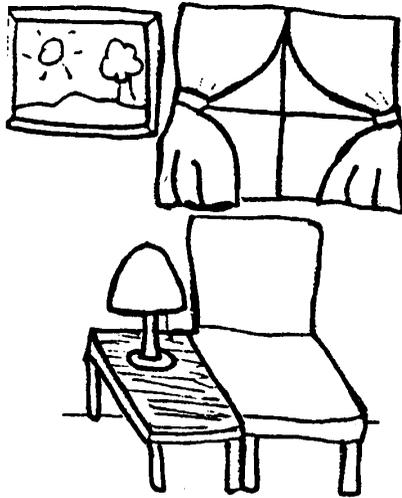


CHAPTER 9

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 people with special educational needs and disabilities 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 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. Pressures from an increasing population, high property prices, pockets of poor quality housing, limited opportunities for new development and the effects of welfare reform are impacting on many families, particularly the most vulnerable people living in the city. The city has one of the highest average house prices outside London, coming within the top 10 local authorities, and high rents in the private sector make rent unaffordable for many households (Brighton & Hove City Council's Housing Strategy 2015).

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

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% 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 & Hove City Council has a Housing Strategy which specifies a joint approach to housing for people with learning disabilities across housing, health and care services.

‘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 workers from the council 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 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 Housing Options Advice Line on 01273 294400 option 1, or email housing.advice@brighton-hove.gcsx.gov.uk. 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. There are big changes happening in social care and the way it's provided, and the council has to make cuts in the amount they spend on social care so they are looking at how services are offered. There is a move away from council run services, which includes council run residential homes.

TYPES OF HOUSING FOR YOUNG PEOPLE

Continuing to live at home with their family

Many 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 and to pay for respite and short breaks. 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 133.

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 other times for the four of them.'

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

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. Be warned though, that however far in advance you've been planning for your young person to move out of the family home, it doesn't always happen when you'd hoped it would.

'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.charechoices.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

'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 Housing Options Service 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 Housing Options Service on 01273 294440 (option

1), e-mail housing.advice@brighton-hove.gcsx.gov.uk. 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 and shares that family's life and their network. 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.'

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. If not, go through the council's social care Access Point.

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. It will be the young person's finances that are assessed, not their parents.

'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 young 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 in 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 eligibility criteria. If the young person meets these 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. 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 improvement 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 residential care homes in Brighton and Hove and further afield on the Care Choices website at 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. Or you can telephone the CQC on 03000 616161.

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 a young person's support needs will need to be arranged before they move in.

How to register for social housing

To apply for social housing locally you need to register with Homemove which is the letting scheme for council and housing association homes in Brighton & Hove and other places across East and West Sussex. You can use Homemove if you are an existing tenant seeking a transfer within your council's area or a home seeker applying for the first time. The scheme covers all the available council and housing association homes, including sheltered housing.

You need to log in with your Homemove number in order to see the property adverts and place your bids. If you're not registered, you need to fill in a housing application form. Visit www.brighton-hove.gov.uk and look under Housing or visit www.homemove.org.uk. Or you can visit the Brighton Customer Service Centre in Bartholomew Square or any of the local housing offices and if you need help to fill out the form you can ask a member of staff.

You can get help with bidding from Homemove or contact the council's Housing Options team who may be able to help. You may need to complete a medical self-assessment form for (or with) 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. Or, if they have a social worker, transition worker or care manager, you could ask them for a supporting letter.

A word about accessible housing

Brighton & Hove has 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 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. To qualify for this support the person must be getting DLA on the higher or middle rate for care.

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 Agreement 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 help from the council's Local Discretionary Social Fund. You can call the team on 01273 293117 or apply on-line through the council's website www.brighton-hove.gov.uk or email them on LDSF@brighton-hove.gov.uk to find out more about this. The council's Housing Options Service 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. Remember, if your young person needs support to live independently you will need to arrange this before they move in.

PARENT TIPS:

- ☺ Listen to what the young person wants
- ☺ When you look around see if people look relaxed and happy with 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
- ☺ 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 you 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.'

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 or ring Access Point on 01273 295555 and ask for an assessment.

'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)