

## CHAPTER 6

### Social care



*'You know how it is, you deal with the short term because the long term is just so difficult to even imagine.'*

When our children are heading towards adulthood, we need to know that they will be supported to live as independent and fulfilling a life as possible and be appropriately cared for. In this chapter, we explain the current rules about social care and assessments for disabled adults and give details of how assessments are carried out locally. We also explain the range of services that may be available, and how those services are paid for.

### **MOVING TO ADULT SOCIAL CARE**

Once your child is 18, the social care support they need is provided through the council's Adult Social Care Team. Adult

social care workers carry out assessments to decide what the young person's support needs are, whether the young person is eligible for support and, if they are, what support social care can offer you and your child. Because of this, it's vital to make sure that someone from social care attends the transition planning meeting organised by your child's school as these are the people who will decide whether they're likely to need or get support from the council in the future.

Adult Social Care for people with additional needs is divided into two services: the Adult Physical Disability Service and the Community Learning Disability Service. To get support from either of these teams you should contact Access Point on 01273 295555 or email [accesspoint@brighton-hove.gov.uk](mailto:accesspoint@brighton-hove.gov.uk). You can find more information about social care services on the council's website or at their health and social care information hub [www.mylifebh.org.uk](http://www.mylifebh.org.uk)

## **Who gets support from adult social care?**

Not all young people with a Statement of special educational needs or an Education, Health and Care Plan will be entitled to social care support as an adult.

Some young people might not have had support from social care before, but when they become an adult, things may change. On the other hand, some children who receive social care support when they are young find they don't qualify for adult services.

If your child has an EHC plan or a Statement of special educational needs, you should begin to discuss your child's possible future needs for social care support during their Year 9 annual review as part of the process of transition planning.

If your child doesn't have an EHC plan or Statement but is getting social care support via the Integrated Child Development and Disability Service, you should speak to your social worker or casework officer about moving to adult social care.

Young people with more complex disabilities may be able to get more intensive support from the Transition Team, part of the Adult Social Care Team. The Transition Team provide a link between children's and adult health and social care services for children with more complex needs. They work alongside these services to ensure that as far as possible, support is well planned and coordinated and transitions go smoothly.

*'Rachel's transition from Children to Adult Services has been very smooth. I feel that the different agencies, like the Youth Employment Service, social care and the health professionals, have all communicated well between themselves so bringing about a positive experience of transition. Throughout the process I always felt everyone involved worked with Rachel's best interests at heart.'*

### **PARENT TIP**

- ☺ If a social worker has not been involved before, or if changed circumstances mean you feel you or the young person need more help than before, contact the Access Point and request a needs assessment

But whether your child has complex needs, has a Statement or EHC plan or not, they will need to undergo a 'needs assessment' in order to get support from social care.

## **ASSESSING YOUR CHILD'S NEEDS FOR SOCIAL CARE**

### **Recent changes to the law**

There have been significant changes to the law regarding special educational needs and social care provision for children and young people with special educational needs and disabilities. Part 3 of the Children and Families Act 2014, which focuses on Special Educational Needs and Disability and Part 1 of the Care Act 2014, which focuses on the care and support of adults are the two pieces of law that have the greatest influence on support for disabled young people preparing for adulthood.

The Children and Families Act introduced Education, Health and Care (EHC) plans; a single assessment and planning process for young people with SEND which can potentially continue up to age 25. The Care Act deals with adult social care for anyone over the age of 18. This means there are a group of young people aged 18-25 who are entitled to support through both pieces of legislation. Both Acts share the following goals and themes:

- working towards clearly defined outcomes
- engagement and participation of parents and young people
- joint commissioning and developing a Local Offer of support (see page 43)
- coordinated assessments and EHC plans
- personalisation and personal budgets

Preparation for adulthood is a key element of the reforms that cuts across all of these themes.

*'I think you need some pointers; people will need to know they can ask certain things. I think the legal things are important to give parents the*

*confidence...To know that you've got the basic right (in law) gives you the confidence to challenge things.'*

## **Ensuring there is no gap in services**

When the local authority assesses a child who is receiving support under legislation relating to children's services, the Care Act requires them to continue providing him or her with that support through the assessment process. This will continue until adult care and support is in place to take over, or until it is clear after the assessment that adult care and support does not need to be provided. These changes are meant to prevent someone who is already receiving support suddenly finding themselves without the care and support they need when they reach 18.

## **Working together**

Everyone knows that a successful transition to adult care and support involves the young person, their families and professionals working together. The Care Act 2014 enshrines this in law, giving local authorities a legal responsibility to cooperate, and to ensure that all the right people work together to get the transition right.

## **CHILD'S NEEDS ASSESSMENTS**

The Care Act 2014 introduced a new duty on local authorities to carry out Child's Needs Assessments (CNA) for a young person, where there is "likely to be a need for care and support post 18". The purpose of a CNA is to find out what adult social care a young person might be eligible for once they reach 18 so they can make informed choices about their future.

## **When does planning start?**

The Care Act does not say that a young person has to be a certain age to be able to ask for an assessment. Young people or their parents can request a CNA at any time before their 18th birthday whether or not they have an EHC plan. The CNA should be carried out at a time when it is of “significant benefit” to the young person’s preparation for adulthood and should include an “indicative personal budget” (more about that later) so that young people are able to plan what their future support might look like.

The local authority can decide not to carry out an assessment if they think your child will not need adult social care support or you are asking too early for a CNA to be useful. In these circumstances they must provide reasons for this in writing and include information and advice on what can be done to prevent or delay the young person developing the need for care and support. If they do not carry out an assessment because the timing is not of “significant benefit” the local authority should advise when it is likely to be of significant benefit and contact the young person and their family to arrange the assessment at that time.

For a young person with an EHC plan, the conversation about whether they need a CNA should begin in the Year 9 review as part of the preparation for adulthood planning.

If your young person does not have an EHC plan, but is still supported by children’s social care, you should ask their social worker about when it might be useful to have a CNA at their next review.

## **What should the Child’s Needs Assessment include?**

The assessment should provide person-centred information about a young person’s needs, plans and aspirations for their

future. It should include clear, short and medium term outcomes which can then be used as the basis for a conversation with the young person, their family, a professional from adults' services who has a good knowledge of the support options that may be available to them in the future, as well as the other professionals involved in the young person's care and support.

Under the Children and Families Act, EHC plans must clearly set out the care and support which is reasonably required by the young person's special educational needs. For people over 18 with a care and support plan, this should be incorporated into the EHC plan, where there is one, rather than developed separately. It will include those elements of their care and support which are directly related to their SEN and also specify other care and support. It should be noted clearly which elements are not directly related to SEN.

## **ELIGIBILITY AND THE ASSESSMENT PROCESS**

The council must carry out a needs assessment for people who appear to be in need of care and support, regardless of their financial status or whether the council think that their needs will be eligible. To arrange a needs assessment, if your young person is already 18, or if they are under 18, a CNA, contact Access Point.

Since the Care Act came into force in April 2015, it has changed the way the council decides if adults are eligible for care and support services. All three of the following must apply to your young person for them to be eligible for adult care or support services:

- Your young person's needs are due to a physical or mental impairment or illness

- Your young person's physical or mental impairment or illness affects their ability to achieve two or more 'specified outcomes' (see below)
- Your young person's wellbeing is significantly affected by the inability to achieve these outcomes.

## **Achieving 'specified outcomes'**

When considering whether someone is eligible for adult care and support services, the assessor will look at 'outcomes'. This means they look at the impact of your young person's physical or mental impairment on their daily life. This is measured by checking if they are unable to achieve **two or more** of the following:

- Managing and maintaining nutrition
- Maintaining personal hygiene
- Managing toilet needs
- Being appropriately clothed
- Being able to make use of their home safely
- Maintaining a habitable home environment
- Developing and maintaining personal relationships
- Accessing and engaging in work, training, education or volunteering
- Making use of facilities or services in the local community including public transport and recreational facilities or services
- Carrying out caring responsibilities if they have a child

The council say that they may measure your young person's needs against other 'outcomes' too – so ask what these might be. They also consider whether your young person's needs may change by looking at their care and support needs over the last year.



## **The assessment process**

The needs assessment or CNA will be coordinated by one of the two adult disability teams in Adult Social Care; the Adult Physical Disability Service or the Community Learning Disability Service.

During the assessment, a 'care manager' will gather information from you, the young person and workers from education, health and social care. Assessments are usually done in your home and may take more than one visit. There are different types of care managers with different job titles – including social workers, assessors, resource officers, transition workers and reviewing officers.

The assessor should keep notes of what's said, any services your child needs and whether there's anything you disagree with.

During the assessment process, it's important to involve the young person as much as possible. They may need specialist support to help them communicate their thoughts and feelings. See Chapter 2, 'Involving your child' for more information.

The eligibility criteria for Adult Social Care are different to those used by Children's Services via the Integrated Child Development and Disability Team. So, although you might have received support while your child was at school, this may not continue when they become an adult. Our experiences vary.

*'We found it confusing to work out what was meant to happen and what things were important to flag up with the social worker who was doing Sarah's assessment.'*

## **What happens after the assessment?**

If it is decided that your young person is eligible for services or support, you should get a written record of the assessment

which may be in the form of a 'support plan'. The support plan will outline the young person's and carer's needs and the support that is needed (more about this later). A representative from adult social care should discuss the recommendations with you before presenting them to the Funding Panel. The panel is where decisions about the financial aspects of your child's support needs are made.

If your young person is eligible for support, they will be allocated an approximate sum of money called a '**personal budget**' to cover the cost of their support – read more about personal budgets on page 132.

If your child isn't eligible, you should get a written statement telling you why. Even when an assessment says that someone does not have needs that the local authority should meet, the local authority must advise people about what needs they do have, and how to meet them or prevent further needs developing.

### **PARENT TIPS**

- ☺ Don't assume because your child has had a Statement or an EHC plan they will be eligible for adult services
- ☺ Get as much information as you can from other people in similar situations – including information about services, waiting times for assessments and recent examples of provision
- ☺ Ask questions and explore possibilities. Get used to writing down the correct name and job title of the person you speak to about the situation and getting their phone number
- ☺ Don't be afraid to suggest things that haven't been tried before. If you know why your idea may work, others may see your point of view

- ☺ Don't assume it's you against them – try to explain yourself clearly, and to see their point of view. If you don't agree, say so politely and explain why. Ask what happens next.

## **YOUR YOUNG PERSON'S SUPPORT PLAN**

After the assessment, if your young person is considered eligible for support, someone from adult social care will help you put together a care and support plan. The support plan will confirm which of your young person's needs are to be met and how they will be met and it should be reviewed on a yearly basis.

The care manager will be responsible for making sure that any agreed services are put into place. However, be aware that there can be delays between finalising the plan and putting it into action.

The support your young person receives will depend upon their individual situation but may include:

- Equipment to help them stay independent
- Technology to keep them safe in their home
- Help looking after themselves at home
- Help with going out
- Help getting a job or studying
- Access to supported living or other housing support

The care and support could come from a variety of places including family and friends, the NHS, Brighton & Hove City Council or community and voluntary organisations.

## **How a support plan works**

Your social worker or care manager will discuss with you, and if appropriate, your young person, how their needs can be met. They should ask you what you want to happen and what is important to your young person. This is meant to give you and your son or daughter the chance to take control in deciding how they will receive support, and to have a clear idea of when and how this support will be provided. The support plan will also look at how to improve the young person's wellbeing and prevent problems developing in the future.

You will be given a copy of your young person's support plan which will include details of any decisions taken. You can ask to see personal information held by Adult Social Care about you and your child. You can also ask staff to change anything you think is incorrect.

If you or another family member or friend is providing your young person with support on a regular basis, the support plan should include how your young person's needs can be met if you or other carers are not available.

### **PARENT TIPS**

- ☺ Once you get a copy of your child's support plan, check and check again that all their needs have been taken into account. Once a support package has been agreed, it's hard to renegotiate
- ☺ Once support has been provided, it can't be taken away without the person's needs being reassessed
- ☺ If the support plan isn't monitored properly, contact the care manager and request a review date

## Keeping the support plan up to date

Completing the planning process and putting in place care and support arrangements does not mean the end of the local authority's responsibilities. The local authority has a legal duty to review the plan to make sure that the person's needs and outcomes continue to be met over time. If anything has changed, the authority must carry out a new assessment. The person themselves also has a right to request a review of their care and support plan, if they wish. Your young person's support plan will be reviewed from time to time – but the Care Act doesn't specify how often this has to happen.

### **PARENT TIP**

- ☺ Let the council know if anything changes as soon as possible so they can make adjustments to your young person's care and support

## What if you don't agree with the assessment findings and support plan?

If you don't agree with the assessment findings, contact the care manager to discuss the matter. The support plan could be changed by agreement.

You have the right to ask for a review of the assessment, and to ask someone to advise you or act on your behalf. You could ask for support from the Disability Advice Centre run by The Fed Centre for Independent Living or the Carers Centre.

If you still disagree with the assessment, or with how social care intends to meet your child's needs, you can go through a formal complaints procedure.

*'We did not want to have to complain, we are not a complaining family, but we were advised to complain as it was the only way they could get funding.'*

## **What if your young person's support plan isn't working?**

From time to time things may go wrong with your young person's care. Your social worker or care manager should have already discussed with you and your young person what should happen if a crisis occurs and this should be included in their support plan.

If there is a more everyday problem with the way your young person's care is being provided, you should first speak directly to their care provider. If this doesn't resolve the problem, then call Access Point.

*'I was very impressed when I saw Rachel's support plan, it was accurate and thorough. The social worker made great efforts to ensure that I was completely happy with it.'*

*'When I saw Charlotte's Support Plan there was nothing in it about night waking staff even though she has epilepsy and could fit at night. I flagged this up with Charlotte's Care Home Manager. They had to go back to the council to give them more funding to do this. There was a lot of resistance to this, because the council had already agreed a package that seemed expensive.'*

## **PAYING FOR ADULT SOCIAL CARE AND SUPPORT**

The council sets a charge for most of the social care services it provides – things like residential care homes, short breaks, day services, home care, community support and adaptations to

property – and the Care Act 2014 gives them the power to charge people for this care and support.

Depending on your young person's financial situation they may be asked to pay towards the cost of their support which the council will help to arrange. This might sound scary or surprising but be aware that very few people have to pay the full cost of their care as the amount payable is based on an assessment of the young person's income and not your family income as a whole.

Your young person is entitled to financial support from the council (depending on their financial circumstances) if one of the following applies:

- the type of care and support your child needs is already provided free of charge
- your young person can't afford to pay for the full cost of their care
- your young person asks the council to meet their needs
- your young person does not have the mental capacity and has no-one else to arrange care for them.

## **Financial assessments**

A financial assessment of your young person is carried out alongside their needs assessment. The financial assessment takes into account the young person's financial position and is used to check whether they are getting the correct state benefits. The assessment will work out how much the young person will have to pay towards the service they receive and how much the council will pay. The mobility component of DLA (Disability Living Allowance) or PIP (Personal Independence Payment) should not be taken into account when the young person's income is assessed. If the service is for the young person, your financial situation should not be taken into account.

**Young people should not have to pay for services if they are:**

- Between 16 and 18 years and on Employment and Support Allowance (ESA), or
- Receiving a service under Section 117 of the Mental Health Act 1983

If there is a dispute about charges, the service must remain in place while the issue is resolved. More detailed information can be found in the council's Social Care Charging and Financial Assessment for Adult Care and Support Services Policy which is on their website or ring the council's Financial Assessment team on 01273 295662 or the Welfare Rights Team on 01273 291116 if you want to talk to someone about charges for services.

## **Personal budgets**

The way services are organised for people who need extra care and support has changed. If your young person has been assessed as being eligible for support, you can choose to be given money to organise and pay for their support or services yourselves instead of relying on a 'one size fits all' package decided by the council. This is called a personal budget.

The personal budget is meant to help the young person or you as their parent, decide how much control you want to have over arranging their care and support, by seeing how much money is available to buy the care that is needed.

The Children and Families Act gives young people and their families the right to request a personal budget as part of an EHC plan. The Care Act requires local authorities to include a personal budget in the care and support plan (care element of an EHC plan) for young people over the age of 18.



### **How personal budgets work**

A personal budget is the amount of money the local authority has worked out it will cost to arrange the necessary care and support for your young person. This includes any amount that the local authority is going to pay itself towards those costs (which might range from all, to none of the total).

Personal budgets allow support to be arranged in a number of ways. Your young person may choose to receive their personal budget as a **direct payment**, which they can use to arrange and pay for their support themselves. Or they may choose for you or another carer to receive the direct payment and arrange support for them. Alternatively, the council can use your young person's personal budget to arrange the support on their behalf – this is called a 'managed personal budget'. Or their social care and support may be a mixture of both direct payments and 'managed' care.

*'The problem we now have is that she is getting heavier and one person can't lift her, so if we had any respite we'd have to have two people.'*

*'I wanted to sort out some housing for Steven but they said I had to have an assessment first. I've been waiting 10 months and I still don't know when they'll get round to us. You just learn to wait!'*

*'I found it amazing that he was in an out of county placement costing a lot of money, he comes back to Brighton and Hove and they say he doesn't even have a learning disability and all the services just dropped off as he didn't fit the criteria!'*

### **Direct payments**

Direct payments are the main type of funding associated with personal budgets. You or your young person can use direct payments to employ someone to care for your child (often called a personal assistant or PA) or to buy into a local service

like a day centre or short break unit, but you can't use them to buy into a service run by Brighton & Hove City Council – these would be arranged separately as part of the personal budget. Unless there are exceptional circumstances you cannot use direct payments to employ a close relative who lives in your household, although you can use them to employ a relative who lives elsewhere.

Until a child is 18, parents can use direct payments to pay for and arrange services for their child. Young people over 16 can take responsibility for direct payments, or – if they're 16 or 17 – choose to share responsibility with their parent.

Once a young person is 18, they can still get a parent or carer to receive their direct payments and arrange support for them if they prefer. In this case a parent or another person manages their child's financial affairs as an 'appointee'.

If your young person is assessed as needing support, they can't be refused direct payments if they want them. The law says local councils must tell you about direct payments and support you if you want them. If you're already getting services, your child's care manager or social worker should already have told you about direct payments.

### ***Why choose Direct Payments?***

Direct payments are worth thinking about if your child has been assessed as needing a service, but has been on the waiting list for a long time. They may also work if you feel you are having to fit in with what's on offer, rather than getting the services you think could really benefit your child.

Direct payments give you greater flexibility, but be aware that you will need to take responsibility for finding and organising the support or services you want and for keeping accounts and records of how the money is spent. The Fed offer support with

managing direct payments and a payroll service if you employ personal assistants to support your young person.

Amaze has more information about direct payments in our companion handbook, *Through the Maze*, or in the Advice for Parents section of our website at [www.amazebrighton.org.uk/advice-for-parents/money-matters/direct-payments](http://www.amazebrighton.org.uk/advice-for-parents/money-matters/direct-payments)

## **WHAT SUPPORT IS AVAILABLE TO OVER 18S?**

The way adult social care support is provided in Brighton and Hove is changing and so how things will be in the future is uncertain. Because of cuts to funding from central government to local authorities, the council has to make huge savings and adult social care budgets are affected by this.

Many services aren't provided directly by Adult Social Care, but are commissioned or contracted out to independent organisations. However, the first point of contact for all the services we describe is the Access Point at Brighton & Hove City Council. Call 01273 295555 or email [accesspoint@brighton-hove.gov.uk](mailto:accesspoint@brighton-hove.gov.uk). You can read details about the kind of adult social care support provided by Brighton & Hove City Council on their website or on the My Life website at [www.mylifebh.org.uk](http://www.mylifebh.org.uk).

Finally, the council has recently published its Local Offer, a detailed online guide to the services they expect to be available for children and young people with SEND aged 0-25 years. All local authorities are now obliged to publish and update this information as part of a directive from central government. The Local Offer should include information about all sorts of local services including health and social care. See [www.brighton-hove.gov.uk/localoffer](http://www.brighton-hove.gov.uk/localoffer)

The following list provides a summary of the types of support your young person may be able to use if they're assessed as needing them. Remember, providers can change and new services frequently become available for purchase. In all cases, your young person will need an assessment of needs before they can access these services. If your young person has a social worker or transition worker, talk to them, or call the council's Access Point for more information.

## **Day activities**

Day activities refer to a range of provision and might include spending time at a day centre, a building where activities take place. For example, a young person may have a package of daytime activities that includes attendance at a day centre, working in paid or voluntary jobs supported by social care's Supported Employment Team, and doing a college course.

Day services like those provided by the Grace Eyre Foundation and the Day Options Service (provided by Adult Social Care) usually include a range of activities and are used by different age groups. They may provide a hot meal at lunchtime and transport is frequently arranged, although a charge may be made. There are no day centres catering specifically for young people.

### **PARENT TIPS**

- ☺ Ask your care manager for a list of day activities and where they take place
- ☺ Arrange to see different activities and centres yourself. Ask how they could help meet the needs of your child. It's important to get an idea of what's available and whether you think your child would be happy there
- ☺ The young person needs to see the activities and centres too

## **Short breaks or respite**

Short breaks or respite care aim to give families who care for a family member a short break from caring. Disabled children may have gone to Drove Road or Tudor House, which offer overnight stays to children and young people. But once your child is over 18, they will no longer be able to access these services. There are no rules about where short breaks take place, but it's usually provided at other family homes, residential homes, or by people coming into your home or taking the young person out. Beach House is the only short breaks adult overnight provision for people with learning disabilities and/or autism. To access this support, your young person will have to be eligible for adult social care support and have had an assessment of their needs.

Crossroads offers daytime and evening care in your own home, either temporarily or regularly. You can also arrange your own support, through a personal budget or direct payments (see page 133).

## **Home care services**

Home care services provide personal care for people in their own homes. Home care used to be called home help and in those days included help with housework. Home care services now only help with personal care like washing and bathing, getting up and dressed or getting ready for bed. Adult Social Care has its own home care service, called Independence at Home, but this generally specialises in providing short term care. Long term care needs are mostly provided by private agencies, all of whom are registered with the Care Quality Commission. You can download a list of the council's current home care providers on the council's website.

Some people assessed as needing home care services choose to get direct payments (see page 133) so they can employ their own personal assistants (PAs).

## **Personal Assistants**

A personal assistant (PA) is someone who provides support to disabled children and adults. They may offer support in everyday activities such as shopping, leisure activities, washing and personal care. Instead of a service, your young person may have a personal budget to pay for the support they need (see page 132). If you are looking to employ a PA to provide this support, the 'Support with Confidence' scheme might be helpful. Support with Confidence is a council initiative, a partnership between Adult Social Care and Trading Standards services which provides a register of approved PAs. You can download the current list on the council's website or contact Access Point.

To become 'approved', a PA has had an enhanced DBS (previously CRB) check, two reference checks, successfully completed ten training modules and signed the code of conduct. The Fed also has a PA noticeboard where you can advertise for a PA and PAs advertise their services. Look at the Fed's website ([www.thefedonline.org.uk/pa-noticeboard](http://www.thefedonline.org.uk/pa-noticeboard)) or give them a ring. The Fed also offers a Payroll service, if you are employing a PA and want some help with this.

## **Shared Lives Carers**

Shared Lives is a scheme that links up adults with learning and/or physical disabilities with carers who provide support and accommodation in the carers' own home. Carers are paid, trained and supported by the Shared Lives team in the council and support can be either on a full time or short breaks basis. Read more about Shared Lives and schemes that help

adults to live independently in our 'A place to live' chapter or contact Access Point for further information.

## **Equipment and housing adaptations**

Whether your young person still lives at home, in private rented accommodation or social housing, the council may be able to help them to live more independently by providing equipment or adaptations to the home that make daily life a bit easier. To get any specialist equipment or adaptations your child will need to be assessed by an occupational therapist from Adult Social Care.

Adaptations might include providing ramp 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 might be part or fully funded by the council, depending on your young person's circumstances. To find out more, contact Access Point or visit the council's website.

## **Carers Emergency Back-Up Scheme**

This scheme aims to give peace of mind to carers by providing home-based care for up to 48 hours in an emergency where the cared for person can't be looked after by the carer. This could include: the carer's admission to hospital or other health needs; a family emergency like a close relative being taken ill; a real risk to the carer's employment; or the funeral of a close friend or relative.

You will be asked to draw up and register an emergency plan, give details of people who may be able to provide care in your absence. If you don't have family or friends who could help at short notice, back-up services may be provided by the council. There's no charge for carers of disabled children. Plans are held by Carelink Plus, the 24 hour Community Alarm service. The

scheme includes a card for you to carry in case you have an accident or fall ill and can't explain you care for someone.

If you, or your young person has a social worker or care manager working with you, then they can help you register with the Emergency Back-Up Scheme otherwise call Access Point.

## **Sight and hearing difficulties**

The Brighton & Hove Sensory Services Team provides specialist information, advice, assessments and equipment to support independence for people of any age with a visual or hearing impairment. The Access Point Team deals with referrals for people with sight or hearing difficulties, their friends or family or other professionals. Contact them on 01273 295555 or email [accesspoint@brighton-hove.gov.uk](mailto:accesspoint@brighton-hove.gov.uk)

## **YOUR NEEDS AS A CARER**

Asking for help can be difficult for parents who've always had to cope, but your needs as a carer matter too. If you look after your son or daughter as their carer, you may be eligible for carers' support. You will need to have an assessment of your needs as a carer. If your young person is under 18 then this assessment will be carried out via the Integrated Child Development and Disability Service social work team. If they are over 18, you can ask for a carer's needs assessment via Access Point.

*'As parents, we feel we should cope; we push ourselves time and again. I've learnt that at certain points I can say, "I'm sorry I can't do this anymore"; it seems we should learn that if you've got to get to crisis point, the thing to do is to accept it and say "I CANNOT DO THIS".'*



## The carer's assessment

The carer's assessment considers the impact the care and support you provide is having on your own wellbeing. It also helps social care services to understand the impact your caring has on other aspects of your life such as whether you are able or willing to carry on caring, whether you'd like to work or whether you want to socialise more.

*'I personally found the Carers Assessment emotionally draining. Thinking about my role as a carer, Rachel eventually living away from the family home and what might happen to her when I am no longer around were really difficult issues to verbalise. These and other difficult issues needed to be raised but were terrifying.'*

The council offers a range of more generalised support to help carers look after their own health and wellbeing such as the Carers' Card (see below) but you may also be entitled to other services such as your own support plan and personal budget.

### **PARENT TIPS**

- ☺ Be realistic about what you can manage in the long term and when your son or daughter is not at school or college every day
- ☺ Don't hold back. Spell things out and don't expect others to read between the lines
- ☺ Try to get reports and supporting material before you apply to back up your case and check that you're applying under the appropriate act
- ☺ Make sure your needs as a carer are fully considered. An assessment under the Care Act can be requested
- ☺ Talk to as many people as possible who've managed to get funding so you can learn from their experience
- ☺ If you are turned down at first, get a written reason why. Try to address the problem and reapply

- ☺ Contact the Carers Centre if you need further support and information about social care

*'People have different thresholds. You accept your own threshold and never question whether it's reasonable to have to do all that you do.'*

Make sure you are getting all the financial support and benefits you're entitled to as a carer. They can help with some of the costs of caring or contribute towards your pension entitlements in the future. Amaze can give advice about disability benefits like DLA, PIP and Carers' Allowance so call our helpline on 01273 772289.

We have also found that talking with other parents and carers not only about ideas and tips regarding services and provision, but also about our worries and concerns, can really help you feel as though you're not the only one going through these changes. Some of us have also found it helpful to talk to counsellors. The Parental Support Counselling Service, which operates from Downs View School, understands the experiences of parents of disabled young people. The Fed also runs a counselling service which is available to disabled children and adults and their carers or family members.

## **The Carers' Card**

The Carers' Card is a discount card funded by the council and developed by Amaze that aims to help carers to look after their own health and wellbeing. If your child has a Compass Card (see page 72), you will automatically qualify for a Carers' Card.

There are around 50 offers included in the scheme, including gyms, the Duke of York's cinema and complementary therapies - you can see the full range of offers on Amaze's website at [www.amazebrighton.org.uk/services-and-support/the-carers-card](http://www.amazebrighton.org.uk/services-and-support/the-carers-card). To apply, call 01273 295153 if your child is under 18, or

01273 295555 if they're over 18. Have your Compass Card to hand because you'll be asked for the number on the back. Young carers aged 8 to 25 also qualify for a Carers' Card.

## **Young carers**

Living with a young disabled person can be demanding on everybody. Brothers and sisters may have to help with some care jobs or with household chores and it can also be emotionally draining living with people whose behaviour is odd or whose disabilities are complex.

We think the quality of life for brothers and sisters needs to be protected. Under the Care Act 2014, their needs can be assessed, and respite for them considered. Ask Adult Social Care for a 'Young Carer's Assessment' and explain why you are worried. You can also contact the Carers Centre to find out about its Young Carers Project. If you have another child or children aged 8 to 25 who help to care for your disabled son or daughter, or if they help care for you if you are disabled yourself, they can apply for a Young Carers' Card with a range of young carers' offers. The Young Carers' Card is usually issued through the Young Carers Project at the Carers Centre. Call 01273 746222.

## **MAKING COMPLAINTS ABOUT ADULT SOCIAL CARE**

So what if you're not happy with decisions made by children's or adult social care or the support your young person receives?

### **What the law says**

By law, social care departments must have a complaints procedure and a complaints officer. Anybody who receives support from social care services can make a complaint, as can a family member or friend of the person who receives a service (or believes they should). You will need to get permission from

the person to raise a complaint on their behalf (if they have the 'mental capacity' to give their consent), or anyone who believes they have been unfairly refused a service. Social care services must be able to give you information about how to make a complaint, where you can get help to make one, and how quickly the complaint will be dealt with.

## **How to complain**

To make a complaint about either adult or children's social care, you should call the council's Customer Feedback Team on 01273 291229, email [customerfeedback@brighton-hove.gov.uk](mailto:customerfeedback@brighton-hove.gov.uk) or download the feedback form from the council's website. The team can send you their leaflets about how to make complaints or help you write a letter of complaint if you find this difficult.

Your complaint should be acknowledged within three working days and the service aims to provide a response within 10 working days. You should be kept informed about the progress of your complaint.

Usually, they'll try to deal with complaints informally first, perhaps by seeing if you and the manager of the service can sort things out between you. They should ask you what you want to happen to put things right. This stage is called '**problem solving**'. If this informal stage doesn't solve the problem, you may want (or be asked) to go through a more **formal** stage.

If you're not happy with the result of the formal stage, the Customer Feedback Team at the council can help explore further options, including providing information about raising the complaint with the Local Government Ombudsman (LGO). Call them on 0300 061 0614 or email [advice@lgo.org.uk](mailto:advice@lgo.org.uk). You can visit their website for more information about how they might help at [www.lgo.org.uk](http://www.lgo.org.uk).

You can also use the council's complaints procedure if you are unhappy with the assessment – for example, if:

- the council refuses to assess you
- you have been waiting too long for an assessment
- you are not happy with how the assessment was done
- you feel your child is not getting the services they need
- you are being asked to pay too much for the services
- you have problems with the services being provided

Councils have to have a 'monitoring officer' (someone who makes sure the council is doing what the law says it must do). So if you think it has broken the law (for example, if it won't pay for residential care when you think the law says it should), you can ask the monitoring officer to look at your case. Your local councillor or MP may also be able to help. If these steps don't sort out your problem, you can take your case to the Secretary of State for Health – but you'll need legal advice before you do this.

Another possibility is to use (or threaten to use) the courts, either:

- to sue the council for a 'breach of its legal duty' (though this can be difficult to prove), or
- to get a judge to rule on whether the council's actions were legal, rational and reasonable (a process called 'judicial review')

Again you'll need legal advice. If you can't afford to pay for a solicitor, and you meet other conditions, you may be able to get public funding (legal aid) to help pay for legal expenses. The Disability Law Service offers free legal advice and a casework service for disabled people. Visit [www.dls.org.uk](http://www.dls.org.uk) to find out more, or call 0207 791 9800.

This may all sound very daunting but don't be put off making a complaint if you have genuine concerns – most problems are resolved in the 'problem solving' or early formal stage of a complaint. Call Amaze if you have any worries or issues and we'll see if we can help.