'critical and substantial' needs criteria. If the young person meets these eligibility criteria and moves into residential care they get a full 'package' of support and care - which means all of their accommodation, support and care costs are met by the council. This also means, however, that the person has a very low personal income as nearly all their money goes towards their support and care costs.

#### **Choosing residential care**

In Brighton and Hove, use of residential care is declining, but there are still a number of providers in the city managing over 30 care homes. The council uses most of these services, but they are also used by other local authorities.

Historically, it was difficult to find the right specialist services in the city and significant numbers of people with complex needs are placed out of the city (mostly within Sussex). With improvements in local residential care and much more supported accommodation, this happens less frequently now and, where possible, people are supported to move back to local services.

You can find details of local care homes in Brighton and Hove and further afield on the Care Choices website at [www.carechoices.co.uk](http://www.carechoices.co.uk). You just put in your postcode and the type of care you are looking for and get results for all the relevant care homes in the area.

Care homes have to be registered, so are subject to inspection by the Care Quality Commission. You can see details and recent inspection reports of care homes on the above website or on the Care Quality Commission's website [www.cqc.org.uk](http://www.cqc.org.uk). Or you can telephone the CQC on 03000 616 161.

#### **Social housing**

Social housing is property that you rent from the council or a housing association. People living in social housing have a secure or assured tenancy which means they can only be evicted for breaking certain rules and only if a judge agrees. So if a young person sticks to the rules of the tenancy, this could be a home for life.

Social housing has cheaper rents, which can usually be paid in full by housing benefits, depending on the young person's income. The landlord - the council or the housing association is responsible for most repairs and maintenance.

As we mentioned before, unfortunately, there is very little social housing in Brighton and Hove and it can sometimes take a long

time bidding before there is an offer of a property. Also remember that all of the young person's support needs will need to be arranged before they move in.

To apply for social housing locally you need to register with the Choice Based Letting Scheme Homemove by filling in an application form that you can download from the council's website. Visit [www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk) and look under Housing or visit [www.homemove.org.uk](http://www.homemove.org.uk). You can also visit the Brighton Customer Service Centre in Bartholomew Square or any of the local housing offices. If you need help to fill out the form you can ask a member of staff. You can get help with bidding by asking Homemove or contact the Learning Disability Housing Officer and you may be able to get help from them. You may need to complete a medical self-assessment form for your young person with information about any disabilities, impairments, medical conditions or mental health needs they may have. For young people with mobility needs, there is a separate mobility self-assessment form. Ask the young person's GP or any other medical workers for supporting information. If the young person has a social worker, transition worker or care manager, you could ask them for a supporting letter.

#### **A word about accessible housing**

Brighton & Hove have a register of all their adapted and wheelchair accessible homes. All those applying for the accessible housing register are assessed for mobility needs (and grouped / coded 1, 2, 3 depending on the severity of the need). All properties available to let are then advertised as being suitable for particular codes with the priority going to that group.

#### **Sheltered housing**

Sheltered housing means that the young person lives in their own flat but there is a scheme manager on site at certain hours.

It is a type of social housing that was designed for older people. There is no longer an age limit, but the young person would need to have certain support needs to live there. You can bid for sheltered housing using the council's Homemove scheme and you will need to complete a separate support needs form when applying to Homemove. See above.

#### **Home ownership schemes**

My Safe Home is an organisation that provides guidance and support for carers or disabled people wanting to buy their own home. See their website [www.mysafehome.info](http://www.mysafehome.info). To qualify for this support the person must be getting DLA on the higher or middle rate for care.

There have previously been Shared Ownership schemes funded by the government specifically for people with disabilities, but there are currently no schemes of this kind operating.

#### **The private rental sector**

This means renting a property owned by a private landlord. For some people, it can be a good option for finding somewhere to live as there is so little social housing (owned by the council or housing associations) in Brighton and Hove.

There are lots of different types of properties available to rent privately. This is one of the fastest ways to find somewhere to live and there is lots of choice about where you live. You can look for properties in local letting agent's shops, local papers like the Argus and the Friday Ad or on the internet.

#### **Tenancies**

Private sector landlords normally give their tenants a six or twelve month fixed term Assured Shorthold Tenancy to begin with. After the fixed term is up, the landlord may decide to give another fixed term tenancy, or decide not to but allow the

tenancy to continue on what is called a statutory period tenancy or may decide to end the tenancy. If the landlord doesn't want to extend the tenancy they must usually give two months' notice and may have to seek possession through the courts. The landlord is responsible for most repairs and maintenance.

#### **Housing benefit in private accommodation**

Rents are higher in the private sector than in social housing. Some rents may be higher than housing benefit will pay and it may be difficult to find an affordable property in Brighton and Hove. Rents in the surrounding areas tend to be cheaper. Some private landlords will not take tenants who are on housing benefit. Contact the housing benefit department to work out how much housing benefit the young person may be able to get.

#### **Moving in costs**

You usually need one month's deposit and one month's rent in advance before you can move in and if you go through an agency you may also have to pay agency fees. If you do not have the money for rent in advance, the young person may be able to apply for a crisis loan from the social fund. The Council's Learning Disability Housing Options Officer will be able to give you more advice on the private rented sector and may be able to help with finding a property and money for a deposit and rent in advance. Housing Options also have an easy read leaflet about renting privately which you can find at local housing offices or by calling Housing Options and asking for one or look on the [www.brightpart.org](http://www.brightpart.org) website. Remember, if your young person needs support to live independently you will need to arrange this before they move in.

## **GETTING ADAPTATIONS TO HOUSING**

The council can help adapt a property whether you own it, rent privately, or are a council or housing association tenant. This can include providing equipment to make daily tasks easier,

adapting your home to improve access or help with bathing facilities. Adaptations include providing ramped access, adding handrails, widening doors, raising electrical sockets, replacing a bath with a level access shower or installing special equipment for people with hearing or visual difficulties. These adaptations may be funded or part funded by the council depending on your circumstances through a Disabled Facilities Grant. For further information speak to your child's social worker or transition worker if they have one, or look at the council's website [www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk) or ring Access Point on 295555 and ask for an assessment.

#### **PARENT TIPS:**

- ☺ When you look around see if people look relaxed and happy with the staff
- ☺ Try and find a nice short break placement first that you feel happy with, be it one or two nights a week. Then your child can get used to this separation and depending on what's available, you can build it up
- ☺ It's important to have good communication with all the people who are looking after your young person
- ☺ Give the carers as much information as you can. Even down to your own little routines
- ☺ Listen to what the young person wants
- ☺ Be very assertive with social services, keep pushing them
- ☺ Build a relationship with the carer and be flexible about the fact that their way of doing things might be different
- ☺ Accept that if you have gained in having less responsibility that also means we do have less influence

*They are all learning because they don't know that person at all. So what I did was I got myself some cards and I put: these are the foods he likes; these are the activities that he likes. I put different things on*

*different cards and gave them to the carers to give them some guidelines. And also what might upset him, anything to do with that.*

*If everyone was quietly in their rooms I would be uncomfortable. I would look for staff that are really understanding and who join in with them.*

*Social workers and transition workers have a massive caseload and my impression is that if things are going fine with one client they just leave well alone because they're dealing with a crisis with someone else, so you've got to be pushy for what you think your child needs.*

#### **YOUNG PERSON'S TIP FOR PARENTS**

- ☺ Support them by helping them do washing up and washing their clothes and putting clothes in the washing machine and helping them put the machine on and teach them to do it and then they can do it the next time.

(Becky 18)