

CHAPTER 6

Social care



If your child needs a lot of support now, we know it can be hard to look ahead. Sometimes coping day to day takes up all your energy and looking ahead seems too painful, but it is well worth doing.

'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, including the option of Direct Payments (DP).

MOVING TO ADULT SOCIAL CARE

During the Year 9 Annual Review meeting at school, one of the things that should be looked at is whether your child may need support from Adult Social Care. The arrangements for transition (described in Sections 5 and 6 of the Disabled Persons Act 1986), require social care, education and health services to cooperate, exchange information and jointly assess the young person's needs as they approach school leaving age.

The act places a legal duty on the local authority's education department to consult with Adult Social Care when the disabled young person with a Statement reaches 14 in Year 9. The education department of the council has to supply information to Adult Social Care at least eight months before the young person leaves school, and Adult Social Care has to undertake an assessment within five months of being notified.

Adult Social Care is divided into two services: the Adult Physical Disability Service and the Community Learning Disability Service. Contact the social care Access Point or look on the council website at www.brighton-hove.gov.uk (click on social care and health) for more information. Accessing support for both services is via the Access Point.

If a young person with disabilities is receiving support from the Integrated Child Development and Disability team, their information should be transferred to the relevant adult team in Adult Social Care as they reach 18. If Adult Social Care is to pay for aspects of the young person's care, the relevant team will need to make a full assessment and decide whether the young person is eligible for services. If they are, a 'Care Plan' will be prepared, or the young person will be given Direct or Indirect Payment or a Personal Budget to pay for their support (see page 145 to 149 for more information).

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 an 'Assessment of Needs'

Once your child is 18, the social care support they need is provided through the council's Adult Social Care Team. This support is known as 'community care' and can be vital in helping young people with lots of care needs to achieve greater independence as adults. For us as parents, getting to grips with community care has often been important in helping us prepare for the long term future of our family.

The provision of adult services for your child should have been discussed and agreed during the transition planning process – so hopefully there should be no surprises when your child reaches 18. Not all young people with a Statement of special educational needs (SEN) are considered disabled or entitled to adult social care.

Some might not have had support from social care (previously called social services) before, but when a young person becomes an adult, things may change. On the other hand, some of us found that although our children had received services and support as children, they didn't qualify for adult services.

Adult Social Care is responsible for arranging community care services or providing the funding for you to pay for services yourself through Personal Budgets and Direct Payments (DP) (see page 145 to 149 for details). 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.

The legal framework

The law around social care is complicated. We will summarise the law as it stood when updating this handbook, but things are likely to change once the new Care and Support Bill becomes law.

Once a young person reaches 18, their support from the local authority is no longer a legal obligation under the Children Act 1989. Instead, an assortment of laws provides a new framework for adult services.

Some legal provisions overlap, others leave 'grey areas' or don't say who should provide services or whether they must be provided – so don't be surprised if you get confused! It's taken most of us ages to work out who has a responsibility to support our young people and how to make sure they do.

'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.'

The new Care and Support Bill was going through parliament as we were updating this handbook. If this bill becomes law, it will have an impact on how social care support and services are organised and delivered locally. One of the things the new bill proposes is that young people and their parent carers will be given a legal right to request an assessment before the young person turns 18 regardless of whether they currently receive children's services. This is in recognition that more time is needed to plan ahead for adulthood. The bill also says that assessment for care and support needs can also take place alongside other assessment, for example, this could be an

assessment for an Education, Health and Care plan proposed under the Children and Families Bill (see page 10)

Two things to remember:

- A 'duty' to provide a service means it must be provided
- A 'power' to provide a service means it may be provided

As things stand at the moment in law, at 18, the young person's needs should be assessed (or reassessed) under the NHS and Community Care Act 1990. The act doesn't say precisely who's eligible for community care services or what they're eligible for - but it does say (under section 47) that when the council believes a person may be in need of community care services, it has a duty to carry out an assessment, to decide if they should be provided.

If Adult Social Care decides services are likely to be needed, it must also assess the person under the Disabled Persons Act 1986 and let them know their rights under the act. This is why it is so important to have someone from social care invited to transition planning meetings organised by the school. They decide if the young person is disabled as defined by the act and whether they're likely to need support from the council in the future, so they're key to the planning process.

Your child is entitled to an assessment, no matter how much money you or they have. The assessment is the first step in accessing community care services or support. Staff from social care should complete an assessment within 28 days of you asking for it, although complicated cases often take longer.

If an assessment is carried out under the Disabled Persons Act, Adult Social Care has to decide if services are needed when the young person leaves school under the NHS and Community Care Act 1990 -which incorporates the Chronically Sick and Disabled Persons (CSDP) Act 1970.

The CSDP Act applies to both children and adults with disabilities. Under the act, councils have a duty to provide information about services and arrange for them to be provided. This does not mean the council will necessarily provide the services themselves. Services provided under the CSDP Act might include:

- practical help in the home
- equipment to help with a disability
- help with adaptations to the home
- provision of meals at home or somewhere else
- provision of a telephone or help to buy one and any special equipment needed
- help to take part in educational and recreational activities at home and outside (a place at a day centre for example), including help with transport
- holidays

WHO PAYS FOR ADULT SOCIAL CARE?

We all contribute towards community care through council tax and extra funding comes through government initiatives.

The council sets a charge for most of the social care services provided. These services include residential care homes, short breaks support, day services, home care, community support and adaptations to property. Only some people have to pay the full cost of the service but the amount you may have to pay will depend on the money the person being assessed for the service may have (your young person). This means that alongside a needs assessment for the support and care your young person may need, a financial assessment is also carried out. 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) 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. Further detailed information can be found in the Council's Social Care Charging Policy 2012-2013 which is on their website or ring the Council's Financial Assessment and Welfare Rights Team if you want to talk to someone about charges for services on 291116.

SOCIAL CARE ASSESSMENTS OF NEED

The 'carers' needs assessment', coordinated by one of the two adult disability teams in Adult Social Care, is the key to accessing services for disabled people over 18.

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 assessment should consider the following:

- accommodation - short and long term
- health care - medical, nursing and psychiatric needs

- personal care
- social needs, including day time activities
- employment, education and finances

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.

"To me the meeting just seemed like a parents' meeting. You sit there and it doesn't seem the right environment for me to say "this is a problem or that is a problem". (Steven 16)

The law says an assessment should be led by the needs of your child ('needs led') and the resources of the council should only be taken into account when considering care in the home. But you may still feel you don't get all the support you need.

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.

'Rachel's transition from Children to Adult Services has been very smooth. I feel that the different agencies, like Connexions [now called the Youth Employability 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.'

'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.'

Eligibility criteria

Brighton & Hove City Council's eligibility criteria follow national guidance used by all local authorities to provide community care. This guidance is called Fair Access to Care Services (FACS). There are four bands – critical, substantial, moderate or low – which describe the seriousness of the risk to independence if the need for services isn't met. Each council sets a threshold that takes into account available resources.

Brighton & Hove City Council currently commits resources to people whose needs are assessed as critical and substantial.

Critical and substantial risks are life-threatening or significantly detrimental to your child's health, safety, wellbeing or development. Without support your child would be unable to make informed choices, manage personal care, or maintain relationships with family or friends. They would be at immediate risk of neglect and financial, emotional, psychological, physical or sexual abuse.

'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.'

Young people whose needs are critical or substantial are likely to have complex communication difficulties, severe learning and/or physical disabilities, or life-threatening medical needs.

Assessments have to take account of need and balance the degree of 'risk' against the amount of support available in the home and outside it and the amount of support required. If a parent is able to provide support, the degree of risk for the

disabled person is likely to be less than if the parent is no longer able to provide care.

'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!'

Once the assessment is complete, it's decided whether your child fits the eligibility criteria for support.

'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!'

PARENT TIPS

- ☺ 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
- ☺ Don't assume because your child has had a Statement they will be eligible for adult services

After the assessment

If your child is eligible for support, you should get a written record of the assessment which may be in the form of a 'Care Plan'. The Care Plan will outline the young person's and carer's needs and the support that is needed. If your child isn't eligible, you should get a written statement telling you why.

Although there is no duty on Adult Social Care to provide a copy of the assessment and Care Plan, it's considered good practice to do so. In Brighton and Hove, care managers should give you a copy of the assessment findings in writing – if they don't, ask for it. They should also 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.

The Care Plan

According to government guidelines, the Care Plan must consider:

- The capacities and incapacities of both the young person and their carer
- The preferences and aspirations of both the young person and their carer
- The young person's living situation
- The support available from relatives and friends or any other sources of help

The Care Plan covers the support to be provided, who will provide it and when. It should show which of your child's needs have been taken into account and include a date when the plan will be reviewed.

'I was very impressed when I saw Rachel's Care 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 Care 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.'

Once it's completed, the care manager should make sure that the services are put into place. However, there can be delays between finalising the plan and putting it into action.

The progress of the Care Plan should be monitored and a formal review carried out each year (although the first review should happen within the first three months). If the young person has complex care needs, review meetings may need to be more frequent.

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.

PARENT TIPS

- ☺ Once you get a copy of your child's Care Plan, check and check again that all your child's needs have been taken into account. Once a care 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 Care Plan isn't monitored properly, contact the care manager and request a review date

What if you don't agree with the assessment findings and Care Plan?

If you don't agree with the assessment findings, contact the care manager to discuss the matter. The Care 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 (formally Brighton & Hove Federation of Disabled People) 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 SUPPORT IS AVAILABLE TO OVER 18S?

It's impossible to cover the whole range of support and services for disabled adults and their families but we tell you about some of the key services below. 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

You can read details about the kind of adult social care support provided by Brighton & Hove City Council's on their website. Lots of services are provided by the Community Learning

Disability Team whose aim is to enable adults with learning disabilities to achieve more in their lives. Brighton and Hove's Information Prescriptions website (www.ipbh.org.uk) also has lots of information about local health and social care services, as well as advice for carers and information about support groups, voluntary organisations, charities and more.

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 SEN 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

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 on 01273 295555 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 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 an Individual or Personal Budget or Direct Payments (see pages 145 to 149).

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 145) 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 145). 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) or give them a ring. The Fed also offers a Payroll service, if you are employing 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 on 01273 295555 for assistance with registering with the scheme or visit Brighton & Hove City Council's website for more information.

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 the Access Point team on 295555 or email 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.

'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".'

Brighton & Hove City Council can offer the following to carers:

- a carer's needs assessment to consider your ability and willingness to provide care and any help that you may need to do so
- help to take a break from your caring role (for example relaxation days or classes at the Brighton Buddhist Centre, and the Carers' Card)
- services to assist you in your caring role
- services to support your employment

There's also a Carers' Grant that can help you with transport costs and paying for activities that give you a bit of time for yourself such as leisure activities, adult education or complementary therapies. For young carers, (children who help care for a sibling or parent) the grant may help with play schemes, school trips or holidays and out of school sports and leisure activities.

The Carer's Assessment

The Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 establish the right for the needs of carers to be assessed and for services to be delivered that support them. This is known as a Carer's Assessment and

although separate, it can happen at the same time as the assessment of the young person.

If your child regularly relies on you for care, you have a legal right to ask for an assessment of your needs as a carer. This assessment will be carried out by social care and it supports carers by ensuring:

- The person being cared for (your child) gets the right support and services
- As the carer, you have a choice over the type of caring tasks you do
- Your work, education, training and leisure needs are considered

Social care must make you aware of your right as a carer to an assessment of your needs. If you need an interpreter, the council should provide one.

If your child has a social worker or transition worker, ask for a Carer's Assessment, or contact the Integrated Child Development and Disability Team at Brighton & Hove City Council on 01273 295313 if the young person you care for is under 18; or the Adult Social Care Access Point on 01273 295555 if the young person is over 18 and ask for a Carer's Assessment.

'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.'

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 Carers 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.'

We have 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. Or you could come along to Amaze's Parents of Teens meetings for parents of young people with special needs and disabilities.

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 73), 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. 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 Carers (Recognitions and Services) Act 1995, 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.

INDIVIDUAL / PERSONAL BUDGETS AND DIRECT PAYMENTS

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 self-directed Support (SDS) or Personalisation.

The money given to people is called an Individual Budget or a Personal Budget. Personal budgets or Individual Budgets are similar to Direct Payments in that they have the same principles of people having more choice and control over their support. However, an Individual Budget, unlike Direct Payments, does not have to be a cash payment made to the individual, but can be a pot of money that someone else spends on their behalf.

Individual Budgets have a number of key features:

- It should be clear how much money has been allocated to the person to spend on their care and support package.
- The person should be central to the process, using their money in a way that suits their own situation and needs, with more of a focus on self-assessment.
- Resources from different agencies, not just social care money, can be collected together and accessed as one single budget to give the person a more joined-up package of support.

Direct Payments

Direct Payments (DP) are the main type of funding associated with Individual Budgets.

You can find an explanation of Self Directed Support or Personalisation at The Rowan Organisation website on www.therowan.org/individual-and-personal-budgets.

Until a child is 18, parents can use DP to pay for and arrange services for their child when and how they want, instead of accepting the package of services offered by social care. Young people over 16 can take responsibility for DP, or – if they're 16 or 17 – choose to share responsibility with their parent.

Once a young person is 18, 'indirect payments' should be possible if they can't manage Direct Payments themselves. As an 'appointee', a parent or another person can manage their child's financial affairs.

Your child needs to have been assessed by social care as needing support to get DP. If your child isn't currently getting any services and you think they may be entitled to them, call the Integrated Child Development and Disability Service on 01273 265825 or, if they're 18 or over, call the Adult Social Care Access Point on 01273 295555 to get an assessment. Ask for an assessment of your needs as a carer at the same time. See pages 129 to 135 for information about the assessment process.

Why choose Direct Payments?

DP 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're having to fit in with what's on offer, rather than getting the services you think could really benefit your child.

If your teenager is assessed as needing support, they can't be refused DP if they want them. The law says local councils must tell you about DP 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 DP.

DP gives you greater flexibility, but 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.

Negotiating DP: what are the issues?

What do you need? Be clear how many hours and what sort of help your child needs on a daily or weekly basis so they can do things other teenagers who are not disabled would expect to do. Be clear how much of this need you can't meet and how much of a break you need from each other. Although services may be organised on a daily, weekly or monthly basis, plan it out for the whole year – and take school and college holidays into account. The Fed can help you with this – get their details at the back of this book. This will give you an idea of the number of hours you need. All families have different needs: what other families get is irrelevant.

How much money is enough? The money you get should be based on the cost of an equivalent service from the council. If there's no council equivalent, you may have to negotiate over the cost. Councils have to cover the reasonable cost of buying in a service to meet your family's assessed needs. There should not be a standard DP rate that's offered to everyone on a 'take it or leave it' basis.

You will have legal obligations as an employer and the amount you get must cover things like NI (National Insurance) payments, holiday and sick pay, as well as basic pay. Remember, you need to negotiate on the basis of a 56-week year. That's because anyone you employ is entitled to paid

holiday. You'll need someone else to cover while they are away – and they need paying too! Again, The Fed can help with this.

Getting to grips with DP and who can help

The Fed runs a comprehensive Direct Payments Support Service to support parents of disabled children and disabled adults who use DP. It can help with finding or recruiting a PA, PA training, tax and insurance, payroll services and being an employer. You can contact the Fed on 01273 296747 or at www.bhfederation.org.uk

Finding the best people to support your young person. The council has a register of approved PAs who have had extra training as part of the Support with Confidence scheme. See www.brighton-hove.gov.uk/content/health-and-social-care/caring-and-carers/personal-assistants or call 01273 296424 for details. Parents and disabled young people have the legal right to disregard discrimination laws, so you can specify that you want a male or female PA for example.

The Fed has a PA noticeboard on their website at www.thefedonline.org.uk and the At Home Childcare Service (part of the council's Family Information Service or FIS) has databases of potential Personal Assistants or PAs. Parents tell us good places to advertise for free are Brighton Gumtree (www.gumtree.co.uk/brighton) and on the Sussex University Career and Development website (www.sussex.ac.uk/cdec).

'I tell potential employees, "If Naomi does not like you for any reason at all, you will not be employed." We need to trust our own judgement but it's important Naomi has the final decision.'

If writing a job description, advertising, interviewing and recruitment feels overwhelming, there are some useful sources of information.

Paying people. The biggest worry with DP can be the responsibilities of being an employer, but this doesn't need to be complicated.

Because you're not being paid and are just receiving and handing out money, you don't need to act as a business employer. Managing deductions for tax, National Insurance, holiday and sick pay is straight forward if you use the government's online Simplified PAYE Deduction Scheme. It does the calculations for you month by month for everyone you employ, you can print off payslips and at the end of the tax year it files your tax return at the click of a button. Or if you really don't want to do this yourself the Fed's Payroll Service can do this for you at a small cost. To find out how to get started as an employer, visit www.hmrc.gov.uk or www.gateway.gov.uk or call the Fed.

Keeping track of spending. You'll need to open a bank account just for DP and, of course, it's important to keep receipts and bank statements. The law says councils must check the money you're given is used for what's been agreed. So you'll need to keep accounts and records of how the money is spent. But you shouldn't have to make weekly or even monthly returns if this doesn't make sense in your circumstances.

MAKING COMPLAINTS ABOUT ADULT SOCIAL CARE

So what if you're not happy with decisions made by Adult Social Care or the support your young person receives? By law, social care departments must have a complaints procedure and a complaints officer. Anybody who receives an Adult Social Care service under Community Care law 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. 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, 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. If this informal stage doesn't solve the problem, you may want (or be asked) to go through a more formal stage. For both Adult and Children's Social Care services complaints, contact the council's Standards and Complaints team, detailed at the back of this book.

If you're not happy with the result of the formal stage, the Standards & Complaints 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. You can visit their website for more information about how they might help at 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 (Member of Parliament) 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 to find out more or ring 0207 7919800.

The Standards & Complaints Team can send you their leaflets about how to make complaints about services provided by Children & Families and Adult Social Care services. Or if you have any other worries or issues, contact Amaze to see how we might help.